

Psychosocial assessment of lung cancer patients and their caregivers

Cátia Andreia Clara* / Sara Otilia Marques Monteiro** / Ana Cláudia Pereira Bártolo**

* Universidade de Aveiro, Aveiro, Portugal; ** CINTESIS, Universidade de Aveiro, Aveiro, Portugal

Lung cancer (LC) is one of the most common types of cancer disease worldwide. Studies in the field show that the appearance of a pathology of this form causes changes not only in the patient's life, namely psychological problems, functional limitations and poorer health due to the clinical consequences of treatments, but also in their family, where caregivers often face the challenge of providing long-term daily care that induces a physical, psychosocial and financial burden (Borges et al., 2017; Hewitt et al., 2003; Tan et al., 2018). The main objective of the present study is to compare and relate the two groups (patients and caregivers) considering the quality of life (QoL) and symptoms of psychological distress (anxiety and depression). The total sample consisted of 30 patient/caregiver dyads. The instruments used were: Hospital Anxiety and Depression Scale; European Organization for Research and Treatment of Quality of Life Questionnaire (EORTC QLQ C-30) and its specific module for lung cancer (LC13); Caregiver Oncology Quality of Life Questionnaire (CarGOQoL) and Zarit Burden Interview Scale (ZBI). The results suggest the influence of depressive symptomatology on patients' QoL [$F(1)=6.390$; $p<0.05$] and depressive and anxious symptomatology and burden on caregivers' QoL [$F(3)=7.815$; $p<0.001$]. A positive association was found between depressive symptomatology of patients and caregivers ($r=0.458$; $p=0.011$) and differences in anxious symptomatology were also observed, with a higher result in the patient's group.

Key words: Lung cancer, Quality of life, Psychopathological symptomatology, Patients, Caregiver.

Introduction

Lung cancer is the leading cause of cancer related deaths, accounting annually for 27.4% (2.093.876) of new cancer cases and 23.1% (1.761.007) of the world's leading causes of death (IARC, 2018). In Portugal, according to the World Health Organization (WHO), lung cancer appears in fourth place of incidence, with an estimate of over 5.200 cases in 2018, with the highest mortality rate in males (Bray et al., 2018).

Compared to individuals without oncological disease, patients are more likely to have psychological problems, functional limitations and poorer health due to the clinical consequences of treatments (Hewitt et al., 2003). As the cancer patient goes through numerous changes in their life, considering the new reality, the same changes equally affect their family. In most cases, caregivers tend to become affected by social isolation, limiting their activities and daily routines in order to provide care (Borges et al., 2017). This scenario leads to feelings of exhaustion, emotional distress and even neglecting their own health needs (Moreira de Souza & Turrini, 2011).

This article was supported by National Funds through FCT – Fundação para a Ciência e a Tecnologia within CINTESIS, R&D Unit (reference UIDB/4255/2020).

Correspondence concerning this article should be addressed to: Cátia Andreia Clara, Universidade de Aveiro, Campus Universitário de Santiago, 3810-193 Aveiro, Portugal. E-mail: catia.clara@hotmail.com

LC is associated with higher symptom burden compared to other types of cancers. Studies in the field relate this burden to poorer QoL, significantly lower than the general population and this issue may be exacerbated by side effects of the treatments (Kim et al., 2016). Informal caregivers of LC patients are often confronted with the management of this symptomatology in care delivery. Using the CareGiver Oncology Quality of Life Questionnaire (CarCOQoL) tool, a study was carried out comparing 47 caregivers of cancer patients (glioma) with a sample of 188 normative caregivers of the population, which found that cancer caregivers generally have a poorer QoL. Patient quality of life depends largely on the well-being of caregivers, as without their assistance hospital care costs would be significantly higher and patient survival rates dramatically lower, so it is of utmost importance to pay attention to the feelings and symptoms manifested by both (Flores et al., 2014).

Distress (anxiety and depression) in QOL and the influence of burden

Distress is an experience that varies over a continuum of common normal feelings of vulnerability, sadness and fear to problems that can become disabling. Symptoms of anxiety and depression are the most common in patients with this type of pathology (Pandey et al., 2006). According to Ashbury et al. (1998), patients who do not have help treating distress-related symptoms use health facilities five times more, twice as much urgency service, and are more often prescribed with treatments of third and fourth line of chemotherapy.

Anxiety symptoms often overlap with the symptoms of the cancer disease itself. Studies in the field have found that individuals with LC experience the highest anxiety levels (43.4%) compared with individuals with other neoplasms. This symptomatology significantly increases during treatment and is associated with a decrease in QoL (Buchanan et al., 2010).

Regarding the relationship between anxiety and depression levels in the diade, studies in the area sustain that caregivers tend to have significantly higher results of this type of symptomatology compared to patients (Nipp et al., 2016). Caring for LC patients is a long journey and caregivers often face the challenge of providing long-term care, leading to physical, psychosocial and financial burden induced by daily patient care (Tan et al., 2018). The literature in the area suggests that there is a positive correlation between the diade with regard to the levels of distress experienced, as well as between the time of diagnosis and the levels of distress (Hodges et al., 2005). In the same line, a study carried out taking into account the psychosocial adjustment of the diade reveal that patients are more likely to report greater symptoms of psychological problems compared to their partner (Gilbar & Zusman, 2007).

As regard to burden, caregivers who have high levels of burden present higher levels of depression and have a lower QoL (Romito et al., 2013). Burden and distress levels reported by caregivers are a significant problem regarding the patient's psychosocial adjustment. Longitudinal studies show that when family caregivers are under high levels of distress, they have a negative effect on long-term patient adjustment, as over time a highly anxious caregiver may increase patient anxiety (Northouse et al., 2012).

Therefore, an appropriate adjustment to oncological disease depends on the emotional and cognitive responses given by the diade before the diagnosis and evolution of the disease (Gilbar & Zusman, 2007). Considering the previous literature, the main objectives of this study were to: (i) investigate the relationship between depressive and anxious symptoms and QoL in LC patients; (ii) explore the relationship between depressive, anxious and burden symptoms and QoL of caregivers; (iii) examine the relationship between the diade regarding depressive and anxious symptoms; (iv) analyse the role of caregiver burden in the patient's psychosocial adjustment; and (v) analyse and explore the influence of sociodemographic (e.g., gender), clinical/care (e.g., daily care hours) variables on depressive, anxious and QoL symptoms in both groups of patients and

caregivers. We expected that: (i) depressive and anxious symptoms negatively influence QoL; (ii) burden and depressive and anxious symptoms negatively influence the caregiver's QoL; (iii) caregivers have higher levels of depressive and anxious symptoms compared to patients; (iv) caregiver burden negatively influences the psychosocial adjustment of the patient; (v) females score significantly higher than males regarding depressive and anxious symptomatology in both groups; (vi) females are more likely to have worse overall QoL in both groups.

Method

Participants

The present cross-sectional study comprised a convenience sample of 30 patient/caregiver dyads made up of 34 (56.7%) female and 26 (43.3%) male subjects, aged 21 to 88 years ($M=60.8$). The patient group included 15 (50%) female and 15 (50%) male individuals with a mean age of 68.6 years. This group consisted mostly of individuals who never had smoking habits (60%), and the most common type of LC was adenocarcinoma (70%). Regarding treatment, the majority have and/or are undergoing chemotherapy (60%), with some individuals previously undergoing another type of therapy. The caregiver group consisted of 19 (63.3%) female and 11 (36.7%) male individuals with a mean age of 52.9 years. Care is mainly performed by the patient's husband/wife (46.7%), with help from another family member or in many cases outside help (60%). The time caregivers devote to care varies from less than 6 hours (46.7%) to 18-24 hours (33.3%) (Tables 1, 2 and 3).

Table 1

Sociodemographic characteristics

		Patient group $n=30$		Caregiver group $n=30$	
		<i>n</i>	%	<i>n</i>	%
Marital status	Single	8	26.7	10	33.3
	Married	17	56.7	18	60.0
	Divorced	2	6.7	2	6.7
	Widower	3	10.0	0	0

Note. n =sample size; %=percentage.

Table 2

Characteristics related to care provision

		Caregiver group $n=30$	
		<i>n</i>	%
Relationship to the patient	Husband/Wife	14	46.7
	Son/Daughter	9	30.0
	Son/Daughter in law	2	6.7
	Grand daughter/Grand son	1	3.3
	Niece/Nephew	3	10.0
	Brother/Sister	1	3.3
Help in care provision	Yes	18	60.0
	No	12	40.0
Duration of care	Less than 6 months	9	30.0
	6 months-1 year	5	16.7
	1-2 years	7	23.3
	More than 3 years	9	30.0
Daily hours dedicated to care	Less than 6 hours	14	46.7
	6-12 hours	2	6.7
	12-18 hours	4	13.3
	18-24 hours	10	33.3

Table 3

Clinical characteristics

		Patients group n=30	
		n	%
Current smoking habits	Yes	2	6.7
	No	28	93.3
Past smoking habits	Yes	12	40.0
	No	18	60.0
Abstinence time ^a	Less than 1 year	1	10.0
	Between 1 to 2 years	3	30.0
	Between 3 to 5 years	4	40.0
	More than 10 years	2	20.0
Histological type of disease	Adenocarcinoma	21	70.0
	Large cells carcinoma	1	3.3
	Squamous cancer cell	5	16.7
	Non-small cancer cells	3	10.0
Time since diagnostic	Less than 3 months	3	10.0
	3 – 6 months	8	26.7
	6 months – 1 year	5	16.7
	1 – 2 years	5	16.7
	2 – 3 years	3	10.0
	More than 3 years	6	20.0
Type of treatment	Chemotherapy	18	60.0
	Chemotherapy and Radiotherapy	3	10.0
	Chemotherapy and Surgery	6	20.0
	Chemotherapy, Radiotherapy and Surgery	2	6.7
	Surgery	1	3.3

Note. ^a=sample size (n=10).

Instruments

The instruments used to measure the studied variables are described below: Sociodemographic and Clinical Data/Care Provision Questionnaire developed for the present study and intended to obtain some sociodemographic, clinical and care-related characteristics of the caregivers.

HADS – Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983; Portuguese version of Pais-Ribeiro et al., 2007) for evaluation of anxiety and depression indices. This scale consists of 14 items (7 related to anxiety and 7 related to depression) of self-fulfilment and all refer to the emotional state of the person. It ranges from 0 to 21 points, where values from 0-7 are considered normal, between 8-10 mild, between 11-14 moderate and between 15-21 severe for any of the dimensions evaluated. In order to assess the internal consistency of the scale, in the study sample, Cronbach's alpha was calculated and values of .80 were obtained for the anxiety subscale and .76 for the depression subscale.

QLQ-C30 – The European Organization for Research and Treatment of Quality of Life Questionnaire (Aarason et al., 1993; Portuguese version of Pais-Ribeiro et al., 2008) composed of multiple item scales and individual items that reflect the multidimensionality of the QoL construct. Its 30 items incorporate five functional scales (physical, functional, cognitive, emotional and social), three symptom scales (fatigue, pain and nausea/vomiting), and a global health and QoL scale. Individual items in turn assess additional symptoms commonly reported by cancer patients (dyspnea, loss of appetite, etc.), as well as the perceived financial impact of the disease and treatment. All scales are scored on 4-point Likert scales except the two items of the global health and QoL subscale that use a version of a modified 7-point linear analogue scale (Aarason et al., 1993). The total rating of the scales and individual items vary on a score from 0 to 100, with a higher result on the functional scales reflecting better QoL and on the symptom/individual item scales representing a greater presence of the symptomatology. In the present study,

Cronbach's alpha values between .45 and .89 were obtained for the 9 scales. The nausea/vomiting symptom scale was eliminated because it had a Cronbach's alpha value (.45) below the minimum acceptable reliability value (.60) (Freitas & Rodrigues, 2005). In turn, the LC13 module (Lung Cancer specific module), as the name suggests, covers 13 typical symptoms of lung cancer patients such as cough, pain and dyspnea. Their score is based on the principle applied to the QLQ-C30 symptom subscales and individual symptom items (Koller et al., 2015).

CarGOQoL – The CareGiver Quality of Life Questionnaire (Minaya et al., 2012; Portuguese version of Pereira & Ferreira, 2016) consists of 29 items based on the caregivers' unique viewpoint and assesses the impact of cancer and its treatment on QoL (Flores et al., 2014). It covers 10 dimensions: psychological well-being (1-4); burden (5-8); relationship with health care (9-11); administration and finance (12-14); coping (15-17); physical well-being (18-21); self-esteem (22 and 23); leisure time (24 and 25); social support (26 and 27), private life (28 and 29) and a total result. The score for each dimension is calculated by averaging each of its containing elements and the total instrument score is arrived at by averaging the dimension results. The scores for all the domains and the CarGOQoL index range from 0 to 100 where the higher the score the better the QoL. To calculate the total result, the following items should be inverted: 1,2,3,4,5,6,7,8,12,13,14,15,16,17,18,19,20,21 and 28. Cronbach's alpha values between .52 and .90 for the respective dimensions and .88 for the global scale were obtained in the present study. The coping dimension was eliminated because it did not present an acceptable Cronbach's alpha value (.52).

ZBI – Zarit Burden Interview Scale (Zarit et al., 1980; Portuguese version of Sequeira, 2007) has 22 items and each is scored using a Likert scale from 0 to 4 points. In this version an overall result ranging from 0 to 88 points is obtained, and according to the cut-off points a score below 21 indicates no burden; between 21 to 40 slight burden; between 41 and 60 moderate burden and above 61 severe burden (Ferreira et al., 2010). Considering the predefined objectives for the current study and most of the research consulted, we resorted only to the global scale, obtaining a Cronbach's alpha value of .81.

To the patients, it was applied protocol consisting on the following instruments: Sociodemographic Questionnaire, HADS and QLC-C30. On the other hand, to the caregivers it was applied the following: Sociodemographic Questionnaire, HADS, CarGOQoL and ZBI. Participants were informed of the possibility to withdraw at any time and to clarify any doubts that might arise during the collection.

Procedures

The present study was carried out at Coimbra Hospital and University Centre (CHUC), namely at the Oncology Day Hospital (São Jerónimo Building). Ethical approval was obtained from the hospitals' Ethics Committee (Appendix 1). The general inclusion criterion was the dyad (patient/caregiver) attendance at the oncological pneumology appointment and criteria were subsequently established which varied according to each group. Thus, for the group of patients, the following inclusion criteria were established: (i) history of LC and (ii) no cancer recurrence. The family caregivers should have no personal cancer history. Additionally, all participants should (i) be Portuguese-speaking and; (ii) having no current diagnosis of psychiatry disorders. Informed consent was obtained from all participants Data collection had an average duration of 15 minutes per participant and was performed during October 2018. In some cases, the questionnaires were administered in the form of an interview, since the participants had visual or writing difficulties, having been carried out in person in an office from the hospital; the protocol was applied by the

head researcher simultaneously to the diade, with the individuals being in different desks during these procedures.

Statistical procedures

The statistical analyses required for data processing were performed using IBM SPSS Statistics version 25.0. Data was subjected to descriptive and inferential analyses. The Kolmogorov-Smirnov test was used to verify the distribution of the sample. Correlational analyses in both groups were carried out using Pearson's correlation coefficient considering that for values greater than .10, .30, .50, the effect size is small, medium and large, respectively. Simple linear regression analyses were performed based on the significant correlational results obtained with the assumption that depressive or anxious symptomatology explains the variance in the quality of life of both patient and caregiver. Student's *t*-test were used to compare both groups with regard to depressive/anxiety symptoms assessed using the same instrument. Mann-Whitney test for independent samples were used to compare variables analysed using different instruments in each of the groups due to normality of data distribution. The level of statistical significance was set at $p < .05$ (Field, 2009).

Results

Relationship between patients' depressive and anxiety symptoms and QoL

Regarding anxious symptomatology, no significant correlations were found with patients' QoL. However, depressive symptomatology showed a significant negative correlation of large effect with the emotional scale and of medium effect with the overall health and QoL scale. A significant positive correlation of large effect was also found with sleep disorders, namely insomnia symptoms (Table 4).

Table 4

Relationship between patient depressive symptomatology and QoL

	Patient QoL					
	Emotional scale		Overall health and QoL scale		Sleeping disorders	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Depressive symptomatology	-.544**	.002	-.431*	.017	.600**	.000

Note. *r*=Pearson correlation coefficient; *p*=probability; * $p < .05$; ** $p < .01$.

Predictive effect of depressive symptoms on patients' QoL. In order to analyse the existing effect of depressive symptomatology on patients' health and overall QoL, it was found that depressive symptomatology ($B = -1.741$, $p = .017$) acts as a predictor of QoL in the tested model and explains 16% of the existing variance (Table 5).

Table 5

Linear regression of depressive symptomatology as predictor of patient QoL

	R^2	R^2 adjusted	<i>B</i>	<i>t</i>	<i>p</i>	<i>F</i>
Depressive symptomatology	.186	.157	-1.741	-2.528	.017*	6.390*

Note. R^2 =determination coefficient; *B*=regression coefficient; *t*=student *t*-test; * $p < .05$; *F*=*F*-statistic.

Relationship between caregivers' depressive, anxiety and burden symptoms and QoL

Through the results analysis it was possible to verify that both anxious and depressive symptomatology have a significant negative correlation of large effect with the overall QoL scale and some of the respective dimensions (e.g., psychological and physical well-being). With regards to caregiving burden, it was possible to analyse a significant negative correlation of large effect with the overall QoL scale and subsequently with scale dimensions (e.g., burden and privacy). The relationships obtained for the global scale are explicit in Table 6 and the results obtained in the respective dimensions can be consulted in Table 7. It is also emphasized that the depressive symptomatology scale showed a significant positive correlation of large effect with anxiety scale $r=.590, p<.01$ and of medium effect with the care burden scale $r=.449, p<.05$.

Table 6

Relationship between caregiver anxious, depressive symptomatology and burden and QoL

	Overall QoL	
	<i>r</i>	<i>p</i>
Anxious symptomatology	-.593**	.001
Depressive symptomatology	-.526**	.003
Burden	-.519**	.003

Note. *r*=Pearson correlation coefficient; *p*=probability; ***p*<.01.

Table 7

Relationship between caregiver anxious, depressive symptomatology and burden and QoL dimension scales

QoL Dimensions		Anxious symptomatology		Depressive symptomatology		Burden of care	
		<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
		Physical well-being	-.634**	.000	-.643**	.000	-.692**
	Psychological well-being	-.655**	.000	-.835**	.000	-.568**	.001
	Leisure time	-.645**	.000	-.270	.149	-.206	.274
	Private life	-.480**	.007	-.440*	.015	-.500*	.010
	Burden	-.296	.112	-.446*	.014	-.638**	.000

Note. *r*=Pearson correlation coefficient; *p*=probability; **p*<.05; ***p*<.01.

Predictive effect of caregiver depressive, anxious symptomatology and burden on QoL. By analysing the predictive effect of depressive, anxious symptomatology and burden on caregiver's QoL, the results show that only anxious symptomatology ($B=-1.408, p=.037$) was shown to be a significant predictor of caregivers' QoL in the tested regression model ($F=7.815, p=.001$) which explains 41% of the variance (Table 8).

Table 8

Linear regression of caregiver anxious, depressive symptomatology and burden as predictors of QoL

	<i>R</i> ²	<i>R</i> ² adjusted	<i>B</i>	<i>t</i>	<i>p</i>	<i>F</i>
Anxious symptomatology			-1.408	-2.193	.037*	
Depressive symptomatology	.474	.413	-.531	-.851	.403	7.815**
Burden of care			-.399	-1.923	.065	

Note. *R*²=determination coefficient; *B*=regression coefficient; *t*=students *t*-test; **p*<.05; *F*=*F*-statistic; ***p*<.01.

Relationship between groups regarding depressive and anxious symptomatology

It was possible to infer with respect to depressive and anxious symptomatology a significant positive correlation of medium effect between caregiver and patient depression levels, with no other significant relationships between groups ($r=.458, p=.011$) (Table 9).

Table 9

Relation between groups regarding anxious and depressive symptomatology

		Patients group			
		Anxious symptomatology		Depressive symptomatology	
		<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Caregiver group	Anxious symptomatology	.264	.158	.312	.093
	Depressive symptomatology	-.001	.997	.458*	.011

Note. *r*=Pearson correlation coefficient; *p*=probability; * $p<.05$.

Differences between groups regarding depressive and anxious symptomatology. Statistically significant differences were found regarding anxious symptomatology between groups, with a higher result in the patients' group ($t=2.922, p=.005$) (Table 10).

Table 10

Differences between groups regarding anxious and depressive symptomatology

	Patients group		Caregivers group		<i>t</i>	<i>p</i>
	<i>M</i>	<i>DP</i>	<i>M</i>	<i>DP</i>		
Anxious symptomatology	7.23	3.29	4.60	3.68	2.922	.005**
Depressive symptomatology	6.43	4.12	8.03	3.96	-1.534	.130

Note. *M*=average; *DP*=standard deviation; *t*=students *t*-test; *p*=probability; ** $p<.01$.

Role of caregiver burden in patient psychosocial adjustment

No significant data suggestive of the influence of caregiver burden on either patient's depressive ($U=101.500, p=.705$) and anxious symptomatology ($U=107.000, p=.883$) or overall QoL ($U=110.000, p=.983$) and respective scales were found. The results obtained for depressive, anxious symptomatology and overall QoL are described in Table 11, and the results of QoL dimensions can be found on Table 12.

Table 11

Influence of caregiver burden on patient psychosocial adjustment

Patients group	Caregivers group	<i>M</i>	<i>Mdn</i>	<i>DP</i>	<i>U</i>	<i>p</i>
Depressive symptomatology	High	6.18	5.00	3.81	101.500	.705
	Low	6.77	6.00	4.62		
Anxious symptomatology	High	7.47	7.00	3.11	107.000	.883
	Low	6.92	7.00	3.62		
Overall QoL	High	45.10	41.67	16.153	110.000	.983
	Low	45.51	41.67	17.88		

Note. *M*=average; *Mdn*=median; *DP*=standard deviation; *U*=Mann-Whitney test; *p*=probability.

Table 12

Influence of caregiver burden on patient's psychosocial adjustment (QoL dimensions)

Patients group	Caregiver burden	<i>M</i>	<i>Mdn</i>	<i>DP</i>	<i>U</i>	<i>p</i>
Physical scale	High	41.18	33.33	22.64	97.500	.584
	Low	49.23	46.67	27.56		
Functional scale	High	40.20	33.33	30.65	99.500	.641
	Low	46.15	50.00	35.46		
Emotional scale	High	70.10	66.67	15.88	98.500	.611
	Low	71.79	75.00	22.19		
Cognitive scale	High	74.51	83.33	25.76	107.500	.897
	Low	75.64	83.33	25.11		
Social scale	High	64.71	66.67	33.27	109.000	.949
	Low	64.10	83.33	36.54		

Note. *M*=average; *Mdn*=median; *DP*=standard deviation; *U*=Mann-Whitney test.

Influence of sociodemographic, clinical/care delivery variables

No significant statistical differences were found regarding gender in either the patient group or the caregiver group for depressive and anxious symptomatology. In the same line, the observed data also do not suggest differences in the overall QoL level for both groups ($U=88.500, p=.321$). Finally, no data suggesting the influence of daily care hours on the patient's overall QoL and respective scales were found (Table 13).

Table 13

Influence of daily hours dedicated to care provision on patient QoL

Patient group	Hours dedicated to care	<i>M</i>	<i>Mdn</i>	<i>DP</i>	<i>U</i>	<i>p</i>
Overall QoL	Less than 12h	42.71	41.67	15.18	88.500	.321
	More than 12h	48.21	50.00	18.25		
Physical scale	Less than 12h	41.67	36.67	23.15	96.000	.504
	More than 12h	48.10	46.67	26.95		
Functional scale	Less than 12h	42.71	41.67	28.53	108.000	.866
	More than 12h	42.86	33.33	37.90		
Emotional scale	Less than 12h	67.71	66.67	20.83	93.500	.435
	More than 12h	74.40	75.00	15.49		
Cognitive scale	Less than 12h	67.71	66.67	27.53	72.000	.086
	More than 12h	83.33	83.33	19.61		
Social scale	Less than 12h	67.71	75.00	29.48	106.500	.815
	More than 12h	60.71	58.33	39.55		

Note. *M*=average; *Mdn*=median; *DP*=standard deviation; *U*=Mann-Whitney test; *p*=probability.

Discussion

The present study has intended to add a contribution to the field by analysing the effect of depressive and anxious symptomatology on QoL in the groups, by studying the role of caregiver burden in patients' psychosocial adjustment as well as exploring the influence of sociodemographic variables. The results show the effect of patient's depressive symptomatology on QoL and its

predictive capacity, such that the higher the levels of depressive symptomatology experienced, the worse their overall QoL. We would expect to find results that support the influence of anxiety on QoL as reported in the literature, however in the present study this influence was not verified, contradicting the hypothesis that patient's anxious symptomatology plays a predictive role in QoL. The existence of a relationship between depressive symptomatology and sleep disorders (insomnia), supported by the literature in the area and shown in the present study may still have played an essential role for this symptomatology to have a significant influence on QoL rather than anxious symptomatology. The long-term effects of sleep deprivation affect the physical and mental health of individuals, leading to poor health and weakened immune system that contribute to lower QoL (Weatherspoon, 2017). In the group of caregivers, the results show the presence of the effect of depressive and anxious symptomatology and burden on the overall QoL, and the anxious symptomatology acts as a significant predictor according to the tested model.

The data obtained supports the results reported in the study by Tan et al. (2018) corroborating the hypothesis that depressive, anxious and burden symptoms negatively influence caregiver QoL. The revelation that only anxious symptomatology acts as a significant predictor of QoL may be related to the fact that caregivers who experienced anxious symptomatology had simultaneously depressive symptoms and there was a significant correlation of large effect between them, which may have caused an exacerbation of the anxiety symptoms, as well as the fact that the caregivers included in the study have mostly mild burden levels, thus not evidencing the burden of care as a good predictor of overall QoL (Croft, 2016).

Regarding the relationship between anxiety and depression levels in patients and caregivers, the data suggest a significant positive relationship between the depressive symptomatology of the groups. On the other hand, regarding differences between groups, the only significant result found was related to anxious symptomatology with a higher result in the patient group. This result differs from the data found in the literature, thus contradicting the expected hypothesis that caregivers show higher levels of depressive and anxious symptomatology compared to patients. Most of the caregivers included in the study had help with caregiving activities and the number of hours dedicated to these tasks was less than six hours per day. Social support plays a particularly important role on individuals in stressful situations, as is the case of care provision, acting as a protective factor in the health and QoL of caregivers (Nijboer et al., 2001) which may justify the lower levels of symptoms reported. Regarding the relationship between caregiver burden and patient's psychosocial adjustment, no data was found to support the negative influence of burden on both QoL and depressive and anxious symptomatology reported by the patient.

Social support in this context plays an important role in the way care burden is perceived, and the lower the support, the higher the burden levels experienced by caregivers (Nijboer et al., 2001). In the present study, caregivers generally reported slight results of burden and good social support. Given that patient and caregiver influence each other in the fight against cancer disease, the fact that high burden levels were not obtained in most caregivers may have conditioned the evidence of significant results in the patient's psychosocial adjustment.

Regarding sociodemographic, clinical and care provision variables, no significant gender differences were found in depressive/anxious symptoms and QoL in either group. Although studies in the area have shown a higher prevalence of depressive and anxious symptomatology in females (Gater et al., 1998), and consequently a decrease in self-perception of QoL (Michelson et al., 2000), other factors must be considered, such as educational level and socioeconomic status, in order to further understand how these elements can act as protective factors in the relationship between this type of symptoms and QoL (Oliveira, 2011). Considering the influence of daily hours devoted to care on patient QoL, although it is possible to verify through the data a slightly higher QoL level when the duration of care exceeds twelve hours, this difference was not significant. No studies have yet been found in the field that showed an association between these dimensions.

However, the literature review reveals a negative influence of the hours devoted to care on the burden experienced, being that the higher the workload, the higher the burden levels reported by individuals (Bevans & Sternberg, 2012).

The results presented in this paper should also consider its limitations. The homogeneity of the sample does not allow the generalization of the results for the population with oncological disease, as well as its size, since a larger sample could show other significant relationships or differences. Although patient/caregiver dyads were selected, the protocols applied differed in some of the instruments since appropriate questionnaires were chosen taking into account the specificities of the groups.

Another aspect to be considered is the length of the protocols applied, allowing participants' tiredness or demotivation to influence the results. The cross-sectional nature of the study should also be emphasized, and it is not possible to establish a temporal relationship between certain variables (e.g., time since diagnosis of cancer disease and depressive/anxious symptomatology). Finally, since the sample was restricted to CHUC, caution is due when extrapolating it as a generalization of the hospital population in the national context.

Despite these limitations, the present study represents an important evolution with regard to the current state of the art. When studying depressive and anxious symptomatology, the importance of recognizing distress by health professionals as a key indicator of health and QoL of this population is highlighted (Bultz & Carlson, 2005). Nowadays, and even more often, caregivers assume an important role in the care of cancer patients and for this reason the present study intends to highlight the importance of developing multidisciplinary programmes that include not only patients but also caregivers, considering their needs, with the goal of minimizing the risk of burnout. As suggestions for future investigations, it is considered an advantage to explore and compare the dyad (patient and caregiver) using the same tool in relation to QoL and to conduct the present study in a longitudinal emphasis, accompanying patients and caregivers from the moment of diagnosis, in order to map QoL, overload and depressive and anxious symptomatology along the disease trajectory and the way patients and caregivers influence each other.

References

- Aarason, N., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., Filiberti, A., Flechtner, H., Fleishman, S. B., de Haes, J. C. J. M., Kaasa, S., Klee, M., Osoba, D., Razavi, D., Rofe, P. B., Schraub, S., Sneeuw, K., Sullivan, M., & Takeda, F. (1993). The European organization for research and treatment of cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute*, *85*(5), 365-375. <https://doi.org/10.1093/jnci/85.5.365>
- Ashbury, F. D., Findlay, H., Reynolds, B., & McKerracher, K. (1998). A Canadian survey of cancer patients' experiences: Are their needs being met?. *Journal of Pain and Symptom Management*, *16*(5), 298-306. [https://doi.org/10.1016/S0885-3924\(98\)00102-X](https://doi.org/10.1016/S0885-3924(98)00102-X)
- Bevans, M., & Sternberg, E. M. (2012). Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *Jama*, *307*(4), 398-403. <https://doi.org/10.1001/jama.2012.29>
- Borges, E. L., Franceschini, J., Costa, L. H. D., Fernandes, A. L. G., Jamnik, S., & Santoro, I. L. (2017). Family caregiver burden: The burden of caring for lung cancer patients according to cancer stage and patient quality of life. *Brazilian Journal of Pulmonology*, *43*(1), 18-23. <https://doi.org/10.1590/s1806-37562016000000177>
- Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R. L., Torre, L. A., & Jemal, A. (2018). Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *A Cancer Journal for Clinicians*, *68*, 394-424. <https://doi.org/10.3322/caac.21492>

- Buchanan, D., Milroy, R., Baker, L., Thompson, A. M., & Levack, P. A. (2010). Perceptions of anxiety in lung cancer patients and their support network. *Supportive Care in Cancer*, *18*(1), 29-36. <https://doi.org/10.1007/s00520-009-0626-2>
- Bultz, B. D., & Carlson, L. E. (2005). Emotional distress: The sixth vital sign in cancer care. *Journal of Clinical Oncology*, *23*(26), 6440-6441. <https://doi.org/10.1200/JCO.2005.02.3259>
- Croft, H. (2016). *Relationship between depression and anxiety*. <https://www.healthyplace.com/depression/anxiety-and-depression/relationship-between-depression-and-anxiety>
- Ferreira, F., Pinto, A., Laranjeira, A., Pinto, A. C., Lopes, A., Viana, A., Rosa, B., Esteves, C., Pereira, I., Nunes, I., Miranda, J., Fernandes, P., Miguel, S., Leal, V., & Fonseca, C. (2010). Validação da escala de Zarit: Sobrecarga do cuidador em cuidados paliativos domiciliários para população portuguesa. *Cadernos de Saúde*, *3*(2), 13-19.
- Field, A. (2009). *Discovering statistics using SPSS* (3rd ed.). SAGE Publications Ltd.
- Flores, P., Berbis, J., Chinot, O., & Auquier, P. (2014). Assessing the quality of life among caregivers of patients with gliomas. *Neuro-Oncology Practice*, *1*(4), 191-197. <https://doi.org/10.1093/nop/npu027>
- Freitas, A. L. P., & Rodrigues, S. G. (2005, Novembro 7-9). *A avaliação da confiabilidade de questionários: Uma análise utilizando o coeficiente alfa de Chrobach* [Paper presentation]. XII SIMPEP – Bauru, São Paulo, Brasil.
- Gater, R., Tansella, M., Korten, A., Tiemens, B. G., Mavreas, V. G., & Olatawura, M. O. (1998). Sex differences in the prevalence and detection of depressive and anxiety disorders in general health care settings: Report from the World Health Organization Collaborative Study on Psychological Problems in General Health Care. *Archives of General Psychiatry*, *55*(5), 405-413. <https://doi.org/10.1001/archpsyc.55.5.405>
- Gilbar, O., & Zusman, A. (2007). The correlation between coping strategies, doctor-patient/spouse relationships and psychological distress among women cancer patients and their spouses. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *16*(11), 1010-1018. <https://doi.org/10.1002/pon.1168>
- Hewitt, M., Rowland, J. H., & Yancik, R. (2003). Cancer survivors in the United States: Age, health, and disability. *The Journals of Gerontology, Biological Sciences & Medical Sciences*, *58*(1), 82-91. <https://doi.org/10.1093/gerona/58.1.M82>
- Hodges, L. J., Humphris, G. M., & Macfarlane, G. (2005). A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Social Science & Medicine*, *60*(1), 1-12. <https://doi.org/10.1016/j.socscimed.2004.04.018>
- IARC. (2018). *Cancer today*. International Agency for Research on Cancer. <https://gco.iarc.fr/today/home>
- Kim, J. Y., Sun, V., Raz, D. J., Williams, A. C., Fujinami, R., Reckamp, K., Koczywas, M., Cristea, M., Hurria, A., & Ferrell, B. (2016). The impact of lung cancer surgery on quality of life trajectories inpatients and family caregivers. *Lung Cancer*, *101*, 35-39. <https://doi.org/10.1016/j.lungcan.2016.08.011>
- Koller, M., Warncke, S., Hiermstad, M., Arraras, J., Pompili, C., Harle, A., Johnson, C. D., Chie, W.-C., Schulz, C., Zeman, F., van Meerbeeck, J. P., Kuliš, D., & Bottomley, A. (2015). Use of the lung cancer-specific Quality of Life Questionnaire EORTC QLQ-LC13 in clinical trials: A systematic review of the literature 20 years after its development. *Cancer*, *121*(24), 4300-4323. <https://doi.org/10.1002/cncr.29682>
- Michelson, H., Bolund, C., Nilsson, B., & Brandberg, Y. (2000). Health-related quality of life measured by the EORTC QLQ-C30: Reference values from a large sample of the Swedish population. *Acta Oncologica*, *39*(4), 477-484. <https://doi.org/10.1080/028418600750013384>
- Minaya, P., Baumstarck, K., Berbis, J., Goncalves, A., Barlesi, F., Michel, G., Salas, S., Chinot, O., Grob, J.-J., Seitz, J. F., Bladou, F., Clement, A., Mancini, J., Simeoni, M.-C., & Auquier, P. (2012). The CareGiver Oncology Quality of Life questionnaire (CarGOQoL): Development and validation of an instrument to

- measure the quality of life of the caregivers of patients with cancer. *European Journal of Cancer*, 48, 904-911. <https://doi.org/10.1016/j.ejca.2011.09.010>
- Moreira de Souza, R., & Turrini, R. N. T. (2011). Paciente oncológico terminal: Sobrecarga del cuidador. *Enfermería Global*, 10(22). http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S1695-61412011000200013&lng=es&tlng=es
- Nijboer, C., Tempelaar, R., Triemstra, M., Van den Bos, G. A., & Sanderman, R. (2001). The role of social and psychologic resources in caregiving of cancer patients. *Cancer*, 91(5), 1029-1039. [https://doi.org/10.1002/1097-0142\(20010301\)91:5<1029::AID-CNCR1094>3.0.CO;2-1](https://doi.org/10.1002/1097-0142(20010301)91:5<1029::AID-CNCR1094>3.0.CO;2-1)
- Nipp, R. D., El-Jawahri, A., Fishbein, J. N., Gallagher, E. R., Stagl, J. M., Park, E. R., Jackson, V. A., Pirl, W. F., Greer, J. A., & Temel, J. S. (2016). Factors associated with depression and anxiety symptoms in family caregivers of patients with incurable cancer. *Annals of Oncology*, 27(8), 1607-1612. <https://doi.org/10.1093/annonc/mdw205>
- Northouse, L. L., Katapodi, M. C., Schafenacker, A. M., & Weiss, D. (2012). The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Seminars in Oncology Nursing*, 28(4), 236-245. <https://doi.org/10.1016/j.soncn.2012.09.006>
- Oliveira, M. R. M. (2011). *Depressão e o Género: Semelhanças e diferenças* [Dissertação de mestrado, Faculdade de Medicina da Universidade do Porto]. Repositório Aberto da Universidade do Porto. <http://hdl.handle.net/10216/53580>
- Pais-Ribeiro, J., Pinto, C., & Santos, C. (2008). Validation study of the Portuguese version of the QLC-C30-V3. *Psicologia, Saúde & Doenças*, 9(1), 89-102. <https://www.redalyc.org/pdf/362/36290108.pdf>
- Pais-Ribeiro, J., Silva, I., Ferreira, T., Martins, A., Meneses, R., & Baltar, M. (2007). Validation study of a Portuguese version of the Hospital Anxiety and Depression Scale. *Psychology, Health & Medicine*, 12(2), 225-237. <https://doi.org/10.1080/13548500500524088>
- Pandey, M., Sarita, G. P., Devi, N., Thomas, B. C., Hussain, B. M., & Krishnan, R. (2006). Distress, anxiety, and depression in cancer patients undergoing chemotherapy. *World Journal of Surgical Oncology*, 4. <https://doi.org/10.1186/1477-7819-4-68>
- Romito, F., Goldzweig, G., Cormio, C., Hagedoorn, M., & Andersen, B. L. (2013). Informal caregiving for cancer patients. *Cancer*, 119(11), 2160-2169. <https://doi.org/10.1002/cncr.28057>
- Sequeira, C. (2007). *Cuidar de idosos dependentes*. Quarteto Editora.
- Tan, J. Y., Molassiotis, A., Lloyd-Williams, M., & Yorke, J. (2018). Burden, emotional distress and quality of life among informal caregivers of lung cancer patients: An exploratory study. *European Journal of Cancer Care*, 27(1). <https://doi.org/10.1111/ecc.12691>
- Weatherspoon, D. (2017). *The effects of sleep deprivation on your body*. <https://www.healthline.com/health/sleep-deprivation/effects-on-body#1>
- Zarit, S. H., Reever, K. E., & Back-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, 20, 649-655. <https://doi.org/10.1093/geront/20.6.649>
- Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67(6), 361-370. <https://doi.org/10.1111/j.1600-0447.1983.tb09716>

Appendix 1

Research project authorization by the CHUC Health Ethics Committee



Comissão de Ética para a Saúde

Visto/ A.U.D.
para difusão

Dr. Francisco Parente
Diretor Clínico
C.H.U.C. - E.P.E.

Exmo. Senhor
Dr. Francisco Parente
Digmº Diretor Clínico do CHUC

SUA REFERÊNCIA	SUA COMUNICAÇÃO DE	NOSSA REFERÊNCIA	DATA
		N.º 0210/CES	11-09-2018
Proc. N.º CHUC-039-18			

ASSUNTO: Estudo Observacional "Avaliação do Ajustamento Psicossocial em Pacientes com Cancro do Pulmão e seus Cuidadores." - Cátia Andreia dos Reis Clara, aluna da Universidade de Aveiro e estagiária na Unidade de Psicologia Clínica do CHUC (estudo a ser realizado no Serviço de Oncologia Médica do CHUC). (Entrada do processo na CES a 03.04.2018)

Cumprre informar Vossa Ex.ª que a Comissão de Ética para a Saúde do Centro Hospitalar e Universitário de Coimbra, reunida em 07 de Setembro de 2018, com a presença da maioria dos seus membros, após análise do projeto mencionado em epígrafe e ouvido o relator, emitiu parecer favorável à sua realização. Parecer aprovado por unanimidade

Mais se informa que a CES do CHUC deve ser semestralmente actualizada em relação ao desenvolvimento dos estudos favoravelmente analisados e informada da data da conclusão dos mesmos, que deverá ser acompanhada de relatório final.

A COMISSÃO DE ÉTICA PARA A SAÚDE
DO CHUC, E.P.E.

Prof. Doutor José Joaquim Sousa Barros
Presidente da CES do CHUC

LP/CES

A CES do CHUC: Prof. Doutor José Joaquim Sousa Barros; Prof.ª Doutora Maria Fátima Pinto Saraiva Martins; Dr. Mário Rui Almeida Branco; Enf.ª Adélia Tinoco Mendes; Prof. Doutor Carlos Alberto Fontes Ribeiro; Dr. José António Felo; Dr. José Alves Giló Gonçalves; Enf.ª Fernando Mateus; Dr. José António Pinheiro; Dra. Cláudia Santos; Dr. Paulo Figueiredo.

Avaliação do ajustamento psicossocial em pacientes com cancro do pulmão e seus cuidadores

O cancro do pulmão é uma das especificidades de doença oncológica mais frequente em todo o Mundo. Estudos na área oncológica evidenciam que o aparecimento de uma patologia deste foro acarreta alterações não só na vida do paciente, designadamente problemas psicológicos, limitações funcionais e uma saúde mais empobrecida devido às consequências clínicas dos tratamentos, como também na sua família, onde os cuidadores frequentemente enfrentam o desafio de fornecer cuidados diários a longo prazo que neles induzem sobrecarga física, psicossocial e financeira (Borges et al., 2017; Hewitt et al., 2003; Tan et al., 2018). O presente estudo tem assim como principal objetivo comparar e relacionar os dois grupos (pacientes e cuidadores) tendo em conta a qualidade de vida (QV) e sintomas de distress psicológico (ansiedade e depressão). A amostra foi constituída no total por 30 pares de paciente/cuidador. Os instrumentos utilizados foram: Escala de Ansiedade e Depressão Hospitalar; European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30) e o seu módulo específico para o cancro do pulmão (LC13); Questionário de Qualidade de Vida de Cuidadores de Doentes Oncológicos e Escala de Sobrecarga do Cuidador. Os resultados sugerem a influência da sintomatologia depressiva na QV dos pacientes [$F(1)=6.390$; $p<0.05$] e da sintomatologia depressiva, ansiosa e sobrecarga na QV dos cuidadores [$F(3)=7,815$; $p<0.001$]. Foi ainda evidenciada uma associação positiva entre a sintomatologia depressiva dos pacientes e cuidadores ($r=0.458$; $p=0.011$) e diferenças ao nível da sintomatologia ansiosa, com um com um resultado mais elevado no grupo dos pacientes.

Palavras-chave: Cancro do pulmão, Qualidade de vida, Sintomatologia psicopatológica, Pacientes, Cuidadores.

Submitted: 09/05/2020

Accepted: 11/11/2020

