Original Article

Quality of life of hospitalized patients submitted to hematopoietic stem cells transplantation*

Qualidade de vida de pacientes internados submetidos ao transplante de células tronco hematopoiéticas

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ABSTRACT

The objective of this study was to assess the quality of life and to identify the altered domains of adult patients with blood cancer, submitted to hematopoietic stem cells transplantation during hospitalization time. A longitudinal, observation and analytical study, conducted in a reference hospital for hematopoietic stem cell transplant. The data collection was during September of 2013 and September of 2014, including 25 patients and using questionnaires for sociodemographic and clinic characteristics, QLQ-C30 and FACT-BMT. A significant statistical worsening ($p<0.05$) was found in global quality of life, functional scales, physical, social and family function, personal performance, additional worries and symptoms, fatigue, nausea and vomit, pain, loss of appetite and diarrhea. There is impairment in quality of life of patients during hospitalization for the transplantation. This study can subsidize the direction of actions for adequate support during all therapeutic period.

Descriptors: Quality of Life; Hematopoietic Stem Cell Transplantation; Blood Neoplasms; Oncology Nursing.

RESUMO

O objetivo deste estudo foi avaliar a qualidade de vida e identificar os domínios alterados de pacientes adultos, com câncer hematológico submetidos ao transplante de células tronco hematopoiéticas durante o período de hospitalização. Estudo longitudinal, observacional e analítico, realizado em um hospital de referência em transplante de células tronco hematopoiéticas. A coleta de dados ocorreu entre setembro de 2013 a setembro de 2014 incluiu 25 pacientes com o uso dos questionários de caracterização sociodemográfica e clínica, QLQ-C30 e FACT-BMT. Demonstraram piora estatisticamente significativa ($p<0,05$) na qualidade de vida global, escalas funcionais, função física, social e familiar, desempenho pessoal, preocupações adicionais e sintomas, fadiga, náusea e vômito, dor, perda de apetite e diarreia. Há comprometimento da qualidade de vida dos participantes durante o período de hospitalização para o transplante. Este estudo poderá subsidiar o direcionamento das ações para o suporte adequado em todo o percurso terapêutico.

Descritores: Qualidade de Vida; Transplante de Células-Tronco Hematopoéticas; Neoplasias Hematológicas; Enfermagem Oncológica.

INTRODUCTION

The need of special care during hospitalization of patients submitted to hematopoietic stem cells transplantation (HSCT) causes intense changes of social roles in the family and work contexts and, in society. Thus, the abrupt rupture in the routine, which is invaded by new routines during therapeutic path that can impair quality of life (QoL) (1).

For 2015, the American Cancer Society calculated 162,020 new cases of blood cancer in United States, being 80,900 lymphoma cases, 54,270 leukemia cases and 26,850 cases of multiple myelomas. The mortality rate for this disease is 35% and it corresponds to approximately 10% of total cancer mortality(2). The National Cancer Institute highlights in Brazil the incidence of two new types of blood cancer, leukemia and lymphomas, with 21,340 new cases in 2014/2015, and a growth of approximately 18% in comparison to the previous estimate(3).

Patients with blood cancer diagnosis have been benefited with HSCT, however, they face a difficult step in their lives. At the peak of their productive phase, they experience the disease drama, the treatment complexity, and the exposed risks. They experiment physical, emotional and psychologic issues, financial and family worries, frustrations, and social isolation that compromise QoL. This require changes in daily activities, in the studies, at work, in leisure activities and in the family and social interactions(1,4).

Facing questions mentioned above, it is necessary to undertake improvements in nursing care modalities for patients submitted to HSCT in all steps of the prolonged treatment(5). Studies assessing QoL in cancer patients(6-10) have helped health professionals to identify impairments in the physical, emotional, social, personal and family domains, as well as the impact of interventions to which patients were submitted(11).

Thus, the objective of this study was to assess the QoL and to identify altered domains of adult patients, with blood cancer submitted to HSCT during hospitalization.

METHODS

A longitudinal, observational and analytical study, conducted at the Bone Marrow Transplantation Service (BMTS) of a pioneer and reference hospital in Brazil for HSCT, responsible for approximately 16% of allogenic transplantations performed in the country(12).

Twenty-five adult patients were included in the study with confirmed diagnose of blood cancer, attended during the September of 2013 to September of 2014, with a HSCT proposal. Patients without physical or neurological conditions to complete the questionnaires were excluded.

The data collection followed the following steps: (1) Pre-transplantation; (2) Immediate post-transplantation, characterized by pancytopenia period (period in which the patient's immunity is more compromised and when the main complications occur); (3) Graft "catch" phase, (period when the patient is prepared for discharge). From the 25 participants that did the first data collection step, only 24 constituted the sample of the subsequent steps due to a death.

For the data collection, three instruments were used: (Q1) Sociodemographic and clinical data; (Q2) Quality of Life Questionnaire – C30 (QLQ-C30) – version 3.0 Portuguese – Brazil; (Q3) Functional Assessment Cancer Treatment-Bone Marrow Transplantation (FACT-BMT) – version 4.0 Portuguese – Brazil specific for HSCT.

The instruments Q2 and Q3 were translated and validated by two independent institutions, which developed research for cancer treatment. One European, the European Organization Research Treatment of Cancer (EORTC), and one American, The Functional Assessment of Chronic Illness Therapy (FACIT), both authorized the questionnaire's use.

The QLQ-C30, created by EORTC is composed by 30 items divided as: five functional scales; three symptom scales; six individual items assessing symptoms; a scale to assess financial, treatment and disease impact, and two questions about the general health state and QoL. The FACT-BMT, created by FACIT is composed by 50 items divided in five domains: physical wellbeing, functional, emotional, social and familiar, and additional worries.

The sociodemographic data were analyzed with descriptive statistics and expressed in simple and absolute frequencies. The QLQ-C30 results were expressed in scores varying from zero to 100 in accordance with the Scoring Manual from EORTC(13). A higher score in the functional scales represent better general state. For symptoms, a higher score represent a worsening in general state. The FACT-BMT results were expressed in scores varying from zero to 148. For the physical wellbeing, functional, social and family, and emotional domains, the scores vary from zero to 28, additional worries vary from zero to 40, Trial Outcome Index (TOI) from zero to 96, Functional Assessment Cancer Treatment General (FACTG) from zero to 108, in accordance with the FACIT Scoring Manual(14). In the final FACT-BMT score, the higher ones represent better QoL.

A descriptive analysis of the scales was done to resume the data, expressed in means (Ms), standard deviations (SDs) and minimum and maximum values that each item can have. To compare steps, a Friedman's test was applied, complemented by the Minimal Significant Difference for multiple comparisons (*p* value). Results with a *p* ≤0.05 were considered significant.

This study was approved by the Ethics in Research Committee from the Health Sciences Sector of Universidade Federal do Paraná under the protocol nº 411.548. The participants were informed about the objectives and research methods, as well as all existing questions were clarified. Thus, patients who accepted to participate in the study were invited to sign the Free and Informed Consent.

RESULTS

Based on the sociodemographic data, the mean participant's age was 36 years, ranging from 18 to 69 years, 52% (n=13) were female, 72% (n=18) of white ethnicity, 56% (n=14) were married or in a stable relationship and 48% (n=12) had one to three children. Regarding education, 56% (n=14) completed high school and 52% (n=13) declared themselves as economically active, with a monthly income of up to three minimum wages (R$724 = national minimum wage).

In relation to diagnosis, 64% (n=16) had leukemia and 52% (n=13) with one to three years of diagnosis. Eleven patients (44%) were submitted to unrelated allogenic HSCT, and the cell source was peripheral for 64% (n=16) of patients.

The results from the QLQ-C30 questionnaire demonstrated the initial global QoL of participants with a mean value of 83. In the second and third step, it was observed respectively, that mean global QoL values obtained a significant drop, 56.25 and 69.44. In the functional scales, the basal means varied from 50 to 92, for social and cognitive domains, respectively. The mean of these domains on subsequent steps were 25.69 to 85.42 and 34.42 to 92.83. The social domain assumed a lower mean value on second and third steps. In the symptoms scales, the insomnia with mean 20 and financial difficulties with mean 44 were the most frequent at the basal moment. During pancytopenia, pain was more predominant, obtaining a mean of 59.72, with attention to loss of appetite, mean 58.33 that maintained elevated mean of 50 until pre-discharge.

Regarding the comparison of results from questionnaires QLQ-C30 obtained in the three steps (Table 1), it was possible to observe a worsening statistically significant for global quality of life, functional and symptom scales.

Table 1: Significant scores of QLQ-C30 in the comparison between the three steps of the study. Curitiba, PR, Brazil, 2014.

Domains	p value	1st step X 2nd step	1st step X 3rd step	2nd step X 3rd step
Global quality of life	0.000001*	$p<0.001$*	-	$p<0.05$*
Functional scales				
Physical function	0.00016*	$p<0.001$*	-	-
Personal performance	0.00003*	$p<0.001$*	$p<0.05$*	-
Emotional function	-	-	-	-
Cognitive function	-	-	-	-
Social function	0.00176*	$p<0.05$*	-	-
Symptoms scales				
Fatigue	0.00003*	$p<0.001$*	$p<0.01$*	-
Nausea and vomit	0.00001*	$p<0.001$*	$p<0.05$*	-
Pain	0.000001*	$p<0.001$*	-	$p<0.001$*
Dyspnea	-	-	-	-
Insomnia	-	-	-	-
Loss of appetite	0.000001*	$p<0.001$*	$p<0.01$*	-
Constipation	-	-	-	-
Diarrhea	0.000001*	$p<0.001$*	-	$p<0.01$*
Financial difficulties	-	-	-	-

NOTE: *Statistically significant data

Results from the FACT-BMT questionnaires are described on Table 2. Regarding the comparison of results from FACT-BMT questionnaires obtained in the three steps (Table 3), it was possible to observe emotional wellbeing not having a worsening statistically significant, but all other domains were worse.

Table 2: Results of FACT-BMT obtained on the three study steps. Curitiba, PR, Brazil, 2014

FACT-BMT	Basal (n=25)				Pancytopenia (n=24)				Pre-discharge (n=24)			
Domains	**Mean**	**Min**	**Max**	**SD**	**Mean**	**Min**	**Max**	**SD**	**Mean**	**Min**	**Max**	**SD**
Physical wellbeing	24.6	11	28	4.3	15.6	3	26	6.8	21.2	11	27	4.5
Social and family wellbeing	21.2	9	28	5.1	16.7	7	23	3.8	15.8	9	22	3.1
Emotional wellbeing	19.9	9	24	3.7	20.7	14	24	2.6	21.7	11	24	2.8
Functional wellbeing	21.9	6	28	4.7	14.2	5	25	4.4	15.7	7	25	4.7
Additional worries	31.4	13	39	5.3	23.2	16	32	4.6	24.4	16	32	3.9
TOI*1	78	30	94	12.6	53.1	30	80	13.7	61.4	40	80	10.9
FACTG*2	87.8	35	103	14.5	67.4	44	89	11.3	74.6	44	87	10.5
General QoL	119.2	48	140	18.7	90.6	61	118.2	15	99.1	62	118.2	13.9

NOTE: *1: TOI – Trial outcome index *2: FACTG – General assessment

Table 3: Significant scores of FACT-BMT in the comparison between the three study steps. Curitiba, PR, Brazil, 2014

Domains	p value	1st step X 2nd step	1st step X 3rd step	2nd step X 3rd step
Physical wellbeing	0.000001*	$p<0.001$*	-	$p<0.05$*
Social and family wellbeing	0.000001*	$p<0.01$*	$p<0.001$*	-
Emotional wellbeing	-	-	-	-
Functional wellbeing	0.000001*	$p<0.001$*	$p<0.001$*	-
Additional worries	0.000001*	$p<0.001$*	$p<0.001$*	-
TOI	0.000001*	$p<0.001$*	$p<0.001$*	-
FACTG	0.000001*	$p<0.001$*	$p<0.01$*	-
General QoL	0.000001*	$p<0.001$*	$p<0.001$*	-

* Statistically significant data

DISCUSSION

In this study, patients with blood cancer submitted to HSCT are married or in a stable relationship and had one to three children, a result corroborated with international research(7-8). Such fact refers to the multidisciplinary team, to the need for assistencial planning adding family members/companions in their guidance, to help the patient to face physical, psychological, and social changes caused by therapy.

The high school education is different from studies conducted in Chicago (USA), that compared patients' QoL submitted to HSCT, and a study in Omaha (USA), that assessed QoL and intensity of HSCT symptoms; in both patients with a under graduate education is prevalent. This study corroborates with these same studies regarding socioeconomic data, participants were economically active before hospitalization and at HSCT they were distant from their professional activities, with a permit for health treatment(7,15).

Among many negative events from cancer, financial difficulty is responsible for vulnerability of conditions. The lack of financial resources is a family problem when the disease affects the providing member, leading this member to withdraw from work. The sick employee is less paid and the payment comes as retirement or sickness payment, and not having another source of income, the family suffers with lack of money. Even with the treatment assumed by the SUS (Unified Healthcare System), there is no coverage for expenses with prescribed drugs.

It is important to comprehend financial problems influences accentuated with the expenses generated by the treatment, becoming important for nurses to orient, to promote clear information about rights of the cancer patient, to suggest cheaper options when some acquisition is needed by the transplanted patient, and to refer the family members to Social Services professionals.

Regarding the clinical data, leukemias are the more prevalent blood cancers followed by lymphoma and myeloma(7). The diagnosis time of these is one to three years (52%) similar to a study from Los Angeles (USA)(16). Between participants, 44% were submitted to allogenic HSCT, compatible with studies developed in Germany and USA(6,7). Regarding cells source, peripheral cells were predominant. American and Chinese researchers highlight the use of peripheral cells in comparison to bone marrow cells, revealing that although bone marrow presents lower risk of graft-versus-host (GVH) disease, the blood recovery is slower, interfering on the marrow graft "catch" (9,17).

Each patient will have different perceptions according to their disease, time of diagnosis and their life perspectives. To identify altering domains in patients with blood cancer submitted to HSCT becomes important, once these changes directly reflect their QoL.

According with the EORTC Scoring Manual(13), QoL is a broad and subjective construct and, the general health state found in the QLQ-C30 or FACT-BMT should be used as a measure of global synthesis for QoL of oncologic patients submitted to HSCT(14). Before initiating the HSCT, patients consider their QoL as good. However, when the pancytopenia period occurs, there is a statistically significant drop in this index, demonstrating how severe is the treatment.

In reviews published in 2012, with summarized available data about QLQ-C30 scores from studies published about HSCT(6) using the FACT-BMT(7), it was observed a smaller variation of minimum and maximum values and mean values for general health status during hospitalization and pre-HSCT, and the mean value at discharge. The variations seem equivalent to the present study, a fact that indicates impaired QoL during treatment, with gradual improvement in the continuation.

Analyzing the QLQ-C30 and FACT-BMT functional scales, it was observed a deficit in physical function/wellbeing and in the personal development/functional wellbeing throughout the therapy, with differences statistically significant between study steps. These data corroborate with a research conducted using the scale QLQ-C30 in 40 individuals receiving intervention and 40 individuals in the control group with blood cancers submitted to allogenic HSCT. For the control group, similarly to the results of this study, physical function at the basal period was 76, with lower values in hospitalization steps, as well as 30 to 40 days post-HSCT (equivalent to the discharge period), with mean values of 53.5 and 63.5, respectively to the periods(10). These results denote QoL impairment of patients in the actual study in relation to these domains.

In the data from a study in Chicago (USA), for the FACT-BMT scale, the mean found for physical wellbeing varied for the three periods between 17.73 and 31.73, designating a negative impact on QoL, with attention to the hospitalization period, as occurred in this study, when the mean value during hospitalization was 15.67(7).

The functional wellbeing domain presents significant results, predominant in QoL assessments. It interferes in other symptoms related to therapy as fatigue, physical weakness, sleep disturbance and lack of appetite(15). In the present study, the functional wellbeing and personal performance presented significant worsening during treatment, with attention for pancytopenia period. During this period until the first 100 days, functional wellbeing permeates with the worse scores, returning to basal values when completing one year post-HSCT, following in continuous improvement(18). The main difficulties experienced are at discharge, when the patient is debilitated to execute work-related and daily activities at home(19).

During the period when the patient stays hospitalized, multiple adverse events from the conditioning regimen are noted, thus, physical function and personal development are domains really impaired at this moment. When hospitalized in isolation, this individual needs care which should be expanded beyond the biomedical model, attending other demands that can arise during treatment that should be guided by the nurse. These care should englobe facilitating measures to adapt the patient to their reality, stimulating autonomy facing cancer adversities.

In the present study, the social function from the QLQ-C30 scale had a basal mean of 50, pancytopenia: 25.69 and pre-discharge: 34.72. This is a similar result to the German study with a mean value of 53.8 at basal step, hospitalization as well as in discharge periods, the same social function kept an average of 42.1 and 46.7(10). The study using the FACT-BMT scale, revealed the basal value for social and family wellbeing of 24.35, a little above what was found in this study (21.29), yet all other assessed steps are not compatible with this study(8).

Variables as gender and age can be associated to social wellbeing, and can be compromised in patients presenting GVH(16). Thus, it can be inferred that clinical complications result in QoL losses to patients submitted to HSCT, including in relation to psychosocial adjustment. Social support can serve as “cushion” leading to better coping, humor improvement and, consequently, better health results(20-21). Moreover, social support construction can incorporate elements that have been associated with better immune function leading to positive clinical results(22).

A limitation is perceived when mentioning about the social and family wellbeing due to lack of literature investigating the QoL while the patient stays hospitalized for the HSCT, considering this as the period to show the impairment of this domain. Thus, it is important for nursing to appropriate care extended to all QoL impaired dimensions, to establish a relationship of support and trust with the patient and family/companions is a fundamental action for this process.

Analyzing the QLQ-C30 symptom scales, there is an increase of symptomatology referring to fatigue, nausea and vomit, pain, loss of appetite and, diarrhea throughout therapy. In the FACT-BMT the loss of appetite was the most predominant symptom in the steps. Similar findings were seen by a study in Omaha (USA), the symptom loss of appetite assumed elevated mean values since the conditioning period, with a peak in the pancytopenia period and, with light regression after the graft(15), the physiological effects caused worsening in QoL, however, those are the domains in which the multidisciplinary team is more ready to act.

Regarding additional worries with data referring to body image, sexuality, and financial difficulties, in the FACT-BMT results it was seen QoL impairment in participants. Agreeing with the study in Chicago (USA) (7), the *p* value was similar for the same steps. The therapy can affect diverse dimensions in these people’s lives, being directly related to symptomatology and to body image perception by patients submitted to HSCT.

Changes in body image were reported by some patients after the transplantation treatment, including the loss of hair and muscle mass, eruptions in the skin, skin dryness and sensitivity, scars, weight changes and edema, especially in the face. The altered body image can disturb feelings about themselves as a sexual being(23).

An item that significantly decreased during the basal period until discharge, in the additional worries domain, was regarding sexual interest(7). Elevated doses of radiation and chemotherapy antineoplastic are associated to a number of toxic effects in short and long term, what can result in changes of sexual functioning and satisfaction. Although the impact of a life threatening disease on sexuality in not the first or more immediate preoccupation for patients submitted to transplantation, it is an important aspect sometimes forgotten to recover and for QoL after treatment(23).

One of the main determinants of sexual dysfunction in patients submitted to allogenic HSCT is the GVH, that can be manifested in many organs, causing adherence in blood vessels, skin eruptions and increase of skin sensitivity around the penis. In female genital organs, it can lead to vaginal stenosis(24).

One of the nursing functions is the integral and humanized care, providing pertinent information to patients, as well as to their partners, to clarify issues about changes in body image and sexuality during and after the treatment, possible changes related to medication and/or therapeutic modalities that can affect sexual performance, so they can adjust to these changes in the best way possible.

Financial difficulty in the QLQ-C30 questionnaire did not show significant difference between steps, it was one of items, which kept mean values, between 37.5 and 44. In this study, 56% life with governmental support, that is, they are people unable to work, they worry about financial matters, and normally they are the family providers.

CONCLUSION

Results of this study demonstrate that HSCT changes QoL of patients with blood cancers during hospitalization. These changes were perceived on global/general QoL, physical function/physical wellbeing, personal performance/functional wellbeing, social function/social and family wellbeing, additional worries, besides symptoms of fatigue, nausea and vomit, loss of appetite and diarrhea.

From the findings, it is possible to reflect about the actual nursing care, in which symptomatology related to treatment is the focus of guidance. Facing this, the nurse should be present in each moment of the therapeutic process, promoting actions to reach balance between maintenance of physical, emotional and social dimensions, considering personal and social characteristics of each patient in their care and orientations, aiming to adapt them to the moment experienced with better life conditions.

It is possible to highlight that observed statistical associations in this study between the variables of QoL questionnaires reproduce similar results in the literature, but, the steps in which studies approach them is considered as a limitation, because not all steps were similar to this study, some studies do not assess QoL during pancytopenia, only basal and 30-day, or basal and graft “catch”.

The reduced sample size is another limitation of the study, thus, results are applicable only to the same population. Therefore, we cannot generalize our results. In addition, this study only considered the hospitalization HSCT step. Therefore, future research is important to approach other HSCT steps.

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