

The influence of psychological factors on the burden of caregivers of patients with advanced cancer: Resiliency and caregiver burden

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ABSTRACT

Objective: The aim of our study was to identify the influence of such psychological factors as emotional intelligence and perceived competence on caregiver burden in those who care for patients with advanced cancer.

Method: A total of 50 informal caregivers completed self-report assessments of resilience, perceived competence, emotional regulation, positive aspects of care, emotional distress, and burden. We conducted a quantitative study with a cross-sectional design. Descriptive statistics were obtained. Associations between the different variables were assessed using nonparametric and multiple regression analyses.

Results: Participants were mainly female (88%) and had an average of 20 months of caregiving. Their mean age was 47 years (range = 20–79). More than half of scored high on resilience, positive aspects of caring, and emotional distress, moderately on perceived competence, and low on burden. Most caregivers used cognitive restructuring and social support as coping strategies. Inverse negative correlations were observed among emotional distress, emotional state, and burden with perceived competence and positive aspects of caring ($p < 0.05$). Significant differences were obtained for emotional distress, cognitive restructuring, and resiliency. Multiple regression analyses demonstrated that perceived competence, resiliency, and positive aspects of caring were the main predictors of burden.

Significance of Results: Resilience, perceived competence, emotional regulation, and positive aspects of care constitute protective factors against caregiver burden. Taken together, these aspects should be promoted by the healthcare staff in order to facilitate caregiver adaptation and well-being.

KEYWORDS: Caregiver, Resiliency, Emotional regulation, Perceived competence, Burden

INTRODUCTION

Cancer comes with important social, economic and emotional repercussions (International Agency for Research on Cancer, 2014). It is now considered a public health problem, particularly in developing countries. In Colombia, its incidence increased from

2002 to 2006, with 70,877 new cases (International Agency for Research on Cancer, 2014). Care is defined as the act of assistance and support directed to improve a patient's condition (Vélez Angel, 2008; Galviz et al., 2004; Carretero et al., 2009). Caregiving may become an experience that has an intense emotional impact due to affective and relationship issues and the commitment that it requires (Sterckx et al., 2013; Arber et al., 2013). Caregiving is generally performed by family members and, in most cases, is assumed by a single person (known as the principal

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caregiver), who is most commonly a woman between the age of 45 and 65 years (Vélez Angel, 2008; Krikorian et al., 2010).

Caregiver burden is caused by the many responsibilities involved and the changes that occur in family and social life. In accordance with Zarit (Vahidi et al., 2016), caregiver burden is related to the physical, psychological, and social responses of the caregiver, which may arise from an imbalance between care needs and fulfilling care tasks (Vahidi et al., 2016; Truzzi et al., 2012). Caregiver burden has been found to increase emotional distress—for example, the prevalence of emotional distress in caregivers of patients with advanced cancer ranges between 20 and 50% (Donnelly et al., 2008; Hodges et al., 2005). It may be associated with negative attitudes toward the disease, avoidance, relationship problems between caregiver, patient, and other family members, as well as difficulties related to anticipated bereavement (Donnelly et al., 2008; Hodges et al., 2005; Harding et al., 2012). Between 20 and 25% of caregivers manifest feelings of not being ready to face death (Grov et al., 2005) and suffer negative repercussions in terms of their physical and psychological well-being (Schulz & Sherwood, 2008; Hudson et al., 2012).

Although caring for an advanced cancer patient becomes challenging due to the associated emotional distress (Hudson & Payne, 2011; Papastavrou et al., 2012), the use of active coping strategies may increase perceived competence (PC) and lessen the stress associated with caregiving tasks (Limonero et al., 2006; Herrera-Jiménez & Delgado Suárez, 2008). PC is defined as the expectation that a person has about the possibility of acting positively in the face of events, and it includes perception of contingency and self-efficacy. Persons with high PC tend to see stressful situations as a challenge, thereby enabling coping by focusing on the problem and controlling their emotional responses (Angeles Pastor et al., 2009). PC mediates psychosocial adaptation to anxiety and stress by stimulating positive reevaluation of stressful events while reducing their negative consequences (Ángeles Pastor et al., 2009).

During the previous decades, special attention has been focused on the study of emotions and the role they play in adaptation to one's environment (Papastavrou et al., 2012). In this context, the concept of "emotional Intelligence" (EI) emerged, which is defined as the capacity to recognize, comprehend, and regulate one's own and others' emotions, to differentiate them, and to use this information as a guide for thought and actions (Limonero et al., 2010; Lengua & Long, 2002). It modulates emotional discomfort in stressful situations and has been found to predict coping, happiness, and psychological adjustment in teenage depression, anxiety, and subjective fatigue,

among other things (Papastavrou et al., 2012; Limonero et al., 2010). "Emotional regulation" (ER) is a key component of EI and is defined as the ability to regulate or control one's emotions (positive and negative) and those of others. It plays an important role in coping with stressful and anxiety-provoking situations, and contributes positively to personal well-being (Papastavrou et al., 2012; Limonero et al., 2010; 2004; Lengua & Long, 2002).

The concept of resilience was developed (Limonero et al., 2015) along with the construct of EI and within the paradigm of positive psychology. In accordance with Forés and Granés (Limonero et al., 2015) and Rutter (Becoña, 2006), resiliency is understood as the capacity to overcome adversity, to achieve recovery, and to become stronger after exposure to a traumatic psychosocial event. It is considered a coping strategy (Limonero et al., 2015; Becoña, 2006; Limonero et al., 2012a).

According to Limonero et al. (2012a), most people can overcome adverse situations. Although they may initially manifest intense negative emotions, these feelings tend to decrease over time and with adaptation. A study carried out in Mexico with mothers of children with cancer found that the characteristics of resilience in caregiving mothers were linked to altruism, self-esteem, and social affiliations, while a positive correlation was found between resilience and establishing an empathetic relationship with the sick child they were caring for (Sinclair & Wallston, 2004).

Unfortunately, research on the role of resilience, EI, PC, and other psychological factors in the adaptation process of caregivers of patients with cancer and other chronic illnesses has been scarce (González-Arritia et al., 2011). Identifying protective factors in caregivers is relevant, as it may help in designing strategies and interventions to prevent burden in caregivers while helping them to better cope with caregiving tasks.

Consequently, the present study aimed to identify the influence of such psychological factors as EI and PC on levels of burden in the main caregivers of Colombian advanced cancer patients. We hypothesized that (1) high levels of resilience would be related to increased emotional well-being, and (2) competent caregivers with high levels of ER who find positive motivation in caring will manifest lower levels of burden.

METHOD

Participants

A convenience sample of caregivers was employed. A total of 50 informal caregivers of adult patients

with advanced cancer who attended the pain and palliative care units or the psychological unit at the Instituto de Cancerología Clínica las Américas in Medellín, Colombia, were invited to participate. Caregivers who voluntarily accepted to participate and signed the written informed consent were included. Caregivers of children with cancer and those who did not care for a patient with an advanced disease were excluded.

Materials

A sociodemographic instrument was designed, and the following instruments were administered.

The Emotional Distress Detection Questionnaire (EDDQ) in its Spanish version (DME–C) was utilized to assess the emotional distress of caregivers of patients with an advanced illness (Lavretsky et al., 2010; Limonero et al., 2012b; Maté et al., 2009). It consists of two questions that examine emotional distress and coping efforts in a 0-to-10 visual analogue scale format. This scale was also developed for use in populations of caregivers of patients with advanced illness.

Resilience strategies were evaluated using the Brief Resilient Coping Scale (BRCS) (Limonero et al., 2012a; 2014) in its Spanish-adapted version (Limonero et al., 2016). Total scores range between 4 and 20. Scores below 13 indicate low resilience, while scores above 17 indicate high resilience (Limonero et al., 2016).

Anxiety and depression were evaluated using the Hospital Anxiety and Depression Scale (HADS) (Rico et al., 2005). It was validated in Colombia in 2005 by Rico and coworkers. It is a 14-item self-administered questionnaire and comprises two subscales: anxiety and depression. The maximum score for each subscale is 21. Cutoff scores below 7 are considered normal, between 8 and 10 are considered to indicate probable cases, and above 11 indicate problems with clinical depression or anxiety (Rico et al., 2005; Zigmond & Snaith, 1983).

The abbreviated Zarit Caregiver Burden Scale was employed to assess level of burden. A Spanish version validated in Chile was administered (Breinbauer et al., 2009). It consists of 7 items. Scores >6 indicate lack of burden, while scores ≥ 17 are indicative of intense burden (Breinbauer et al., 2009).

Coping strategies were examined using the Coping Strategies Instrument (CSI) in its Spanish version, which was adapted by Cano and colleagues (Cano et al., 2007; Tobin et al., 1989). It is a 40-item instrument and examines 8 dimensions of coping strategies: self-criticism, emotional expression, problem solving, wishful thinking, social support, cognitive restructuring, problem avoidance, and social isolation (Tobin et al., 1989).

The Positive Aspects of Caring Scale was used to evaluate the emotional and affective aspects of the caring experience (Hilgeman et al., 2007; Pires & Limonero, 2008). This scale was developed in the United States and Spanish-adapted by Pires and Limonero (2008). It comprises 9 items that examine the positive aspects of caregiving at the end of life in the palliative context. Total scores range from 9 to 54.

The Perceived Competence Scale, created by Wallston in 1992 (Smith et al., 1995; Sanz et al., 1998), was utilized to evaluate PC. A validated Spanish version was administered. The instrument comprises eight items that measure individual expectations on how efficiently they can manage their environment. Total scores fluctuate between 8 and 48, with higher scores indicating greater perceived competence (mean score = 35.4) (Sanz et al., 1998).

Emotional intelligence was assessed via the Emotion Regulation Scale, developed by Gross and John (Cabello et al., 2013), and translated into Spanish by Cabello and colleagues (Gross, 1999). This instrument was derived from the process model of emotion regulation proposed by Gross (1999), where emotion regulation can occur either before or after the generation of emotion, resulting in two different strategies: “cognitive reappraisal” and “expressive suppression.” It is a 10-item self-administered questionnaire.

Procedure

The ethics committee of the institution approved our study protocol. A written informed consent was requested from all respondents. Anonymity and confidentiality were guaranteed. The study was conducted in accordance with the Declaration of Helsinki. Patients who attended the psychological consultation and the pain and palliative care unit were invited to participate. Once the caregivers agreed to participate, they were informed about the details of the study and asked to sign a written informed consent form. Data were then collected using a structured interview performed by an experienced and trained clinical psychologist who guided the interview (Gysels et al., 2014).

Statistical Analysis

The data were collected and analyzed using the Statistical Package for the Social Sciences (SPSS, v. 20.0). Descriptive statistics were obtained. Associations between the different variables were explored, and the following statistical tests were employed: (1) the Mann–Whitney *U* test was used to compare differences in study variables between groups; (2) Pearson’s correlation coefficient; and (3) multiple regression analysis of repeated measures, using burden and emotional distress as dependent variables and perceived

competence, resilience, coping strategies, emotional regulation, positive aspects of care, and demographics variables as independent variables.

RESULTS

Most caregivers were women (88%), with an average age of 48 years ($SD = 13$, range = 20–79). They mostly lived in urban areas (94%), and 70% had completed high school or had more advanced education (college or university). Half of the caregivers were married, and 84% lived with their families. They were most commonly the daughters, sisters, or wives of the patient they cared for. The most frequent occupational status was housekeeper, independent worker, or employee. They were predominantly practicing Catholics. The average length of care was 20.4 months ($SD = 20.70$, range = 1–96). (For detailed sociodemographic data, see Table 1).

According to the results obtained with the CSI, the most common coping strategies used by caregivers were problem solving, social support, cognitive restructuring, emotional expression, and wishful thinking, and the least-used ones were problem avoidance, self-criticism, and social withdrawal (Table 2).

Some 56% of caregivers reported high levels of resilience, with scores ≥ 17 . Cognitive restructuring was employed more frequently than emotional suppression. According to the EDDQ, levels of emotional distress were found to be moderate to high. Regarding emotional distress as assessed by the HADS, caregivers had higher anxiety scores than depression scores. More than half of them (54%) did not present with burden scores ≤ 16 . Caregivers scored high on positive aspects of caring and moderately on perceived competence (Table 2).

Since variables presented a normal distribution, a Pearson correlation analysis was carried out in order to test for associations between them, and a negative and significant correlation between cognitive restructuring and burden was found. Emotional suppression was found to have a significant positive relationship with depression and with HADS global score, and a significant negative association with PC (Table 3).

Emotional distress as assessed by the EDDQ and HADS indicated a positive and significant correlation with burden and an inverse significant correlation with PC and positive aspects of care. Cognitive restructuring had an inverse significant correlation with emotional distress (Table 3).

A Mann–Whitney U analysis was carried out to examine differences between emotional distress (low emotional distress < 10.5 , high emotional distress > 10.5) and burden (low burden < 16 , high burden > 17). Differences were found between emotional

Table 1. Sociodemographic data

Variable	<i>n</i> (%)
Female	44 (88)
Male	6 (12)
Marital status	
Single	14 (28)
Divorced/separated	7 (14)
Married/living together	28 (56)
Widowed	1 (2)
Lives with family	42 (84)
Alone	6 (12)
Relationship with patient	
Other	7 (14)
Mother	3 (6)
Son	2 (4)
Daughter	14 (28)
Sister	11 (22)
Brother	1 (2)
Husband	2 (4)
Wife	8 (16)
Friend	2 (4)
Place of residence	
Urban	47 (94)
Rural	3 (6)
Educational status	
No education	5 (10)
Elementary school	10 (20)
High School	12 (24)
Studies beyond high school	23 (46)
Work status	
Employee	6 (12)
Independent worker	8 (16)
Unemployed	3 (6)
Retired	3 (6)
Housekeeper	29 (58)
Other	1 (2)
Religion	
Catholic	39 (92.9)
Christian	2 (4.8)
Evangelical	1 (2.4)
Religious practice	
Nonpracticing believer	4 (8)
Practicing believer	44 (88)

distress and resilient style and cognitive restructuring among caregivers. In addition, differences were found between lower emotional distress, higher cognitive restructuring ($Z = -2.236$, $p < 0.05$), and high resilience ($Z = -2.23$, $p < 0.05$). Low levels of emotional distress resulted in increased resilience and cognitive reevaluation.

Multiple linear regression analyses using successive steps showed that PC had a negative predictive effect on burden levels ($R^2 = 0.08$, $t = -2.15$, $p < 0.05$). Positive aspects of care were found to have a negative predictive effect on burden ($t = -4.33$, $p < 0.05$), resilient style had a positive predictive effect on burden ($t = 2.351$, $p \leq 0.05$, $t = 3.2$, $p < 0.05$), and the interaction between PC and resilient style

Table 2. Descriptive statistics

	Mean	SD	Percentiles		
			25th	50th	75th
CSI	77.50	21.01	64.50	78.50	88.25
Self-criticism	6.46	4.86	3.00	5.00	9.00
Emotional expression	11.22	4.67	7.75	11.00	16.00
Problem solving	13.54	4.98	9.75	14.50	18.00
Wishful thinking	12.94	5.419	9.00	13.50	17.00
Social support	11.24	5.049	8.00	12.00	16.00
Cognitive restructuring	10.38	4.517	7.00	10.00	14.00
Problem avoidance	5.88	4.270	2.75	5.00	8.00
Social isolation	5.84	4.278	3.00	5.00	9.00
Resilience	16.56	2.260	15.75	17.00	18.00
Cognitive reevaluation	32.68	7.617	28.50	34.50	39.00
Emotional suppression	12.98	6.052	9.00	12.00	16.25
Positive aspects of caring	49.58	6.952	46.75	53.00	54.00
EDDQ	9.16	4.002	7.00	10.00	12.00
HADS	16.54	8.617	9.00	17.00	24.00
Anxiety	9.60	5.139	5.00	9.50	14.00
Depression	6.94	4.191	3.00	7.00	10.00
Zarit	16.30	4.879	11.75	16.00	20.00
PC	35.90	5.578	31.75	35.50	40.00

was found to have a negative predictive effect on burden ($t = -2.78, p < 0.05$). In summary, PC, resilient coping style, and positive aspects of care had a significant influence on burden, but not on emotional distress (Table 4).

DISCUSSION

The purpose of our study was to identify the role of resilience, ER, PC, and coping strategies on levels of burden in the caregivers of patients with advanced cancer.

Regarding sociodemographic characteristics, the data indicating that caregivers were mostly women is consistent with the findings reported in the literature (Vélez Angel, 2008; Goldzweig et al., 2013). In addition, caregivers were between 20 and 34 years of age, indicating that young adults were becoming more responsible for the care of these patients.

Caring for advanced cancer patients in most cases has consequences for the caregiver: reduction in and sometimes interruption of many daily activities, financial problems, psychological changes, social changes (particularly in terms of social roles), and spiritual changes—all affecting the overall quality of life (Cormio et al., 2014; Prue et al., 2015). These consequences are usually detected after long periods of caregiving and after they have had psychological and physical effects, not only upon caregivers but also on the patients themselves (Groß et al., 2005; Schulz & Sherwood, 2008; Hudson et al., 2012).

Most caregivers of patients with advanced cancer report high levels of burden, which affects adaptation

to their role as well as patient support (Carretero et al., 2009; Donnelly et al., 2008; Hodges et al., 2005). In our study, levels of burden were lower than those reported in previous studies (Carretero et al., 2009; Donnelly et al., 2008; Hodges et al., 2005). This is possibly associated with the length of time of care, which was 20 months on average. There was also no single main caregiver per patient, and the tendency to view positive aspects, the search for support, and less emotional suppression are aspects that may contribute to protecting caregivers from burden.

The results obtained showed an inverse and significant relation between emotional distress (as assessed by the EDDQ), HADS global score, anxiety, depression, burden, PC, and positive aspects of care. Higher emotional distress and burden are associated with lower PC and lesser recognition of the positive consequences of caregiving.

The perception of control and competence not only influences acknowledgment of the caregiver's abilities but also leads them to play an active role in care. In turn, it promotes mobilization of personal resources when facing stressful situations, decreases negative consequences, and favors identification of personal benefits (Limonero et al., 2006). For example, one study carried out in Spain with nursing students found a positive relationship with reduction of anxiety when faced with death, and higher levels of PC indicated that PC becomes a protective factor when facing potentially threatening situations, promoting psychological adjustment to difficulties with

Table 3. Correlation matrix of study variables

	EDDQ	ZBS	CR	ES	PACS	R	HA	HD	HADS	PC
Zarit Burden Scale (ZBS)	0.35*									
Cognitive restructuring (CR)	-0.27	-0.36*								
Emotional suppression (ES)	0.07	0.00	0.25							
Positive Aspects of Caring Scale (PACS)	-0.38**	-0.48**	0.19							
Resiliency	0.03	0.17	-0.04	-0.05	0.16					
HADS anxiety	0.32*	0.53**	-0.27	0.27	-0.41**	0.09				
HADS depression	0.3*	0.25	-0.07	0.35*	-0.31*	-0.08	0.70**			
HADS total	0.34*	0.43**	-0.2	0.334*	-0.39**	0.016	0.94**	9.91**		
PC	-0.28*	-0.3*	-0.04	-0.45**	0.12	0.11	-0.36*	-0.43**	-0.42**	-0.04

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

the activities of daily life and higher satisfaction with life (Herrera-Jiménez & Delgado Suárez, 2008).

Meanwhile, caregivers who had high cognitive restructuring scores experienced less emotional distress. Understood as the capacity to regulate emotions, emotional intelligence can favor selection of coping strategies that result in better emotional adjustment and an increased sensation of control and self-efficacy. It has been found that subjects with a greater ability to regulate emotions demonstrate greater efficacy in social relations, adopt empathic attitudes, and are more cooperative and satisfied with affective relationships (Ángeles Pastor et al., 2009; Limonero et al., 2010; 2004).

Regarding coping efforts, we found that searching for social support, attending to positive aspects, expressing emotions, wishful thinking, and problem resolution were the strategies more frequently used by the caregivers in our study. They constituted protective factors with respect to burden and enabled a diligent search for benefits within the caregiving experience in our participants. These findings are similar to those of a descriptive study carried out in 2008, where three ways of coping were identified: search for support, problem solution, and self-control (Hudson & Payne, 2011). Accordingly, emotion-focused coping strategies have been found to be related to a decrease in perception of burden (Hudson & Payne, 2011).

Such aspects as personal beliefs in self-control, emotional regulation when facing stress, reliance on personal abilities, and the capabilities of caregivers can have determinant effects on decreasing emotional discomfort and burden (Donnelly et al., 2008). They may also influence the use of direct actions to improve caring activities and can yield personal benefits and well-being for caregiver and patient (Galvis et al., 2004; Carretero et al., 2009; Donnelly et al., 2008; Goldzweig et al., 2013; Cormio et al., 2014). Our results suggest that healthcare staff should promote these competencies among the main caregivers through psychoeducational processes. Improving their competency will impact their immediate well-being as well as providing long-term benefits (e.g., facilitating adaptation to the death of a loved one and to bereavement processes).

As mentioned earlier, studies on resiliency, ER, PC, and psychological factors in caregivers of patients with advanced cancer are still scarce. The available studies indicate that burden and emotional distress are closely related to adjustment problems in caregivers, resulting in diminished well-being in both caregivers and patients (Carretero et al., 2009; Sterckx et al., 2013; Krikorian et al., 2010). Although the present study has limitations related to sample size, the data obtained are relevant to understanding caregiver behavior and experiences, mainly related

Table 4. Regression analysis: Prediction for perceived competence, resilience coping style, positive aspects of caring vs. burden

		<i>B</i>	Tip. error	β	<i>t</i>	<i>p</i>	<i>CI</i> _{95%}		<i>F</i>	<i>R</i> ²	<i>R</i> ² corr
							Lower limit	Upper limit			
1	(Constant)	25.63	4.37		5.85	0.000	16.83	34.44	4.65	0.088	0.069
	PC	-0.26	0.12	-0.29	-2.15	0.036	- .50	-0.01			
2	(Constant)	39.82	5.47		7.27	0.000	28.80	50.84	9.733	0.293	0.263
	PC ⁺⁺	-0.21	0.10	-0.24	-1.98	0.053	-0.43	0.00			
	Positive aspects of caring	-0.32	0.08	-0.45	-3.68	0.001	-0.49	-0.14			
3	(Constant)	32.03	6.16		5.20	0.000	19.634	44.43	9.03	0.37	0.33
	PC	-0.23	0.103	-0.27	-2.29	0.026	-0.44	-0.03			
	Positive aspects of caring	-0.35	0.08	-0.5	-4.18	0.000	-0.51	-0.18			
	BRCS ⁺	0.61	0.25	0.28	2.38	0.021	0.09	1.13			
4	(Constant)	27.524	-22.15		-1.24	0.220	-72.13	17.09	9.70	0.46	0.41
	PC	1.409	0.6	1.61	2.35	0.023	0.20	2.61			
	Positive aspects of caring	-0.338	.07	-0.48	-4.32	0.000	-0.49	-0.181			
	BRCS	4.25	1.33	1.97	3.20	0.003	1.55	6.92			
	CP.BRCS	-0.10	0.03	-2.68	-2.78	0.008	-0.17	-0.02			

Dependent variable: Zarit Burden Scale score.

⁺Resilient strategies style.

⁺⁺Perceived competence.

to their capacity to care and the emotional consequences of caregiving. Further research on the positive aspects of caring and such psychological aspects as resiliency, perceived competence, and emotional regulation that favor coping in caregivers will help us to understand how they promote health and adaptation to the caregiving experience along the course of the disease trajectory. This is of particular importance given the relevant role that caregivers play in the support of advanced cancer patients.

Given the results of our study, we find that some of the characteristics of caregivers who achieve better adaptation can be trained and enhanced—for example, perception of personal competence, self-esteem, assessment of situations in the coping process (changing threats presented by challenges), active coping strategies, and regulation of emotions, among others. With this knowledge, we could provide effective resources for caregivers that would enable them to be more competent, thus facilitating their adaptation abilities and reducing the impact of caregiver burden. These aspects should be taken into account when designing a protocol about preventive action.

CONFLICTS OF INTEREST

The authors hereby declare that they have no conflicts of interest to disclose.

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