



## ORIGINALES

### Effect of an Educational Intervention for Family Caregivers of Individuals with Cancer in Surgery

Efecto de una intervención educativa para cuidadores familiares de personas con cáncer en cirugía

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#### ABSTRACT:

**Objective.** To evaluate the effect of an educational intervention on family caregivers of adults with cancer who are in the postoperative period of oncological surgery, to strengthen the competence of home care and reduce overload.

**Method.** This was a quasi-experimental quantitative approach with intervention group and control group; 290 family caregivers of patients undergoing surgery were included, educational intervention was applied from admission to six weeks after discharge, measurement was made before and after competence for home care and care overload. **Results.** In the group intervened, a positive and statistically significant impact was obtained in the competence for home care and decreased overload.

**Conclusions.** The educational intervention is a strategy that increases skills for care at home, and reduces the burden on caregivers of people with cancer undergoing surgery.

**Keywords:** Patient discharge; General surgery; Education; Oncology nursing, Caregivers.

#### RESUMEN:

**Objetivo:** Evaluar el efecto de una intervención educativa en cuidadores familiares de adultos con cáncer que se encuentran en postoperatorio de cirugía oncológica, para fortalecer la competencia de cuidado en el hogar y disminuir la sobrecarga.

**Método:** Se trata de un abordaje cuantitativo cuasi-experimental con grupo de intervención y grupo control; se incluyeron 290 cuidadores familiares de pacientes intervenidos por cirugía, se aplicó la intervención educativa desde el ingreso hasta seis semanas después del egreso, se realizó medición antes y después de la competencia para el cuidado en el hogar y de la sobrecarga de cuidado.

**Resultados:** En el grupo intervenido se obtuvo impacto positivo y estadísticamente significativo en la competencia para el cuidado en el hogar y disminución de sobrecarga.

**Conclusiones:** La intervención educativa es una estrategia que aumenta la competencia para cuidar en el hogar, y disminuye la sobrecarga en cuidadores de personas con cáncer sometidos a cirugía.

**Palabras clave:** Plan de alta; Cirugía general; Educación; Enfermería oncológica; Cuidadores

## INTRODUCTION

Cancer is the second cause of death in the world <sup>(1)</sup>. Living with cancer, as a condition that tends to be chronic, is a complex, dynamic, cyclical process<sup>(2)</sup> with varied needs for care due to the multidimensional nature of the treatment<sup>(3)</sup>.

Surgery, as one of the central treatments in caring for patients with cancer, implies lifestyle changes and modification in the subject of care and in the family caregiver in charge, affecting the quality of life <sup>(4)</sup>, overburden with caring, and even emotional alterations. Caregivers report high levels of stress and serious autonomic imbalances, which can in the mid and long term trigger a higher risk of considerable health problems, affecting the physical, social, and emotional financial spheres <sup>(5)</sup>.

As well as patients, caregivers may experience anxiety and fear about what will happen during the hospitalization period, potential complications and results of the surgery and, in this sense, require preparation to manage aspects, like pain and postsurgical discomfort, among other aspects related with care at home, to further optimize services <sup>(4)</sup> and lower overburden.

Caregivers require special guidance upon accepting responsibilities regarding the patient's health, need basic instrumental knowledge and skills, bearing in mind that the time and types of activities dedicated to caring can affect the results of their physical, psychological, and social health<sup>(6)</sup>. Finding the best strategies in caring for the caregiver of the individual suffering from cancer is determinant. For this reason, there is growing interest in interventions that facilitate transitions between institutions that provide services and the home/residence of patients and caregivers <sup>(7)</sup>.

Interventions must explore the patient's and family's adapting to the new lifestyle after one or several treatment modalities against cancer, including rehabilitation, as well as minimizing the burden for the caregiver and the economic aspects that affect the family group. One of the purposes of the programs is to empower patients and caregivers to manage actively the health condition by using strategies in a variety of ways, such as telephone, individualized care, on-line, and group workshops <sup>(8)</sup>.

It is clear that evidence is limited on the potential benefits provided by efforts of these characteristics in the perioperative process for caregivers of patients with cancer. Studies have explored the effect of psycho-educational interventions for caregivers accompanying patients with cancer during the end of life with moderate effects on quality of life <sup>(9)</sup>, use of reflexology to deal with the caregiver's fatigue and depression <sup>(6)</sup>, programs that increase the care skills of caregivers of children with cancer <sup>(10)</sup>. However, the needs of oncology populations during advanced cancer or in children cannot be generalizable for caregivers of oncological surgical patients. Surgery to treat cancer often takes place shortly after the diagnosis when patients and caregivers are in emotional states that result in information overload.

Perioperative education in patients with cancer has better results when administered in a face-to-face format; clinicians need skills to deliver education, have formally constituted schemes, time, and information systems that ensure follow up and continuity<sup>(4)</sup>. This type of intervention is constituted an alternative care approach that involves the entire health staff, diminishes the burden of specialist physicians, and supports caregivers for the patient's preparation and recovery.

The aim of the study was to assess the effect of an educational intervention that enhances the competence for home care and diminishes overload of family caregivers of people with cancer undergoing surgery and under care in a cancer reference center in the city of Bogotá.

## **METHOD**

### **Design**

This was a quasi-experimental study with quantitative approach with pre- and post-test design, with intervention group (IG) and control group (CG), conducted in Instituto Nacional de Cancerología in Bogota, Colombia from November 2016 to May 2018.

### **Population and study environment**

The sample was selected through probabilistic sampling in the medical-surgical services and outpatient surgical consultation.

Inclusion criteria considered: 1) principal caregivers of adults cancer diagnosis who are in the post-operative of oncological surgery; 2) over 18 years of age; 3) who assume the work of caregiver at home during the post-operative.

The study calculated a sample size of 145 caregivers for each of the two randomized groups for the purpose of judging the statistical hypothesis that refers to the difference between the mean scores acquired with respect to skills for caring at home and caregiver overload (type-I error of 0.05 ( $\alpha$ ), type-II error of 0.01 ( $\beta$ ), a 20-point difference ( $\delta$ ), and a higher level of the standard deviation of 60).

### **Data collection**

Firstly, the Ethics and Research Committee at Instituto Nacional de Cancerología granted approval. A list of scheduled surgeries and hospital discharges was available for each week. The caregivers were contacted through the patients with simple random assignment to CG or IG through a coded Excel file.

Nursing professionals monitored all the caregivers during five moments: the day of recruitment, prior to the patient's surgery, during the post-operative in recovery and hospitalization services, and between the first and fourth week after hospital discharge. Each meeting lasted approximately 40 minutes, time used to apply the instruments. A registry was kept of the conventional intervention by the institution in the CG and the educational intervention was implemented in the IG.

The family caregivers filled out the questionnaires used with the aid of research

assistants during recruitment.

The educational intervention consisted in a strategy coordinated and executed by the nursing staff, including three parts:

1) group sessions lasting 20 minutes to evaluate the patient and the caregiver from admission to the institution, and includes knowledge of the type of care associated with the treatment at home: polypharmacy, medications, and/or invasive devices; delivery of educational material according to the medical prescription on discharge; face-to-face specific instruction and information prior to the surgery and during the post-operative; demonstration workshop on managing invasive devices; detecting warning signals and when to consult.

2) Face-to-face sessions lasting 30 minutes to explore aspects that scare the caregivers and how to approach such, the factors that relax them and generate wellbeing, and exploration of support networks available to them.

3) Telephone follow up during discharge once a week during four weeks with a previously established guide of topics to address.

The conventional intervention in the institution for these caregivers consists in delivering educational material according with the medical prescription, demonstration workshop for the patient discharged with colostomies or drainages, and referral to a caregiver program to those who report the need for intervention.

Six weeks after discharge, the participants again filled out the CUIDAR and caregiver overload instruments.

### **Instruments**

The instruments applied were:

1. Caregiver characterization: items that explore aspects of the family caregiver with respect to age, gender, marital status, occupation, relationship with the patient, time as caregiver, number of hour daily dedicated to caring, and socioeconomic level.
2. CUIDAR: Competence for home care, caregiver version. It is defined theoretically as the capacity, skill, and preparation of the individual to perform the labor of caring at home. It comprises six categories organized under the CUIDAR acronym in Spanish for Knowledge, Uniqueness (personal conditions), Instrumental, Enjoyment (wellbeing), Anticipation, and Social Relation and Interaction. It has 20 items measured through a Likert-type scale with scores ranging from 0 to 3; 0 is never, 1 a few times, 2 frequently, and 3 almost always or always. It is stratified into low, medium, or high ranges with higher scores that indicate greater degree of competence. It has psychometric properties for its use in Spanish<sup>(11)</sup>.
3. Perception of the burden of care by Zarit: 22-item version in Spanish, which includes Likert-type questions with five response options. The score ranges from 22 to 110 points and overload is scored: lack of overload ( $\leq 46$ ), slight overload (47 to 55), intense overload ( $\geq 56$ ). It has psychometric tests in Spanish (15) and for Colombia<sup>(12)</sup>.

## Data analysis

The data analysis used the SPSS v23. Continuous variables were expressed in the median and standard deviation, the categorical variables in percentages. To compare the CUIDAR and caregiver overload variables, after verifying non-compliance with the normality assumption, through the Kolmogorov test, a combination of non-parametric tests were used, such as the Wilcoxon test for two related samples and the Mann-Whitney U for two independent samples (establishing differences between the CG and IG). Furthermore, the chi-squared test was used to identify differences between competences and overload levels. Values of  $p < 0.05$  established statistical significance.

## Ethical considerations

The study kept in mind the ethical guidelines for biomedical research prepared by the Council of International Organizations of Medical Sciences (CIOMS) <sup>(13)</sup> and the parameters established in Resolution 8430 of 1993 issued by the Colombian Ministry of Health. The work contemplated aspects related with the informed consent, voluntary participation, and confidentiality of the information.

## RESULTS

The final sample was comprised by 290 caregivers, 145 were assigned to the intervention group (IG) and 145 in the control group (CG).

The patients had similar characteristic both in the CG and the IG: the mean age of the patients was 56.8 years with standard deviation (SD) of 13.4 years; most were of female gender (59.3%); intact mental state (97.2%); low dependence level (97.2%). By type of cancer and surgical intervention, the prevalence in both groups involved patients undergoing mastectomy/quadrantectomy (30.3%), colectomy plus colostomy (16.6%), prostatectomy (13.1%), gastrectomy (8.3%), hysterectomy (6.2%), thyroidectomy (5.5%), cystectomy (4.1%), nephrectomy (2.1%), oophorectomy (2.1%), and tumor resection from other types of cancer (12.5%).

The characterization of the caregivers evidence homogeneity in the CG and IG composition, without statistically significant changes in the variables.

The mean age was 43.58 years (SD = 14.3) in the IG and 46.33 years (SD = 14.98) in the CG.

Regarding gender, most caregivers were of female gender in the IG (73.8%) and the CG (76.6%), with low levels of schooling in both groups, prevalence of married/common-law marital status, occupation in independent work, low socioeconomic level, of urban origin.

Most caregivers are in charge of the relative since the moment of the diagnosis, with dedication of 13 to 24 hours per day, the relationship sons or daughters in charge of their parents prevails (Table 1).

**Table 1.** Descriptive statistics of sociodemographic variables of family caregivers of adults with cancer

Sociodemographic variables		Intervention group n (%)	Control group n (%)	p
Gender	Male	38 (26.2)	34 (23.4)	0.29
	Female	107 (73.8)	111 (76.6)	
Degree of schooling	Low	91 (62.8)	93 (64.1)	0.17
	Medium	24 (16.6)	75 (51.7)	
	High	30 (20.7)	16 (11)	
Marital status	Single	43 (29.7)	37 (25.5)	0.40
	Married	94 (64.8)	93 (64.1)	
	Separated	6 (4.1)	9 (6.2)	
	Widowed	2 (1.4)	6 (4.1)	
Occupation	Home	40 (27.6)	44 (30.3)	0.47
	Employed	42 (29.0)	33 (22.8)	
	Independent work	51 (35.2)	52 (35.9)	
	Student	5 (3.4)	6 (4.1)	
	Pensioned	7 (4.8)	8 (5.5)	
Socioeconomic level	Low	88 (60.7)	86 (59.3)	0.29
	Medium	57 (39.3)	57 (39.3)	
	High	6 (4.1)	9 (6.2)	
Origin	Urban	127 (87.6)	133 (91.7)	0.24
	Rural	18 (12.4)	12 (8.3)	
Caring for the person since the moment of the diagnosis	Yes	131 (90.3)	131 (90.3)	1.0
	No	14 (9.7)	14 (9.7)	
Number of hours dedicated to caring for the person with cancer	1 to 6	29 (20.0)	39 (26.9)	0.23
	7 to 12	50 (34.5)	40 (27.6)	
	13 to 24	62 (42.8)	52 (35.9)	
Caregiver's relationship with the patient	Spouse	37 (25.5)	48 (33.1)	0.3
	Son/daughter	68 (46.9)	57 (39.3)	
	Parent	6 (4.1)	11 (7.6)	
	Friend	5 (3.4)	2 (1.4)	
	Sibling	18 (12.4)	15 (10.3)	
	Niece/Nephew	4 (2.8)	7 (4.8)	
	Other	7 (4.8)	5 (3.4)	

p: Significance

## Competence for home care

In the first measurement of competence for caring of the caregivers, no perceivable differences exist between the IG and the CG. Medium and high levels prevail, with the highest-scoring dimensions being the instrumental, relation and interaction, and enjoyment, respectively; the dimension of knowledge and anticipation reports the lowest level.

After the intervention, statistically significant changes are identified between the IG and CG in levels of competence for care and knowledge, uniqueness, instrumental, enjoyment, and anticipation dimensions. In the IG, the competence levels of caregivers went from medium to high levels, while in the CG the trend was to descend from the high to the medium range (Table 2).

**Table 2.** Levels of competence for home care before and after the intervention

Variable of competence for care		Before the intervention			After the intervention		
		IG (%)	CG (%)	P	IG (%)	CG (%)	p
<b>Competence for care</b>	Low	8.3	7.6	0.771	0.7	3.4	0.000 <sup>a</sup>
	Medium	53.8	50.3		11.0	31.0	
	High	37.9	42.1		88.3	65.5	
<b>Knowledge</b>	Low	55.9	47.6	0.300	1.4	8.3	0.002 <sup>a</sup>
	Medium	22.8	24.1		20.7	29.7	
	High	21.4	28.3		77.9	62.1	
<b>Uniqueness</b>	Low	7.6	8.3	0.370	1.4	5.5	0.025 <sup>a</sup>
	Medium	33.8	26.2		17.9	26.2	
	High	58.6	65.5		80.7	68.3	
<b>Instrumental</b>	Low	2.8	0.7	0.305	0.0	1.4	0.001 <sup>a</sup>
	Medium	8.3	11.0		2.1	13.1	
	High	89.0	88.3		97.9	85.5	
<b>Enjoyment</b>	Low	6.2	7.6	0.644	9.7	14.5	0.000 <sup>a</sup>
	Medium	15.2	11.7		22.1	40.0	
	High	78.6	80.7		68.3	45.5	
<b>Anticipation</b>	Low	7.6	5.5	0.679	0.7	9.0	0.000 <sup>a</sup>
	Medium	17.2	20.0		8.3	20.0	
	High	75.2	74.5		91.0	71.0	
<b>Relation and interaction</b>	Low	6.9	4.1	0.568	0.7	0.7	0.861
	Medium	15.2	14.5		4.1	5.5	
	High	77.9	81.4		95.2	93.8	

IG: Intervention group; CG: Control group; p: Significance

<sup>a</sup> indicates the dimensions with statistically significant differences < 0.05

In each of the groups, the differences existing in the means of the competence indices before and after the intervention are statistically significant; the means of the IG in the competence for caring at home and in the knowledge, uniqueness, instrumental, enjoyment, and anticipation dimensions are statistically superior to those of the CG. The relation and interaction dimension increased in both groups after the intervention, without evidencing statistically significant differences (Table 3).

**Table 3.** Competence for home care and its dimensions, and overload with care before and after the intervention in the sample. Mean difference between groups

Groups	Before the intervention			After the intervention		
	S	SD	p	S	SD	p
<b>Competence for home care Possible (0 to 60)</b>						
<b>IG</b>	50.2	7.4	0.1	56.7	3.9	0.00 <sup>a</sup>
<b>CG</b>	51.0	7.1		53.5	5.9	
<b>Knowledge (0 to 9)</b>						
<b>IG</b>	4.0	3.3	0.24	8.2	1.2	0.00 <sup>a</sup>
<b>CG</b>	4.5	3.3		7.4	1.8	
<b>Uniqueness (0 to 12)</b>						
<b>IG</b>	10.39	2.0	0.18	11.2	1.37	0.002 <sup>a</sup>
<b>CG</b>	10.56	2.1		10.8	1.6	
<b>Instrumental (0 to 9)</b>						
<b>IG</b>	8.5	1.1	0.54	8.8	0.4	0.000 <sup>a</sup>
<b>CG</b>	8.5	0.8		8.4	1.0	
<b>Enjoyment (0 to 12)</b>						
<b>IG</b>	10.74	1.9	0.69	10.7	1.9	0.000 <sup>a</sup>
<b>CG</b>	10.69	2.2		9.7	2.4	
<b>Anticipation (0 to 6)</b>						
<b>IG</b>	5.4	1.1	0.94	5.8	0.5	0.000 <sup>a</sup>
<b>CG</b>	5.4	1.0		5.3	1.1	
<b>Relation and interaction (0 to 12)</b>						
<b>IG</b>	11.0	2.0	0.91	11.7	0.8	0.105
<b>CG</b>	11.2	1.6		11.7	0.8	
<b>Overload with caring</b>						
<b>IG</b>	36.9	12.9	0.159	32.74	7.6	0.017
<b>CG</b>	38.36	12.1		34.74	7.7	

S: Sample; SD: Standard deviation; IG: Intervention group; CG: Control group; p: Significance

<sup>a</sup> indicates dimensions with statistically significant differences < 0.05

#### Overload for caring

At the beginning of the study, lack of overload for caring prevails in both groups, with statistically significant changes. After the intervention, statistically significant changes were obtained in the level of overload for caring in caregivers, with that presented by the IG being lower than that of the CG. It is worth indicating that after the intervention in the IG, 96.6% of the participants reported lack of overload, in contrast with the CG with only 81.4% presenting this condition (Table 4).

**Table 4.** Overload levels for caring before and after the intervention

Dimensions		Before the intervention			After the intervention		
		IG	CG	P	IG	CG	p
<b>Overload</b>	No overload	82.1	76.6	0.4	96.6	81.4	0.00 <sup>a</sup>
	Slight	9.0	13.8		3.4	14.5	

	overload						
	Severe overload	9.0	9.7		0.0	4.1	

IG: Intervention group; CG: Control group; p: Significance

<sup>a</sup> indicates dimensions with statistically significant differences < 0.05

## DISCUSSION

The most-relevant results of this research indicate the effectiveness of an intervention that includes face-to-face instruction and information given to caregivers since admission to the institution, workshops, and telephone follow up to one month after discharge with impact on two variables, like competence for home care and overload for caring experienced by the family caregiver. Competence for home care is a central variable of the health care process that involves procedural and information aspects with respect to cancer management and the surgical intervention, along with those dimensions determinant for recovery, like personal conditions of the caregiver, the perception of wellbeing, and the social relation and interaction. It also involves the capacity to make decisions to anticipate in approaching aspects concerning their own health. Thus, the work sought to consolidate an integral strategy, which is easy to apply and feasibly replicated in the health services within the local context.

About patient profile, it is similar to that reported in other studies with increased cases in the female gender, high incidence of breast, prostate, colorectal, gastric, thyroid, and cervical cancer reflecting the problematic of this neoplasia within the Colombian context <sup>(14)</sup>. The prevalence of low levels of schooling may reflect greater need for support and time from the health staff to provide education for patients to understand and apply the instructions given. Chambers *et al.*, state that it is determinant to adapt and guide psychosocial interventions, having as basis the educational level of the patients to achieve their greater adherence with these <sup>(15)</sup>.

The profile of the caregivers accounts for the prevalence of the female gender, in reproductive age, in charge of caring for the patient since the moment of the diagnosis, with a dedication from 13 to 24 hours; findings that coincide in different studies conducted in the local context <sup>(16)</sup>. However, this study highlights that the prevalent occupation of the caregivers is independent work, contrary to others <sup>(10)</sup>, where most of the caregivers report household work as occupation, aspects that imply analyzing the additional burden assumed and which constitute potential factors of frustration and impotence, given the limitation of projected goals.

With respect to the characteristics of the intervention, the study reflects the need for a team of nurses formally constituted that can provide permanent support and feedback to caregivers and patients with concise and simple instructions, guidance on the transition from the hospital and the home, and use of support networks available, as reported by Chambers *et al.*, <sup>(15)</sup>. The nursing intervention with a documented scheme and with a record system that facilitates decision-making, differentiating caregiver needs by level of skill and using a standard valuation increases significantly the competence for the caregiver in the home and diminishes overload, as in other studies<sup>(7)</sup>.

In the dimensions of knowledge and anticipation of the competence for home care, the study reflects significant changes in the IG and CG, with the highest value obtained in the IG. It is deduced that the information provided with respect to the disease, indications of the therapy, and activities to carry out daily is effective in the conventional intervention offered by the institution and in the intervention proposed, which allows for most of the users to achieve high levels of knowledge. These findings are consistent with other studies on caregivers with colorectal cancer subjected to surgery <sup>(17)</sup> and endometrial cancer <sup>(18)</sup>, which manage to increase levels of knowledge with respect to the disease stemming from the information support coupled to telephone follow up.

The study reports the impact of education with strategies, like demonstration workshops with patients and caregivers to enhance skills in managing devices, feeding, and medications at home; personalized instruction on planning upon the occurrence of unexpected events; and identification of risks. These aspects relate to a scoping review <sup>(19)</sup> that emphasizes on the importance of providing basic information regarding standard treatments for caregivers to acquire security and confidence, and – thus – make correct decisions.

In the wellbeing dimension, which inquires on basic aspects of daily life, as well as personal satisfaction related with quality of life perceived, the findings coincide with other studies that show the effect of follow-up interventions on empowerment, trust, and keys for self-management in the family caregiver <sup>(20)</sup>.

In the relation and interaction component, contrary to that identified in other studies conducted within the local context <sup>(21)</sup>, caregivers of people with cancer subjected to surgery have primary and secondary support networks as factors that favor enhancing the labor of caring. Said situation may be related because many of these caregivers assume the role when the patient has a recent cancer diagnosis. This is a stage of the process during which most of the family is gathered, which is why the object of the intervention must focus on maintaining said networks, that may be fractured or weakened during more advanced stages when the side effects of adjuvant treatments emerge, along with dependence, and greater demand for care.

Regarding caregiver overload, the study coincides with others conducted in the local <sup>(7)</sup> and international <sup>(22)</sup> contexts on the importance of a scheme documented through a nursing educational intervention to diminish the burden represented by assuming the care of the patient at home. It is fundamental to combine personalized education, workshops, and follow up outside the hospital.

The study had some limitations. The results are partial, bearing in mind that a measurement was made of the competence and overload of caring only after the intervention. It is likely that other factors can influence upon the effect of the intervention on the variables of interest in the mid and long term, when caregivers must assume the role more intensely, by including other oncological therapies, greater deterioration of the patient's state of health and functionality that trigger overload with caring. Further, other resources should be explored, besides the telephone follow up, such as the home visit and the follow-up nursing consultation to determine other variables from the context that can be influencing upon the caregiver overload in the scenario outside the hospital. Future research should include, additionally, other variables, like quality of life perceived, the burden of the caregiver's symptom,

lifestyles, and health habits. Moreover, it is necessary to approach the burden from qualitative and quantitative perspectives, from mixed methods that permit greater comprehension of the phenomenon and generate greater findings useful in decision-making in health and public policies aimed at person-centered care models.

## CONCLUSIONS

The educational intervention in caregivers of adults with cancer subjected to surgery coordinated and executed by nursing staff that includes assessment from admission to the institution, delivery of educational material, face-to-face specific instruction and information, demonstration workshop, and telephone follow up increases competences in home care in its six dimensions and diminishes caregiver overload.

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