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QUALITY OF LIFE OF THE MAIN CARETAKERS OF POST-HEMATOPOIETIC STEM-CELL TRANSPLANT PATIENTS

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ABSTRACT

Objective: to evaluate and to identify the areas affected in the quality of life, to correlate with the care overload and the emotional discomfort of adult patients with hematologic cancer submitted to the hematopoietic stem-cell transplant.

Method: cross-sectional and retrospective study carried out with 59 main caretakers of patients submitted to this treatment modality. The sociodemographic profile was characterized and the life quality assessment (*Medical Outcomes 36 Study - Item Shorts Form Health Survey*), emotional discomfort assessment (*Self Reporting Questionnaire*) and the care overload (*Zarit Burden Interview*) questionnaires were applied.

Results: the participants were predominantly female, married and with high school education level. In the life quality assessment, the correlation between the Functional Capacity and Pain, and between the Emotional Aspects and Mental Health was observed. The highest score presented by the emotional discomfort was not significant. In relation to the care overload, the greatest frequency was between moderate and moderate to serious overload.

Conclusion: the life quality of these patients' main caretakers is harmed in different areas and the care overload is significant; it is suggested that the main caretakers of the patient who undergoes a hematopoietic stem-cell transplant is also the focus of the multiprofessional team that assists the transplanted patient aiming at promoting the quality improvement in both lives.

DESCRIPTORS: Quality of life. Oncologic nursing. Hematopoietic. Stem-cell transplant. Caretakers. Neoplasia.

QUALIDADE DE VIDA DOS CUIDADORES PRINCIPAIS DE PACIENTES PÓS-TRANSPLANTE DE CÉLULAS-TRONCO HEMATOPOÉTICAS

RESUMO

Objetivo: avaliar e identificar os domínios afetados na qualidade de vida, correlacionar com a sobrecarga de cuidado e o desconforto emocional dos cuidadores principais de pacientes adultos com câncer hematológico submetidos ao transplante de células-tronco hematopoéticas.

Método: estudo transversal e retrospectivo realizado com 59 cuidadores principais de pacientes submetidos a esta modalidade de tratamento. Foi caracterizado o perfil sociodemográfico e aplicado o questionário de avaliação de qualidade de vida (*Medical Outcomes Study 36 – Item Short Form Health Survey*), avaliação do desconforto emocional (*Self Reporting Questionnaire*) e de sobrecarga de cuidado (*Zarit Burden Interview*).

Resultados: os participantes foram predominantes cuidadores principais do sexo feminino, cônjuges e com nível médio de escolaridade. Na avaliação da qualidade de vida foi observada correlação entre a Capacidade Funcional e Dor e entre Aspectos Emocionais e Saúde Mental. O maior escore apresentado pelo desconforto emocional não foi significativo. Em relação à sobrecarga de cuidado a maior frequência se deu entre sobrecarga moderada e moderada a grave.

Conclusão: a qualidade de vida de cuidadores principais destes pacientes é prejudicada em diferentes domínios e a sobrecarga de cuidado é significativa; sugere-se que os cuidadores principais do paciente que realiza o transplante de células-tronco hematopoéticas sejam foco também da equipe multiprofissional que assiste o transplantado visando a promover a melhoria da qualidade de vida de ambos.

DESCRITORES: Qualidade de vida. Enfermagem oncológica. Transplante de células-tronco hematopoéticas. Cuidadores. Neoplasia.

CUALIDAD DE VIDA DE LOS CUIDADORES PRINCIPALES DE PACIENTES POS-TRANSPLANTE DE CÉLULAS-TRONCO HEMATOPOYÉTICAS

RESUMEN

Objetivo: evaluar e identificar los dominios afectados en la cualidad de vida, correlacionarla con la sobrecarga del cuidado y el desánimo emocional de los cuidadores principales de pacientes adultos con cáncer hematológico sometidos a un trasplante de células-tronco hematopoyéticas.

Método: estudio transversal y retrospectivo realizado con 59 cuidadores principales de pacientes sometidos a esta modalidad de tratamiento. Se caracterizó el perfil sociodemográfico y se aplicó el cuestionario de evaluación de cualidad de vida (*Medical Outcomes Study 36 – Item Short Form Health Survey*), evaluación del desánimo emocional (*Self Reporting Questionnaire*) y de la sobrecarga del cuidado (*Zarit Burden Interview*).

Resultados: los participantes fueron, predominantemente, cuidadores principales del sexo femenino, cónyuges y con nivel secundario de escolaridad. En la evaluación de la cualidad de vida se observó la correlación entre la Capacidad Funcional y el Dolor, entre Aspectos Emocionales y de Salud Mental. El mayor resultado presentado por el desánimo emocional no fue significativo. En relación a la sobrecarga del cuidado, la mayor frecuencia se dio entre la sobrecarga moderada y de moderada a grave.

Conclusión: la cualidad de vida de los cuidadores principales de estos pacientes es perjudicada en diferentes dominios y la sobrecarga del cuidado es significativa. Se sugiere que los cuidadores principales del paciente que realiza el trasplante de células-tronco hematopoyéticas sean considerados también por el equipo multiprofesional que atiende al trasplantado con el objetivo de promover la mejoría de la cualidad de vida de ambos.

DESCRIPTORES: Cualidad de vida. Enfermería oncológica. Transplante de células-tronco hematopoéticas. Cuidadores. Neoplasia.

INTRODUCTION

The diagnosis and the therapeutical itinerary of the patient with hematologic cancer may alter their Quality of Life (QL)[1] as well as of their main caretaker, who experiences this as a factor of chronic stress with negative psychological, behavioral and physiological effects on their daily lives and health.[2] The main caretaker is understood as the one who undertakes the task of caring, without technical preparation nor remuneration to do this activity.[3]

Among the therapeutical modalities used for the hematologic cancer is the Hematopoietic Stem-Cell Transplant (HSCT),[4] a complex procedure that may not be completely resolutive. It may recover the patient's health, but it may also lead to death or to restrictions that interfere in life and survival routine,[5] as well as in the main caretaker's life.

The main caretakers of patients with cancer, although satisfied with taking care of them and contributing significantly to their recovery and the success of their treatment, feel overloaded by the act, resulting from the addition of new tasks to their daily routine and changes in the social and professional sphere. Thus, the overload may compromise different areas, leading to a deterioration of their QL.[3]

The overload suffered by the main caretaker is directly related to the practice of the care and is manifested through diverse physical, psychological and emotional symptoms, such as: pain, fatigue, emotional discomfort and depression.[6] Regarding the main caretaker, one of the nursing approaches is about the impacts caused by the emergence of the illness, the experience in the face of crisis situations, as well as the experience of this person regarding the care practices that will be necessary in the continuity of the treatment of the patient.[7]

The nursing care offered to patients and main caretakers in oncology promotes comfort, helps to act and to react before the death situation for both. And, when effective, it articulates the patient's involvement with the main caretaker, so that they are assisted humanely, once their interaction is a key step in the recovery process.[8]

Concerned about this theme, the development of studies and evaluation methods of the main caretaker's QL emerges, since this treatment's global survival is from 40% to 50%. Therefore, its monitoring seeking the improvement of the QL for both is necessary.[5,9]

In a study on QL carried out in Colombia with 209 main caretakers of adult patients with cancer, it was revealed that all the areas had been affected, the psychological and social well-being were the most harmed and the physical and spiritual well-being were designated as positively affected.[10] The care length can positively change the QL of the main caretakers that gradually acquire mechanisms or means to adaptat to the illness and to the care routines.[11]

The literature registers the challenges of being the caretaker of a patient with cancer. However, the studies on main caretakers of patients in HSCT are incipient.[12] Thus, it is necessary to deepen the knowledge of the specific needs of the main caretakers of patients submitted to the HSCT, in order to contribute to the quality of nursing care providade and to implement interventions directed to this main caretaker.

Thus, the objective of this research is to evaluate and identify the areas affected in the QL and to correlate them with the care overload and the emotional discomfort of the main caretakers of adult patients with hematologic cancer submitted to the HSTC.

METHOD

This is a cross-sectional study, with retrospective data collection, carried out at a reference university hospital in HSCT between October of 2014 and February of 2015. To compose the sample, all the adult patients with hematologic cancer submitted to the HSCT between June of 2009 and June of 2013 were identified, (n=130). Out of those, 65 died and six were not found or did not answer to the contact, coming to a total of 59 patients.

The data was collected from the patients who underwent the HSCT in the last five years, because it is the minimum monitoring time in the service. It was decided to collect the data one year after the hospital discharge, for it is believed that only after this time the caretaker may suffer some impact resulting from the care received. During the hospitalization, the caretaker only acts as a visitor to the patient and, therefore, does not take care of them.

After the patients selection, the 59 main caretakers who met the following inclusion criteria have been identified: older than 18 years old, who resides and has been providing patient care for at least a year and since the beginning of the treatment. The caretakers hired to provide care were excluded.

For the data collection, four instruments were used: the participants characterization questionnaire, the *Medical Outcomes Study 36* (SF-36) - *Item Shorts - Form Health Survey* questionnaire, validated for Brazil in 1999,[13] the *Self Reporting Questionnaire* (SRQ-20) questionnaire, validated for Brazil in 1986[14] and the *Zarit Burden Interview* scales, validated for Brazil in 2002.[15]

The SF-36 is a generic instrument for the evaluation of the QL that contains 36 items of multidimensional evaluation, included in 8 scales or areas: Functional capacity, Physical Aspects, Pain, General State of the Health, Vitality, Social and Emotional Aspects and Mental Health. It is evaluated by a score from 0 to 100. The zero corresponds to worst general state of health and the 100 the best one.

The SRQ-20 intends to generally detect the emotional discomfort in the population. It contains 20 questions, with two possible answers (yes/no) and it approaches emotional and physical symptoms associated to psychiatric conditions (chronic headache, insomnia, appetite alteration, concentration, nervousness, fatigue, sadness and suicidal thoughts). The greater the frequency of 'yes', the greater the emotional discomfort degree. The cut-point used is ≤ 7 for non-significant emotional discomfort and ≥ 8 for significant emotional discomfort.

The Zarit's Overload Scale - *Burden Interview*, which approaches the care overload evaluation, covers 22 items and aims at assessing the impact felt by the main caretaker on their physical and emotional health, social activities and financial conditions resulting from the care practice. The sum of all the points may vary from 0 to 88, considering that the higher the score, the greater the overload felt by the main caretaker. Associated to the this score, the cut-point for the overload diagnosis was used.[16-17] The score is considered from 0-20 as small overload, from 21-40 points as moderate overload, 41-60 as moderate to severe overload and above 61 points until the limit of 88 represents as a severe overload.

For the analysis, the data was tabulated on Microsoft Excel® 2010 using descriptive statistical analysis procedures with results expressed in simple and absolute frequency for the sociodemographic and clinical data. To evaluate the relation between the scores acquired through the questionnaire SF-36, the *Burden Interview* and the SRQ-20, the dispersion diagram, correlation of *Spearman* and a test of significance (*p*-value) for the correlation were used. To observe the correlation between the areas of the questionnaire SF-36, the correlation of *Spearman* was calculated and a test of significance (*p*-value) was performed two by two between the eight areas of the questionnaire, strong correlation for values ≥ 0.05. The values considered for a very weak correlation were between 0.00-0.19, weak were between 0.020-0.39, moderate between 0.40-0.69, strong between 0.70-0.89 and very strong between 0.90-1.00.[18]

The project participants filled in the Free and Informed Consent Term and the research was approved by the Research Ethics Committee of the Clinical Hospital at the Federal University of Alfenas in Parana under the Opinion No. 668,454 and EAC (Ethics Appreciation Certificate) 31042214.1.0000.0096.

RESULTS

Regarding the main caretakers' sociodemographic data, 67.80% (n=40) are female, four (6.78%) are not related to the patient and 38.99% (n=23) completed high school (Table 1).

Table 1 - Characterization of the sociodemographic and clinical profile. Curitiba, PR, Brazil. 2014-2015.

Variable	Absolute frequency (n=59)	Relative frequency (%)
Gender		
Female	40	67.80
Male	19	32.20
Degree of kinship		
Mother	17	28.81
Spouse	23	38.99
Siblings	8	13.56
Children	7	11.86
Others	4	6.78
Age group (years)		
18≥29	7	11.86
30≥59	43	72.89
60≥80	9	15.25
Occupation		
Employed	43	72.88
Unemployed	6	10.17
Retired	10	16.95
Family income*		
1-4	38	64.41
4-8	16	27.12
8-12	5	8.47
Education		
Illiterate	5	8.47
Elementary school	19	32.20
High school	23	38.99
Higher education	12	20.34

Family income* Minimum wage at the time of data collection: R$ 718.00

In the results of the QL SF-36 questionnaire presented in Table 2, it was possible to observe that the Functional Capacity area presented the highest average 0.7839, (SD=0.1949) followed by Pain and Emotional Aspects, with 0.6754 (SD=0.2117) and 0.6554 (SD=0.3607), respectively. The area that presented the lowest average was Vitality, with 0.5526.

Table 2 - Areas of the *Medical Outcomes Study* 36. Curitiba, PR, Brazil, 2014-2015.

Areas	Minimum	Maximum	Average	Standard Deviation
Functional capacity	0.30	1	0.7839	0.1949
Physical limitations	0	1	0.6525	0.3536
Pain	0.41	1	0.6754	0.2117
General state of health	0.12	1	0.5969	0.1942
Vitality	0.20	0.95	0.5526	0.1728
Social aspects	0.25	1	0.6398	0.1626
Emotional aspects	0	1	0.6554	0.3607
Mental health	0	0.96	0.5654	0.2214

When correlating the areas of the SF-36, greater correlations were observed between the areas 1 and 3, Functional Capacity and Pain (r=0.68, p-value <;0.001) and between the areas 7 and 8, Emotional Aspects and Mental Health (r=0.67, p-value <;0.001) as observed in Table 3.

Table 3 - Test of significance between the areas of the *Medical Outcomes Study* 36. Curitiba, PR, Brazil, 2014-2015.

Areas	Functional capacity	Physical limitations	Pain	General state of health	Vitality	Social aspects	Emotional aspects
Functional capacity	-	-	-	-	-	-	-
Physical limitations	0.54*	-	-	-	-	-	-
Pain	0.68*	0.40*	-	-	-	-	-
General state of health	0.26†	0,16	0,12	-	-	-	-
Vitality	0.49*	0.56*	0.23	0.40*	-	-	-
Social aspects	0.1	0.2	-0.01	0.18	0,2	-	-
Emotional aspects	0.2	0.51*	0.18	0.21	0.27†	0.47*	-
Mental health	0.2	0.31†	0.07	0.37*	0.50*	0.54*	0.67*

*p<;0.001; †0.01<;=p<;0.05

Regarding the results of the *Burden Interview* questionnaire, referring to the care overload felt by the main caretakers, it can be observed that the biggest frequency happened to the moderate and moderate to serious overload, both with 35.59% (n=21). The score average was 33.22 points and the standard deviation was 17.03. Two (3.4%) of the main caretakers considered the overload severe and 25.42% (n=15) did not consider the overload care-related. This result shows that the main caretakers related that their daily life activities are harmed in a moderate-to-severe degree by the care provided to the patient who experienced the HSCT.

Seeking to assess the existing correlation between the result of the SF-36 questionnaire and the *Burden interview Scale,* the results show positive correlations for the Functional Capacity and Pain areas and negative for Physical Limitations, General State of Health, Vitality, Social Aspects, Emotional Aspects and Mental Health. Despite the correlation existence, the statistical significance is low and, therefore, the correlation is considered weak. However, it is important to point out that the Functional Capacity area presents decline when compared to the care overload results of the *Burden Interview questionnaire* (Table 4).

Table 4 - Correlation of *Spearman* among the areas of the *Medical Outcomes Study* 36 and the *Burden Interview.* Curitiba, PR, Brazil, 2014-2015.

Areas of the *Medical Outcomes Study* 36	Burden *Interview Score*	
	Correlation	p-value
Functional capacity	0.05805	0.6623
Physical limitations	-0.28056	0.0314*
Pain	0.28603	.0.0281*
General state of health	-0.26690	0.0410*
Vitality	-0.35114	0.0069*
Social aspects	-0.15782	0.2326
Emotional aspects	-0.18104	0.1700
Mental health	-0.49420	0.0001*

* *p*- significant value

For the SRQ-20 questionnaire, 51% (*n*=30) of the main caretakers presented a score less than or equal to 7 points, which characterizes non-significant emotional discomfort and 49% (n=29) scored 8 points or more, characterizing significant emotional discomfort.

To observe the correlation among the areas of the SF-36 and the score of the SRQ-20, the correlation of *Spearman* and the test of significance, presented in Table 5, were conducted. The Pain area had a positive correlation with the SRQ-20 questionnaire.

Table 5 - Correlation of *Spearman* among the areas of the *Medical Outcomes Study* 36 and the SQR-20 - Curitiba, PR, Brazil, 2014-2015.

Areas of the *Medical Outcomes Study* 36	**Score of the *Self Report Questionnaire***	
	Correlation	***p*-value**
Functional capacity	-0.0976	0.4621
Physical limitations	-0.3017	0.0202*
Pain	0.1705	0.1968
General state of health	-0.4431	0.0004*
Vitality	-0.4034	0.0017*
Social aspects	-0.3511	0.0064*
Emotional aspects	-0.1470	0.2665
Mental health	-0.3447	0.0075*

* *p*- significant value

DISCUSSION

In relation to the participants' sociodemographic data, it was observed the prevalence of females, what reinforces the role of the woman as the main caretaker,[19] and the spouses represented the highest percentage. This fact may be related to the characteristics of the place where the research was carried out because of the prevalence of young adults in relation to the elderly. This result corroborates a study conducted in Boston, USA, which evaluated the QL of 47 main caretakers of patients with hematologic cancer submitted to HSCT, in which 70.02% were female and 72.03% were companions.[1]

The female caretakers who experience cancer come across different commitments, among them the couple's privacy. In this context, nursing needs to understand the difficulties faced in order to contribute to the mitigation of the impact throughout the path so that, besides offering the necessary support in the continuity of the care, the caretaker's well-being is kept.[19]

In the predominant age group (30-59) is it is clarified that main caretakers are in economically active age, data reinforced by the occupation, since the highest percentages of the participants related that they are employed at the moment. The fact that they have a formal occupation, in addition to the care provided, can be considered as a potential impact on their QL, once there is the need to reconcile the professional life with the routine change that the transplanted person's care requires.

Regarding schooling, it was observed that caretakers predominantly have elementary and high school education, which may influence the understanding of the care required for the transplanted person. This data diverges from the study conducted in the United States, with 56 patients and their informal caretakers after the HSCT when 73.6% have some college education or specialization.[20]

The low educational level is a potentially negative factor for the after-HSCT patient care, once this caretaker may present difficulties in understanding the necessary care demands. As well as the low income, which is also related with a negative factor to the main caretaker. Although the treatment for HSCT is funded by the Unified Health System (SUS – Sistema Único de Saúde), an investment is needed for home care, such as the acquisition of certain medicines, special and quality food and adequate infrastructure.

The financial needs persist after the HSCT and may be problematic for the patient and the caretaker, because a great part of the developed strategies is not adjusted to treat the subjective experiences that are related to economic stressors.[21]

In relation to the participants' QL, clarified by the e SF-36questionnair, the average presented by the main caretakers related to the functional capacity was 78.39 points. This result may be considered satisfactory, that is, their functional capacity was not seriously harmed, considering the care provided to the patient after the HSCT. This fact may be related to the elapsed time since the care was provided until answering the present study, when these main caretakers may not remember the limitations of the daily life activities imposed by the treatment.

When comparing this data with the result of the study that evaluated the QL of 47 main caretakers of patients with hematologic cancer during the hospitalization for the HSCT, it is noted that there was a reduction of the score throughout the time, bearing in mind that, in the period prior to the HSCT, the presented average was 87.3 and eight days after the transplant, it was 82.4. The same relation occurs with the Pain area, in which averages 82.4 and 79.2 were observed, respectively.[1] In the present study, the Pain area presented an average score of 67.54 reported by the main caretakers. The average population in the South of Brazil for the Pain area is 74.73 points.[22]

It might be considered that the main caretakers of patients who underwent HSCT feel more pain when compared to the general population. This fact can be related to the care provided to the patient after the hospital discharge, in which the main caretaker is overloaded with care-inherent activities, such as bath, aid to the locomotion, besides the care that the domestic tasks already demand in relation to cleaning, organization, feeding of other family members, care regarding children, among others. These activities demand from the main caretaker physical conditioning and excessive disposition to supply the patient's disability to perform their own personal activities and the others that they previously had help with.

The Emotional Aspect was another area that presented discrepancy with the general population, with an average of 70.02[22] against the average of 65.54 felt by the main caretakers of patients who underwent HSCT. The latter participate in the whole treatment process together with the patient, since the admission to the care provided after hospital discharge, and experience insecurity as to the therapy outcome and the possibility of healing, which may result in emotional shock. In the service in which this research was conducted, the nurse works with the multiprofessional team in the support to this patient and the visiting relative aiming at mitigating the impact suffered.

The emotional distress suffered by the main caretakers is possibly linked to the reduction in the Vitality area, which was the most expressive in relation to the other areas in the SF-36 questionnaire. Vitality is related to the capacity of living and developing activities with vigor.[6] The presented average was 55.26 and it can be connected to the task of taking care, once the items assessed in this dimension (such as low energy, exhaustion, unwillingness and fatigue) may be consequences of overwork.

In the above-mentioned research, the areas of the SF-36 and the care overload were correlated, having that the Vitality area presented significant relation. The caretakers of patients in an intensive care unit in Pennsylvania presented an average of 45 points to Vitality. According to the authors, the area was related to the fatigue presented by the caretakers, depression symptoms and worse quality of sleep.[23]

When correlating all the areas of the SF-36 questionnaire with one another, in pairs, it was observed that the Functional Capacity area presented statistical significance when related to Pain, and in a similar way the Emotional Aspect when related to the Mental Health, possibly due to the fact that the items evaluated in these scales are common to the correlated areas, being the Pain influential to the reduction of the individual's Functional Capacity and the Emotional Aspects in Mental Health.

Thus, the magnitude of the physical and psychological suffering experienced by the caretakers during the HSCT must become the main reason for active interventions that improve the QL and the care for this vulnerable population.[1] Action must be directed to all the areas that contemplate the QL. Guidelines and clarifications related to the physiological and social changes resulting from the treatment are examples of activities that reduce doubts and calm down the relatives.

Parallel to the QL evaluation, it was described in the present study the overload felt by the main caretakers resulting from the care practice, using the *Burden Interview* questionnaire. It gives us the evaluation of the overload that the main caretaker is experiencing through the care practice, and based on this, it is possible to assess this overload impact in the QL. In this matter, the participants considered the overload as moderate and moderate to serious, both with 35.59% (n=21). The overload is characterized by the accumulation of activities inherent to the patient care, changes in the social and professional sphere of the main caretaker, concern with the well-being and health of the family member under their care, feeling heavy and uncomfortable when performing certain functions.[24]

In caretakers of elderly people in an outpatient monitoring in the city of Campinas-SP, a moderate and moderate to serious overload was evident, with 68.2% and 38.6%, respectively.[25] The main caretakers of patients who undergo the HSCT, possibly feel overloaded due to home care routine, with frequent accompaniment to outpatient appointments, in the preparation and administration of medicines and constant observation of the possible clinical alterations of the patient who needs intervention and search of specialized aid. All these factors compose the main caretaker's routine and, with time, it may lead to an overload.

The transformations in the caretaker's family and professional routine may lead the individual to physical and emotional exhaustion, affecting their state of health. Factors such as the lack of preparation for the care and the lack of family and professional support may overload the caretaker.[24]

The main caretakers, when overloaded, consider that their capacity for performing daily activities is compromised due to the necessary dedication for the care and the time for their own tasks becomes scarce. In a study that correlated the area scores of the SF-36 with the caretaker's general overload, it was observed that the Vitality and Mental Health areas correlated in a statistically significant way with the care overload.[26]

The care overload presented a strong association as a risk factor for the emotional discomfort, which is characterized by migraines, insomnia, lack of appetite, sadness, anxiety, among others.[6] When evaluated in this study with the SRQ-20 questionnaire, it was observed that 51% (n=30) of the participants reported non significant emotional discomfort. The practice of taking care of a patient who underwent the HSCT does not seem to interfere with the caretaker's emotional sphere, and when correlated with the areas of QL, the Pain area presents a positive association with the emotional discomfort.

The HSCT is a procedure with chances of cure and it possibly brings along a feeling of hope for the main patient and their caretakers. It is likely that this strengthens both for facing the illness and its difficulties, mitigating the possible impacts in the QL.

Considering the originality of the application of this questionnaire for informal caretakers of patients after-HSCT, the discussion of this matter is pointed out as a limiting factor of the study. Another limitation was between the time of the transplant and of the home monitoring with the beginning of the data collection, the feelings and difficulties of the relatives were possibly already mitigated over time.

CONCLUSION

The use of the different instruments in the present study allowed to evaluate and to identify the areas affected in the quality of life, correlating them to the care overload and the caretaker's emotional discomfort. It was identified that the caretaker's quality of life was harmed in the Pain, Emotional Aspects and Vitality areas when compared to the caretakers of other chronic illnesses.

However, the activities of daily life could be kept in a satisfactory way. Regarding the care overload, it was identified moderate to severe overload, which indicates how their routine is tiring and the importance of the multiprofessional team support so that they do not get sick and can effectively provide care. With respect to the emotional discomfort, it was verified that the treatment did not cause emotional distress that harmed the QL of these main caretakers during the treatment.

Thus, it is suggested that the main caretakers of the patient who undergoes the HSCT are the focus of new scientific approaches aiming at supplying the formal support that they need, making it safer to perform a more effective care of the patient and, in the end, to promote the improvement of the QL of both.

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