

Coping and emotional discomfort in primary caregivers of cancer patients

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ABSTRACT

Objectives. To assess the psychometric properties of the Carer's Assessment of Managing Index. To compare coping styles in caregivers of patients with terminal cancer (CPTC) and caregivers of patients on oncologic treatment (CPOT). To revise the association between coping styles, socio-demographic variables, and emotional discomfort in caregivers. **Material and methods.** A cross-sectional and correlational study was conducted, in which 133 caregivers, 59 CPOT and 74 CPTC, were interviewed. Emotional discomfort (depression, anxiety, caregiver's burden) and coping styles were measured. **Results.** The instrument was defined by three factors (alternate perception of events, active coping, and emotional regulation), with an internal consistency of $\alpha = 0.78$. The alternate perception of events was the only coping style with statistically significant difference between CPOT and CPTC, and CPOT score higher in this regard. Different coping styles allow for more accurate prediction of emotional discomfort in CPTC, which showed more symptoms of anxiety, depression, caregiver's burden and physical illness. The study found a high occurrence of behaviors such as crying, screaming, smoking, anxiety eating and alcohol consumption in both CPOT and CPTC, all of which related to intense emotional discomfort. Active coping scores were higher when the caregivers had social support and a higher level of education (bachelor's degree or postgraduate studies). Active coping scores went down when different aspects of the caregiver's life were affected, when physical or psychological symptoms were present, and when the caregivers had more time in their role.

Key words. Coping. Primary caregiver. Cancer. Anxiety. Depression. Terminal illness.

Afrontamiento y malestar emocional en el cuidador primario del paciente con cáncer

RESUMEN

Objetivos. Evaluar las propiedades psicométricas del índice de evaluación del manejo del cuidado. Comparar estilos de afrontamiento de cuidadores de pacientes con cáncer terminal (CPCT) y cuidadores de pacientes en tratamiento oncológico (CPTO). Revisar la asociación entre estilos de afrontamiento, variables sociodemográficas y malestar emocional en el cuidador. **Material y métodos.** Se realizó un estudio transversal y correlacional en el que se entrevistaron a 133 cuidadores, 59 CPTO y 74 CPCT. Se midió malestar emocional (depresión, ansiedad y síndrome de carga) y estilos de afrontamiento. **Resultados.** El instrumento quedó conformado por tres factores (percepción alternativa de eventos, afrontamiento activo y regulación emocional), con una consistencia interna de $\alpha = 0.78$. La percepción alternativa de eventos es el único estilo de afrontamiento con diferencias estadísticamente significativas entre CPCT y CPTO, su puntuación fue mayor en CPTO. Además los distintos estilos de afrontamiento permiten predecir con mayor precisión el malestar emocional de los CPCT, quienes presentan mayor cantidad de síntomas de ansiedad, depresión, síndrome de carga y malestares físicos. Tanto en CPCT como en CPTO se encontró una alta frecuencia de diversos comportamientos, como llorar, gritar, fumar, comer por ansiedad o beber alcohol, conductas que se relacionaron con malestar emocional intenso. Las puntuaciones de afrontamiento activo fueron mayores cuando los cuidadores tenían apoyo social y un nivel educativo superior (licenciatura o posgrado). Las puntuaciones de afrontamiento activo disminuían cuando se afectaban áreas de la vida del cuidador, cuando había síntomas físicos o psicológicos y cuando el cuidador tenía más tiempo realizando este rol.

Palabras clave. Afrontamiento. Cuidador primario. Cáncer. Ansiedad. Depresión. Síndrome de carga. Enfermedad terminal.

INTRODUCTION

Being a primary caregiver causes several negative effects such as sleep disorders, lack of free time, economic stress, depression, anxiety,¹ poor self-care,² low antibody production,³ and therefore, a high predisposition towards infectious disease, slow cicatrization,⁴ headaches, insomnia, gastrointestinal and cardiovascular illness, etc.^{5,6}

These negative effects of caregiving can be mediated by the type of coping used by the caregiver and the social support he or she receives.⁷ The higher the demands of the illness in relation to the resources of the caregiver to cope with it, the more likely these problems are to develop.^{8,9}

Most studies support the idea that active coping strategies (such as research, planning and problem-solving), or coping strategies oriented to modify emotion (reappraisal, relaxation, etc.), are associated with better results.¹⁰ Training caregivers in problem-solving strategies improves their social functioning and decreases depression and emotional distress.¹¹

On the other hand, it seems that reappraisal reduces caregiver burden,^{12,13} since it creates the impression of control over the disease,¹⁰ can reduce health problems, and increases growth and personal well-being. Nevertheless, reappraisal depends on resources such as spirituality and social support.¹⁴ Other variables associated with adaptive coping styles are having a caucasian background^{4,9,15} and personality traits such as dominance, optimism, and low neuroticism.¹²

Less adaptive coping styles, i.e. evasive or diverting behaviors such as venting negative emotions, avoiding the solution of problems, criticizing or blaming oneself, consuming alcohol or drugs, and denial, are associated with feelings of depression, sleep disorders, low self-esteem, guilt and caregiver burden.^{7,9,12,16} These coping styles are linked to high levels of stress,¹⁷ multiple roles,¹⁸ and a Latin, African or Asian background.^{4,9,15} It is worth noting that certain studies suggest that these coping styles are associated with relapse or the terminal phase in cancer.^{1,19} However, such studies do not make a clear comparison between caregivers of patients with terminal cancer (CPTC) and caregivers of patients on oncologic treatment (CPOT), in order to observe any possible differences between their coping styles and ascertain whether coping is associated with the psychological distress suffered by caregivers.

Some studies suggest that emotional distress is higher among caregivers in charge of terminal pa-

tients,²⁰ due to the suffering they witness,⁴ which is caused by various intense symptoms,²¹ physical and mental decline, and increased limitations and dependence,^{22,23} which means an increase in the amount of time the caregiver has to devote to his or her role.²⁴⁻²⁶ Furthermore, one must not forget that caregivers not only help patients cope with death; they also work on their own mourning.⁸

The effects of poor stress management affect the physical health of caregivers even after the patient has died; the risk of suicide increases in elderly caregivers,²⁷ as does the risk of dying from physical and mental health problems.^{28,29} Additionally, inadequate coping also affects the ability of patients to adapt to their illness^{10,11,14} and the quality of the attention they receive, since it is associated with dehumanized assistance, anger,³⁰ lack of organization, low performance, and attention and memory problems.³¹

With regard to this, the objectives of this study include:

- To assess the psychometric properties of the Carers Assessment of Managing Index.
- To identify any possible differences between the coping styles between caregivers of patients with terminal cancer and caregivers of patients on oncologic treatment, and
- To measure the relationship between coping styles, socio-demographic variables and emotional distress in caregivers (caregiver burden and symptoms of depression and anxiety).

MATERIAL AND METHODS

A non-experimental, correlational study was conducted, with the participation of 133 primary caregivers (identified by their patients), who had been working as caregivers for at least three months. All of them were adults in charge of cancer patients undergoing oncologic treatment (chemotherapy, radiotherapy or awaiting surgery) or in charge of terminal cancer patients (under palliative treatment to control the symptoms, since their cancer was considered irreversible and would lead to death in a few months). All the patients received medical care at the Pain and Palliative Treatment Clinic at the High Specialty Medical Unit, in the oncology hospital at Centro Médico Nacional Siglo XXI, in Mexico City. The study was approved by the ethics committee at said institution, and all participants signed their informed consent, establishing the conditions of their participation and its anonymous and vol-

Table 1. Socio-demographic data (sex, education, marital status).

Socio-demographic data (n = 133)		Caregivers		χ^2	p
		CPOT (n = 58)	CPTC (n = 75)		
Sex of the caregiver	Male (n = 41)	22 (37.93%)	20 (26.66%)	1.92	0.11
	Female (n = 91)	36 (62.07%)	55 (73.33%)		
Sex of the patient	Male (n = 58)	24 (41.37%)	34 (58.62%)	1.48	0.14
	Female (n = 75)	39 (52%)	36 (48%)		
Education	Elementary (n = 47)	23 (39.65%)	25 (33.33%)	0.878	0.64
	High school (n = 47)	19 (32.75%)	28 (37.33%)		
	College (n = 39)	16 (27.58%)	22 (29.33%)		
Marital status	Single (27)	10 (17.24%)	17 (22.66%)	3.15	0.36
	Married (87)	42 (72.41%)	45 (60%)		
	Divorced (9)	4 (6.89%)	6 (8%)		
	Domestic partnership (9)	2 (3.44%)	7 (9.33%)		

CPTC: caregivers of patients with terminal cancer. CPOT: caregivers of patients on oncologic treatment.

untary nature, as well as their right to leave the study.

The interview with the caregiver allowed the application of the measuring instruments: coping, anxiety symptoms, depression symptoms, caregiver's burden and other socio-demographic variables.

Psychometric instruments

- *Zarit Burden Interview*. Measures subjective burden with 22 Likert-type items with four options; the original instrument was first published in 1980 by Zarit, Reever and Bach-Peterson,³² has been validated in several languages, and is among the most widely used. Divergence regarding evaluation exists. Originally, each item was marked 0-4 points, with a maximum score of 88. However, in Spain the items are often marked 1-5, which can increase the number of caregivers diagnosed with caregiver burden.

Regarding the cut-off point, some propose that a score under 46 must be interpreted as the absence of caregiver burden, 47-55 as light caregiver burden, and over 56, heavy caregiver burden. However, Zarit himself did not establish any criteria for the cut-off point,³³ only in 2006 did a study suggest that a score between 24 and 26 may identify with 72% accuracy the depressed caregivers diagnosed using the Geriatric Depression Scale, CES-D.³⁴ This study used the validation established by Alpuche, *et al.*,³² developed with 141 caregivers of patients with chronic

degenerative disease. It uses a 0-4 scale for scoring, has an internal consistency of $\alpha = 0.90$, and its concurrent validity with the Perceived Stress Query and the GHQ-28.31 General Health Query.

- *Hospital Anxiety and Depression Scale (HADS)*. Created in 1983 by Zigmond and Snaith, it measures anxiety and depression, excluding somatic symptoms. It consists of 14 Likert-type items with four options. The cut-off point for the depression subscale is seven, and eight for the anxiety subscale. In México, it has been validated on subjects with morbid obesity, chronic renal failure, drug dependency, burn victims, elderly people, and women in high risk pregnancy. Its reliability is between $\alpha = 0.81$ and $\alpha = 0.86$, and its validity is convergent with structured clinical interview, Beck Depression Scale, Clinical Anxiety Scale and Montgomery-Asberg Rating Scale.³⁵
- *Carers Assessment of Managing Index*. Created in 1995 by Nolan, Keady and Grant³⁶ to measure coping strategies in caregivers in charge of Alzheimer patients, it has been validated on caregivers in charge of elderly or learning-impaired patients. It uses a four-point Likert scale. A high score suggests more effective coping. The original instrument has 38 items ($\alpha = 0.86$) and three subscales:

- Problem solving and coping ($\alpha = 0.77$).
- Alternate perception of events ($\alpha = 0.76$), and
- Stress symptom-delaying strategies ($\alpha = 0.70$).

Table 2. Comparison of emotional distress between caregivers of patients with terminal cancer (CPTC) and caregivers of patients on oncologic treatment (CPOT).

Emotional distress variables	t	CPTC, mean (SD)	CPOT, mean (SD)
Depression symptoms	2.15*	9.40 (4.60)	7.75 (4.14)
Anxiety symptoms	2.21*	7.35 (4.47)	5.72 (3.96)
Caregivers burden	3.39**	30.09 (15.17)	21.98 (12.29)

* $p < 0.05$. ** $p < 0.01$.

A later study with European caregivers resulted in seven subscales and eliminated one item ($\alpha = 0.84$). The resulting subscales were:³⁷

- Reasons and realization: $\alpha = 0.80$.
- Internal or external help: $\alpha = 0.74$.
- Free time: $\alpha = 0.74$.
- Emotional expression: $\alpha = 0.69$.
- Positive thought and behavior: $\alpha = 0.74$.
- Routine and planning: $\alpha = 0.69$, and
- Stoicism: $\alpha = 0.64$.

The instrument was translated and validated for this study and the McKee, *et al.*, version was used.³⁷

- *Informal Primary Caregiver Health Query*. Created in 2006 by Ramos, Barcelata, Alpuche, Islas and Salgado,³⁸ it consists of 73 multiple-choice questions, organized into five sections: socio-demographic characteristics, patient care, perceived social support, preventive health practices, and health perception (checkup attendance, exercise, physical symptoms, alcohol and tobacco consumption). It was designed for Mexican caregivers.³⁹

Procedure

The subjects attended out patients at the clinic. Each was asked for his or her voluntary participation, and the instruments were applied via individual interview at the doctor's office, after informed consent was signed. After the interview, the results were explained to each caregiver, and, when necessary treatment options were offered. Afterwards, the data were captured for their analysis.

For the validation of the Carers Assessment of Managing Index, the international norms for health instrument adaptation were used,⁴⁰ the first translation from English was done by two psychologists whose first language was Spanish. The second translation was independently done by two psychol-

ogists whose first language was English. Two Spanish-speaking psychologists (different from those who had done the first translation) simultaneously revised all translations in order to choose the most adequate version for each item. Lastly, five judges (psychologists with at least one year of clinical experience with cancer patients or palliative care patients) checked the consistency of the items with regard to the objectives of the test and the coherence of the language, using the Osterlind's item-objective congruence index.

For the data analysis, the Statistical Program for Social Sciences IBM SPSS, version 21 was used; to check the psychometric properties of the Carers Assessment of Managing Index, an analysis of internal consistency with Cronbach alpha reliability analysis was conducted, as well as a factorial analysis test and a confirmatory factorial analysis with structural equation modeling, using the AMOS Graphics software for SPSS 21.

Next, Pearson correlation tests and linear regression were applied in order to analyze the relationship between coping and emotional distress. Student's *t*-tests and analysis of variance (ANOVA) were used to compare coping styles with regard to emotional distress and socio-demographic variables, with a reliability level of $\alpha < 0.05$ in all tests.

RESULTS

Of the 152 caregivers interviewed, only 133 met the criteria for inclusion. The mean age of the caregivers was 49 years old (SD = 14). The 31.57% (42) of the participants were men and 68.42% (91) were women. The average time elapsed since the cancer diagnosis was 36.27 months (SD = 46.68). 43.6% (58) were caregivers of patients with terminal cancer (CPTC) and 56.3% (75) were caregivers of patients on oncologic treatment (CPOT) No statistically significant differences were found between the caregivers with regard to sex, education, marital status (Table 1), age or time elapsed since the cancer diagnosis.

Table 3. Relationship between coping styles and emotional distress.

	Variables		Correlation		Regression	
	Independent	Dependent	r	r	r ²	F
CPTC	Emotional regulation	Anxiety symptoms	-0.316**	0.316	0.100	8.18**
		Depression symptoms	-0.265**	0.265	0.070	5.60*
	Alternate perception of events	Anxiety symptoms	-0.333**	0.333	0.111	9.22**
		Depression symptoms	-0.321**	0.321	0.103	8.52**
		Caregivers burden	-0.306**	0.306	0.094	7.66**
	Global score	Anxiety symptoms	-0.340**	0.340	0.115	9.65**
		Depression symptoms	-0.310**	0.310	0.096	7.84**
		Caregivers burden	-0.276*	0.276	0.076	6.07**
	CPOT	Emotional regulation	Depression symptoms	-0.471**	0.471	0.222
Alternate perception of events		Caregivers burden	-0.303*	0.303	0.092	5.86*
Global score		Depression symptoms	-0.365**	0.365	0.133	8.91**

* p < 0.05, ** p < 0.01 Correlations (Pearson) Regressions (simple linear). CPTC: caregivers of patients with terminal cancer. CPOT: caregivers of patients on oncologic treatment.

Validation of the Carers Assessment of Managing Index

- *Review by judges.* The percentage of agreement between judges for the Osterlind's item-objective congruence index, was 84%. Twenty-seven out of 31 items scored a high degree of congruence, two items scored a medium degree, and two scored a low degree. Some items were rewritten. A Student's t-test was conducted to ensure that the items acknowledged the difference between high and low scores, as well as an analysis of internal consistency with Cronbach alpha reliability analysis. Items 2, 7, 16, and 22 were removed in these steps. Next, an exploratory factorial analysis with orthogonal rotation was conducted. Its adjustment measures were KMO = 0.805 and Bartlett's test of sphericity $\chi^2 = 879.94$, $p < 0.001$, which resulted in seven factors that explained 57.58% of the variance. The items with high scores in more than one factor were deleted and the analysis was repeated. The adjustment measures were KMO = 0.785, $\chi^2 = 398.20$, $p < 0.001$, with four factors that explained 52.53% of the variance. The instrument was subjected to a confirmatory factorial analysis with structural equations, in which one of the factors was deleted. The adjustment measures for the final test were satisfactory: $\chi^2 = 86.48$, $gl = 74$, $p = 0.153$, IFI = 0.95, TLI = 0.94, CFI = 0.95, RMSEA = 0.036 IC [0, 0.064].

The scale had an internal consistency of $\alpha = 0.78$, and consisted of 14 items grouped in three factors:

- Active coping ($\alpha = 0.719$), which is the search for information or support from the health professionals and problem-solving activities.
- Emotional regulation ($\alpha = 0.618$), which includes venting emotions, exercising, searching for free time and activities not related with the patient, and
- Alternate perception of events ($\alpha = 0.606$), including humor, pleasant memories, positive comparisons, and focusing on the present.

Coping styles: comparison between CPTC and CPOT.

CPTC scored higher on symptoms of depression, anxiety and caregiver burden. These differences were found to be statistically significant (Table 2).

Regarding the differences between coping styles, alternate perception of events ($t = 3.31$, $p = 0.001$) was higher among CPOT (mean = 6.7, SD = 2.47) than among CPTC (mean = 5.3, SD = 2.29); no significant differences were found among the other coping styles.

Table 4. Coping styles and difficulties faced by CPTC and CPOT.

	Coping	t	Difficulties faced by caregivers	Mean (SD)
CPOT	Active coping	2.23*	Has affected times	5.82 (2.53)
			Does NOT have affected time	7.33 (1.97)
	Emotional regulation	2.28*	Has felt irritable	5.75 (2.54)
			Has NOT felt irritable	7.23 (2.02)
		4.95**	Exercises	5.85 (1.59)
			Does NOT exercise	3.07 (2.21)
	Alternate perception of events	2.93**	Has decreased appetite	2.62 (2.33)
			Does NOT have decreased appetite	4.57 (2.23)
		2.30*	Has felt symptoms like those of the patient	4.85 (2.73)
			Has NOT felt symptoms	7.08 (2.34)
CPTC	Active Coping	3.08**	Fears having cancer in the future	5.66 (2.74)
			Does NOT fear having cancer	7.59 (1.93)
	Emotional regulation	2.07*	Household chores affected	5.15 (2.71)
			Household chores NOT affected	6.52 (3)
	Alternative event perception	2.16*	Sex life affected	3.39 (2.06)
			Sex life NOT affected	4.51 (2.21)
		2.27*	Exercises	4.91 (2.20)
			Does NOT exercise	3.70 (2.12)
		2.94**	Has felt tachycardia	3.08 (2.15)
			Has NOT felt tachycardia	4.60 (2.08)
4.07**		Has experienced hand trembling	2.20 (1.85)	
		Has NOT experienced hand trembling	4.56 (2.04)	
2.65**		Smokes	3.04 (2.03)	
		Does NOT smoke	4.50 (2.16)	
Alternative event perception	2.40*	Has experienced memory problems	3.35 (2.57)	
		Has NOT experienced memory problems	4.81 (1.96)	
	2.11*	Has trouble looking after own health	4.89 (2.12)	
		Does NOT have trouble looking after own health	6 (2.40)	
	2.51*	Has felt sad	5.18 (2.17)	
		Has NOT felt sad	7.10 (2.64)	
	2.49*	Has experienced memory problems	4.87 (2.19)	
		Has NOT experienced memory problems	6.17 (2.28)	
Alternative event perception	2.54*	Has trouble making decisions	4.63 (1.99)	
		Does NOT have trouble making decisions	5.97 (2.38)	
	2.05*	Has felt tired often	5 (2.26)	
		Has NOT felt tired often	6.10 (2.27)	
Alternative event perception	2.54*	Has thought he/she is not useful	4.35 (1.18)	
		Has NOT thought he/she is not useful	5.83 (2.37)	

* p < 0.05. ** p < 0.01. Student t-test.

Association between coping, socio-demographic variables and emotional distress in the caregiver

Regarding emotional stress variables (symptoms of anxiety, depression and caregiver burden), the regression analysis showed that global coping (score of the whole scale), emotional regulation and alternate perception of events predict emotional distress variables better for CPTC than for CPOT (Table 3).

Regarding non adaptive ways of coping with events, no differences were found between CPTC and CPOT. It must be stressed that 62.8% of the caregivers sampled vent their anger by screaming. Among them, the scores are higher for symptoms of depression ($t = 3.76$, $p < 0.001$, mean = 7.60, SD = 4.39) and caregiver burden ($t = 2.04$, $p < 0.05$, mean = 28.26, SD = 14.90), in contrast to caregivers who do not exhibit such behavior. These have the following data for symptoms of depression: mean = 4.95,

Table 5. Social support and coping in caregivers.

	Coping	t	Type of support received by the caregiver	Mean (DE)
CPOT	Alternate perception of events	2.31*	Has somebody who listens and understands	7.41 (2.18)
			Does NOT have somebody who listens and understands	6 (2.88)
	2.45*	Has a substitute for when he/she cannot care the patient	7.26 (2.13)	
		Does NOT have a substitute	5.58 (2.87)	
CPTC	Active coping	2.24*	Receives information and counseling from health professionals	6.73 (2.75)
			Does NOT receive enough information and counseling	5.24 (2.95)
	Emotional regulation	2.52*	Has somebody who listens and understands	4.57 (2.02)
			Does NOT have somebody who listens and understands	3.38 (2.30)
		2.43*	Has somebody to help care the patient	4.52 (2.02)
			Does NOT have somebody to help care the patient	3.24 (2.36)
	Alternate perception of events	2.15*	Receives information and counseling from health professionals	6.05 (2.20)
			Does NOT receive enough information and counseling	4.92 (2.31)
	2.18*	Has economic support	5.97 (2.21)	
		Does NOT have economic support	4.82 (2.31)	

*p < 0.05. **p < 0.01. Student t-test. CPTC: caregivers of patients with terminal cancer. CPOT: caregivers of patients on oncologic treatment.

SD = 3.60 and caregivers burden mean = 23.10, SD = 13.54.

Besides, 73% of the caregivers vent their emotions through weeping. It was found that these score higher on depression symptoms (t = 2.20, p < 0.05, mean = 7.10, SD = 4.27), compared with those who do not vent through weeping (mean = 5.26, SD = 4.16).

On the other hand, it is important to note that half the caregivers smoked or drank alcohol to cheer up, although only 25% of these were regular smokers and 16.54% were regular drinkers. Also, 46.96% thinks they ate more than usual in the last months, and anxiety symptoms were more common among them (t = 2.62, p < 0.05), as well as caregiver burden (t = 2.09, p < 0.05).

With regard to the time the caregivers have been working as such, it was found that the scores for active coping are higher among caregivers who have been caring their patient for a shorter time (caregivers who have been with a patient for less than a year: mean = 4.69, SD = 2.38; 1 to 3 years: mean = 4.09, SD = 2.19; over 4 years: Mean = 3.42, SD = 2.20; F = 3.09, p < 0.05, gl = 3, 130, 132).

As for the habits of the caregivers, it is important to note that those who smoked and/or did not exercise scored lower on emotional regulation, unlike those whose hobbies or household chores were affected by their current job like caregiver, and who scored lower on active coping.

The coping scores were also reduced when the caregivers had difficulties looking after their own

health, found in themselves symptoms similar to those of their patients, expressed fear of suffering cancer in the future, or showed symptoms such as sadness, lack of appetite, fatigue, tachycardia, trembling hands, thoughts of futility, memory loss, or difficulty making decisions (Table 4).

With regard to the support received by the caregivers, information and counseling from health professionals were associated with higher active coping scores in CPTC and higher alternate perception of events scores for both kinds of caregivers. But it was also observed that alternate perception of events scores were higher for CPTC with economic support and CPOT with somebody who could care the patient if the caregiver could not be present.

Alternate perception of events was higher for both kinds of caregivers when they had somebody who could listen to them, understand them or help with caregiving tasks. This kind of support was also associated with higher emotional regulation scores, but only for caregivers of terminal patients (Table 5).

Lastly, coping scores were higher for caregivers with college education (graduate and postgraduate), and in those who are the children of the patient under their care. These differences only came up among caregivers of terminal patients (Table 6).

DISCUSSION

Regarding the adaptation of the Carers Assessment of Managing Index, compared to previous adaptations,^{36,37} several active coping items were

Table 6. Relationship between coping styles, education and kinship of terminal patient caregivers.

Coping	Caregivers (n = 75)	Mean	ANOVA			Tukey test		
			SD	gl	F	Mean difference		
• Education								
Active coping								
	Elementary (n = 24)	4.12	2.99	2	7.95**	Elementary	High school	-2.44**
	High school (n = 28)	6.57	2.53	72		Elementary	College	-2.87**
	College (n = 23)	7	2.57	74				
Emotional regulation								
	Elementary	3.25	2.11	2	5.76**	Elementary	College	-2.01**
	High school	3.85	2.36	72		High school	College	-1.40*
	College	5.26	1.62	74				
Alternate perception of events								
	Elementary	4.7	2.42	2	3.91*	Elementary	College	-1.76*
	High school	5.21	2.06	72				
	College	6.47	2.23	74				
Global score								
	Elementary	12.03	6.59	2	8.81**	Elementary	College	-6.65**
	High school	15.64	5.27	72				
	College	18.73	4.13	74				
• Kinship								
Global score								
	Parent (n = 6)	12	5.16	3	2.98*	Child	Spouse	4.04*
	Child (n = 32)	17.35	5.59	70				
	Spouse (n = 30)	13.26	5.53	74				
	Sibling (n = 7)	19.16	6.3					

* p < 0.05. ** p < 0.01. ANOVA test with Tukey pair comparisons.

deleted due to their low frequency, such as problem prevention, testing different solutions, planning schedules or activities, and identifying priorities, among others, however, it is important to test if these results reoccur with other Mexican caregivers. For now, previous studies^{4,9,15} suggest that Latin caregivers use these strategies less often than Caucasian caregivers. The results seem to conform to this. The test is an important contribution of the study; the questions show the activities in the everyday experience of caregivers, and since the test is short, its application is easy.

As for the second objective of the study, to ascertain if there are any differences between the coping styles of CPTC and CPOT, only alternate perception of events shows differences and it is higher for CPOT, since CPTC are less capable of using this strategy due to stressing situations increasing when the patient gets worse^{22,23} and demand for care grows.²⁴⁻²⁶ The same reasons can influence emotional distress in the caregiver, as in other studies, where such distress is higher for CPTC.²⁰

The last objective was to measure the relationship between coping, socio-demographic variables, and emotional distress in caregivers (caregiver burden, depression and anxiety symptoms), It was found that emotional regulation was inversely related to emotional distress, especially in CPTC, while active coping was not related in any way. These results were unexpected, given that in other studies,^{10,11} active coping reduces emotional distress and emotional regulation strategies increase it.^{9,10,12,16}

On the other hand, alternate perception of events showed an inverse relationship with caregivers burden, which has been documented before,^{12,13} but also showed an inverse relationship with anxiety and depression symptoms, a result that reflects important cultural differences, since, according to other studies, Latin caregivers use more coping styles focused on reappraisal or emotional regulation,^{4,9,15} apparently due to the emotional discharge they cause. Furthermore, the caregivers said there were not many situations they could foresee or control regarding the health of their patients.

As for non-adaptive coping styles, activities such as weeping, screaming, smoking, eating and drinking alcohol to decrease anxiety were associated with higher emotional distress. Other studies^{9,10,12,16} have also pointed to their negative effect on caregivers, but, unlike previous research,^{1,19} this study did not find a higher occurrence of these activities in CPTC. They were more frequent, however, in caregivers with low coping scores, perhaps because a lack of coping causes a higher perception of stress.¹⁷

A lack of coping is also associated with decreased self-care behavior (difficulties looking after their own health, lack of exercise, smoking) and health concerns (looking for symptoms similar to those of the patient or fear of getting cancer); decreased self-care behavior has also been associated with stress.²

Problems with coping are also associated with decline in different areas of life (sexuality, household chores and hobbies) and several symptoms such as lack of appetite, irritability,³⁰ tachycardia, trembling hands, sadness, memory loss,³¹ difficulty making decisions, and fatigue. CPTC showed these negative consequences more often.

This makes sense in light of transactional stress model: CPTC have higher demands, and those with low social support⁷ and low coping scores (regardless of the type of patient under their care) have fewer resources; this lack of balance between demands and resources can cause the observed negative effects: more symptoms, health concerns, and decreased self-care behavior.^{8,9}

Lastly, among the limitations to this study, it is important to note that there are few males in the sample. This limitation is shared with other studies, where the number of male caregivers does not usually exceed one fourth of the samples. This is, no doubt, due in no small part to the roles culturally assigned to each gender, and it hinders the observation of differences between men and women.

Another important limitation of this study is the fact that most patients were referred to the clinic for the treatment of pain. The stress caused by this symptom on caregivers¹⁵ might affect the reported emotional distress scores. Another point that could be expanded upon in future research is the use of non-adaptive behaviors for coping with stress.

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REFERENCES

1. Stajduhar K, Martin W, Barwich D, Fyles G. Factors Influencing Family Caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nursing* 2008; 31(1): 77-85.
2. Nguyen M. Nurse's assessment of caregiver burden. *Medsurg nursing* 2009; 18(3): 147-51.
3. Janevic M, Connell C. Exploring self-care among dementia caregivers: The role of perceived support in accomplishing exercise goals. *J Women & Aging* 2004; 16(2): 71-86.
4. Herbert R, Schulz R. Caregiving at the End of Life. *Journal of palliative medicine* 2006; 9(5): 1174-87.
5. Araya L, Guamán M, Godo C. Estrés del cuidador de un enfermo terminal, Universidad Austral de Chile, 2006. Disponible en: http://medicina.uach.cl/saludpublica/diplomado/contenido/trabajos/1/La%20Serena%202006/Estres_de_%20cuidado_%20de_%20enfermo_terminal.pdf.
6. Expósito. C. La calidad de vida en los cuidadores primarios de pacientes con cáncer. *Revista Ciencia Médica La Habana* 2008; 7(3). Disponible en http://scielo.sld.cu/scielo.php?script=sci_arttext&pid=S1729-519X2008000300004&lng=es.
7. Lavretsky H. Stress and depression in informal family caregivers of patients with Alzheimer's disease. *Aging Health* 2005; 1(1): 117-33.
8. Hudson P. A conceptual model and key variables for guiding supportive interventions for family caregivers of people receiving palliative care. *Palliative and Supportive Care* 2003; 1(5): 353-65.
9. Pinquart M, Sörensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist* 2005; 45(1): 90-106.
10. Lambert S, Girgis A, Turner J, McElduff P, Kayser K, Vallentine P. A pilot randomized controlled trial of the feasibility of a self-directed coping skills intervention for couples facing prostate cancer: Rationale and design. *Health and Quality of Life Outcomes* 2012; 10: 119-30.
11. Ko C, Malcarne V, Varni J, Roesch S, Banthia R, Greenbergs H, et al. Problem-solving and distress in prostate cancer patients and their spousal caregivers. *Support Care Cancer* 2005; 13(6): 367-74.
12. Carter P, Acton G. Personality and coping predictors of depression and sleep problems among caregivers of Individuals who have cancer. *Journal of Gerontological Nursing* 2006; 32(2): 45-53.
13. Di Mattei V, Prunas A, Novella L, Marcone A, Cappa S, Sarno L. The burden of distress in caregivers of elderly demented patients and its relationship with coping strategies. *Neurological Sciences* 2008; 29(6): 383-9.
14. Jones P, Winslow B, Lee J, Burns M, Zhang X. Development of a caregiver empowerment model to promote positive outcomes. *Journal of Family Nursing* 2011; 17(1): 11-28.
15. Farran C. Family caregiver intervention research: where have we been? Where are we going? *Journal of Gerontological Nursing* 2001; 27(7): 38-45.
16. Garity J. Caregiver burden in multiple sclerosis: The impact of neuropsychiatric symptoms. *Journal of Gerontological Nursing* 2006; 32(6) 39-48.

17. Mora de la Rubia J, Martínez J. Reacción ante el diagnóstico de cáncer de un hijo: estrés y afrontamiento. *Psicología y Salud* 2009; 19(2): 189-96.
18. Bernard L, Guarnaccia C. Two Models of caregiver strain and bereavement adjustment: A comparison of husbands and daughter caregivers of breast cancer hospice patients. *The Gerontologist* 2003; 43(6): 808-16.
19. Espada M, Grau C, Fortes M. Enseñar estrategias de afrontamiento a padres de niños con cáncer a través de un cortometraje. *Anales del Sistema Sanitario de Navarra* 2010; 33(3): 259-69.
20. Hodges L, Humphris G, Macfarlane, G. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Social Science & Medicine* 2005; 60(1): 1-12.
21. Dumont S, Turgeon J, Allard P, Gagnon P, Charbonneau C, Vezina L. Caring for a loved one with advanced cancer: Determinants of psychological distress in family caregivers. *Journal of Palliative Medicine* 2006; 9(4): 912-21.
22. Gaugler J, Linder J, Given C, Kataria R, Tucker G, Regine F. Family cancer caregiving and negative outcomes: The direct and meditational effects of psychosocial resources. *Journal of Family Nursing* 2009; 15(4): 417-44.
23. Jordhoy M, Ringdal G, Helbostad J, Oldervoll L, Loge J, Kaasa S. Assessing physical functioning: A systematic review of quality of life measures developed for use in palliative care. *Palliative Medicine* 2007; 21(8): 673-82.
24. Barzil K, Bedard M, Willson K, Hode M. Caregiving and its impact on families of the terminally ill. *Aging and Mental Health* 2003; 7(5): 376-82.
25. Kim J, Spillers R. Quality of life of family caregivers at 2 years after a relative's cancer diagnosis. *PsychoOncology* 2010; 19(4): 431-40.
26. Mendez-Luck C, Kennedy D, Wallace S. Concepts of burden in giving care to older relatives: A study of female caregivers in Mexico City neighborhood. *Journal of Cross-Cultural Gerontology* 2008; 23(3): 265-82.
27. Hill S. Self-Care in Caregiving. *Journal of Human Behavior in the Social Environment* 2007; 14(1): 95-115.
28. Harding R, Higginson J. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine* 2003; 17(1): 63-74.
29. Mittelma M. Taking care of the caregivers. *Geriatric Psychiatry* 2005; 18(6) 633-09.
30. Halm M, Treat-Jacobso D, Lindquist R, Savik K. Caregiver burden and outcomes of caregiving of spouses of patients who undergo coronary artery bypass graft surgery. *Heart & Lung* 2007; 36(3): 170-87.
31. Mackenzie C, Smith M, Hasher L, Leach L, Behil P. Cognitive functioning under stress: Evidence from informal caregivers of palliative care. *Journal of Palliative Medicine* 2007; 10(3): 749-58.
32. Alpuche V, Ramos B, Rojas M, Figueroa C. Validez de la entrevista de carga de zarit en una muestra de cuidadores primarios informales. *Psicología y Salud* 2008; 18(2): 237-45.
33. Álvarez L, González AM, Muñoz P. El cuestionario de sobrecarga del cuidador de Zarit. Cómo administrarlo e interpretarlo. *Gaceta Sanitaria* 2008; 22(6): 618-20.
34. Schreiner A, Morimoto T, Arai Y, Zarit S. Assessing family caregiver's mental health using a statistically derived cut-off score for the Zarit Burden Interview. *Aging & Mental Health* 2006; 10(2): 107-11.
35. López J, Vázquez V, Arcilla D, Sierra A, González J, Salin R. Exactitud y utilidad diagnóstica del Hospital Anxiety and Depression Scale (HAD) en una muestra de sujetos obsesos mexicanos. *Rev Invest Clin* 2002; 54(5): 403-9.
36. Yeh PM, Bull M. Influences of spiritual well-being and coping on mental health of family caregivers for elders. *Gerontological Nursing* 2009; 2(3): 173-81.
37. McKee K, Spazzafumob. L, Nolana M, Wojszelc. B, Lamurab. G, Bienc. B. Components. of the difficulties, satisfactions and management strategies of carers of older people: A principal component analysis of CADI-CASI-CAMI. *Aging & Mental Health* 2009; 13(2): 255-64.
38. Ramos del Río B, Barcelata J, Alpuche R, Islas S, Salgado G. Evaluación diagnóstica del síndrome de burnout y entrenamiento para el manejo del estrés en cuidadores primarios informales de enfermos crónico degenerativos. México: Facultad de Estudios Superiores Zaragoza, UNAM. 2006.
39. Islas-Salas NL, Ramos del Río B, Aguilar-Estrada MG, García-Guillén ML. Perfil psicosocial del cuidador primario informal del paciente con EPOC. *Revista del Instituto Nacional de Enfermedades Respiratorias* 2006; 19(4): 266-71. Disponible en: http://www.scielo.org.mx/scielo.php?script=sci_arttext&pid=S0187-75852006000400006&lng=es.
40. Costa N, De Brito E. Adaptación cultural de instrumentos utilizados en salud ocupacional. *Revista Panamericana de Salud Pública* 2002; 11(2): 109-11.

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