

# Burden, depression and fatigue in caregivers of lung transplantation candidates

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## ABSTRACT

**Objective:** A great deal of social support is often provided by the caregiver of the patient. The purpose of this study is to evaluate the burden, fatigue and depression of the primary caregiver of patients with pulmonary transplantation candidates.

**Patients and Method:** The primary caregivers of patients who were admitted to our hospital's pulmonary transplant outpatient clinic with end-stage pulmonary disease and no definite contraindications for transplantation, were included in the study. Zarit Burden Scale, Beck Depression Inventory and Short-Form (SF)-36 – Vitality questionnaires were applied to participants.

**Results:** Thirty-nine patients and their caregivers were evaluated. Caregivers experienced low levels of depression. Mean score for Beck Depression Inventory was  $12.7 \pm 10.1$ . Caregivers generally experienced medium levels of burden. Mean score for Zarit Burden Scale was  $26.9 \pm 14.2$ . Majority of caregivers experienced clinically significant fatigue. Mean score for SF-36 – Vitality was  $61 \pm 16.7$ . Zarit Burden Scale scores and Beck Depression Inventory scores showed a statistically significant positive correlation ( $r:0.962$   $p<0.01$ ).

**Conclusion:** Increased burden of caregivers of lung transplant candidates was associated with depression and fatigue. The presence of depressive symptoms is noteworthy even in the mild to moderate levels of burden. Supporting caregivers, has a great importance in terms of patient care and quality.

**Keywords:** Lung transplantation, Caregivers, Burden, Depression, Fatigue

## 1. INTRODUCTION

Lung transplantation has emerged as a remedy for some of the end-stage pulmonary diseases in the world over the last 25 years. Although, progress was slow for 15 years following first transplantation in 1968, the number of procedures and centers implementing lung transplantation since the beginning of the '80s has increased rapidly [1-3]. According to the International Society for Heart and Lung Transplantation (ISHLT) data, between 1993 and 2000, the number of annual pulmonary transplants worldwide reached 2000, and in 2012 more than 3,700 pulmonary transplants were performed [4].

To become a candidate for lung transplantation, in addition to medical parameters it is necessary that there is a full family support and the psychosocial state is stable [5]. When patients with transplantation necessity are assessed, it is known that the vast majority are in need of physical support during daily activities and administration of treatments. After transplantation, especially in the early period, caregiver support

may often be required during complications and intense routine follow-up [5].

In the follow-up of chronic patients, the caregiver concept is defined as the primary person undertaking the care of the patient [6]. Studies have shown that the stress, burnout and fatigue of the caregiver directly affect both the physical and mental state of the patient requiring care [7, 8].

There are very few studies on caregiver burden, fatigue, burnout, and depression in pre-transplant caregivers of lung transplant candidates, as well as studies on the burden and depression of caregivers for some chronic advanced organ failure and terminal diseases.

The aim of this study is to evaluate the care burden, fatigue, burnout syndrome and depression of the primary caregiver in cases with pulmonary transplant candidates.

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## 2. PATIENTS and METHODS

### Participants

Caregivers of patients who were evaluated for lung transplantation at our hospital lung transplantation outpatient clinic between December 2016 and September 2018 were recruited for this study. A caregiver has been identified for each patient. If more than one person within family members is included in care of patient, the eligible individual is asked to be selected by family members. Caregivers who are younger than 18 years old or who cannot understand/speak Turkish are excluded from study. Characteristics of patients were recorded. Patients were classified according to their care needs by clinicians as almost independent, partially dependent, greatly dependent and completely dependent according to Barthel index [9]. Barthel index was validated in Turkish [10]. The questionnaire block was administered during the first visit if the primary caregiver of the patient was with him/her. If not, primary caregiver was requested to come to the next appointment. All participants provided an informed consent. This study was approved by the Institutional Review Board of Marmara University School of Medicine local ethics committee (approval no:09.2016.441).

### Measures

- Assessment of Care Burden:** Zarit Burden Scale was developed in 1980 by Zarit et al [11]. It is a measure used to assess the stress experienced by caregivers. This scale can be used to assess relationship between patients and caregiver, caregiver's health status, psychological comfort, social life and economic burden. Zarit Burden scale was validated in Turkish and has shown good reliability in clinical practice [12, 13]. The scale has a Likert-type rating that ranges from 0 to 4 corresponding to never, rarely, sometimes, frequently, or almost always. 0-20 points indicate light burden, 21-40 points indicate medium burden and > 40 points indicate heavy burden. The higher the scale score, the more intense the experience burden.
- Assessment of Depression:** The Beck depression inventory is a self-reported inventory consisting of 21 questions and was developed by Beck in 1961 [14]. Basically, it is based on evaluating the characteristics and symptoms of depression. Each question is scored from 0 to 3 points, with 0-9 minimal depression, 10-16 mild depression, 17-29 medium depression and 30-63 severe depression. It is validated in Turkish [15].
- Assessment of Fatigue:** Short Form (SF)-36 provided internal consistency, reliability, and content validity criteria that were tested in various populations [16]. SF-36 Turkish validated formula was used to evaluate the fatigue of the caregiver [17]. The four questions in the survey asks how much time they spent in last week: 1) felt full of pep; 2) had a lot of energy; 3) felt worn out; or 4) felt tired. The answers were sorted from "always" to "never". Score ranges from 0 to 100. The scores at 45 and below represented clinically significant fatigue.

### Statistical Analysis

Descriptive statistics were reported for all variables as mean±standard deviation or n (%) when appropriate. Kruskal-Wallis test was used for comparing continuous variables of more than two groups. Pearson's r was used to measure correlation of two continuous variable. The sample size was not calculated because lung transplantation was performed on a very limited number of patients. All eligible patients and their caregivers were included in the study. P value <0.05 was accepted as a sign of statistical significance. Statistical analyses were performed using the PSPP version 1.0.1 (GNU Project Development; San Carlos, CA, USA).

## 3. RESULTS

### Demographic Characteristics

Thirth-nine patients and their caregivers were evaluated. Caregivers consisted of 31 (79.5%) female and 7 (21.5%) males. Mean age was 41.8±9.8. Most of them were married (92.3%) and were at least primary school graduates (92.3%). Majority of caregivers were either spouse or child of the patient (56.4%). Only 4 (10.2%) caregivers received professional help for their patients care. Demographic characteristics of caregivers and demographic and clinical characteristics of lung transplant candidates are shown in Table I.

**Table I.** Characteristics of patients and caregivers

Caregiver Characteristics		Patient Characteristics	
Age, mean ± SD	41.8 ± 9.8	Age, mean ± SD	41.2 ± 13.3
Female, n (%)	31 (79.5)	Male, n (%)	23 (59)
Caregiving Duration, n (%)		Smoking, packs/year, mean ± SD	6.9 ± 9.5
< 1 year	1 (2.6)	BMI, kg/m <sup>2</sup> , mean ± SD	29 (6.8)
1-3 years	13 (33.3)	Primary Diagnosis, n (%)	
> 3 years	25 (64.1)	COPD	11 (28.2)
Income, n (%)		Interstitial Lung Disease	12 (30.8)
Very High	4 (10.2)	Bronchiectasis	9 (23.1)
High	3 (7.7)	Cystic Fibrosis	5 (12.8)
Middle	12 (30.8)	Idiopathic Pulmonary Arterial Hypertension	2 (5.1)
Low	15 (38.5)	Care Need, n (%)	
Very low	5 (12.8)	1 – almost independent	4 (10.3)
Educational Status, n (%)		2 – partially dependent	13 (33.3)
Illiterate	3 (7.7)	3 – greatly dependent	19 (48.7)
Primary School	14 (35.9)	4 – completely dependent	3 (7.7)
Secondary School	9 (23.1)	Duration of Primary Diagnosis	
High School	9 (23.1)	Years, mean ± SD	9.5 (6.3)
University	4 (10.3)	Oxygen Support, n (%)	30 (76.9)
		NIV Support, n (%)	10 (25.6)
		6MWT, meters, mean ± SD	264 (100.3)

SD: Standard Deviation, BMI: Body Mass Index, COPD: Chronic Obstructive Pulmonary Disease, NIV: Non-Invasive Ventilation, 6MWT: 6 Minutes Walking Test

### Level of Burden, Depression and Fatigue

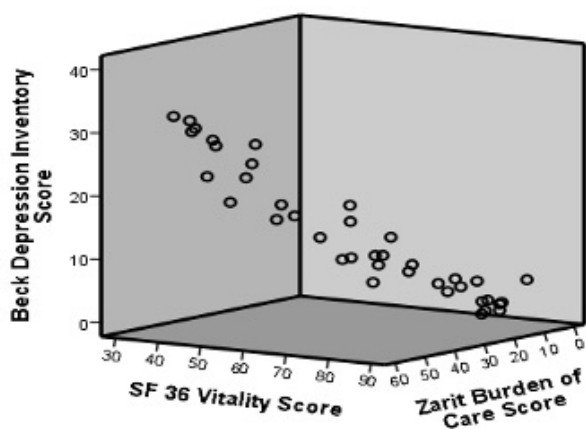
Caregivers experienced low levels of depression. Mean score for Beck Depression Inventory was  $12.7 \pm 10.1$ . Cutoff point for Beck Depression score to determine clinically significant emotional distress was identified as  $\geq 14$  in the literature. Among participants 16 (41%) were having clinically significant emotional distress. Caregivers generally experienced medium levels of burden. Mean score for Zarit Burden Scale was  $26.9 \pm 14.2$ . Majority of caregivers experienced clinically significant fatigue. Mean score for SF-36 Vitality was  $61 \pm 16.7$ .

Distribution of levels of burden, depression and fatigue are described in Table II.

**Table II.** Distribution of levels of burden, depression and fatigue

Depression n (%)	Burden of Care n (%)	SF-36 Vitality n (%)
Minimal 20 (51.3)	No burden 16 (41)	$\leq 45$ Fatigue 10 (25.6)
Mild 6 (15.4)	Moderate Burden 13 (33,3)	$> 45$ 29 (74.4)
Moderate 9 (23.1)	Severe Burden 10 (25.6)	
Severe 4 (10.3)		

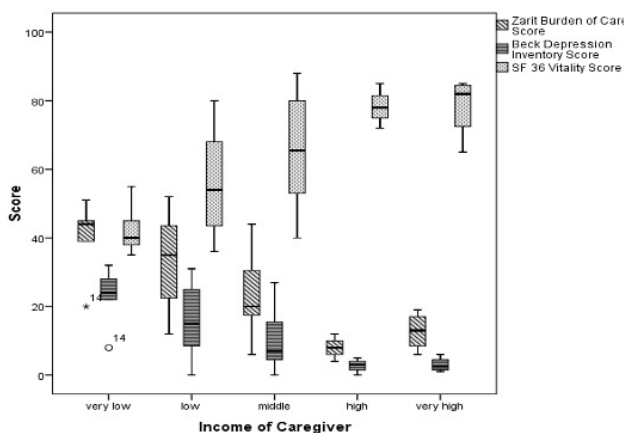
Correlation between measures is shown in Figure 1. Zarit Burden Scale scores and Beck Depression Inventory scores showed a statistically significant positive correlation ( $r: 0.962$   $p < 0.01$ ). SF-36 Vitality scores found to be negatively correlated with both Zarit Burden Scale scores and Beck Depression Inventory score ( $r: -0.854$   $p < 0.01$ ;  $r: -0.87$   $p < 0.01$  respectively).



**Figure 1.** Correlation between burden, depression and fatigue

SF-36: Short Form 36

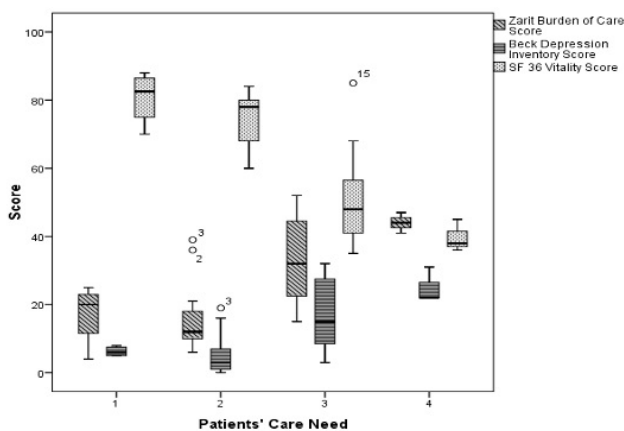
Educational status did not influence Zarit Burden Scale, Beck Depression Inventory and SF-36 Vitality scores ( $p=0.705$ ,  $p=0.584$  and  $p=0.365$  respectively). But there was a statistically significant difference among income groups for Zarit Burden Scale, Beck Depression Inventory and SF-36 Vitality scores ( $p=0.001$ ,  $p=0.002$  and  $p=0.003$  respectively). Figure 2 shows distribution of all 3 scores among care givers according to their income.



**Figure 2.** Evaluation of burden, depression and fatigue among caregivers according to income

SF-36: Short Form 36

Patients were grouped according to their care needs. In this case 1 referred to almost independent, 2 referred to partially care dependent, 3 referred to greatly care dependent and 4 referred to completely care dependent. Figure 3 shows distribution of all 3 scores among caregivers according to their patient's care need. There was a statistically significant difference among income groups according to Zarit Burden Scale, Beck Depression Inventory and SF-36 Vitality scores ( $p=0.001$ ,  $p=0.001$  and  $p < 0.001$  respectively).



**Figure 3.** Evaluation of burden, depression and fatigue among caregivers according to their patient's care need

Care need was defined as: 1. almost independent, 2. partially dependent, 3. greatly dependent, 4. completely dependent, SF-36: Short Form 36

### 4. DISCUSSION

In this study, the symptoms of fatigue, depression and caregiver burden were evaluated in primary caregivers of lung transplantation candidates. As a result; the increased burden of

caregivers in the group of patients with predominantly COPD and ILD, resulted in an increase in depressive symptoms and fatigue.

Today, lung transplantation is not close to the desired success in terms of long-term outcomes compared to other solid organ transplants [18]. Because most of the patients are in the end-stage in the pre-transplant period, a large proportion of patients fail to reach the targeted exercise capacity in the early post-transplant period due to a number of systemic changes secondary to chronic respiratory failure, and expected recovery time may be prolonged [19]. Even in stable cases; close monitoring at home (such as spirometry and vitals), frequent hospital inspections, general life changes (diet, exercise) and lifelong drug treatment which require close follow-up are needed. In addition, there may be medical conditions in some patients such as infections, ongoing chest pain, intestinal dysfunction, dyspnea, anxiety, which require treatment and support after transplantation. Therefore, when compared to other organ transplantations, the need for care of these patients in the preoperative period can continue for a while in the post-operative period.

At present, the caregiver concept is mainly used for chronic and terminal medical conditions, and patient groups are mainly composed of stroke, dementia, chronic care patients after ICU and cancer patients [20-22]. It has been shown that regardless of the underlying disease, individuals who do not do caregiving professionally choose to have socialize less, change their lifestyles and habits, choose half-time work, change jobs or quit, show depressive symptoms [23]. In addition; lack of social support, and low socioeconomic status have significant effects on Quality of Life. It has been reported that the greatest sources of stress in caregivers of palliative care patients are patient's treatments, dietary needs, doctor's appointments, and psychosocial status of the patient [24]. The number of studies in specific chronic organ failures is less than in the other groups. One study compared COPD, congestive heart failure and patients with chronic renal failure and found that physical burden and stress in COPD caregivers were greater than in the other groups [7]. The caregiver's burden was assessed in COPD-diagnosed patients and it was determined that the most important factor that increased the burden in caregivers was the patient caregiver incompatibility. Caregivers' SF-36 survey indicated that the worst scoring was in the mental status, vitality and general health status sections [25]. Again, in the same study, as supported by others, it is emphasized that caregivers feel sicker and need to go to the doctor more than other individuals with the same characteristics [26].

Studies have also shown that in the caregivers of solid organ transplantations, physical health deterioration was associated with psychosocial stress [27]. In addition, it has been argued that if the patient is married and spouse is the caregiver, postoperative long-term outcomes are better due to good care [28, 29].

While, there is no data on lung transplantation caregivers, in a study of caregivers of renal transplant cases; it has been reported that psychosocial support to caregivers resulted in reduction of depression and facilitated care [30].

Lung transplantation cannot always provide the expected improvement in the quality of life, or it can take time [31]. Like our study, Claar et al., assessed quality of life and emotional burden of the caregiver of lung transplantation candidates in the waiting list. Caregiver burden and emotional stress was found to be less than expected. They speculated that caregivers fear of patient not receiving psychosocial support impression resulted in underestimation by caregiver. While accepting the patient's illness in caregivers was associated with depression, caregivers who did not accept the illness were reported to have high anxiety rates [32].

When caregivers are family members, patient related future concerns, responsibilities and financial reasons have been reported to be an additional source of stress for the caregiver [33]. Mollberg et al., have found that primary caregivers have an impact on long-term transplantation success in cases of lung transplantation. Unlike previous studies in transplant patients they report that being married was not associated with good care; especially in post-transplant care, caregiver's psychological and physiological health was the most important factor in good care [34].

When we look at the general profile of caregivers in our study; most of them were family caregivers and most of the caregivers were the patient's wife or daughter. This can be considered as a risk factor for emotional maladjustment of the medical problems or worsening of the patient at the same time. Patients who were cared by their spouses or daughters could not be assessed thoroughly because of the lack of validated questionnaires in Turkish. When the socioeconomic status was evaluated, it was determined that the middle-poor income group was the forerunner. Educational status is predominantly primary school graduate, parallel to income situation. Since, most caregivers are in the low socioeconomic status, it may be difficult to find sufficient financial support for the problems that arise and being at a lower educational level may make it difficult to reach solutions.

The burden of care was directly related to depression scoring and fatigue assessment in our study. Although, cases were mostly in the mild group; depressive symptoms were found to be higher than workload, and these results were associated with the fact that the caregiver was mostly close family members like the study of Dew et al.[33].

There is no special unit for social services in the centers where transplantation is performed in our country. Because of the lack of social workers that may be helpful in the programming of the medical services or non-medical problems this rises as an additional burden on caregivers. A supportive service can be an effective way to reduce emotional stress and fatigue, especially when caregivers are supported by these institutions or individuals in groups that require high cost and labor, such as transplantation. Improvements in caregiver conditions can improve the patient's quality of care before and after the transplant and the long-term survival of the patient.

One of the limitations of our study is small sample size. Also, post-transplant evaluation could not be done due to the small

number of transplanted cases. The risk assessment for depression and fatigue in caregivers is insufficient due to the low number of cases. Assessment of coping strategies for depressive symptoms identified in caregivers in similar studies is not included in this study. The marital status of the patient and the relationship with the caregiver on care were not assessed due to the low number of cases after the distribution. Comprehensive evaluations of the caregiver were not implemented because some questionnaires were not validated in Turkish. Additionally, we did not have a control group for burden comparison which may provide insight for other chronic respiratory diseases.

In conclusion, in this study, increased burden of caregivers of lung transplant candidates was associated with depression and fatigue. The presence of depressive symptoms is noteworthy even in the mild to moderate levels of burden. Lung transplantation is a long-lasting and exhausting process. Post-operative burden is relatively high. We think that the psychosocial support applied to the primary caregivers in the pre-operative and post-operative period will provide a positive contribution to the long-term outcomes of the patients.

### Compliance with the Ethical Standards

**Ethical Approval:** This study was approved by the Institutional Review Board of Marmara University School of Medicine local ethics committee (approval no:09.2016.441).

**Financial Support:** The authors have no relevant financial information to disclose.

**Conflict of Interest:** The authors have no potential conflicts of interest to disclose.

**Author Contributions:** SOY and ATC: Conceived the study, SOY and HA: Data collection; HA: Managed the data, including quality control, analyzed the data, SOY, ATC, HA, and EE: Drafted the manuscript, EE: provided critical revision of the manuscript and all authors contributed substantially to its revision, SOY: Takes responsibility for the paper.

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