



ORIGINALES

Burden on family caregivers of children and adolescent in immediate post hematopoietic stem cell transplantation

Sobrecarga de cuidadores familiares de crianças e adolescentes em pós-transplante de células-tronco hematopoéticas imediato

Sobrecarga de los cuidadores familiares de niños y adolescentes en post-trasplante inmediato de células madre hematopoyéticas

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ABSTRACT:

Objective: To evaluate the burden on family caregivers of children and adolescents in immediate post hematopoietic stem cell transplantation.

Method: Study of quantitative nature, of analytical and traverse type, accomplished in two institutions of health with 31 caregivers of children and adolescents in immediate post transplantation. The data collection was accomplished between October of 2018 and June of 2019. The caregivers' social-demographic profile was characterized, and the burden was evaluated by Caregiver Burden Scale. The descriptive statistics and the Spearman correlation were used.

Results: It was obtained a burden global score of 2.4/4; the domains with larger scores were: general stress and frustration, both with 2.8/4.

Conclusion: The understanding of how the family faces the challenges imposed by the immediate post hematopoietic stem cell transplantation guides the multiprofessional team a care centered in the family and to offer maximum support and guidance to the caregiver.

Keywords: Caregivers; Family; Hematopoietic stem cell transplantation.

RESUMO:

Objetivo: Avaliar a sobrecarga de cuidadores familiares de crianças e adolescentes em pós-transplante de células-tronco hematopoéticas imediato.

Método: Estudo de natureza quantitativa, do tipo analítico e transversal, realizado em duas instituições de saúde, com 31 cuidadores de crianças e adolescentes no pós-transplante imediato. A coleta de dados foi realizada entre outubro de 2018 e junho de 2019. Caracterizou-se o perfil sociodemográfico dos cuidadores e avaliou-se a sobrecarga pela *Caregiver Burden Scale*. Utilizaram-se a estatística descritiva e a correlação de Spearman.

Resultados: Obteve-se um escore global de sobrecarga no valor de 2,4/4, tendo sido os domínios com maiores escores: tensão geral e decepção, ambos com 2,8/4.

Conclusão: A compreensão da sobrecarga vivenciada pela família e o modo como enfrenta os desafios impostos pelo pós-transplante de células-tronco hematopoéticas imediato orienta a equipe multiprofissional a um cuidado centrado na família e a ofertar o máximo de apoio e orientação ao cuidador.

Palavras-chave: Cuidadores; Família, Transplante de células-tronco hematopoéticas.

RESUMEN:

Objetivo: Evaluar la sobrecarga de los cuidadores familiares de niños y adolescentes en el post-trasplante inmediato de células madre hematopoyéticas.

Método: Estudio de tipo cuantitativo, analítico y transversal, realizado en dos instituciones de salud, con 31 cuidadores de niños y adolescentes en post-trasplante inmediato. La recolección de datos se llevó a cabo entre octubre de 2018 y junio de 2019. Se trazó el perfil socio demográfico de los cuidadores y se evaluó la sobrecarga de los mismos utilizando la *Escala Caregiver Burden*. Se utilizó estadística descriptiva y la correlación de Spearman.

Resultados: Se obtuvo un puntaje de sobrecarga global de 2.4/4, los dominios que presentaron los puntajes más altos fueron: tensión general y decepción, ambos con 2.8/4.

Conclusión: La comprensión sobre la forma como la familia enfrenta los desafíos impuestos por el TCMH en la etapa inmediatamente posterior le sirve de orientación al equipo interprofesional para realizar cuidados centrados en la familia y para ofrecer el máximo apoyo y orientación al cuidador.

Palabras clave: Cuidadores; Familia; Trasplante de células madre hematopoyéticas.

INTRODUCTION

The Hematopoietic Stem Cells Transplantation (HSCT) is a procedure aimed at replacing the abnormal lympho hematopoietic system by a healthy one, by using high doses of myelosuppressives. The source of cells may be bone marrow, peripheral blood and cord blood⁽¹⁾.

The therapy requires exclusive dedication from the family caregiver of the child or adolescent, which may lead the person to distance from the place where he lives and, sometimes, from the spouse and the other children, as well as the need to adapt to the new routine⁽²⁾. After hospital discharge, the family caregiver becomes the main and, sometimes, the only person who provides physical and emotional support at home for the child and adolescent. It is a moment when the patient is particularly fragile, dependent on others and incapable of returning to his previous routine⁽³⁾.

At this moment, the family caregiver who is looking after the patient post- HSCT at home may be overburden. Caregiving overburden is a psychological condition resulting from physical and emotional stress, social changes and financial demands deriving from caregiving⁽⁴⁾. Etymologically, overburden “derives from the English term burden, which is straightly related to the influence and development of psychiatric, physical, emotional and social symptoms and usage of medicines ”⁽⁵⁾. It is comprised by objective and subjective dimensions. The first one is related to the activities carried

out, care supervision and issues faced by caregivers in their daily lives, such as limitations imposed to social and professional life and family financial changes, lack of privacy, conflicts in family relationships, financial problems and medication management⁽⁵⁾. The subjective dimension refers to all activities related to the patient, associated with feelings caused by the fact of being a caregiver, such as blaming, outrage and other emotional reactions, besides the sensation of bearing a burden and discomfort while caregiving⁽⁵⁾.

Besides these factors, literature shows financial burden impacts caregivers' lives, even years after transplantation, due to medical expenses, such as visit to doctors and medicines, as well as changes in the routine and work due to the physical and psychological distress resulting from this burden. Therefore, it impacts the life of family caregivers of children and adolescents after immediate post-HSCT ^(6,7).

Thus, overburden, its aspects and repercussions on caregiver's life are related to the concept of care, which refers to love devoted to someone; zeal, affection and solidarity declared by the other⁽⁸⁾.

Current studies are focused on the overburden in the late post-HSCT period⁽⁹⁾, thus, highlighting the need of deepening researches which analyze the specific overburden of immediate post-HSCT, period between D+1 and D+100, characterized by high levels of stress resulting from the demands imposed by caregiving at home.

Based on these aspects, the following guiding principle was set: what the overburden of family caregivers of children and adolescents after immediate post-HSCT is? Therefore, the objective is assessing the overburden of family caregivers of children and adolescents in immediate post hematopoietic stem cells transplantation.

METHOD

It was a cross-sectional, analytic and prospective study carried out in two services of hematopoietic stem cell transplant, in Curitiba, a city in the State of Paraná, Brazil, between October 2018 and June 2019. The non-probabilistic convenience sample comprised 31 family caregivers of children and adolescents, aged between 1 and 16 years old, immediate post-HSCT, between the 15th and the 100th day after hospital discharge. Inclusion criterion was: main family caregiver of children and adolescents with Acute Lymphoblastic Leukemia, Mucopolysaccharidosis Type II, Severe Aplastic Anemia, Fanconi Anemia, Adrenoleukodystrophy and Severe Combined Immunodeficiency.

Two instruments were used to collect data: the first one with sociodemographic information with personal and housing variables and the second one based on Caregiver Burden Scale (CBS), which was validated in Sweden in 1996⁽¹⁰⁾, in order to measure the subjective impact on caregivers of patients with Cerebrovascular Accident (CVA). In Brazil, in 1998⁽¹¹⁾, CBS adaptation and validation were carried out with 22 questions divided into five domains: general stress, isolation, disappointment, emotional involvement and environment.

The values of each question vary from 1 to 4 (1 - no way, 2 - rarely, 3 - sometimes and 4 - frequently). The total score varies - the higher the score, the higher will be the

overburden and vice-versa. In data analysis, a global score and a score for each domain are obtained. Thus, overburden is determined by the global score and by the domains which have the main scores.

Data collection was carried out at the ambulatory unit of HSCT service, according to time and date scheduled by the family caregiver. The CBS (Caregiver Burden Scale) questionnaire was applied by the researchers.

Data collected were encrypted and stored in sheets of Microsoft Office Excel® 2018 program. The results of the sociodemographic and CBS questionnaires were assessed through descriptive analysis, averages, medians, minimum and maximum values and standard deviations or through frequencies and percentages. In order to assess the correlation among the CBS domains, the Spearman correlation coefficient was used; values of $p < 0.05$ represented statistical significance. Data were analyzed by the computational program IBM SPSS Statistics v.20.0. Armonk, NY: IBM Corp.

This research was approved by the Ethics Committee in Research of Healthcare Sector of Federal University of Paraná, according to Statement no. 2.910.328.

RESULTS

From 31 family caregivers, age varied between 20 and 60 years old, with average of 35 years old and standard deviation of ± 8.2 . The frequencies of sociodemographic variables are presented on Table 1. It is worth mentioning that 93.5% ($n = 29$) were women and 87.0% ($n=27$) were mothers. As for education, 41.9% ($n = 13$) had complete high school education; 77.4% ($n = 24$) were unemployed and 67.7% ($n = 21$) received the support of the spouse; 41.9% ($n = 13$) were married and 61.3% ($n = 19$) were catholic. Around 58.1% ($n = 18$) of the family caregivers were out of their homes. They stayed in support houses near the hospital, which can be used both by the caregiver and the child or adolescent, after being discharged from hospital up to 100 days post-HSCT.

Table 1 – Frequencies of sociodemographic variables of the sample, Curitiba, PR, Brazil, 2020. (N=31)

Sociodemographic variable	Classification	N=31	%
Caregiver age (years)	≤ 35	15	48,4
	> 35	16	51,6
Caregiver gender	Female	29	93,5
	Male	2	6,5
Degree of consanguinity	Mother	27	87,1
	Father	2	6,5
	Aunt	1	3,2
	Grandmother	1	3,2
Number of children	1	9	29,0
	2	14	45,2
	3 a 5	8	25,8

Education			
	Incomplete elementary school	9	29,0
	Complete elementary school	2	6,5
	Incomplete high school	7	22,6
	Complete high school	13	41,9
Profession			
	Employed	4	12,9
	Freelance	3	9,7
	Unemployed	24	77,4
Support network			
	Spouse	21	67,7
	Mother	5	16,1
	Father	1	3,2
	Sister	1	3,2
	Uncle	1	3,2
	Aunt	1	3,2
	Neighbor	1	3,2
Marital status			
	Single/the person has a steady relationship	12	38,7
	Single/the person does not have a steady relationship	5	16,1
	Married	13	41,9
	Separated/divorced	1	3,2
Religion			
	Catholic	19	61,3
	Evangelical	10	32,3
	No religion	2	6,5
Color or race			
	Caucasian	18	58,1
	Mulatto	9	29,0
	Black	4	12,9
The individual receives social benefits			
	Yes	16	51,6
	No	15	48,4
Income			
	None	4	12,9
	Up to 1 minimum wage	15	48,4
	From 1 to 3 minimum wages	11	35,5
Place of Birth			
	Northeast	16	51,5
	South	10	32,3
	North	2	6,4
	Center-West	1	3,2
	Southeast	1	3,2
	Paraguay	1	3,2

Origin			
	Northeast	14	45
	South	10	32,3
	North	2	6,4
	Center-West	3	9,6
	Southeast	1	3,2
	Paraguay	1	3,2

Source: The authors (2020)

Table 2 presents the overburden caused by caregiving, considering the average score, standard deviation, median, maximum and minimum values of care dimensions. The dimensions which obtained the highest scores were general stress and disappointment, both with 2.8.

Table 2 – Overburden of family caregivers of children and adolescents on post-HSCT assessed by CBS, Curitiba, PR, Brazil, 2020. (n=31)

Domain	N	Average	Deviation	Median	Minimum	Maximum
			standard			
General stress	31	2,8	±0,6	2,6	1,3	3,8
Isolation	31	2,6	±0,9	2,3	1	4
Disappointment	31	2,8	±0,8	2,8	1	4
Emotional involvement	31	1,2	±0,4	1	1	3
Environment	31	2,2	±0,7	2	1	4
Global score	31	2,4	±0,4	2,5	1,6	3,1

Source: The authors (2020)

The assessment of the correlation among CBS domains showed there was a statistics significance in the domains general stress and disappointment, with Spearman's correlation coefficient of 0.70; value of $p < 0.001$ shows direct correlation and statistics significance, in other words, the higher the score of general stress, the higher the score of disappointment, as shown in Table 3.

Table 3 – Assessment of the correlation among CBS domains, Curitiba, PR, Brazil, 2020. (N=31)

Variables	N	Coeficiente de correlation of p Spearman	
General stress x isolation	31	0,15	0,406
General stress x disappointment	31	0,70	< 0,001*
General stress x emotional involvement	31	0,20	0,270
General stress x environment	31	0,08	0,668
Isolation x disappointment	31	0,14	0,462
Isolation x emotional involvement	31	0,18	0,327
Isolation x environment	31	0,05	0,780
Disappointment x emotional involvement	31	-0,01	0,978

Disappointment x environment	31	0,26	0,164
Emotional involvement x environment	31	-0,03	0,876

Source: The authors (2020) Note: *Meaningful result

DISCUSSION

Looking after a child or adolescent in the immediate post-HSCT requires family acceptance of the specificities of this practice, which involves daily meal, medication management, personal and environmental hygiene, among others. All these activities are, many times, undertaken only by the caregiver at the patient's home, for many people keep away from their family as they need to find ways to deal with this moment of their lives⁽¹²⁾.

Before this scenario, overburden is straightly related to the care the patient needs. The more care the patient needs, the highest will be the overburden lived by the caregiver and, consequently, the lesser he will look after himself⁽¹³⁾. Thus, it is necessary to ponder on family routine, which is modified due to the demands inherent to caregiving of children and adolescents under these conditions⁽¹⁴⁾.

A Brazilian study which used CBS with 127 caregivers of disabled elderly people obtained global score of overburden of 1.92⁽¹⁵⁾, while a study with 29 caregivers of Alzheimer's patients presented a global score of 2.18⁽¹⁶⁾. In another research with one hundred caregivers of elderly people under palliative oncological care, stratified into three groups of 25 participants, the average of the overburden level of the groups was used as a result (G1, G2 and control group), revealing an average of 2.0 for G1, 1.9 for G2 and 1.4 for the control group⁽¹⁷⁾. Comparing with this study, the results show that family caregivers of children and adolescents submitted to HSCT present a higher level of overburden than other studied populations, by applying the same instrument.

In overburden per domain, general stress and disappointment were the ones with higher averages. These data support a studied carried out with 127 caregivers of disabled elderly people, in which the disappointment domain obtained score of 1.91 ± 0.77 and the general stress domain, 2.18 ± 0.85 ^(13,15). In the study carried out to evaluate the subjective impact of 29 caregivers of Alzheimer's elderly patients, the domains with higher scores were general stress (score of 2.39 and standard deviation of 0.49) and isolation (score of 2.28 and standard deviation of 0.72)⁽¹⁶⁾.

In this study, the lesser overburden was in the domain emotional involvement, supporting a study with one hundred caregivers of elderly people under palliative oncological care, in which, in the three groups, the lesser overburden was in the same domain, with average of 1.2 and standard deviation of 0.4. A similar date found refers to the highest averages of overburden in the domain general stress, followed by disappointment, isolation, environment and emotional involvement⁽¹⁷⁾.

It is highlighted, in this study, that the domain general stress addresses issues that the family caregiver may face while looking after the patient, as well as the increase of responsibilities, impaired health and physical and routine changes. In this regard, researches show that family caregivers perceive general stress as objective overburden, in other words, looking after the patient requires availability to carry out

activities related to caregiving; however, this time may be spent on other activities within the family and on other caregiver's personal activities⁽¹⁸⁾.

Accordingly, the family identity as caregiver is not defined just by the action of caregiving, but also by the awareness and meaning which he gives to this activity in his life, thus representing a relation between this activity and routine and the identification of a new role⁽¹⁹⁾.

Due to this discovery, children's caregivers report that several areas of their lives are affected and their families are reorganized and have another routine, in order to provide conditions for the child/adolescent to keep and develop his existing abilities. The distance, due to the disease, may alter the relationship with other family members, bringing them together and promoting the exchanging of feelings, affection, care and love. On the other hand, it may lead to conflicts inherent to family interaction. These caregivers leave their jobs, studies, barely sleep, have their social life affected; they have lack of leisure time, pleasure, family life and time for their personal care. Time management and the need of reducing stress are the main concerns, because the activities related to caregiving of a child/adolescent under treatment, make impossible, mainly, personal care and leisure⁽¹⁸⁾.

Family is essential in caregiving, for it depicts love and trust; therefore, the multidisciplinary team needs to be introduced to all of them, to know their values, beliefs and what influences and determines the way they look after their ill relatives⁽¹⁹⁾. The domain disappointment, in its turn, addresses issues on the caregiver's perception regarding the moment he is living while looking after the child or adolescent and his own life plans, distance from the place he lives, fatigue caused by caregiving and financial changes. Accordingly, studies show these caregivers perceive disappointment as repercussions which disrupt their lives and are mainly strengthened by the responsibilities related to childhood⁽²⁰⁾.

The domain emotional involvement addresses issues related to children or adolescents' behavior regarding the perception of their family caregivers. In this study, the domain presented lower score, which may be justified by the experience of having a child under post-HSCT causes emotional pain and distress during treatment. This emotional experience brings changes not only in the caregiver's personal life, but also in his children's lives, arising feelings of escape, fear, despair and uncertainties surrounding the future post-transplantation ^(17,18). Thus, overburden expressed as suffering, which is reported in this study, may seriously impair the caregiver's emotional status, leading to depression, stress and anxiety, as well as it may harm his personal care, life quality and social role⁽¹⁹⁾.

The main limitations of this study were: the size of the sample, as HSCT is not a procedure carried out on a large scale, nor even in the place where data were collected, which is considered reference in HSCT in Brazil; this is the first study on CBS application with family caregivers of children and adolescents in immediate post-HSCT, rendering impossible relating it with studies with the same population.

CONCLUSION

This study had the objective of assessing the overburden of family caregivers of children and adolescents in immediate post-HSCT. According to the context presented, the domains general stress and disappointment were the ones with the higher scores, which means the caregivers of children and adolescents in immediate post-HSCT suffer due to the increase of responsibilities, impaired health, physical and routine changes, caregiver's perception related to caregiving, suffering due to the distance from hometown and financial changes. The domain emotional involvement obtained the least scores, suggesting, therefore, the experience of having a child in post-HSCT causes emotional pain and distress during treatment.

Thus, understanding as the family faces the challenges imposed by this kind of transplantation in post-immediate and creates strategies in order to face it guides the multiprofessional team to offer the maximum support, emotional balance and guidance to the caregiver.

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