

## CARE SKILL AND OVERLOAD OF THE FAMILY CAREGIVER OF PATIENTS IN CANCER TREATMENT

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### ABSTRACT

**Objective:** to analyze the relationship between the characteristics of patients in cancer treatment, their family caregivers, the care provided with the overload, as well as between overload and the care skills.

**Method:** a cross-sectional study conducted at the chemotherapy and radiotherapy services of a university hospital in Rio Grande do Sul (Brazil) from March to August 2017, with 132 family caregivers of patients in cancer treatment. Data was collected by an instrument that characterizes patients, caregivers and care (the Brazilian version of the Caring Ability Inventory) and the Zarit Overload Scale. The following coefficients were used: Spearman correlation, Mann-Whitney or Kruskal-Wallis.

**Results:** there was a significant relationship between the total overload and the patient's level of dependence ( $p=0.021$ ) and help from others ( $p=0.009$ ). The "care impact" factor was significantly related with the patient's level of dependence ( $p=0.006$ ), the caregiver's gender ( $p=0.035$ ) and the care help ( $p=0.043$ ). Regarding the "perception of self-efficacy" factor, there was a significant relationship involving the caregiver's age ( $p=0.036$ ) and, in the "caregiver expectation" factor, a significant relationship was observed with the care help ( $p=0.002$ ). There was a significant and negative correlation between the total care skill and the overload factor related to interpersonal relationship ( $p=0.035$ ); and between the "courage" dimension and the "perception of self-efficacy" ( $p=0.032$ ) and "interpersonal relationship" ( $p=0.008$ ) factors.

**Conclusion:** the characteristics of the patient, the caregiver and the care provided influence the overload of the family caregiver, and this overload, in turn, interferes with the care skills. These results should be considered when planning interventions that aim to guide and prepare family caregivers for home care.

**DESCRIPTORS:** Caregivers. Home assistance. Family. Neoplasia. Nursing.

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## HABILIDADE DE CUIDADO E SOBRECARGA DO CUIDADOR FAMILIAR DE PACIENTES EM TRATAMENTO ONCOLÓGICO

### RESUMO

**Objetivo:** analisar a associação entre as características de pacientes em tratamento oncológico, de seus cuidadores familiares e do cuidado prestado com a sobrecarga, e desta com a habilidade de cuidado.

**Método:** estudo transversal desenvolvido nos serviços de quimioterapia e radioterapia de um hospital universitário do Rio Grande do Sul (Brasil), no período de março a agosto de 2017, com 132 cuidadores familiares de pacientes em tratamento oncológico. Os dados foram coletados por instrumento de caracterização dos pacientes, dos cuidadores e do cuidado, - versão brasileira do *Caring Ability Inventory* e a Escala de Sobrecarga de Zarit. Os seguintes coeficientes foram utilizados: correlação de Spearman, Mann-Whitney ou Kruskal-Wallis.

**Resultados:** foi observada associação significativa da sobrecarga total com o grau de dependência do paciente ( $p=0,021$ ) e auxílio de terceiros para o cuidado ( $p=0,009$ ). O fator impacto de cuidado associou-se de modo significativo com o grau de dependência do paciente ( $p=0,006$ ), sexo do cuidador ( $p=0,035$ ) e auxílio para o cuidado ( $p=0,043$ ). No fator percepção de autoeficácia houve associação significativa com a idade do cuidador ( $p=0,036$ ) e, no fator expectativa face ao cuidar, observou-se associação significativa com o auxílio para o cuidado ( $p=0,002$ ). Houve correlação significativa e negativa entre a habilidade de cuidado total e o fator da sobrecarga relacionado à relação interpessoal ( $p=0,035$ ); e da dimensão coragem e os fatores percepção de autoeficácia ( $p=0,032$ ) e relação interpessoal ( $p=0,008$ ).

**Conclusão:** as características do paciente, do cuidador e do cuidado prestado influenciam na sobrecarga do cuidador familiar e esta, por sua vez, interfere na habilidade de cuidado. Esses resultados devem ser considerados no planejamento de intervenções que visem orientar e preparar os cuidadores familiares para cuidados domiciliares.

**DESCRITORES:** Cuidadores. Assistência domiciliar. Família. Neoplasia. Enfermagem.

## HABILIDADES DE CUIDADO Y SOBRECARGA DEL CUIDADOR FAMILIAR DE PACIENTES EN TRATAMIENTO ONCOLÓGICO

### RESUMEN

**Objetivo:** analizar la asociación de las características de pacientes en tratamiento oncológico, las de sus cuidadores familiares y las de los cuidados prestados con la sobrecarga, y entre esta última y la habilidad de cuidado.

**Método:** estudio transversal desarrollado en los servicios de quimioterapia y radioterapia de un hospital universitario de Rio Grande do Sul (Brasil), entre marzo y agosto de 2017, con 132 cuidadores familiares de pacientes en tratamiento oncológico. Los datos se recolectaron por medio de un instrumento para caracterizar a los pacientes, a los cuidadores y a los cuidados, la versión brasileña del *Caring Ability Inventory*, y por medio de la Escala de Sobrecarga de Zarit. Se utilizaron los siguientes coeficientes: correlación de Spearman, Mann-Whitney o Kruskal-Wallis.

**Resultados:** se observó una asociación significativa de la sobrecarga total con el grado de dependencia del paciente ( $p=0,021$ ) y la ayuda de terceros para prestar los cuidados ( $p=0,009$ ). El factor "impacto de los cuidados" se asoció de manera significativa con el grado de dependencia del paciente ( $p=0,006$ ), el sexo del cuidador ( $p=0,035$ ) y la ayuda para ofrecer los cuidados ( $p=0,043$ ). En el factor "percepción de la autoeficiencia" se registró una asociación significativa con la edad del cuidador ( $p=0,036$ ) y en el factor "expectativa con respecto a ofrecer los cuidados" se observó una asociación significativa con la ayuda para ofrecerlos ( $p=0,002$ ). Se registró una asociación significativa y negativa entre la habilidad total de los cuidados y el factor de la sobrecarga relacionado con la relación interpersonal ( $p=0,035$ ); y de la dimensión "coraje" y los factores "percepción de la autoeficiencia" ( $p=0,032$ ) y relación interpersonal ( $p=0,008$ ).

**Conclusión:** las características del paciente, del cuidador y de los cuidados prestados influyen sobre la sobrecarga del cuidador familiar; y dicha sobrecarga, a su vez, interfiere en la habilidad de cuidar. Estos resultados deben ser considerados al planificar intervenciones destinadas a orientar y preparar a los cuidadores familiares para prestar cuidados domiciliares.

**DESCRIPTORES:** Cuidadores. Asistencia domiciliaria. Familia. Neoplasia. Enfermería.



## INTRODUCTION

Chronic illness conditions have multi-factorial characteristics, biological and sociocultural determinants, and are responsible for changing the disease profile of the Brazilian population. Cancer is a Non-Communicable Disease (NCD) of great epidemiological, social and economic magnitude, with high rates of sequelae and limitations, which most often incapacitate the affected individuals and demand permanent care, both at the hospital and at home.<sup>1</sup>

Currently, the health models are able to cure acute diseases or conditions, but they still struggle in meeting the demands for care and rehabilitation resulting from chronic diseases. Given this scenario, home care emerges as an alternative category of health care, which can meet the needs of the population beyond the hospital setting. In addition, it makes it possible to reduce the time and costs from hospitalization and delegates the responsibility of care to the families.

During their life cycle, families many times live with the disease process and face the need to assume the role of caregiver, especially in situations of chronic diseases. The family caregiver is an informal care agent, which generally refers to the person who will be responsible for the care demands, usually mediated by affection and commitment relationships that bond the family member, friends or neighbors to the dependent person.<sup>2</sup>

Getting sick from a chronic condition requires different types of care, such as hygiene, food, and mobility, among others. Depending on the patient's level of dependence, such duties can be intense and prolonged and, therefore, strenuous. This progressively exposes family caregivers to overload and affects their performance.<sup>3</sup> Overload entails physical and mental exhaustion related to the accumulation of stressors, with which caregivers cannot establish adequate coping strategies to adapt to the situation, which may reflect on their health, wellness and quality of life.<sup>4-5</sup>

In this sense, nurses should assess situations of vulnerability of the family caregivers and learn how they mobilize for care in the face of illness, and thus plan strategies and interventions directed to the needs perceived in this population.<sup>6-7</sup> It is also necessary to especially prepare and advise the primary family caregivers for home care in order to acquire or improve care skills. The duties of the family caregiver includes performing procedures or practices and developing their care skill.<sup>2</sup>

Care skill are the abilities of the person who takes on the role of caregiver of a relative or significant person in a situation of disability. These skills have cognitive, instrumental and attitudinal dimensions, which can be identified and measured according to indicators of knowledge, courage and patience.<sup>8</sup> These attributes were based on the conception of care, where certain characteristics are considered as necessary skills for care, namely: knowledge and technical skills, the courage to develop them, the desire to be with the person being taken care and the patience to perform the necessary actions in the care process.<sup>9</sup>

Some conditions involved in home care may be related to overload and, consequently, influence the care skills and result in negative consequences for both the caregiver and the care itself. When taking this type of responsibility, family caregivers should be the focus of nurse's actions to minimize burden and support new skills. Knowing the factors associated with overload also allows planning interventions that impact on the wellness and preparation of the caregiver, aiming at the quality of life and care provided.

In Brazil, the overload of family caregivers is a widely explored theme,<sup>5-6</sup> but national studies evaluating the care skills of the Brazilian population and the relationship between these variables are scarce. International studies show that overload can interfere with the care skills of the family caregivers.<sup>2,10</sup> Thus, knowledge about this theme allows to increase the visibility of the aspects involved in the caregiver's experience, direct care and strategies to minimize overload and develop skills.

From this context, this study sought to answer the following research question: is there any relationship between the characteristics of patients in cancer treatment, their family caregivers, the care provided and the overload, as well as between the overload and the care skills? The hypothesis was that there is a relationship between care skills and overload, and the latter is related to the characteristics of the patients in cancer treatment, their family caregivers and the care provided.

The aim of the study was to analyze the relationship between the characteristics of patients in cancer treatment, their family caregivers, the care provided and the overload, and between overload and care skill.

## METHOD

This is a cross-sectional study conducted in the chemotherapy and radiotherapy services of a hospital in Rio Grande do Sul (Brazil), from March to August 2017, with family caregivers of patients in cancer treatment. The sample was selected by the non-probabilistic sampling, for convenience, and all caregivers who met the inclusion criteria were invited to participate in the study.

The screening of family caregivers occurred through the identification of dependent patients using oncology services. The inclusion criteria for caregiver selection included the following: being 18 years old or older; providing home care; being the primary caregiver of a patient in cancer treatment with some level of dependence for activities of everyday life, verified by the Barthel Index. It assesses people's level of dependence on daily activities and ranges from "0" (fully dependent) to "100" (independent).<sup>11</sup> The exclusion criterion was to present evident cognitive impairment in the initial approach.

During the data collection period, 167 patients showed some level of dependence; however, when approaching their caregivers, 23 did not self-report as their primary caregiver, five showed difficulties in communication and/or understanding, two were under 18 years old, and five refused to participate in the study. Thus, the sample consisted of 132 family caregivers.

For data collection, the researchers used a questionnaire to characterize patients in cancer treatment, which was completed during an interview with family caregivers. A socio-demographic characterization questionnaire of family caregivers was also used, composed by questions related to the care provided and including the following variables: gender, age, marital status, current work situation and employment status. The profession and employment status of the caregivers were classified according to the Brazilian Classification of Occupations (*Classificação Brasileira de Ocupações*, CBO).<sup>12</sup> Regarding care, the time of care, help from others and previous experiences variables were addressed.

In addition to these instruments listed for the characterization of patients and family caregivers, the Zarit Overload Scale and the Brazilian Portuguese version of the Caring Ability Inventory (CAI-BR) instrument were used. The original denomination in English and the acronym "CAI-BR" were kept according to the desire of the authors responsible for the cross-cultural adaptation of the instrument.<sup>13</sup>

The Zarit Overload Scale was created in 1987<sup>14</sup> and validated for Brazilian Portuguese in 2002.<sup>15</sup> It assesses the perceived impact of caring on the caregiver's physical and emotional health. In this context, it allows evaluating the objective and subjective overload of the informal caregiver and includes information about health, social life, personal life, financial condition, emotional status and type of relationship. It consists of 22 items, evaluated on a Likert scale ranging from 0 to 4 points, where 0=Never, 1=Rarely, 2=Sometimes, 3=Quite frequently and 4=Nearly always. Adding the score results in an overall score ranging from 0 to 88. A higher score corresponds to a higher perception of overload, classified as follows: <20: little or no overload; 21-40: mild to moderate overload; 41-60: moderate to severe overload; >60: severe overload.<sup>15</sup>

In addition to objective overload, this instrument also assess subjective overload, which includes four factors: impact of caregiving (it groups items referring to burden related to direct care delivery); interpersonal relationship (it presents and groups items that assess the burden of interpersonal impact on care delivery); expectations for care (related to the expectation regarding the caregiver); perception of self-efficacy (related to the caregiver's opinion about their performance). The validated version translated into Brazilian Portuguese obtained a Cronbach's alpha of 0.93.<sup>15</sup> In this study, the internal consistency verified by Cronbach's alpha was 0.84.

CAI-BR comes from the CAI instrument, proposed by an American nurse in 1990.<sup>8</sup> The instrument was validated and translated into Spanish in 2005<sup>16</sup> and into Brazilian Portuguese in 2016.<sup>13</sup> Its objective is to evaluate the skills of a person from their own perceptions to provide adequate care to someone else, highlighting instrumental and cognitive aspects. The instrument consists of 37 items divided into three dimensions: knowledge (understanding of oneself and others), courage (ability to face the unknown) and patience (tolerance and persistence), with 14, 13 and 10 items, respectively. The answers to the items are measured with a Likert scale, ranging from 1 to 5: 1 is "strongly disagree" and 5 is "strongly agree". The scores obtained are added, providing a total score and one for each dimension.

For the classification of scores as low, medium and high level of care skills, the mean (M) and standard deviation measures were used. According to the author of the original instrument, the standard deviation range above and below the mean was considered medium level; below this value it was considered low level, and above, high level.<sup>8</sup>

The reliability of the CAI, the original instrument, verified by Cronbach's alpha, was 0.84,<sup>8</sup> and the translated and validated version for Spanish reports a value of 0.86.<sup>15</sup> In the Portuguese version, the internal consistency was 0.78<sup>13</sup> and, in this study, the Cronbach's alpha coefficient for the total CAI-BR was 0.60.

Family caregivers were interviewed individually after reading and signing the Free and Informed Consent Form, without the patient's presence, in the nurse's office, in the absence of noise and interference, and ensuring the participants' privacy. Initially, the patient's characterization data and level of dependence for daily activities were obtained. Subsequently, the family caregiver characterization questionnaire was applied, followed by the Zarit Overload Scale and the CAI-BR instrument. The procedure for data collection took approximately 30 minutes.

Data was organized and entered concurrently with the collection period by two independent typists in a spreadsheet, in Excel (Office, 2011). After checking for inconsistencies in typing, the information was analyzed electronically using the Statistical Package for Social Science (SPSS), version 23.0.

The qualitative variables were presented by the distribution of absolute (n) and relative (%) frequencies, and the quantitative variables, in measures of central tendency, standard deviation ( $\pm$ ) and measures of variation. The normality of the groups was tested using the Kolmogorov-Smirnov test and, from this the Spearman Correlation Coefficient, Kruskal-Wallis or Mann-Whitney tests were performed. For all, a confidence interval (CI) of 95.0% and a significance level  $\leq 5\%$  were considered. The study complied with the principles of Resolution 466/12 of the National Health Council.

## RESULTS

Among the patients, there was a predominance of males (78; 59.1%), with mean age of 66.5 years old ( $\pm 12.7$ ) and from 29 to 91 years old. Regarding the level of dependence, the score ranged from 10 to 90 on the Barthel scale, with a predominance of moderate dependence (95; 72.0%), followed by severe/total dependence (37; 28.0%) for daily activities.

Regarding the characteristics of the caregivers, the female gender was predominant (103; 78.0%), aged between 18 and 76 years old and with a mean of 48.7 ( $\pm 14.0$ ), with a partner (101; 76.5%). As for the work situation, most did not work at the time of the survey (93; 70.6%). Of these, 68 (73.1%) were unemployed, 22 (23.7%) were retired, and 3 (3.2%) were on work or sick leave. The caregivers who worked (39; 29.5%) acted as commercial workers (21; 53.8%); did mid-level administrative and technical services (5; 12.8% each); agricultural, forestry and fishery workers, and were science and arts professionals (4; 10.8% each).

Regarding the characteristics of the care provided, the caregivers received support for the care (88; 66.7%), mainly from family members (74; 84.1%) daily (60; 68.2%) in the integral care with the dependent person (66; 75.0%).

Upon application of the Zarit Overload Scale, the sum of the scores ranged from 4 to 59, with a mean of 22.62 ( $\pm 11.75$ ), showing a prevalence of caregivers with no overload, which is equivalent to 50.8%. Of the others, 53 (40.1%) of the family caregivers had mild to moderate overload, and 12 (9.1%), moderate to severe overload.

The subjective overload of the caregivers showed a greater influence of the "impact on care delivery" factor, with a score ranging from zero to 35 and a mean of 8.98 ( $\pm 7.95$ ). This corresponds to direct care activities, such as the change in health status, the high demand for care, the change in social and family relationships, the lack of time and the physical and mental stress of the family caregiver. The other factors, "perception of self-efficacy", "caregiver expectations" and "interpersonal relationship" had mean values of 2.85 ( $\pm 2.25$ ), 8.96 ( $\pm 3.14$ ) and 1.91 ( $\pm 2.17$ ), respectively.

By associating the demographic and clinical characteristics of the cancer patients with family caregiver overload (Table 1), the level of dependence was statistically and significantly related with the family caregiver's total and subjective overloads, related to the "impact of caregiving" factor ( $p=0.021$ ;  $p=0.006$ ). The socio-demographic characteristics of the family caregivers and the care provided were equally associated with overload (Table 2). This shows that the caregivers' gender is statistically and significantly related with subjective overload, which is linked to the impact of caregiving ( $p=0.035$ ), and the caregivers' age is statistically and significantly related to subjective overload on perceived self-efficacy ( $p=0.036$ ). The help of others in home care was significantly associated with total overload and with the subjective factors regarding the impact of caregiving and the expectations for care ( $p=0.009$ ;  $p=0.043$ ;  $p=0.002$ ).

**Table 1** – Correlation between demographic and clinical variables of cancer patients and the family caregiver's overload. Rio Grande do Sul, RS, Brazil, 2017. (n=132).

Variables	n (%)	Overload											
		Total		Impact of caregiving		Perception of self-efficacy		Expectations for care		Interpersonal relation			
		Mean(±)	p-value*	Mean(±)	p-value*	Mean(±)	p-value*	Mean(±)	p-value*	Mean(±)	p-value*		
Gender													
Female	54(40.9)	20.9(10.9)	0.185	7.7(6.7)	0.250	2.9(2.4)	0.876	8.5(3.1)	0.264	1.8(2.1)	0.983		
Male	78(59.1)	23.9(12.2)		9.9(8.6)		2.8(2.2)		9.2(3.2)		1.9(2.2)			
Age													
29-65 years old	57(43.2)	23.7(12.4)	0.508	9.1(8.2)	0.976	3.0(1.9)	0.211	9.4(3.2)	0.152	2.2(2.3)	0.203		
66-91 years old	75(56.8)	21.9(11.3)		8.9(7.8)		2.7(2.5)		8.6(3.1)		1.7(2.0)			
Degree of dependence													
Severe/Total	37(28.0)	27.2(13.8)	0.021 <sup>†</sup>	12.6(9.6)	0.006 <sup>†</sup>	2.7(2.4)	0.566	9.7(3.3)	0.064	2.1(2.9)	0.689		
Moderate	95(72.0)	20.9(10.4)		7.5(6.7)		2.9(2.2)		8.7(3.0)		1.8(1.8)			

\*p-value: Mann-Whitney Test; <sup>†</sup>Significance level ≤5%.

**Table 2 – Correlation between the socio-demographic variables of the family caregivers, the characteristics of care and overload. Rio Grande do Sul, RS, Brazil, 2017. (n=132).**

Variables	n (%)	Overload									
		Total	Impact of caregiving	Perception of self-efficacy	Expectations for care	Interpersonal relation					
		Mean(±)	p-value	Mean(±)	p-value	Mean(±)	p-value	Mean(±)	p-value		
Gender											
Female	103(78.0)	23.6(12.2)	0.138†	9.7(8.1)	0.035*‡	2.8(2.3)	0.982‡	9.1(3.2)	0.486‡	1.9(1.9)	0.868‡
Male	29(22.0)	19.4(9.6)		6.2(6.6)		2.8(2.1)		8.6(2.8)		1.9(2.3)	
Age											
18-37 years old	29(22.0)	23.0(11.2)	0.917†	8.4(6.8)	0.904†	3.9(2.4)	0.036*†	9.0(3.6)	0.699†	1.6(1.3)	0.841†
38-57 years old	70(53.0)	22.5(11.8)		9.2(8.0)		2.6(2.2)		8.8(3.0)		1.9(2.2)	
58-76 years old	33(25.0)	22.8(12.5)		9.0(8.8)		2.4(1.9)		9.2(3.0)		2.2(2.7)	
Marital status											
Has a partner	101(76.5)	22.5(11.4)	0.906†	8.9(7.9)	0.865†	2.8(2.2)	0.952‡	8.9(3.0)	0.656‡	1.8(1.9)	0.604‡
No partner	31(23.5)	23.4(13.0)		9.2(8.2)		2.8(2.3)		9.1(3.6)		2.3(2.9)	
Occupational situation											
Works	39(29.5)	22.7(12.1)	0.891†	8.6(7.3)	0.902‡	3.2(2.7)	0.383‡	8.9(3.2)	0.831‡	2.0(2.1)	0.451‡
Does not work	93(70.5)	22.7(11.7)		9.1(8.2)		2.7(2.0)		9.0(3.1)		1.9(2.2)	
Care time											
1 to 3 months	47(35.6)	21.6(11.4)	0.412†	8.3(6.7)	0.356†	2.6(2.2)	0.846†	9.0(3.2)	0.448†	1.8(2.3)	0.564†
4 to 6 months	36(27.3)	20.9(11.4)		7.5(7.7)		3.0(2.5)		8.5(3.2)		1.9(2.3)	
7 to 12 months	25(18.9)	23.5(10.5)		10.2(7.5)		2.8(2.0)		8.7(3.3)		1.7(1.5)	
>12 months	24(18.2)	26.5(13.9)		11.2(10.4)		3.1(2.1)		9.8(2.8)		2.4(2.3)	
Help from others in caregiving											
Yes	88(66.7)	20.9(11.4)	0.009*‡	8.1(7.7)	0.043*‡	2.7(2.2)	0.217†	8.3(3.0)	0.002*‡	1.8(2.1)	0.516†
No	44(33.3)	26.2(11.7)		10.8(8.1)		3.2(2.3)		10.2(3.1)		2.0(2.3)	

\* Significance level ≤5%; † Kruskal-Wallis Test; ‡ Mann-Whitney Test.

When assessing care skills, the scores on the full scale and dimensions showed that caregivers have an average level of care skills, both for the total CAI-BR and for its knowledge, courage and patience dimensions (Table 3).

**Table 3** – Scores and classification of the total care skills and their dimensions. Rio Grande do Sul, RS, Brazil, 2017. (n=132).

Variable	Mean	Standard Deviation	Variation	Low		Medium		High	
				n	%	n	%	n	%
Knowledge	52.20	3.54	44 - 61	22	16.67	87	65.91	23	17.42
Courage	46.31	3.98	37 - 57	20	15.15	91	68.94	21	15.91
Patience	40.54	2.71	34 - 48	16	12.12	100	75.76	16	12.12
CAI-BR Total	139.05	7.10	125 - 160	22	16.67	89	67.42	21	15.91

When the relationship between overload and care skills was verified (Table 4), there was no significant correlation between the total scores of the scales. However, there was a statistically significant and negative relationship between total care skills and the courage dimension and overload, related to the caregiver's interpersonal relationship with the sick person, and the higher the overload associated with this factor, the lower the care skills and courage of the family caregiver. There was also a significant correlation between courage and overload regarding the "perception of self-efficacy" factor, since the higher the overload related to this factor, the lower the courage.

**Table 4** – Correlation analysis (Spearman's coefficient) between the scores obtained in the total care skills and its dimensions and the burden of care scores and its factors. Rio Grande do Sul, Brazil, 2017. (n=132).

Variable	Overload		Impact of caregiving		Perception of self-efficacy		Expectations for care		Interpersonal relation	
	r	p-value	r	p-value	r	p-value	r	p-value	r	p-value
CAI-BR Total	-0.143	0.101	-0.133	0.128	-0.070	0.425	-0.061	0.490	-0.183	0.035*
Knowledge	-0.103	0.241	-0.091	0.299	0.005	0.952	-0.134	0.124	-0.053	0.542
Courage	-0.161	0.065	-0.099	0.258	-0.187	0.032*	-0.048	0.583	-0.227	0.008*
Patience	-0.018	0.839	-0.044	0.618	0.003	0.974	0.050	0.571	-0.072	0.411

\*Significance level  $\leq 5\%$ .

## DISCUSSION

Regarding the characterization of the family caregivers, the results of this study are similar to the data described in the literature, reinforcing the majority presence of women with a mean age of 52.62 years old and with a partner in care activities.<sup>6,17-19</sup> When providing care, there is a tendency for the family caregiver to refrain from paid work activities outside the home for exclusive dedication to the care demands at home. In this study, 70.6% of the caregivers did not work, which is similar to the literature data<sup>20</sup> and may represent the isolation of the family member in care, favoring physical and emotional changes, as well as interfering with their health, well-being and quality of life.

On the other hand, the presence of care help was reported by 66.7% of the participants in this study, which may also be related to the low levels of overload evidenced, since 50.8% demonstrated absence of overload. Although in lower percentages, family caregivers presented mild to moderate (40.1%) and moderate to severe (9.1%) overload, which, added to the many care responsibilities,

may indicate incipient evidence of an exhaustion process, which should be intervened in advance to improve the quality of life of these caregivers.<sup>2</sup>

Some factors that may interfere with the family caregiver overload should also be considered, such as: the level of dependence and age of the patients in cancer treatment, the characteristics of the family caregivers themselves and the care, such as age, gender, number of hours devoted to caregiving. According to the literature, these factors are related with the onset of emotional symptoms, such as anguish and suffering, and consequently higher mean levels of overload.<sup>18,22</sup> In this study, it was shown that the higher the level of dependence of the patient on cancer treatment, the greater the family caregiver's perception of objective or subjective overload, and this perception is directly related to the impact of caregiving.

When the subjective overload is related to the impact of caregiving, it refers to the consequences of direct care on the caregiver's life, and is related with the care demanded by the sick person, with social and family changes, as well as with physical and emotional distress. In this sense, the high level of dependence can cause negative repercussions for the family caregivers, as their total overload and the impact of caregiving increase. This fact was also found in other studies that evidence the relationship between the dependent person's functional capacity and the overload, and the higher the dependency, the greater the caregiver overload.<sup>5,23</sup>

Regarding the characteristics of caregivers that may interfere with overload, there is a statistically significant relationship between gender and the overload related to the impact caused by caregiving. This shows that women find themselves more overwhelmed by the direct consequences of the care demands, such as social isolation, lack of time and physical and emotional distress, similar to results already mentioned in the literature.<sup>5</sup>

Support from family members, institutions and/or health professionals to family caregivers is important to strengthen the coping mechanisms and to minimize overload.<sup>6</sup> This was also verified in this study, given the statistically significant relationship between the help from others in care and total overload; the impact factor on care delivery and expectations for care.

Thus, when the caregiver has no help to meet the care demands, the impact of caregiving is accentuated. In this case, the caregiver performs the tasks alone, which may affect their expectations for care. The high demand for care makes it difficult for the caregiver to perform the activities completely, resulting in frustration about their expectation and resulting in overload. The dedication to care without any help is a reality evidenced in other studies, and confirms the relationship between the intensity of care, lack of preparation, support and help, and the appearance of physical and mental changes in the caregiver.<sup>2</sup>

The level of care skills found to be predominant among the participants in this study was medium, which is below the levels identified in similar international studies, considering the total scores and the knowledge and patience dimensions. In the courage dimension, the literature refers to a medium level, similar to this investigation.<sup>2,24</sup> The difference observed between the skill levels may be related to the fact that data from the aforementioned international studies were collected in Colombia, where interventions are developed which impact psychosocially on the family caregiver's behavior and favor empowerment, ease of decision making, reorganization of activities and positive attitudes towards the situations. These actions are part of the program called *Cuidando a los cuidadores*. They were positive to strengthen care skills focused on chronic diseases, and were more effective when compared to conventional health education interventions.<sup>25</sup>

When combining the level of overload and the care skills, there was a statistically significant and predominantly negative correlation, i.e., care skills and caregiver overload are inverse constructs. Significant but weak correlations among subjective factors of the overload scale and the scores of total skills and the courage dimension stand out. In the overload related to the family caregiver's perception

of self-efficacy, caregivers themselves perceive and expose their opinion about their own performance in caregiving. This factor may interfere with their care skills because, as they feel dissatisfied with their practice, their courage to face the unknown and learn from experiences decreases.

When the subjective overload is related to the interpersonal relationship between the caregiver and the sick person, there is a negative but weak correlation with total care skills and the courage dimension. This overload factor portrays aspects related to inter-relational difficulties between the caregiver and the sick person, which can sometimes impair the family caregiver's communication and performance, affecting their courage and also their care skills. Moreover, the adversities in the interpersonal relationship in the care setting make it impossible for both to express their feelings, fears, anxieties, and to constitute a relationship permeated with affection, love and consideration, factors seen as capable of favoring the development of the necessary dimensions for strengthening care skills.

## CONCLUSION

The results of this study confirmed the hypothesis that the care skills of family caregivers are related with overload, and that overload, in turn, is related with the demographic and clinical characteristics of patients in cancer treatment, and with the characteristics of the caregivers themselves and the care they provide.

The study has some limitations related to the context of access to the study participants, as the fact that it is a public cancer care service may restrict the possibility of generalizing the results. As it is a cross-sectional study, there is also the bias of temporality.

Despite these limitations, this research offers relevant findings to nurses, as it allows directing nursing care, building strategies to minimize overload, and favoring the development of care skills. The interventions aimed at guiding and preparing the family caregivers are also important, as they provide appropriate conditions to meet the care demands of dependent people, which can be done through inter-professional work aimed at identifying and intervening according to the needs of each caregiver.

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## NOTES

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### CONTRIBUTION OF AUTHORITY

Study desing: Coppetti LC, Girardon-Perlini NMO, Andolhe R.

Data collection: Coppetti LC, Machado LG.

Analysis and interpretation of data: Coppetti LC, Girardon-Perlini NMO, Andolhe R, Dapper SN.

Discussion of the results: Coppetti LC, Girardon-Perlini NMO, Andolhe R, Dalmolin A.

Writing and/or critical review of content: Coppetti LC, Girardon-Perlini NMO, Andolhe R, Dapper SN, Machado LG, Dalmolin A.

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### CONFLICT OF INTEREST

There is no conflict of interest.

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