

## FOCUS ON RELATIONSHIP BETWEEN THE CAREGIVERS UNMET NEEDS AND OTHER CAREGIVING OUTCOMES IN CANCER PALLIATIVE CARE

### NECESIDADES INSATISFECHAS Y CONSECUENCIAS DEL CUIDAR EN CUIDADORES DE PACIENTES CON CÁNCER EN FASE TERMINAL

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#### Abstract

**Objetivo:** Study the relationships between caregivers unmet needs and others caregiving outcomes in palliative care and cancer, which is a first and necessary step to offer adequate supporting intervention.

**Methods:** 59 caregivers participated in a research that examined the caregiving outcomes using an Unmet Needs Questionnaire, the Hospital Anxiety and Depression Scale, and the Bakas Caregiving Outcomes Scale.

**Results and conclusions:** Results showed a high average of unmet needs, especially emotional ones. One caregiver out of two had significant anxiety levels and one out of four of depression. Caregiving outcomes were almost all negative except for the relationship between the patient and the family. Moreover we found a positive and significant relationship between the number of unmet needs and outcomes like burden or emotional outcomes. Finally, the caregivers were interested in receiving a support which, according to their preferences, would have to be brief, group intervention and led by sanitary professionals.

**Key words:** Palliative care, family caregivers, needs, depression, anxiety, burden.

#### Resumen

**Objetivo:** Apreciar y valorar de manera sistemática las posibles relaciones entre las necesidades insatisfechas de los cuidadores primarios y las consecuencias del cuidar, como paso previo y necesario para poder ofrecer programas adecuados de soporte a los cuidadores.

**Método:** 59 cuidadores primarios participaron en una entrevista individual que incluía un cuestionario de posibles necesidades del cuidador, un cuestionario de ansiedad y depresión (HAD), y un cuestionario de sobrecarga y cambios en la vida (BCOS).

**Resultados y conclusiones:** Los resultados revelaron la presencia de un número alto de necesidades insatisfechas sobre todo de tipos emocional y psicológico. Un cuidador de cada dos presentó niveles altos de ansiedad y uno de cada cuatro niveles altos de depresión. Los cambios en la vida del cuidador solieron ser negativos excepto por lo que concernió a la relación con el enfermo y con la familia, que se mantuvo o incluso mejoró. Además se observó una relación significativa entre el número de necesidades y otras consecuencias del cuidar como la sobrecarga y el bienestar emocional. Finalmente, la mayoría de los cuidadores estuvieron interesados en recibir un soporte que fuera breve, preferiblemente de tipo grupal y sobre todo proporcionado por profesionales sanitarios.

**Palabras clave:** Cuidados paliativos, cuidadores informales, necesidades insatisfechas, depresión, ansiedad, sobrecarga.

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## INTRODUCTION

Cancer is one of the most frequently occurring diseases in the Western World. Despite advances in its treatment, a significant number of patients will reach the advanced and terminal stages of the disease after a process that may be long and exhausting. This can have a variety of consequences for the primary caregivers<sup>(1,2)</sup>.

Research has been done on some of the negative consequences of caring for a dependent person for long periods of time. Families with little resources or who have not been prepared for these complicated roles can be seen as especially adversely affected<sup>(2,3)</sup>.

The negative effects are especially observed in the last stage of the disease<sup>(4-6)</sup> in which the patients and their caregivers can experience emotional shock, depression, anxiety, impotence, fear of death, pain, sense of injustice, exhaustion and disruption of their daily life<sup>(7-9)</sup>.

The caregiving outcomes that have been most often analyzed have been the state of psychological health status such as the stress levels, burden and life changes for the caregiver. Next we'll describe each of them in some detail, as well as the unmet needs that go along with this situation.

The depression and anxiety in caregivers stated in published works are rather variables. In Spain, Molina Linde et al.<sup>(10)</sup> showed a tendency for depression and anxiety in caregivers of terminal cancer patients in palliative care units. Rodríguez Vega et al.<sup>(11)</sup> found that 36.4% of the family care givers scored high in the anxiety subscale of the Hospital Anxiety and Depression Scale<sup>(12)</sup> and 9.2% in the depression subscale. In their study on the caregiver needs, Payne et al.<sup>(2)</sup> found that 84% of caregivers showed significant levels of stress related to their caregiving duties. Additionally, 33% of the sample

of caregivers of patients suffering from colorectal cancer in the palliative stage studied by Maguire and his collaborators<sup>(13)</sup> showed stress and/or depression. Toseland et al.<sup>(3)</sup> observed higher levels of anxiety and depression in cancer patient caregivers than in the general population. Grunfeld et al.<sup>(14)</sup> observed that 35% of their sample of caregivers of women with the terminal breast cancer showed anxiety and that 30% were clinically diagnosed with depression. In addition, in the same study, the greatest predictor of anxiety and depression was perceived burden by the primary caregivers. In a review of the psychological repercussions of terminal cancer on families, Pitceathly and Maguire<sup>(5)</sup> concluded that a minority of caregivers of cancer patients develop psychiatric problems but that a significant number showed high levels of emotional stress. In a more recent study it was revealed that between 40% and 60% of families experience a high level of psychological stress when caring for someone at the end of his/her life<sup>(15)</sup>. This is even more observed as the level of the autonomy of the patient diminishes.

Furthermore, the concept of perceived burden has been used to facilitate understanding of the impact of caregiving on the providers of care as well as formulating theoretical links between the demands of care and their repercussions<sup>(16-18)</sup>. A number of empirical studies on the concept of burden distinguish, implicitly or explicitly, between objective and subjective burden<sup>(19)</sup>. The findings in this area seem to indicate that the subjective dimension of burden better predicts physical, social and emotional well-being of the caregivers than the objective one<sup>(1)</sup>. In a study on caregivers of patients receiving chemotherapy<sup>(20)</sup>, the provision of emotional support was considered as one of the most difficult to manage and, as a consequence, was associated with

a greater level of burden. In Spain, Gort et al.<sup>(21)</sup> assessed the burden of caregivers upon patients entering a palliative care unit with a Spanish adaptation of the Caregiver Burden Interview by Zarit<sup>(22,23)</sup>. At the time of entering the unit, 77% of the caregivers showed an intense (74%) or low (26%) level of burden. Although the Zarit scale<sup>(22)</sup> has been often used for assessing the burden of caregivers, it has also been criticized for different reasons<sup>(24)</sup>. The major concerns involve the unidimensionality of the scale, its overly general character derived from low correlations between the variables studied, and its questionable reliability and validity. The Bakas Caregiving Outcomes Scale (BCOS) of Bakas and Champion<sup>(25)</sup> is also oriented to the specific consequences of the caregiving situation but reflects a multidimensional measurement of burden and, in addition, takes into account the positive consequences of caregiving.

The study of the caregivers needs is particularly important in palliative care. The families and loved ones generally represent the greatest source of support for the patient. The needs of the primary caregivers can have an influence on the patients' quality of life: (a) the caregivers who are significantly burdened may carry out their duties less efficiently, to the detriment of the patients<sup>(26)</sup>, (b) the patients may have more unmet needs if their caregivers are significantly burdened<sup>(27)</sup>, and (c) the level of activity of the patient may be diminished if the psychological needs of the caregivers increase<sup>(28)</sup>. Finally, it should be taken into account that the experience of the families as caregivers may have consequences in the subsequent grieving period. Several studies have identified important unmet needs in the caregivers of patients with cancer<sup>(29,30)</sup>. Sothill et al.<sup>(31)</sup> found that 43% of the caregivers showed at least one unmet need. Other authors also

suggest the presence of a larger number of unmet needs in the caregiver than in the patient<sup>(32)</sup>. With regard to the types of needs experienced, the patients' care engenders disease related<sup>(33)</sup>, emotional<sup>(34)</sup>, economic and social<sup>(29,31)</sup> needs in the caregivers.

Although significant efforts have been made to understand the direct and indirect consequences of caregiving (that are consequences that affect both the caregiver and the patient), it is necessary to do further research to facilitate the design of interventions shaped for improving the adjustment of the caregivers<sup>(35)</sup>. To do so, it is necessary to advance in the knowledge of the unmet needs of the primary caregivers, which caregivers may most benefit from an intervention (for example, attention to a more or less high level of burden and an anxious and/or depressed emotional state), and the caregivers' preferences with regard to their interest and availability for a probable intervention<sup>(36-40)</sup>.

## Objectives

Taking the former into account, in the current study we have proposed the following objectives: (a) contribute information on the needs of the caregivers in our environment from their own personal perspective, (b) analyze the possible relationship between the needs of the primary caregivers and some burden, stress, and anxiety indicators in a situation of advanced cancer, and (c) obtain information about the preferences of the caregivers with regards to a possible intervention.

## METHODOLOGY

### Participants

The sample was composed of caregivers of patients diagnosed with terminal cancer who had been contacted through two

ways: (a) families of oncology patients who were attended by the “Asociación Española contra el Cáncer de Barcelona” (Spanish Association against Cancer of Barcelona) which is a non-governmental organization (NGO) that provides psychosocial support and (b) families of patients who were admitted to the “Unidad de Cuidados Paliativos del Hospital Parc Taulí de Sabadell” (Palliative Care Unit of the Hospital Parc Taulí of Sabadell). The size of the sample was 59 primary caregivers of patients in advanced stages of cancer recruited between March and November 2006.

The criteria for including the caregivers were the following: (a) have a family member with cancer in the terminal stage, (b) be more than 18 years old (c) have an educational level that allows them to understand the items in the questionnaire, and (d) not be diagnosed with cancer.

A precise description of their characteristics is postponed until the results section.

## **Instruments**

### *Biomedical and sociodemographical data*

The following biomedical and sociodemographical data were collected on the caregivers: sex, age, family relationship to patient, education level, occupation, psychoactive drugs taken as a result of the illness of the family member patient, and request and/or benefit of psychological support. To this were added the following data related to the patient: sex, age, diagnosis, time of care in the terminal stage, time dedicated to care by the caregiver interviewed, care site at the time of study and types of support received (medical, social and/or psychological support).

### *Primary Caregivers Unmet Needs*

At the time our empirical research began, no questionnaire directed to the caregiver needs adapted to this population in our cultural environment was available. The review in this area allowed us to observe that even in other cultural environments there were few questionnaires on the needs of primary caregivers of patients with cancer that showed satisfactory psychometric properties<sup>(41,42)</sup>. In general the items relative to the needs differed greatly among the instruments and, in addition, the instruments lacked items related to the real needs of the caregivers in palliative care<sup>(41)</sup>. As a result, we opted for creating the first version of a the Caregivers Unmet Needs Questionnaire starting with a review of the scientific literature and semi-structured interviews, firstly with psychologists specializing in psychooncology and, secondly, with primary caregivers of patients with terminal cancer (the process of developing the questionnaire is fully described in Buscemi<sup>(43)</sup>). The questionnaire consists of 30 probable medical, psychological and social/family needs related to a situation generated by the illness of the family member. The response option is dichotomous: the caregivers have to assess and indicate if they have or don't have each one of these needs at the time the questionnaire is administered. An open question at the end of the questionnaire allows them to add additional relevant needs. Finally, the caregivers are asked to enumerate from highest to lowest what they consider as their 5 most important needs. Thus, through this procedure, the unmet needs are identified along with their frequency and their perceived importance.

### *Depression and Anxiety*

The Hospital Anxiety and Depression Scale (HADS) of Zigmond y Snaith<sup>(12)</sup> has been used before on caregivers of patients with cancer<sup>(44,45)</sup>. It is made up of 14 items divided equally into two dimensions consisting of anxiety (HADS-A) and depression (HADS-D). Each item is evaluated through a Likert type response scale with grading between 0 and 3. The person is requested to evaluate each of the affirmations of agreement with their perception of their emotional state considering the time periode of the last 7 days. In the Spanish version used, and for each subscale, values lower than or equal to 7 are considered non-cases, between 8 and 10, doubtful cases, and equal to or greater than 11 are valid cases for both dimensions<sup>(46)</sup>. In this version, the alpha coefficient is 0.85 for the entire scale and 0.86 for each of the subscales<sup>(47)</sup>. In our sample, we obtained an  $\alpha$  value for the whole scale of 0.73.

### *Perceived Burden and Caregiving Outcomes*

Data was collected on caregiver burden starting with a translation of the Bakas Caregiving Outcomes Scale (BCOS) from Bakas and Champion<sup>(25)</sup>. This instrument corresponds to the theoretical position that burden is multidimensional concept that should include positive and negative concepts of the duties of caregiving<sup>(48)</sup> because it assesses both the positive and negative changes in the areas of the caregivers' lives. In this instrument, the caregivers have to assess 15 items that are the aspects of their life that have changed since they have started taking care of the patient. The items assess social functioning, physical health and subjective wellbeing. Each one is evaluated by a 7 point Likert type scale (-3 = has greatly worsened to

+3 = has greatly improved). The responses are recorded on a scale whose value varies between +1 (has greatly worsened) and +7 (has greatly improved). To interpret the total of the scale, the score range between 15 and 105; values above 60 meaning worsening, and values below 60 meaning improvement. At first the BCOS was designed to assess the burden and changes in the lives of the caregivers of people who had suffered from a vascular cerebral accident. Later, the analysis was expanded and its psychometric properties have also been studied with families caring for oncology patients at home<sup>(49)</sup>. In a recent psychometric analysis<sup>(50)</sup> the internal consistency of the BCOS measured by alpha was 0.90 and the test/retest reliability coefficient was 0.67, with item-total correlations ranging from 0.45 to 0.74. The factorial weights ranging from 0.45 to 0.79, supporting the one-dimensional structure of the scale. The correlations with the General Health Subscale of the SF-36 questionnaire ( $r=0.32$ ,  $p<0.001$ ) and with a criterion variable that measures how the life of the caregiver has changed in general ( $r=0.67$ ,  $p<0.001$ ), contributed to the validity of the related criteria. In our sample we obtained an  $\alpha$  index of 0.75.

### *Interest in Receiving Help and Ways of Support*

To determine the possible interest by caregivers in receiving help, and basing ourselves on the questions developed by Wong et al.<sup>(40)</sup> in their study on the information needs of advanced stage cancer patients and their caregivers, we included three semi-open questions on the need for help, the duration of it and preferred forms of support. The participants had to check out their preferences on a list but they were also free to write down any other suggestion or idea.

## Procedure

The collection of the data was done through individual interviews with caregivers who agreed to participate in the study. A written informed consent form had previously been requested by the institutions involved in the collection of the data. The interviews were carried out by a psychologist trained and experienced in the field of psychooncology and palliative care.

The length of time for the interviews ranged from a minimum of 40 to a maximum of 60 minutes to answer all of the questions by the therapist. The degree of completion and understanding of the material was very high. Only one person did not finish the interview, arguing that she was feeling tired.

## Data Analysis

The statistical analysis was done through the SPSS program, version 14.0 for Windows.

We used descriptive statistical methods to present the results related to demographic data, the identified unmet needs of the primary caregivers, the interest in receiving help and the consequences of caregiving. A Pearson's test was used to calculate the correlations between the outcomes of caregiving.

## RESULTS

### Participants

The characteristics of the sample of caregivers are detailed in Table 1. As can be seen, most of the caregivers were women (81.4%). In more than half of the cases, the caregiver was the spouse. Some 69.5% of the caregivers did not attend school and/or engaged in professional activity outside of the home. The average age of the cancer

patients at the time of the interview was 66 years old. Most of the cancer patients had the lung, colon or breast cancer. Of all the patients, 83.1% were being cared for at home. The average accumulated time of care given to the terminal phase of the disease by the caregivers at the time of the interview was 3.61 months. The great majority of the caregivers performed their duties during 9 hours every day.

### Primary caregivers unmet needs

Table 2 presents the needs according to the order given by the caregivers in the questionnaire. The most frequent need was the need *"to know how to face up to feelings of loss"* and, on the overall, the most frequent unmet needs were psychological in nature. The average frequency by need was 30.5% of the sample. Moreover, the results of the questionnaire allowed us to show that the average number of unmet needs identified by the caregiver was 14.1 (DE 4.7), with a minimum of 3 needs and a maximum of 24 needs.

It should be pointed out that among the primary needs considered as most important (n=59) was the need *"to be sure that the patient will suffer as little as possible"* (n=11, 18.6%), followed by the need *"to have more time for myself"* (n=9, 15.2%) and in third place by the need *"to talk about and get off my chest what is worrying me (feelings, fears, etc.)"* (n=5, 8.5%).

To the question *"Do you think that there are other needs than those previously mentioned? If so, what would they be?"*, only 6 caregivers added a need to those already proposed in the questionnaire. The needs mentioned were knowing how to face up to other members of the family, knowing how to manage and maintain relationships with significant others, being more comforted and understood by the patient to get more coordinated monitoring



Table 1. **Caregivers characteristics and information related with the disease.**

Caregivers demographical characteristics		
Sex	Men	11 (18.6%)
	Women	48 (81.4%)
Age in years (men and women)	Mean (SD)	53.36 (15.66)
	Min	18
	Max	86
Primary caregiver	Yes	52 (88.13%)
	No	7 (11.87%)
Caregiver relationship to patient	Spouse	34 (57.6%)
	Son/Daughter	21 (35.6%)
	Brother/Sister	4 (6.8%)
Education level	No studies	5 (8.5%)
	Primary school	15 (25.4%)
	Secondary school	20 (33.9%)
	University	19 (32.2%)
Occupation	Retired	19 (32.2%)
	Wageearner	16 (27.1%)
	Student	2 (3.4%)
	Sick leave	9 (15.3%)
	Unemployed	4 (6.8%)
	Invalidity	1 (1.7%)
	Other	8 (13.6%)
Psychoactive drugs related to caregiving	Yes	30 (50.85%)
	No	29 (49.15%)
Request and/or benefit of psychological support	Yes	34 (57.63%)
	No	25 (42.37%)
Patients diagnosis	Lung	20 (33.9%)
	Colon	8 (13.6%)
	Breast	7 (11.9%)
	Liver	4 (6.8%)
	Other	17 (33.8%)
Time of care in the terminal stage (months)	Mean (SD)	3.61 (2.82)
	Min	1
	Max	12
Time dedicated to care by the interviewed caregiver (Days/week)	Mean (SD)	6.9 (0.66)
	Min	2
	Max	7
Hours/day	Mean (SD)	9.02 (5.13)
	Min	1
	Max	16
Place of care at the time of study	Home	47 (83.1%)
	Palliative Care Unit	10 (16.9%)

Table 2. Rank of the identified needs by the caregivers.

UNMET NEEDS (30) (n=59 caregivers)	Present the need %
To know how to face up to feelings of lost	93.2
To know how to cope with negative feelings	86.4
To talk about and get off my chest what is worrying me (feelings, fears, etc.)	83.1
To know how the patient's situation will change in the future	74.6
To be sure that the patient will suffer as little as possible	72.9
To know what are the possible signs that signal the final stage of the disease	67.8
To know how to maintain self control	66.1
To have more time for myself	59.3
To share the experience with people who are in a similar situation	52.5
To feel more prepared to assume the caregiver role	52.5
To know how to be with the patient when he/she feels in a bad mood	50.8
To have an easy and rapid access to other professionals than doctors	50.8
To prepare for a probable death at home	48.9 <sup>(1)</sup>
To be able to think about the future, about what I'll do after this situation	44.1
To have information about economical help from the State or from any other institution	44.1
To know how to say goodbye to the patient	42.4
To be sure that the patient is receiving the best quality of care	42.4
To have more information about the cancer, the symptoms and the treatments	42.4
To know what I can do to have or to keep a good physical health	42.4
To have a home worker to help us at home	37.3
To talk in an open way with the patient	37.3
Not to feel guilty if I would think: "This situation has to stop. I can't anymore."	33.9
To share responsibilities with other members of the family	32.2
To improve the communication between the members of my family	30.5
To get information about the patient diet and alimentation	30.5
To perceive more support from my professional and social environment	28.8
To get guidelines about hygiene and care of the patient symptoms	27.1
To resolve pending matters with the patient	22
To have access to a medial team specialized in home setting care	19.1 <sup>(*)</sup>
To get information about funeral and other related matters	11.9

(\*) From the sample of patients cared at his/her home place (n=47).



from medical service at home and, finally, not being obsessed with the disease and fear of being afflicted with it.

### **Levels of Depression and Anxiety in Primary Caregivers**

As can be seen in Table 3 and with regards to anxiety, 15 caregivers (26.8% of the sample) could be considered as doubtful cases and more than half ( $n=31$ , 55.3%) were graded with high values in the scale and could be assessed as valid cases. On the scale of depression, somewhat more than one-fourth of the sample ( $n=15$ , 26.8%) could be considered as cases with high grades on the scale, and 11 (19.6%) caregivers could be considered as doubtful cases.

### **Perceived Burden**

The average index was 69.56 points (DE 7.61), with a minimum of 58 and a maximum of 89. All caregivers showed a result greater than or equal to 58 and are located in the area of negative changes (since a result above 60 means a worsening). Table 4 lets us see that the area of life most negatively affected for the caregivers is emotional wellbeing as well as that which experienced the most positives changes is the relationship with the patient. It can be observed in the Table that all of the areas of life of the caregivers had experienced relatively negative changes ( $>4$  points) except in the case of the relationship with the patient and the family.

### **Relationships between the Caregiving Outcomes**

Table 5 shows that depression, anxiety, overall burden and the total number of unmet needs were significantly related in a positive way and with a medium or high magnitude. All these correlations were

statistically significant at 0.01 level. The most important significant and positive correlation was 0.614 between burden and the depression index. We also observed positive and significant correlations between the number of psychological needs and the consequences of caregiving such as levels of anxiety, depression and the overall burden index.

### **Interest in Receiving Professional Help and Preferred Forms of Help**

Most of the caregivers showed an interest in receiving help (41 caregivers, 69.5% of the sample), 3 (5.1%) were unsure and 15 (25.4%) did not show a desire for this. The preferred forms of support by the caregivers favorable to support were, first of all, participation in a psycho-educational group led by a therapist ( $n=32$ , 39% of the sample) and secondly, participation in interviews with health professionals ( $n=25$ , 30.5%). The most appropriate time for receiving this support varied greatly and depended on the situation in which the caregiver and patient find themselves. As to the frequency of help, few caregivers could or desired to get involved on a weekly basis and a most of them opted for a short-term treatment.

## **DISCUSSION**

Through this work, we have tried to contribute information on the needs of caregivers in our cultural environment from their own personal perspective by considering the possible relationship between their needs and burden, stress and anxiety of the caregivers, by assessing the preferences of the caregivers regarding a possible intervention.

Compared with other published studies, we can consider that the number of unmet needs for the caregiver is high even though comparison between the

Table 3. **Results of the Hospital Anxiety and Depression Scale (HAD).**

n=56	HAD-Anxiety	HAD-Depression
Mean (SD)	10.96 (3.83)	7.91 (4.41)
Median	11	7
Mode	8	6
Min	4	0
Max	21	18
≤7: no case	10 (17.9%)	30 (53.6%)
8<x<10: doubtful case	15 (26.8%)	11 (19.6%)
≥11: case	31 (55.3%)	15 (26.8%)

Table 4. **Results of the Bakas Caregiving Outcomes Scale (BCOS).**

BCOS (n=57)	
Items	Mean (SD)
My emotional well-being	5.67 (0.83)
My time for social activities	5.58 (1.13)
My time for familiar activities	5.19 (1.43)
My future outlook	5.14 (1.33)
My physical health	4.98 (0.88)
My physical functioning	4.86 (0.93)
My general health	4.84 (0.80)
My level of energy	4.82 (1.18)
My financial well-being	4.53 (0.78)
My roles in life	4.44 (1.07)
My relationship with friends	4.28 (1.11)
My ability to cope with stress	4.26 (1.40)
My self esteem	4.02 (0.95)
My relationship with family	3.58 (0.98)
My relationship with the patient	3.37 (1.11)

results seems difficult for two reasons: the items in the questionnaire and their assessment differ, and also because there are different definitions of "need". For example, authors like Osse et al.<sup>(41)</sup> and Jansma et al.<sup>(51)</sup> define need as the desire to obtain professional services to satisfy it. In our case, we have opted for a broader criteria in the sense of taking into account

any need regardless of the fact that any professionals could solve it.

The questionnaire collects psychological, family and/or social needs related to the disease. With respect to the direct needs of the family tied to the disease, one of the most important is: "to know what are the possible signs that signal the final stage of the disease". At a social level, the need

Table 5. **Correlations between caregiving outcomes.**

	Depression (HAD)	Anxiety (HAD)	Depression and Anxiety (HAD)	Burden (BCOS)	Total number of unmet needs	Number of unmet physical needs	Number of social needs	Number of psychological needs
Depression (HAD)	1							
Anxiety (HAD)	.576**	1						
Depression and Anxiety (HAD)	.895**	.844**	1					
Burden (BCOS)	.614**	.404**	.565**	1				
Total number of unmet needs	.432**	.438**	.487**	.413**	1			
Number of unmet physical needs	.138	.218	.231	.222	.627**	1		
Number of social needs	.312*	.221	.280*	.304*	.764**	.396**	1	
Number of psychological needs	.445**	.474**	.511**	.380**	.883**	.340**	.461**	1

\*\* Significant correlation at level 0.01 (bilateral).

\* Significant correlation at level 0.05 (bilateral).

for "to share the experience with people who are in a similar situation" stands out, the need to feel less isolated and to want to collaborate or participate in a possible intervention that would bring together different caregivers at the same time. Although all the suggested needs have been considered as such by a more or less significant number of caregivers, the most frequent needs are of a psychological nature. In fact, the most frequent needs match up with the most important ones

cited by the caregivers except for the need "to have more time for myself".

Although the categories we chose appear to be appropriate for the assessment of needs, we can highlight the fact that the distribution of needs as a function of these categories is not exclusive. For example, the need "to know how the patient's situation will change in the future" can be of a psychological nature if we give priority to the need to reduce uncertainty related to the situation and also of a physical nature or related to

the disease if we give priority to the need to be able to obtain more information about the physical state of the patient.

All the caregivers identified unmet needs. To summarize what we have previously mentioned, the caregivers have different types of needs: physical ones or those related to the disease and, more frequently, social and psychological ones. This study also reveals the capability of our caregivers to declare their needs. In other studies it was observed that caregivers, despite having similar (or greater) levels of stress than the patients<sup>(14,52)</sup>, were reluctant to express what they themselves needed<sup>(53)</sup>. This fact may be explained by the appropriateness of the system of questions.

Given that some needs may be very much related and in any case influence each other, it is likely that satisfying one, we will be able to satisfy another. For example, if the caregiver needs access to other professionals that are not doctors (for example, a social worker), the caregiver will be able to stop needing to use the help of a family member in the home or be better informed about help available from the State or others like NGOs. We will have to consider two factors when proposing interventions aimed at improving the wellbeing of the caregivers: (a) respect the order of the most important needs of caregivers— understanding that the most important needs are those that require more urgent attention and that they are more related to emotional distress and burden suffered, and also (b) see which needs are more related to other negative consequences of caring like anxiety, depression and burden.

The results obtained from this research also confirm the fact that caring for a family member with terminal cancer makes for a stressful situation for the caregiver, as several other authors have emphasized (for example, see the review by Kinsella et al.<sup>(19)</sup>

The data related to the presence of high levels of anxiety and, to a lesser degree, depression, generally agree with what we find in the scientific literature on the subject<sup>(2)</sup>. Other studies<sup>(15,54)</sup> have shown evidence of even higher levels of anxiety in comparison with the levels of depression in caregivers.

The results on the burden scale suggest a negative effect on the life of the caregivers. The most negative changes are observed in the following areas: emotional well-being, time for social and family activities and how they see the future. In the case of changes relative to the relationship with the patient and the family, they generally experience a positive change (a result also found in a recent study by Kim et al.<sup>(55)</sup>).

In our study, the Bakas and Champion<sup>(25)</sup> burden scale has been useful at a clinical level because the assessed changes by the scale are changes that the caregivers spontaneously cite when we ask for it openly. It contributes a lot of information on the impact of caregiving in different areas of the lives of the caregivers. It facilitates an assessment in which the caregivers also have to consider the neutral and/or positive factors of their experience (not always focusing or mentioning the negative) and this allows them to put the situation in perspective. We also consider that this scale can be useful for assessing the impact of an intervention.

We have been able to verify that the different outcomes of caregiving that we include in our study are significantly positively correlated. Up to the time of performing our research, we have not identified any work in the literature that analyses the relationships between burden, needs, anxiety and depression in primary caregivers of patients with terminal stage cancer. Nevertheless, indeed we did find works dedicated to analyze the relationship between burden and emotional wellbeing. Dumont et al.<sup>(15)</sup> identify a significant and

positive relationship between burden and stress in caregivers of terminal cancer patients. In a longitudinal study on the burden on caregivers of breast cancer patients, Grunfeld et al.<sup>(14)</sup> found that burden was a factor that more often predicted anxiety and depression suffered by caregivers (compared with other factors like anxiety of the patients, their physical state and emotional support received). In our study, burden and depression are the two consequences that are most significantly correlated. Our results agree with the work of Grov et al.<sup>(56)</sup> on the variables influencing burden of the caregivers of cancer patients where it was observed that depression was the variable most related to burden of caregivers.

In our sample, two caregivers out of three show a desire to receive help. This data exceeds the degree of interest found in other studies (31% of caregivers interested and an additional questionable 40% in the study by Wong et al.<sup>(40)</sup>). In any case, in our sample, we don't know if part of this interest may be related to requests for support prior to the interview. Given the variability in the responses, it makes it difficult to determine the best time to offer this service. In other words, an intervention would have to be offered at any time during the disease in order to be able to allow the caregivers to choose the most opportune time not only according to their unmet needs but also according to their availability. In fact, this agrees with the changing characteristics of the situation of a terminal disease. Indeed, we assert that the caregivers tend to opt for the option of targeted help since they have problems getting involved more frequently. Wong et al.<sup>(40)</sup> detected the potential reasons why the caregivers would not do this: not feeling well, lack of time, not having their own means of transport, not having a person to substitute for the caregiver, not having parking, etc. As for the forms of help, the three options most

often chosen by the caregivers are, from greatest to least importance, a psycho-educational group led by a professional, interviews with health professionals and talks or conferences on subjects of interest. These results reflect, on the one hand, the will to meet with people who are going through a similar experience, and on the other, the will to be in direct contact with health professionals that have experience in the area of palliative care (results that agree with Jansma et al.<sup>(51)</sup>). Consequently, in the study by Wong et al.<sup>(40)</sup>, the caregivers opted above all for interviews with professionals, informative booklets and books and conferences and talks. This difference may be explained by the fact that Wong et al.<sup>(40)</sup> focused only on the informative needs of the caregivers, while in our study, we also considered the possibility of emotional support.

In a recent review of interventions directed at caregivers of the dependent elderly, López and Crespo<sup>(57)</sup> demonstrated the difficulties with these types of interventions. They insist that caregivers traditionally show themselves to be a group difficult to get with it; they usually find high percentages of rejections and neglect in interventions and especially for emotionally affected caregivers. It seems necessary then to adapt the interventions to the needs and specific characteristics of the caregivers (particularly their scarce time availability and their burden due to the many duties involved in caregiving). As a result, it is recommended to offer brief intervention program that do not take on an added stress factor and can offer specific skills for facing up to, control of and solutions to emotional problems. Finally, it is clear that most of the interventions have been directed towards families of persons with Alzheimer's disease and that few studies have been performed in cancer settings in Spain.

The results of this study have to be interpreted and considered in light of

some limitations. First, the number of participants prevented comparison among subgroups and generalization of the results. Second, it is a sample of convenience in the sense that families that participated in the study were not chosen by chance. Firstly, one part of the sample asked for a psychological orientation and, secondly, the percentage of caregivers in the sample with higher education exceeded the percentage of those with higher education in the general Spanish caregiver population (although reference is made to relative data on caregivers of the dependent elderly<sup>(58)</sup>). The possible effects of these factors are unknown. For example, people with a higher education level might express more unmet needs and/or would look for more support resources. Finally, it would be advisable to be able to complement this observational study with a longitudinal type research study that would contribute more information on the process.

## REFERENCES

1. Nijboer C, Tempelaar R, Sanderman R, Triemstra M, Spruijt RJ, Van den Bos, GAM. Cancer and caregiving: The impact on the caregiver's health. *Psychooncology* 1998; 7: 3-13.
2. Payne S, Smith P, Dean S. Identifying the concerns of informal carers in palliative care. *Palliat Med* 1999; 13: 37-44.
3. Toseland RW, Blanchard CG, McCallion PA. Problem solving intervention for caregivers of cancer patients. *Soc Sci Med* 1995; 40: 517-528.
4. Muzzin LJ, Anderson NJ, Figueredo AT, Gudelis SO. The experience of cancer. *Soc Sci Med* 1994; 38: 1201-8.
5. Pitceathly C, Maguire P. The psychological impact of cancer on patients' partners and other key relatives. *Eur J Cancer* 2003; 39: 1517-24.
6. Thomas C, Morris SM, Harman JC. Companions through cancer: the care given by informal carers in cancer contexts. *Soc Sci and Med* 2002; 54: 529-44.
7. Given BA, Given CW. Patient and family caregiver reaction to new and recurrent breast cancer. *J Am Med Womens Assoc* 1992; 47: 201-6.
8. Mahon SM, Cella DF, Donovan MI. Psychosocial adjustment to recurrent cancer. *Oncol Nurs Forum* 1990; 17: 47-52.
9. Northouse LL, Laten D, Reddy P. Adjustment of women and their husbands to recurrent breast cancer. *Res Nurs Health* 1995; 18: 515-24.
10. Molina Linde, JM, Romero Coteló J, Romero Rodríguez Y, Rodríguez Sañudo RM, Gálvez Mateos R. Alteraciones emocionales en el cuidador del enfermo oncológico terminal. *Med Pal* 2005; 12: 83-7.
11. Rodríguez Vega B, Ortiz Villalobos A, Palao Tarrero A, Avedillo C, Sánchez-Cabezudo A, Chinchilla C. Síntomas de ansiedad y depresión en un grupo de pacientes oncológicos y en sus cuidadores. *Eur J Psychiatry* 2002; 16: 27-38.
12. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983; 67: 361-70.
13. Maguire P, Walsh S, Jeacock J, Kingston R. Physical and psychological needs of patients dying from colo-rectal cancer. *Palliat Med* 1999, 13: 45-50.
14. Grunfeld E, Coyle D, Whelan T, Clinch J, Reyno L, Earle CC, et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *CMAJ* 2004; 170: 1795-801.
15. 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. *J Palliat Med* 2006; 9: 912-21.
16. Grov EK, Fosså SD, Sørebo O, Dahl AA. Primary caregivers of cancer patients in the palliative phase: a path analysis of



- variables influencing their burden. *Soc Sci Med*. 2006; 63: 2429-39.
17. Proot IM, Abu-Saad HH, Crebolder HF, Goldsteen M, Luker KA, Widdershoven GA. Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scand J Caring Sci*. 2003; 17: 113-21.
  18. Schumacher KL, Stewart BJ, Archbold PG, Caparro M, Mutale F, Agrawal S. Effects of caregiving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment. *Oncol Nurs Forum* 2008; 35: 49-56.
  19. Kinsella G, Cooper B, Picton C, Murtagh D. A review of the measurement of caregiver and family burden in palliative care. *J Palliat Care* 1998; 14: 37-45.
  20. Carey PJ, Oberst MT, McCubbin MA, Hughes SH. Appraisal and caregiving burden in family members caring for patients receiving chemotherapy. *Oncol Nurs Forum* 1991; 18: 1341-8.
  21. Gort AM, Mazarico S, Ballesté J, Barberá J, Gomez X, de Miguel M. Uso de la escala de Zarit en valoración de la claudicación en cuidados paliativos. *Med Clin (Barc)* 2003; 121: 132-3.
  22. Zarit SH, Reeve KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980; 20: 649-55.
  23. Martín M, Salvadó I, Nadal S, Miji LC, Rico JM, Lanz P, Taussing MI. Adaptación para nuestro medio de la Escala de Sobrecarga del Cuidador (Caregiver Burden Interview) de Zarit. *Rev Gerontol* 1996; 6: 338-46.
  24. Deeken JF, Taylor KL, Mangan P, Yabroff KR, Ingham JM. Care for the caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *J Pain Symptom Manage* 2003; 26: 922-53.
  25. Bakas T, Champion V. Development and psychometric testing of the Bakas Caregiving Outcomes Scale. *Nurs Res* 1999; 48: 250-9.
  26. Kristjanson LJ, Atwood J, Degner L. Validity and reliability of the family inventory of needs (FIN): measuring the care needs of families of advanced cancer patients. *J Nurs Meas* 1995; 3: 109-26.
  27. Siegel K, Raveis VH, Houts P, Mor V. Caregiver burden and unmet patient needs. *Cancer* 1991; 68: 1131-40.
  28. Hileman JW, Lackey NR, Hassanein RS. Identifying the needs of home caregivers of patients with cancer. *Oncol Nurs Forum* 1992; 19: 771-7.
  29. Grande G, Todd C, Barclay S. Support needs in the last year of life: Patient and career dilemmas. *Palliat Med* 1997; 11: 202-8.
  30. Krishnasamy M, Wilkie E, Haviland J. Lung cancer health care needs assessment: patients' and informal carers' responses to a national mail questionnaire survey. *Palliat Med* 2001; 15: 213-27.
  31. Soothill K, Morris SM, Harman JC, Francis B, Thomas C, McIlmurray MB. Informal carers of cancer patients: what are their unmet psychosocial needs? *Health Soc Care Community* 2001; 9: 464-75.
  32. Higginson IJ, Wade A, McCarthy M. Palliative care: views of patients and their families. *BMJ* 1990; 301: 277-81.
  33. Grahn G, Johnson J. Learning to cope and living with cancer. Learning-needs assessment in cancer patient education. *Scand J Caring Sci* 1990; 4: 173-81.
  34. Wingate AL, Lackey NR. A description of the needs of noninstitutionalized cancer patients and their primary caregivers. *Cancer Nurs* 1989; 12: 216-25.
  35. Aoun SM, Kristjanson LJ, Currow DC, Hudson PL. Caregiving for the terminally ill: at what cost? *Palliat Med* 2005; 19: 551-5.
  36. Barg F, Pasacreta J, Nuamah I, Robinson K, Angeletti K, Yasko J, et al. Description of a psychoeducational intervention for family caregivers of cancer patients. *J Fam Nurs* 1998; 44: 394-413.
  37. Harding R., Higginson IJ. What is the best way to help caregivers in cancer and



- palliative care? A systematic literature review of interventions and their effectiveness. *Palliat Med* 2003; 17: 63-74.
38. Hudson P. A critical review of supportive interventions for family caregivers of palliative stage cancer patients. *J Psychosoc Oncol* 2004; 22: 77-93.
  39. Given B, Given C, Kozachik S. Family support in advanced cancer. *CA Cancer J Clin* 2001; 51: 213-31.
  40. Wong RK, Franssen E, Szumacher E, Connolly R, Evans M, Page B, et al. What do patients living with advanced cancer and their carers want to know? - A needs assessment. *Support Care Cancer* 2002; 10: 408-15.
  41. Osse BHP, Vernooij-Dassen MJFJ, de Vree BPW, Schadé E, Grol RPTM. Assessment of the need for palliative care as perceived by individual cancer patients and their families. *Cancer* 2000; 88: 900-11.
  42. Wen K, Gusafson DH. Needs assessment for cancer patients and their families. *Health Qual Life Outcomes* 2004; 2: 11-22.
  43. Buscemi, V. Necesidades y consecuencias del cuidar en cuidadores primarios de enfermos con cáncer en fase terminal. Tesina no publicada, Universitat Autònoma de Barcelona, España, 2007
  44. Glasdam S, Bonde Jensen A, Lindegaard M, Rose C. Anxiety and depression in cancer patients spouses. *Psychooncology* 1996; 5: 23-9.
  45. Hudson PL, Hayman-White K, Aranda S, Kristjanson LJ. Predicting family caregiver psychosocial functioning in palliative care. *J Palliat Care* 2006; 22: 133-40.
  46. Badia X, Salamero M, Alonso, J. (2002). Medidas de bienestar psicológico y salud mental. In: Badia X, Salamero M, Alonso J, editors. *La medida de la salud. Guía de escalas de medición en español*. 3th ed. Barcelona: Edimac. p. 47-92.
  47. Quintana JM, Padierna A, Esteban C, Arostegui I, Bilbao A, Ruiz I. Evaluation of the psychometric characteristics of the Spanish version of the Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 2003; 107: 216-21.
  48. Nijboer C, Triemstra M, Tempelaar R, Sanderman R, Van den Bos GAM. Determinants of caregiving experiences and mental health of partners of cancer patients. *Cancer* 1999; 86: 577-88.
  49. Bakas T, Barr J, Croner D, Schmidt C, Harden K. Psychometric analysis of the Bakas Caregiving Outcomes Scale in the lung cancer population. Paper presentation. Midwest Nursing Research Society. 24<sup>th</sup> Annual Research Conference. March 31-April 3, 2000. Dearborn, Michigan.
  50. Bakas T, Farran CJ, Williams LS. Psychometric testing of the revised 15-item Bakas Caregiving Outcomes Scale. Poster Presentation. American Stroke Association Thirtieth International Stroke Conference, New Orleans, Louisiana. *Stroke* 2005; 36: 476.
  51. Jansma FFI, Schure LM, Meyboom de Jong B. Support requirements for caregivers of patients with palliative cancer. *Patient Educ Couns* 2005; 58: 182-6.
  52. Harding R, Higginson IJ, Leam C, Donaldson N, Pearce A, George R, et al. Evaluation of a short-term group intervention for informal carers of patients attending a home palliative care service. *J Pain Symptom Manage* 2004; 27: 396-408.
  53. Harding R, Higginson IJ. Working with ambivalence: informal caregivers of patients at the end of life. *Support Care Cancer* 2001; 9: 642-5.
  54. Grov EK, Dahl AA, Moum T, Fossa SD. Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Ann Oncol* 2005; 16: 1185-91.
  55. Kim Y, Schulz R, Carver CS. Benefit finding in the cancer caregiving experience. *Psychosom Med* 2007; 69: 283-91.
  56. Grov EK, Fossa SD, Tonnessen A, Dahl, AA. The caregiver reaction assessment: psychometrics, and temporal stability

- in primary caregivers of Norwegian cancer patients in late palliative phase. *Psychooncology* 2006; 15: 517-27.
57. López J, Crespo M. Intervenciones con cuidadores de familiares mayores dependientes: una revisión. *Psicothema* 2007; 19: 72-80.
58. Ministerio de Trabajo y Asuntos Sociales. Secretaría de Estado de Servicios Sociales, Familias y Discapacidad. Instituto de Mayores y Servicios Sociales (IMSERSO). Cuidados a las personas mayores en los hogares españoles. El entorno familiar. Madrid: Ministerio de Trabajo y Asuntos Sociales, 2005.

