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SOCIODEMOGRAPHIC AND CLINICAL FACTORS ASSOCIATED WITH INFORMAL CARE IN HEMATOLOGIC MALIGNANCY PATIENTS: A STUDY BASED ON DIFFERENT TREATMENT PHASES(*)

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ABSTRACT

Background: There is little information on factors related to the use of informal care in cancer patients. Our objective is to study the sociodemographic and clinical factors associated with the use of informal care in patients with hematologic malignancies and analyze how they change throughout the various phases of treatment.

Methods: 139 patients diagnosed with hematologic malignancies, who received a hematopoietic stem cell transplantation between 2006 and 2011 in two different Spanish hospitals, completed the developed postal questionnaire. A binary logistic regression model was used to analyze the factors associated with the use of informal care in each of the four treatment phases (pre-transplant, first year, second and third year, and from the fourth to sixth year post-transplant). The dependent variable was receiving informal care vs. not receiving informal care.

Results: Patients diagnosed with acute leukemia were more likely to receive informal care during the pre-transplant period (OR=6.394) and during the second and third year post-transplantation (OR=42.212). In the long-term (4-6 years), multiple myeloma patients require more informal care (OR=15.977). Health status is statistically significant during all phases. Being male (OR=0.263), having a partner (OR=0.137) and being employed (OR=0.110) are associated with a lower likelihood of receiving informal care in the longterm.

Conclusions: Over 75% of patients diagnosed with hematologic malignancies received informal care during the pre-transplant period and the first year post-transplant. Type of diagnosis and health status are decisive factors influencing the likelihood of receiving informal care during all treatment phases, while the type of transplantation is not. Sociodemographic factors are relevant in the longterm.

Key words: Patient care, Caregivers, Neoplasm, Transplantation, Leukemia, Lymphoma, Multiple myeloma, Spain.

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RESUMEN

Factores sociodemográficos y clínicos asociados a la recepción de cuidado informal en pacientes con neoplasia hematológica: estudio basado en las diferentes etapas del tratamiento

Fundamentos: Los factores relacionados con la recepción de cuidado informal (CI) en pacientes oncológicos es una cuestión poco estudiada. Nuestro objetivo es analizar los factores sociodemográficos y clínicos asociados a la recepción de cuidado informal en pacientes con neoplasia hematológica y estudiar su evolución a lo largo de las diferentes etapas del tratamiento.

Métodos: 139 pacientes diagnosticados de neoplasia hematológica, que recibieron un trasplante de células madre durante el período 2006-2011 en dos centros sanitarios españoles completaron la encuesta elaborada para el estudio. Se estimó un modelo de regresión logística binaria para cada una de las cuatro etapas de tratamiento: pretrasplante, primer año, segundo y tercer año, del cuarto al sexto año postrasplante. La variable dependiente fue recibir vs. no recibir cuidado informal.

Resultados: Pacientes diagnosticados de leucemia aguda presentaron mayor probabilidad de recibir CI durante la etapa pretrasplante (OR=6,394) y durante el segundo y tercer año postrasplante (OR=42,212). A largo plazo (4º-6º año), los pacientes con mieloma múltiple son los que requieren mayor cuidado (OR=15,977). El estado de salud resulta significativo en la mayoría de las etapas. Ser hombre (OR=0,263), tener pareja (OR=0,137), y estar empleado (OR=0,110) están asociados a una menor probabilidad de recibir CI a largo plazo.

Conclusiones: El CI está presente en más del 75% de los pacientes con neoplasia hematológica durante la etapa pretrasplante y primer año postrasplante. El diagnóstico y estado de salud son decisivos en la probabilidad de recibir CI, no siendo así el tipo de trasplante. Los factores sociodemográficos cobran protagonismo a largo plazo.

Palabras clave: Atención al paciente, Cuidadores, Neoplasia, Trasplante, Leucemia, Linfoma, Mieloma múltiple, España.

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INTRODUCTION

Hematologic malignancies are part of a group of malignant disorders that are the result of the clonal expansion of hematopoietic cells. Illnesses such as leukemia, lymphoma and multiple myeloma are just a few of the 28 most common types of cancer found in 184 countries, according to the International Agency for Research on Cancer(1). The treatment associated with hematologic malignancies includes the appropriate administration of chemotherapy and/or radiation, the average length of which is approximately six months. In the above-mentioned illnesses, the therapy is generally followed by a hematopoietic stem cell transplant (HSCT), more commonly known as a bone marrow transplant, thus extending the patient's chances for survival in the long-term(2,3,4). Clinical and technological advances have increased the possibility not only of finding a compatible donor beyond a sibling with identical human leukocyte antigens (HLA) (allogeneic transplant from related donor), but of finding a donor outside the patient's family (allogeneic transplant from non-related donor) and even of the patient themselves acting as their own donor (autologous transplant)(2).

The aggressive nature of both chemotherapy and the transplant itself can cause various side effects including vomiting, mucositis, fatigue, infection, discomfort, pain, etc., as well as problems with anxiety and depression(2,5,6). These symptoms can have a significant effect on the patient's daily activity level, and often result in a need for the support and attention of a caregiver. According to the World Health Organization, an informal caregiver is defined as a person in the patient's life (family or friend) who volunteers to care for them without having any specific training and, generally speaking, without receiving any economic compensation for doing so(7). In this sense, it is worth highlighting the fundamental role played by the informal caregiver when it comes to the patient's care(8,9,10). This includes emotional support, financial advice, personal and home care, transportation assistance and medication supervision(11,12).

Evidence suggests that informal caregiving of cancer patients generates significantly higher levels of stress than the informal caregiving of patients diagnosed with other illnesses(13). For this reason, it is worth mentioning the emotional and functional strain, and health repercussions, that informal caregivers of cancer patients are exposed to(14,15).

Consequently, various studies have estimated the time dedicated to the informal care of cancer patients, its monetary worth and possible associated factors(16,17). Diagnoses such as colorectal, lung and prostate cancer have received special attention(18,19,20,21) but hematologic cancer has yet to be the focus of any such studies.

Nevertheless, before looking at the time and monetary value associated with the informal care of patients with different malignancies, it is interesting to examine which factors are related to a need for informal care, thus enabling the identification of the most vulnerable populations. To our knowledge, just one study(22) focused on cancer patients has taken on this subject, suggesting factors such as increased levels of comorbidity, finding oneself in the terminal phase of an illness, or experiencing metastasis are strongly linked to a cancer patient's need for assistance with personal care, transportation and instrumental activities like food preparation, shopping and domestic tasks. Furthermore, women are more likely than men to need help with instrumental tasks and activities related with transportation. Low income patients and patients over 65 years of age also reveal a greater need for personal care. By comparison, Hayman et al(17) suggest that the likelihood of receiving informal care is significantly greater in those who have received oncological treatment during the previous year, compared to those who have not received treatment or have never suffered from cancer. Still, as indicated by Yabroff et al(16), the demand for informal care can vary considerably depending on the type of diagnosis and the phase of treatment. Accordingly, as far as we know, no national or international study has offered information on the informal care of cancer patients. Even so, there are two reasons why a study of this care is worthwhile: the first being because a higher rate of new hematologic cancer cases and bone marrow transplants are expected to be carried out in the next few years, not only in Spain, but throughout Europe(3,24); while the second is that evidence indicates that informal caregivers for the above-mentioned patients are extremely vulnerable, experiencing emotional burdens and social costs that are on par with the patients themselves(23). It is therefore necessary to shed light on any and all knowledge that would allow for the indentification of social needs among oncohematologic patients and their caregivers, thus anticipating any possible public policies.

The objective of this study is to examine the sociodemographic and clinical factors associated with receiving informal care in patients with hematologic malignancies and to analyze their evolution throughout the various phases of treatment.

SUBJECTS AND METHODS

Study design. Given the lack of public data available in Spain, a descriptive questionnaire was designed to gather sociodemographic and clinical information from patients. The sample included patients diagnosed with acute leukemia, lymphoma (Hodgkin's and non-Hodgkin's), multiple myeloma and other less common malignancies (myelodysplastic syndrome, chronic myeloid leukemia and chronic lymphocytic leukemia, among others), who had received an HSCT sometime between 2006 and 2011 at two hospitals in Spain (University Hospitals Virgen de las Nieves in Granada and Virgen del Rocio in Seville), and who at the time of the survey had survived their illness. Approval was granted by the Committee for Ethical Research and the Hematology Department at each of these healthcare centers.

The questionnaire included a selection of sociodemographic and clinical variables that were both static and dynamic (these varied depending on the patient's phase of treatment). Four different phases were defined with the goal of analyzing the temporary evolution that occurs when receiving informal care. Phase 1 corresponds to the pre-transplant phase, understood as the period which includes the chemotherapy cycles administered before the transplant. Phase 2 (short-term) corresponds to the first year after the patient has received the HSCT. This first year is of vital importance for the patient given that significant comorbidities associated with the transplant can appear, including infection and certain complications, as well as the development of graft-versus-host disease (in the case of allogeneic transplants), which frequently puts at risk the life of the patient. Phase 3 includes the second and third year post-transplant, and is characterized by a clinical situation which is fairly stable, during which the possibility of extreme situations such as death is significantly lower. Finally, Phase 4 (long-term) encompasses the fourth, fifth and sixth years following the transplant. The questionnaire is retrospective in nature and memory-based, given that when the survey was taken, the patients were going through either Phase 3 or Phase 4. Consequently, each patient was responding to the questions by looking back at the previous phases they had gone through.

All living patients who had been diagnosed and received a transplant at the above-mentioned hospitals were contacted by telephone. At random, patients who responded to the first or second call were informed of the study and invited to participate. The questionnaire was mailed to the patients along with a fact sheet, an informed consent form, and a self-addressed stamped envelope for returning the survey. Contact information was provided in case patients had any questions while filling out the questionnaire(25). Recruitment of patients began in January of 2012 and ended in December of 2013. The questionnaire was mailed to 230 patients and a total of 139 completed surveys were received in return (60.43% response rate).

Statistical analysis. A descriptive analysis was carried out on the objective study sample. Later, in accordance with the objectives, four different binary logistic regression models were established given the character of the binary dependent variable and the interpretive potential of the model(26). More specifically, four models were calculated for each temporary analytical phase, in which the explained variable was the reception of informal care by an oncohematologic patient during the corresponding period (yi=1, if they received informal care; yi=0, if they did not receive informal care, with i=1,..,n, with n being the number of individuals in the sample). These models allowed for the evaluation of the personal characteristics of the individual whose parameters proved to be statistically significant and who, was therefore, associated with receiving informal care. Accordingly, the odds-ratios measured the association between the dependent variable (receiving or not receiving informal care) and each of the independent variables (sociodemographic and clinical characteristics), adjusting for the remainder of these.

The sociodemographic characteristics included patient's sex (man or woman); age at time of transplant (median value used for analysis); marital status (in a relationship: married/with a partner; not in a relationship: single/widowed/separated/divorced); level of education (low: no studies/primary studies; medium: secondary studies/high school diploma/intermediate level vocational training; high: university studies/advanced level vocational training), which, after studying its linearity (it follows a distribution of linear probability and is in continual decline), was focused on average level of education; employment (employed: by others/self-employed; not employed: homemaker/student/retired/unemployed); and formal care (receives; does not receive), understood as personal care and home care performed by a professional(27).

Furthermore, the clinical characteristics of each individual were taken into account. This included the patient's state of health on a scale of 1 to 5 (1: very poor state of health; 2: poor state of health; 3: normal state of health; 4: good state of health; 5: very good state of health). After studying the linearity of this variable, a continuous variable focused on normal state of health was fed into the model, and this is therefore the reference value in the model of said variable. Moreover, the type of diagnosis was also included in the models (acute leukemia/lymphoma (Hodgkin's and non-Hodgkin's)/multiple myeloma/other). In the phases after Phase 1, an additional variable was included, which defined the type of transplant received by the patient as far as his relationship to the stem cell donor (autologous or allogeneic transplant). The employment variable could not be included in the Phase 4 model given the lack of variability in the sample.

The relationship involved in receiving informal care was tested among the various phases using a non-parametric contrast for related samples, Cochran's Q test(28), consistent with a specific χ^2 test for dichotomous variables. The statistical software STATA 12.0 was used (StataCorp LP, College Station, TX) to conduct the analysis described above.

RESULTS

Seventy-five of the participants were men (53.96%), with an average age of 46 at the time of the transplant (17-67 years old), 97 of them (69.78%) were in a relationship and 51 of them (36.78%) had a low educational level. Forty-nine of the participants had been diagnosed with lymphoma (Hodgkin's or non-Hodgkin's) and 90 (64.75%) of the patients received an autologous transplant (table 1).

Table 2 shows the evolution of sociodemographic and clinical characteristics by phase. Variations in employment were observed over time, during which 99 (71.22%) patients were employed during the pre-transplant phase. However, in the medium term this drastically reduced to 9 (12.68%). In the long-term, a return to the workplace was observed, with 22 (35.48%) patients employed. Further, the importance of informal care was shown throughout the phases, particularly during the pre-transplant period, with 115 (82.73%) patients, and the first year post-transplant, with 110 (79.14%) individuals receiving informal care. Formal care was present for 12 (8.63%) of the patients during the pre-transplant period. With respect to state of health, 50 (35.97%) patients declared it to be "poor" or "very poor" during the pre-transplant phase, with this figure reduced to 16.55% during the first year post-transplant. In the medium and longterm, a "good" state of health predominated in 43.66% and 40.32% of the patients, respectively (table 2).

Table 1
Sociodemographic and clinical characteristics of patients. Static variables.

Variables		n	%
Total		139	100
Average age at transplantation		46.38	100
Gender	Male	75	53.96
	Female	64	46.04
Marital status	In a relationship	97	69.78
	Not in a relationship	42	30.22
Educational level	Low	51	36.69
	Medium	45	32.37
	High	43	30.94
Diagnosis	Acute Leukaemia	33	23.74
	Hodgkin/ Non Hodgkin Lymphoma	49	35.25
	Multiple Mieloma	41	29.50
	Other	16	11.51
Transplantation according to the type of donor	Autologous	90	64.75
	Allogeneic: related and non related	49	35.25

The estimates found by the four binary logistic regression models are summarised in table 3. As illustrated, overall, all of the models were statistically significant. Likewise, as shown by the percentage of model fit, all four models showed a good adjustment measured using ROC curves that oscillated between 80.07% (Phase 1) and 90.95% (Phase 3).

In phase 1 (pre-transplant), the variable relating to acute leukemia and state of health revealed statistically significant parameters. More specifically, individuals diagnosed with acute leukemia showed a greater probability of receiving informal care (as opposed to not receiving it) than patients diagnosed with lymphoma (OR=6.394). Similarly, the probability of receiving informal care decreased for every one unit of increase in patients' declared state of health (from 1 to 5) (OR=0.138).

In phase 2 (first year post-transplant), the state of health variable again had a parameter that was statistically significant (OR=0.311), along with the sex of the patient. Male patients presented a lower probability of receiving informal care (OR=0.406) compared to female patients in phase 2. It is worth highlighting that in this period, the parameters associated with the diagnosis and type of transplant were not statistically significant.

Table 2
Sociodemographic and clinical characteristics by phases. Dinamic variables.

Variables			Phase 1: Pre-trasplant		Phase 2: 1st year post-trasplant		Stage 3: 2nd-3rd year post-trasplant		Stage 4: 4th-6th year post-trasplant	
			n	%	n	%	n	%	n	%
Sample			139	100	139	100	71	100	62	100
Informal care reception	Acute Leukaemia	Yes	31	93.94	29	87.88	9	60	4	26.67
		No	2	6.06	4	12.12	6	40	11	73.33
	Hodgkin/Non-Hodgkin Lymphoma	Yes	36	73.47	35	71.43	7	26.92	4	18.18
		No	13	26.53	14	28.57	19	73.08	18	81.82
	Multiple Mieloma	Yes	35	85.37	33	80.49	12	63.16	13	65
		No	6	14.63	8	19.51	7	36.84	7	35
	Other	Yes	13	81.25	13	81.25	4	36.36	1	20
		No	3	18.75	3	18.75	7	63.64	4	80
	Total	Yes	115	82.73	110	79.14	32	45.07	22	35.48
		No	24	17.27	29	20.86	39	54.93	40	64.52
Formal care reception	Acute Leukaemia	Yes	2	6.06	2	6.06	0	0	0	0
		No	31	93.94	31	93.94	15	100	15	100
	Hodgkin/Non-Hodgkin Lymphoma	Yes	2	4.08	2	4.08	0	0	1	4.55
		No	47	95.92	47	95.92	26	100	21	95.45
	Multiple Mieloma	Yes	8	19.51	6	14.63	4	21.05	4	20
		No	33	80.49	35	85.37	15	78.95	16	80
	Other	Yes	0	0	1	6.25	0	0	0	0
		No	16	100	15	93.75	11	100	5	100
	Total	Yes	12	8.63	11	7.91	4	5.63	5	8.06
		No	127	91.37	128	92.09	67	94.37	57	91.94
Employment	Acute Leukaemia	Employed	23	69.70	12	36.36	2	13.33	5	33.33
		Unemployed	10	30.30	21	63.64	13	86.67	10	66.67
	Hodgkin/Non-Hodgkin Lymphoma	Employed	33	67.35	16	32.65	4	15.38	11	50
		Unemployed	16	32.65	33	67.35	22	84.62	11	50
	Multiple Mieloma	Employed	29	70.73	10	24.39	2	10.53	3	15
		Unemployed	12	29.27	31	75.61	17	89.47	17	85
	Other	Employed	14	87.50	6	37.50	1	9.09	3	60
		Unemployed	2	12.50	10	62.50	10	90.91	2	40
	Total	Employed	99	71.22	44	31.69	9	12.68	22	35.48
		Unemployed	40	28.78	95	68.35	62	87.32	40	64.52

Table 2 (continuation)
Sociodemographic and clinical characteristics by phases. Dinamic variables.

Variables			Phase 1: Pre-trasplant		Phase 2: 1st year post-trasplant		Stage 3: 2nd-3rd year post-trasplant		Stage 4: 4th-6th year post-trasplant	
			n	%	n	%	n	%	n	%
Health Status	Acute Leukaemia	Very bad	5	15.15	0	0	1	6.67	0	0
		Bad	6	18.18	8	24.24	1	6.67	1	6.67
		Medium	15	45.45	13	39.39	6	40	2	13.33
		Good	6	18.18	11	33.33	3	20	8	53.33
		Very good	1	3.03	1	3.03	4	26.67	4	26.67
	Hodgkin/Non-Hodgkin Lymphoma	Very bad	5	10.20	2	4.08	0	0	0	0
		Bad	11	22.45	5	10.20	0	0	0	0
		Medium	19	38.78	19	38.78	10	38.46	5	22.73
		Good	13	26.53	21	42.86	14	53.85	4	18.18
		Very good	1	2.04	2	4.08	2	7.69	13	59.09
	Multiple Mieloma	Very bad	6	14.63	2	4.88	0	0	2	10
		Bad	11	26.83	3	7.32	1	5.26	1	5
		Medium	15	36.59	15	36.59	6	31.58	5	25
		Good	9	21.95	18	43.20	9	47.37	10	50
		Very good	0	0	3	7.32	3	15.79	2	10
	Other	Very bad	4	25	2	12.50	0	0	0	0
		Bad	2	12.5	1	6.25	2	18.18	0	0
		Medium	7	43.75	9	56.25	2	18.18	1	20
		Good	3	18.75	4	25	5	45.45	3	60
		Very good	0	0	0	0	2	18.18	1	20
	Total	Very bad	20	14.39	6	4.32	1	1.41	2	3.23
		Bad	30	21.58	17	12.23	4	5.63	2	3.23
		Medium	56	40.29	56	40.29	24	33.8	13	20.97
		Good	31	22.30	54	38.85	31	43.66	25	40.32
		Very good	2	1.44	6	4.32	11	15.49	20	32.26

During Phase 3, the probability of receiving informal care was greater in patients who presented with acute leukemia (OR=42.212) and multiple myeloma (OR=23.036) as opposed to those who had lymphoma. Furthermore, for every increase in a value unit for patient declared state of health, it was thought that the probability of receiving informal care would decrease (OR=0.100).

In the final phase of analysis (Phase 4), the sociodemographic variables gained significance, revealing parameters that were statistically significant in multiple myeloma patients, as well as those who were men, who were in a relationship and who were employed. Thus, the probability that an oncohematologic patient would receive informal care in this phase was higher if the patient suffered from multiple myeloma, compared to a patient diagnosed with lymphoma (OR=15.977). Similarly, during the first year following the transplant, men were less likely than women to receiveinformal care during this phase (OR=0.263). Further, a patient

Table 3
Logit regression models of factors associated to informal care.

Variables		Phase 1: Pre-trasplant		Phase 2: 1st year post-trasplant		Stage 3: 2nd-3rd year post-trasplant		Stage 4: 4th-6th year post-trasplant	
		Odds Ratio	Std.Err.	Odds Ratio	Std.Err.	Odds Ratio	Std.Err.	Odds Ratio	Std.Err.
Diagnosis (ref. lymphoma)	Acute Leukaemia	6.394(**)	5.441	2.084	1.629	42.212(***)	60.623	0.355	0.688
	Multiple Mieloma	1.512	0.996	1.508	0.915	23.036(***)	24.480	15.977(**)	19.231
	Other	1.562	1.289	0.996	0.845	3.345	4.061	0.638	1.290
Health Status (ref. medium)		0.318(***)	0.105	0.311(***)	0.116	0.100(***)	0.063	0.607	0.263
Type of transplant (ref. autologous)	Allogeneic transplant	-	-	1.848	1.220	0.208	0.231	6.878	12.903
Gender (ref. female)	Male	0.751	0.411	0.406(*)	0.221	1.019	0.774	0.263(*)	0.210
Age at transplant (ref. 49 years)		0.995	0.022	1.009	0.219	1.011	0.041	0.999	0.037
Educational level (ref. medium)		0.849	0.294	1.064	0.352	0.742	0.367	1.081	0.506
Marital status (ref. without partner)	With partner	2.088	1.334	1.132	0.748	1.821	1.793	0.137*	0.161
Work status (ref. unemployed)	Employed	0.579	0.348	0.443	0.236	3.176	3.661	0.110**	0.119
Formal care (ref. no reception)	Reception	1.837	2.278	1.088	1.295	0.122	0.203	-	-
Constant		3.294	2.543	9.927(***)	7.549	0.630	0.703	2.731	3.020
N		139		139		71		62	
LR χ^2		26.04(***)		28.74(***)		42.13(***)		30.82(***)	
Pseudo R2		0.203		0.201		0.431		0.382	
ROC curve		80.07%		80.71%		90.95%		87.79%	

Significance level at 99% (***), at 95% (**) and at 90% (*); dependent variable: Informal care reception vs. non reception.

who was in a relationship was less likely to receive informal care than a patient who was not in a relationship (OR=0.137). Patients who were employed had a higher probability of receiving informal care in comparison with those who were unemployed during this phase (OR=0.110). It is worth noting that the parameter associated with the state of health was not statistically significant in phase 2.

Finally, the analysis of the constant determined that in Phase 1, the probability of receiving informal care in a baseline individual that was a 49-year-old female, diagnosed with lymphoma, with a normal state of health, not in a relationship, not employed and not receiving formal care was 76.71%. During Phase 2, maintaining as a constant the characteristics of our baseline individual (who by phase 2 had received an autologous transplant), the probability of receiving informal care was 90.85%. During Phase 3 the figure was 38.65% and finally, in Phase 4 it was 73.19%.

The results of the Cochran test are detailed in table 4, reflecting that there were no significant differences between receiving informal care during the pre-transplant phase and the first year following the transplant (p>0.05). This equivalence disappeared when comparing the receipt of informal care during Phase 1 or Phase 2, with Phases 3 and 4 (p<0.000).

Table 4
Cochran's Q test. Relationship between phases in the reception of informal care.

Variables	Phase 2: 1st year post-trasplant		Stage 3: 2nd-3rd year post-trasplant		Stage 4: 4th-6th year post-trasplant	
	Cochran's χ^2	Prob > χ^2	Cochran's χ^2	Prob > χ^2	Cochran's χ^2	Prob > χ^2
Phase 1: Pre-trasplant	1.315	0.251	25	0.0001(***)	31	0.0001(***)
Phase 2: 1º year post-trasplant	-	-	27	0.0001(***)	25	0.0001(***)

Significance level at 99% (***), at 95% (**) and at 90% (*).

DISCUSSION

According to our results, an overwhelming presence of informal care was observed as opposed to formal care in all phases analyzed. This care is especially predominant in the pre-transplant phase and during the first year following the transplant, and is extended in time for those patients who developed complications or serious side effects, or who suffered a relapse of their illness(5,6,29). We have shown a complementary relationship between formal and informal care under the assumption that, given the lack of significance in the parameter associated with formal care in our model, it may be present in certain cases to improve the situation of the caregiver and/or the patient. This relationship has been observed in other studies(19), where formal care becomes more and more necessary given the social changes we've seen in recent decades (such as the incorporation of women into the workforce or the aging of the population)(30). The complementary nature of both types of care has also been observed in dependent populations(31), elderly populations and in those with Alzheimer's disease (in the case of formal care administered at home)(10) in Spain; this trend is much more common in other European countries(32). Nevertheless, there is notable overlap regarding the great importance of informal care, which translates into significant economic savings for both families and public institutions(8,9,10,11,33).

Our results indicate that in Phase 1 (pre-transplant), patients diagnosed with acute leukemia were more likely to receive informal care, given that their chemotherapy treatment was much more aggressive than other diagnoses(2), so side effects and the need for help and support were both more significant. Likewise, the probability of receiving informal care in the medium term continued to be greater. Justification for this assertion comes from the fact that the probability of a suffering a relapse during the first or second year is 52% following an autologous transplant and 25% following an allogeneic transplant34, while in the case of lymphoma, the probability decreases to an average of 35% and 34%, respectively(34). In the longterm, the acute leukemia variable becomes insignificant, as those patients who have managed to survive the disease have regained their quality of life almost entirely, returning to a satisfactory level of physical, emotional and psychological well-being, and daily activity(6).

The opposite trend was observed among those with multiple myeloma, since this is the diagnosis that requires the most informal care in the medium and longterm. This may be because, despite recent improvements in current treatment methods when it comes to prolonging the overall survival of the patient, with the introduction of high doses of chemotherapy combined with an autologous stem cell transplant, the survival ratio of five years after the transplant remains poor at just 35-37%(35) and the probability of relapse at 3-4 years post-transplant is 90%(34).

Variables relating to type of diagnosis and type of transplant during Phase 2 show relevant interest, since none of them determine whether the patient will receive informal care. This may be because HSCT is an extremely complex clinical procedure, given the side effects associated with it and the notable reduction in the patient's quality of life, suggesting a similar implication by family members, irrespective of diagnosis and type of transplant(29).

State of health is a very important variable in receiving informal care(22). A more positive perception of the patient's state of health results in a lesser need for informal care not only in the pre-transplant phase, but in the first, second and third years following the transplant. However, in the longterm, state of health ceases to be statistically significant. This is due to the fact that the employment variable covers the effect of the patients' state of health, given that in the longterm, those with a good state of health normally end up working, since most of them overcome the illness. By contrast, it is uncommon for those with a poor state of health to be employed.

It is important to note that the sociodemographic factors included in all of the phases are not statistically significant in receiving informal care, as opposed to receiving care at a clinic. These results are corroborated by other studies in which factors associated with the caregiver and/or patient, such as age(16,19,20), gender,(19), race(16), marital status(16) or employment(20), have no significant relationship to the time dedicated to informal care in cancer patients. Nevertheless, in our study, gender proved to be significant in Phases 2 and 4, showing that women have a higher probability of receiving informal care than men. This could be due to women expressing a greater need for help with instrumental activities and transportation than men do(22), especially during such critical phases as the first year following the transplant and during any possible recurrence of the illness in the longterm. Furthermore, it is worth highlighting that long-term marital status (having a partner) is associated with a lower probability of receiving informal care. Following the research line of Rogero(8), this could be due to a possible bias in the identification of type of care by married individuals or those in a relationship, who do not identify their partners as informal caregivers as such, but rather consider them to be providing normal care, which is hardly distinguishable from the sort of care they provided previously.

Finally, those caregivers who have provided care in the pre-transplant phase will continue to do so in the first year following the transplant.

However, this continuity is not present in care provided in the medium and longterm(17).

One of the limitations of this study refers to sample size, due principally to a lack of available information from official sources. Further, the selection of transplant recipients can be skewed when it comes to the goal of analyzing not only the chemotherapy phase, but also the phases involved in any treatment that may come later. Hence, future research may benefit from a larger sample size and patients who have not undergone a transplant, providing contrast to test the results. A second limitation is related to the use of a method based on memory for answering certain prompt questions developed for the questionnaire, given the possibility of memory-bias inherent in said methodology.

In conclusion the present study is meant as a possible starting point for a new line of research in the field of oncohematology. This field will be of interest in the future, if we look at the high incidence of new case estimates for Europe in the year 2020. An estimated increase of 9.75%, 8.51% and 11.95% is predicted in new cases of leukemia, lymphoma and multiple myeloma, respectively, as compared with the year 2012(24).

Based on the information processed, leading to the construction of the fourth pillar of the Spanish Welfare State, with the Law for the Promotion of Personal Independence and Care for Dependent People (LAPAD)(36), and following the Resolution published in 2010(37), we would like to mention item 8.1. The section addresses "Relative aspects of the procedure," and specifies that "for those with serious pathological processes requiring aggressive treatment that predetermines a situation of temporary dependency associated with the treatment itself (chemotherapy, radiation, other treatments involving immunosuppression, immobilization, traction, etc): the application process will proceed once the treatment has been completed and the patient has achieved maximum functional recovery". This resolution limits the possibility for cancer patients of benefiting from assistance offered under the LAPAD until they have recovered completely. Nevertheless, according to the results of the present study, the informal caregiver plays a fundamental role in caring for and supporting oncohematological patients, mainly during the pre-transplant phase and in the first year following the transplant. If we add that informal caregivers are under more stress when caring for family members who have cancer as compared to those with other illnesses(13), it does not seem justified that said patients should be excluded from receiving such care. It would be interesting to create a possible service providing provisional home healthcare, on an extraordinary basis within the framework of the LAPAD, with the objective of contributing to the reduction of the burden carried by informal caregivers during Phases 1 and 2, thus improving quality of life not only for the caregivers, but for the patients themselves.

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