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Social impairment of patients undergoing hematopoietic stem cell transplant

Comprometimento social de pacientes submetidos ao transplante de células-tronco hematopoéticas
Deterioro social de los pacientes sometidos a trasplante de células madre hematopoyéticas

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ABSTRACT

Objective: to evaluate the impairment of social and emotional domains of hospitalized patients undergoing hematopoietic stem cells transplantation. **Method:** an observational, longitudinal study with 25 participants evaluated in the period of pre-transplant, pancytopenia and pre-hospital discharge between September 2013 and September 2014, in a reference hospital for this treatment modality in Brazil. Two international instruments were used, both of which translated and adapted to Portuguese (Brazil): Quality of Life Questionnaire-Core 30 and Functional Assessment Cancer Therapy - Bone Marrow Transplantation. **Results:** patients have shown a statistically significant decrease in the social domain, and stability of the emotional function along the course of treatment. **Conclusion:** hematopoietic stem cell transplantation changes the social function of patients with hematologic cancer during hospitalization stage. Thus, patients should receive guidance addressing the social domain in order that it can be less affected.

Descriptors: Quality of Life; Hematopoietic Stem Cell Transplantation; Oncology Nursing; Social Isolation; Hospitalization.

RESUMO

Objetivo: avaliar o comprometimento dos domínios sociais e emocionais de pacientes internados submetidos ao Transplante de Células-Tronco Hematopoéticas. **Método:** estudo observacional, longitudinal, com 25 participantes, avaliados no período pré-transplante, pancitopenia e pré-alta hospitalar, entre setembro de 2013 e setembro de 2014, em um hospital de referência no Brasil para esta modalidade de tratamento. Utilizou-se dois instrumentos internacionais, ambos traduzidos e adaptados para a língua portuguesa (Brasil): *Quality of Life Questionnarie-Core* 30 e *Functional Assessment Cancer Therapy –– Bone Marrow transplantation*. **Resultados:** os pacientes apresentaram queda estatisticamente significativa no domínio social e estabilidade da função emocional ao longo do percurso. **Conclusão:** o Transplante de Células-Tronco Hematopoéticas altera a função social dos pacientes com câncer hematológico durante a etapa de internamento. Deste modo, o paciente deve receber orientações que contemplem o domínio social, de maneira que este possa ser menos comprometido.

Descritores: Qualidade de Vida; Transplante de Células-Tronco Hematopoéticas; Enfermagem Oncológica; Isolamento Social; Hospitalização.

RESUMEN

Objective: evaluar el deterioro de los dominios sociales y emocionales de los pacientes hospitalizados sometidos a trasplante de células madre hematopoyéticas. **Método:** estudio longitudinal observacional con 25 participantes evaluados en el período pre-trasplante, pancitopenia y pre-hospitalario, entre septiembre de 2013 y septiembre de 2014, en un hospital de referencia en Brasil para esta modalidad de tratamiento. Dos instrumentos internacionales traducidos y adaptados al Portugués (Brasil) fueron utilizados: *Quality of Life Questionnaire-Core 30* and *Functional Assessment Cancer Therapy - Bone Marrow Transplantation*. **Resultados:** los pacientes mostraron una disminución estadísticamente significativa en el ámbito social y estabilidad de la función emocional durante el tratamiento. **Conclusión:** el trasplante de células madre hematopoyéticas cambia la función social de los pacientes con cáncer hematológico durante la fase de hospitalización. Por lo tanto, el paciente debe recibir directrices que aborden el ámbito social, por lo que puede ser menos comprometido.

Descriptores: Calidad de Vida; Trasplante de Células Madre Hematopoyéticas; Enfermería Oncológica; Aislamiento Social; Hospitalización.

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INTRODUCTION

Patients undergoing transplantation of hematopoietic stem cell transplantation (HSCT) need special care due to the long period of hospitalization and social isolation. This requires a nursing care that meets the different areas affected in quality of life (QOL) and favors the process of adaptation to the time experienced with the adversities of pathology and treatment.

The relevance of social and emotional support in the hospital environment becomes evident when observing the complexity of therapy, the care demands during hospitalization and the difficulties of patients' reintegration into society after HSCT. This support involves the material, affective, emotional, information and interaction dimensions, together with formal and informal relationships that oncologic patients establish to meet the challenges imposed by the disease(1-2).

The importance of social and emotional support as a means to assist in the process of adjusting and maintaining the QOL of cancer patients implies consolidating the clients' support network for the planning and implementation of quality care(2).

Social support is understood as types of interactions based on the support reciprocity between individuals, groups and institutions that seek to ensure psychological and physical well-being. These interpersonal interactions are promoted and changed according to the cultural and economic characteristics of those involved(1,3).

Patients with hematologic malignancies and recommendation of HSCT face a difficult step in their lives. The diagnosis of a threatening disease brings feelings of sadness, anger and uncertainty about the success of treatment to individuals and their families. Most of these patients are at the peak of their productive years, and experiencing the drama of the disease, complexity of treatment and exposure to risks requires coping with drastic changes in their daily activities.

Therefore, the QOL may be compromised by the abrupt disruption of daily life, withdrawal from studies, work, leisure activities and social and family life. There is a strong psychosocial impact with incorporation of new routines resulting of the disease process and discipline required for treatment(4). All these aspects interfere in the social and emotional domains.

A study evaluated the QOL of patients undergoing HSCT using the specific questionnaire of the Functional Assessment of Cancer Therapy - Bone Marrow Transplantation (FACT-BMT) in the steps of pre-HSCT (30 and 180 days after HSCT). It showed that social and family well-being were not significantly affected during these periods. However, the physical, functional and psychological impairment, and additional concerns were more significant. The authors mention that reintegration problems such as difficulties in returning to their social role, separation from home, family and friends and financial difficulties, are considered social and family welfare issues that compromise QOL in the first year after HSCT(5).

Patients have their QOL affected for being away from their loved ones during cancer treatment. In addition, several circumstances are imposed by life as consequences of cancer, such as fear of isolation and physical deterioration, the probability of not being able to participate in social life, and inability to perform chores. Thus, it is key that nurses are prepared for user embracement and provision of support and care for patients, avoiding greater commitment to their health(6).

Assisting people with cancer requires care with peculiarities related to this nursing practice area. The approach of these complexities implies commitment of the health team through multidisciplinary work to meet the needs of clients and their families within the possibilities and in face of the uncertainty, diversity and unpredictability of the complex reality surrounding these individuals(7).

Thus, it is essential that nurses consider all the affected dimensions during the therapeutic course, and direct actions to a humane, holistic and singular approach, providing better conditions of life and health for patients with hematologic malignancies undergoing HSCT.

OBJECTIVE

To evaluate the impairment of social and emotional domains of hospitalized patients undergoing HSCT.

METHOD

Ethical aspects

This study is part of the macro project: 'Evaluation of quality of life of patients with hematologic neoplasia subjected to hematopoietic stem cell transplantation'. It was approved by the Research Ethics Committee of the Health Sciences sector of the Universidade Federal do Paraná.

The use of questionnaires was authorized upon registration at the European Organization Research Treatment of Cancer (EORTC) and the Functional Assessment of Chronic Illness Therapy (FACIT). These institutions have provided the questionnaires for download directly to the researcher.

Study design, location and period

This is a longitudinal, observational study. It was performed in the bone marrow transplant service (BMTS) of a teaching hospital in Curitiba that is national reference in HSCT. The study period was from September 2013 to September 2014.

Sample

The sample consisted of 25 participants who met the inclusion criteria of age above 18 years, with hematologic malignancy and subjected to HSCT. Participants without physical conditions to complete the questionnaires were excluded of the study. A patient died during the study, so his participation was discontinued.

Study protocol

Data collection was held in the inpatient ward of the BMTS in three stages, namely: before HSCT to establish the baseline, period of pancytopenia, and predischarge period. The sociodemographic and clinical data were collected with a specific instrument before the HSCT. The following questionnaires were applied in the three stages of data collection: the Quality of Life Questionnaire - Core 30 (QLQ C-30) - version 3.0 Brazilian Portuguese, prepared by the EORTC, composed of 30 items divided into functional and symptom scales; and the FACT-BMT - version 4.0 Brazilian Portuguese, prepared by the FACIT, and composed of 50 items divided into domains.

To evaluate the domains of social and emotional functions of the QLQ-C30, the scores ranged 0-100. According to the EORTC scoring manual, higher results represent better QOL(8). For evaluation of domains of social and family well-being, and emotional well-being with the FACT-BMT, the score ranged 0-28, as described in the scoring manual of the FACIT(9). All calculations were performed according to the aforementioned manuals.

Results and statistical analysis

A descriptive analysis of the sociodemographic and clinical data was performed, and information was expressed in absolute and relative frequency. Questionnaire data were organized in tables and analyzed as recommended by the EORTC and FACIT, and values were expressed as average, minimum, maximum and standard deviation.

The Friedman test was applied for comparison between the stages, and complemented by the least significant difference test for multiple comparisons (p value), in which p-value results equal to or below 0.05 were considered significant ($p < 0.05$). All calculations were performed by a professional statistician.

RESULTS

Table 1 shows the sample characterization, highlighting patients' average age of 36 years, 52% (n = 13) of the female gender, 56% (n = 14) married or in a common-law marriage, 48% (n = 12) with 1-3 children, and 52% (n = 13) stated themselves as economically active with monthly family income of up to three Brazilian minimum wages. The diagnosis of leukemia was prevalent in 64% (n = 16), with diagnosis time of one to three years for 52% (n = 13) of the sample, 44% (n = 11) underwent allogeneic unrelated transplant, and in 64% (n = 16) the cell source was peripheral.

Table 2 shows the social function results of the QLQ-C30 and FACT-BMT questionnaires that were collected in the three stages of hospitalization. A decline was observed in the social function, and the emotional function remained stable.

Table 1 – Sample characterization of patients undergoing hematopoietic stem cell transplantation (N=25), Curitiba, Paraná, Brazil, 2013-2014

Sociodemographic variables	n	%
Age (years)	$\bar{X}$ 36.32	min.18-max.69
Gender		
Male	12	48
Female	13	52
Marital status		
Single	11	44
Married or common-law marriage	14	56
Separated or divorced	0	0
Widowed	0	0
Number of children		
None	10	40
1-3	12	48
More than 3	3	12
Educational level		
Illiterate	0	0
Complete primary school	6	24
Complete secondary school	14	56
Complete higher education	5	20
Occupation		
Economically active (employed and self-employed)	13	52
Retirees	3	12
Homemaker	4	16
Students	5	20
Unemployed	0	0
Has a companion		
Yes	25	100
No	0	0
Family income*		
Up to 1 minimum wage	5	20
1-3 minimum wages	13	52
4-10 minimum wages	6	24
10-20 minimum wages	1	4
Receives benefit of the National Institute of Social Security		
None	11	44
Sickness benefit	14	56

*Note: * National minimum wage in the period of data collection = R$724.*

Table 2 – Scores of the Quality of Life Questionnaire – Core 30 and Functional Assessment of Cancer Therapy – Bone Marrow transplantation obtained in the three stages of the study, Curitiba, Paraná, Brazil, 2013-2014

	Baseline (N = 25)				Pancytopenia (n = 24)				Pre-hospital discharge s(n = 24)			
ESCORES	**Average**	**Minimum**	**Maximum**	**SD**	**Average**	**Minimum**	**Maximum**	**SD**	**Average**	**Minimum**	**Maximum**	**SD**
Quality of Life Questionnaire – Core 30												
Social Function	50	0	100	33.6	25.6	0	66.6	23.0	34.7	0	83.3	28.2
Emotional Function	73	25	100	21.4	79.5	50	100	19.1	83.6	8.3	100	22.9
Functional Assessment of Cancer Therapy – Bone Marrow transplantation												
Social and family well-being	21.2	9	28	5.1	16.7	7	23	3.8	15.8	9	22	3.1
Emotional well-being	19.9	9	24	3.7	20.7	14	24	2.6	21.7	11	24	2.8

Note: SD = Standard deviation.

Table 3 – Significant scores of the Quality of Life Questionnaire – Core 30 and Functional Assessment of Cancer Therapy – Bone Marrow transplantation in the three stages of the study, Curitiba, Paraná, Brazil, 2013-2014

	Friedman Test			
SCORES	**p value**	**1st stage X 2nd stage**	**1st stage X 3rd stage**	**2nd stage X 3rd stage**
Quality of Life Questionnaire – Core 30				
Social function	**0.00176***	**p < 0.05***	-	-
Emotional function	0.2116	-	-	-
Functional Assessment of Cancer Therapy – Bone Marrow transplantation				
Social and family well-being	**0.000001***	**p < 0.01***	**p < 0.001***	
Emotional well-being	0.54	-	-	-

*Note: *statistically significant data.*

Comparing the results of the QLQ-C30 and FACT-BMT questionnaires obtained in the three stages (table 3), we observed a statistically significant worsening in the social function.

DISCUSSION

The results show a similar age range of the study population and the national average, of 30-40 years(5,10). However, a review performed in Germany with the main QOL studies using the QLQ-C30 to evaluate the pre- and post-HSCT(11), and another review performed in Chicago (USA) that compared the QOL of patients undergoing autologous and allogeneic HSCT in 105 participants with cancer, showed the patients' age was between 40 and 50 years(12), which differs from the present study findings.

The marital status and number of children in this study corroborate data found in national and international literature, i.e., patients with hematological malignancies are married or in a common-law marriage and have one to three children(12-16).

In a study on the bond between cancer patients and their families, it was observed that the main companions of patients with neoplasia are children, spouses and parents, and family involvement is critical during the disease process. The presence of patients' companion in cases of HSCT favors the support of social and family well-being required during treatment because patients are extremely weak and dependent on care and support in every way. The presence of companions should be encouraged by the nursing team(17). Note that 100% of patients in this study had companions, which has possibly contributed to insignificant negative results in the emotional function.

Another important aspect highlighted in this study was that 52% (n = 13) of patients declared themselves as economically active prior to hospitalization, with family income of one to three minimum wages. A similar economic pattern was found in national and international studies(10,12-13,18).

Among the many negative events of neoplasia, the financial difficulty is responsible for vulnerable conditions. Lack of financial resources was mentioned as a major problem of the family, especially when the disease affects the breadwinner member. The worker who falls ill suffers a decrease of income, which starts to be paid by the National Institute of Social Security through retirement or sickness benefit. Even with treatment in the Unified Health System, there is no coverage for prescription drugs expenses(19). Therefore, the HSCT has social impact by changing the QOL of patients undergoing treatment.

The knowledge of sociodemographic and clinical characteristics of patients undergoing HSCT supports the evaluation of their social and emotional domains, because their characteristics may directly influence the maintenance of the studied domains. For nursing, it is important to understand this experience to provide guidance and clarification about the rights of individuals with cancer, suggesting less expensive options when transplanted patients need some acquisition, and referring their family members to social service professionals.

In relation to emotional function, the QLQ-C30 scale and the emotional well-being of the FACT-BMT scale remained stable during the three stages of the study, with good averages in all phases. This fact indicates that therapy had no influence in participants' emotional factor. In a study performed in Chicago (USA) with 105 cancer patients, the FACT-BMT scale results reached similar averages to those of the current study, between 18.85 and 20.52 (score 0-28)(12).

In a study developed in the cities of Heidelberg and Wiesbaden (Germany) and in a review also conducted in Germany, both using the QLQ-C30 scale, the results in the emotional function had negative scores in the three stages during the hospitalization period, which differs from this study(11,20).

A study performed in Uberaba (state of Minas Gerais) evaluated the QOL of patients with hematologic malignancies undergoing cancer chemotherapy using the QLQ-C30 scale. Low average results were found in emotional functions, ranging from 41.18 to 47.15. The authors found the emotional function of patients has changed, according to patients' own reports, because they were nervous, depressed, worried and irritated for concerns about their family members, friends, their health status, and fear of treatment adverse effects(14).

In this study, the social function (score 0-100) of the QLQ-C30 scale had baseline average of 50, pancytopenia of 25.69 and pre-discharge of 34.72. The review conducted in Germany also found similar results, in which the social function had average below 70% in the three periods(11). Another study in Germany showed that the social function was affected in the baseline stage, with average value of 53.8. In the periods of hospitalization and discharge, the same social function kept the average values of 42.1 and 46.7, respectively(20).

According to evaluation of the FACT-BMT scale, the social and family well-being (score 0-28) had significantly worse results in this study during hospitalization, which remained until the discharge period (16.76 and 15.88, respectively). In the study performed in the city of Ribeirão Preto (state of São Paulo) using the FACT-BMT scale, the average in the discharge period was 18.3, but the average before HSCT was 18.9, which is lower than in the present study. This shows patients already had their social domain affected before the HSCT(5).

In a study in the city of Rochester (USA) using the FACT-BMT scale in patients with hematologic malignancies who underwent HSCT, the baseline value for the social and family well-being was 24.35(16), slightly above the value found in this study (21.29), although the other evaluated steps were not compatible with this work. Only the pre-HSCT result found in the study performed in Chicago (USA) approaches the value of this study (23.15). In the other periods the average values were higher and not considered significant(12).

This time stability is probably related to the fact that patients in that study perceived they had high level of support regardless of the severity of their symptoms in other domains, at least in the early stages of treatment. Satisfaction with social support is a well-established protective factor and has been linked to lower stress levels(21). Thus, it is important that nurses provide guidance and strengthen the social support with family and/or patients' companions from the moment of admission, helping to maintain adequate levels of support throughout the treatment and recovery process.

The study conducted in Los Angeles (USA) refers a possible association between variables such as age and gender with social well-being(22). In the study conducted in Ribeirão Preto (SP), results of the FACT-BMT subscales showed the domains of social/family well-being were affected ($p < 0.001$) in patients with graft versus host disease (GVHD)(23).

Thus, it is possible to infer that clinical complications result in damage to the QOL of patients submitted to HSCT, including in relation to psychosocial adjustment. The concern with social issues is emerging from demands of the own people living with cancer or undergoing HSCT, which makes social support relevant in clinical practice. Since there is better understanding that patients are more likely to adhere to social support, it is possible to adequately adapt to what is offered, such as guidelines, evaluation measures of social support dimensions, and interventions for patients who access the service(24).

The concepts comprising the social well-being are closely related to the social support received and perceived. Although the Canadian review suggests a significant association between social support and overall survival, the underlying variables explaining the positive potential of social support influence on survival in transplantation need to be identified. Potential components of social support may include instrumental and emotional support. Instrumental support - such as better medication adherence, and timely and frequent access to health care - has been considered the reason for the effect of social support. Emotional support is the sense of support to emotional needs and sharing decisions or challenging fears with someone else(25).

The transplant is an especially aggressive treatment that often has physical, psychological, and social well-being effects. Social support is essential during the process in which patients often have to rely on family and/or friends to provide assistance(26).

There is a limitation in addressing the social and family well-being given the lack of literature on the emotional and social function while patients remain hospitalized for HSCT because in this period the effects in this domain may become evident.

HSCT predisposes patients to impairment of the social function. The decrease of this function after hospitalization is accentuated since patients are isolated from social living and activities and their recovery will occur over time(11).

With this demand, nurses must establish a relationship of trust and support with patients and families to overcome possible difficulties in this process, favoring the preservation of their QOL, which again justifies the choice of this domain for deepening and intervention.

Study limitations

Although the sample size is compatible with the calculation for the study location, we point its small size as a limitation, thus, it is not possible to generalize the results. Furthermore, as this study only covered the HSCT hospitalization stage, it is necessary to perform further studies to complement the continuation of treatment.

Contributions

This study enables the reflection about the care currently provided by nursing, in which symptoms related to treatment are the main focus of guidance. However, nursing actions must seek a balance between the maintenance of physical, emotional and social dimensions in patients with hematological malignancies. Thus, nurses should be present in every moment of the therapeutic course and consider the personal and social characteristics of each patient in the care and guidance.

Nursing can help patients coping with situations that could compromise their QOL by providing guidance at all stages of HSCT. This study can direct the development of recommendations aimed at the impairment of the social domain of patients undergoing HSCT.

CONCLUSION

The results of this study shows the occurrence of changes in the social function of patients with hematological malignancies during the hospitalization period of the HSCT. The statistical associations observed in the social and emotional domain reproduce some results found in the literature, i.e., similar associations were found with the same variables for comparison. However, the stages approached by the studies are considered as limitations because not all were similar to this study.

Nurses should reflect on the care currently provided by nursing, in which symptoms related to treatment are the main focus of guidance. However, monitoring the disease impact from other perspectives such as social and emotional, leads to the improvement and adaptation of practices to promote well-being during HSCT.

Thus, nurses should be present in every moment of the therapeutic course and take into consideration in their care and guidance, the personal and social characteristics of each patient. The findings of this study are important for nurses and other health professionals, and each individual has peculiarities that can intensify or lessen the symptoms of treatment and therefore compromise their well-being.

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