

# Comparing the Quality of Life and General Health Status in Thoracic Cancer Patients with their Family Caregivers in Iran

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**Background:** Cancer is one of the leading causes of morbidity and mortality around the world. Caregivers of these patients are affected by various physical, emotional, social, spiritual, and financial factors that can affect their quality of life (QoL). This study aimed to compare the QoL and general health status of thoracic cancer patients with their family caregivers in Iranian population.

**Materials and Methods:** Using the City of Hope-Quality of Life (COH-QOL) questionnaire and the General Health Status (GHQ) questionnaire, this cross-sectional study compared the QoL and general health status in 71 thoracic cancer patients with their family members as the primary caregivers. The study was conducted in Masih Daneshvari Hospital of Tehran, Iran from 2017 to 2018. Demographic data and results of the questionnaires were analyzed using the Statistical Package for the Social Sciences (SPSS v.20). Student's t-test, Chi square test, and Pearson's correlation were used to compare the results.

**Results:** In patients and their caregivers, 53.5% (N=38) and 36.6% (N=26) were male, respectively ( $P=0.043$ ). While the average score of physical wellbeing was  $6.12 \pm 1.95$  in caregivers, it was  $5.32 \pm 2.08$  in patients ( $P=0.021$ ). In case of psychological wellbeing, the average score in caregivers was  $4.14 \pm 1.50$  and in patients was  $5.7 \pm 1.54$  ( $P=0.000$ ). We observed no significant difference between caregivers and patients regarding social concerns ( $4.62 \pm 1.50$  vs.  $4.90 \pm 1.74$ ) and spiritual wellbeing ( $7.03 \pm 1.17$  vs.  $7.2 \pm 1.53$ ). Also, the mean scores of GHQ-12 were  $5.06 \pm 2.5$  and  $4.17 \pm 2.53$  in caregivers and patients, respectively ( $P=0.04$ ). A significant negative correlation was observed between GHQ-12 and QoL scores ( $r=-0.593$ ,  $P<0.001$ ). The probability of acquiring mental disorders in female caregivers was two times higher than male caregivers ( $P=0.05$ ).

**Conclusion:** Our findings demonstrated that family caregivers of thoracic cancer patients suffer from physical and psychological distress, sometimes even more than the patients. This highlights the important role of family caregivers in the process of approaching a patient with thoracic cancer.

**Key words:** Cancer patients; Caregivers; Quality of life; General health

## INTRODUCTION

Cancer is one of the leading causes of morbidity and mortality around the world. According to the estimation by the International Agency for Research on Cancer

(IARC), 9.6 million deaths occurred due to cancer and more than 18 million new cases were diagnosed in 2018 (1). Also, 14.5% of total new cases of cancer in men and 8.4% in women were lung cancer with 2.1 million diagnoses and

1.8 million mortalities in 2018 (1). The incidence of lung cancer was a little lower in Iran compared to other parts of the world (2).

The burden of the disease involves not only the patients, but also their family members. Due to the new progression and approaches in medical care, informal and family caregivers are playing a more important role in looking after cancer patients (3). Consequently, new challenges and responsibilities are made for family caregivers of such patients. These burdens that vary from physical, emotional (4), social, and spiritual to financial and occupational, influence the quality of life (QoL) of caregivers. This highlights the importance of investigating individuals caring for a family member suffering from cancer.

Comparison of patients in the curative phase with those who are terminally ill shows that the caregivers of the latter group report a lower QoL in general (5). This finding has been supported by a substantial body of research focusing on the QoL of cancer caregivers in the last two decades (6-8). A study by Grunfeld *et al.* showed that cancer patients and their caregivers experienced same levels of depression; however, caregivers had higher levels of anxiety (9).

There is a positive correlation between the QoL of family caregivers and the QoL of cancer patients. When the QoL of caregivers declines, it may decrease the QoL of patients (10). Therefore, it is necessary to evaluate the QoL of caregivers to understand the burden they endure and also to create interventional methods that improve their conditions.

This study aimed to compare the QoL and general health of thoracic cancer patients with their family caregivers. It is hoped that our findings can highlight the important role of informal caregivers for those involved in healthcare and medical services.

## **MATERIALS AND METHODS**

In this cross-sectional and analytical study, we compared the QoL and general health status of 71 patients with confirmed thoracic cancer diagnosis with 71

caregivers in Masih Daneshvari hospital, Shahid Beheshti University of Medical Sciences, Tehran, Iran from 2017 to 2018.

The inclusion criteria were patients with thoracic cancer at III & IV stages and the family members as their primary caregivers; admitted to the Department of Medical Oncology of Masih Daneshvari hospital; aged over 18 years old; and adequate mental capacity to understand the meaning of the questions. The exclusion criteria were low functional status with Karnofsky Performance Status (KPS) score  $\leq 50$  (9) and not being able to read and write.

Data were collected using the City of Hope-Quality of Life (COH-QOL) Scale Family Version that contains 37 questions (11). Patients and caregivers were requested to read the questions and choose a score from 0 (worst) to 10 (best) that mostly expressed their opinions; so, the higher scores showed a better QoL. Several questions had reversed scoring. For example, if a participant chose 4 for these questions ( $10-4=6$ ), score 6 would be recorded. The test-retest reliability of the questionnaire was 0.89 and the internal consistency was 0.69. Four subscales of the questionnaire were confirmed by factor analysis that included physical wellbeing, psychological wellbeing, spiritual wellbeing, and social wellbeing.

All the patients and their caregivers gave their oral and written consent to participate in the study. The study was approved by the Ethics Committee of Masih Daneshvari Hospital, Tehran, Iran (code: Sbm1.REC.1392.9).

In our research, the interviewer was a general physician who worked for the oncology department of the hospital. She interviewed each participant separately. After introducing herself and giving information about the research, subjects gave their consent and then the interviewer read each question in an understandable manner and asked the subjects to choose their answer.

### **General Health Questionnaire (GHQ)**

The overall health status of caregivers was assessed using the 12-item General Health Questionnaire (GHQ). This screening tool was first developed by Goldberg to evaluate mental disorders in the community and in a clinical setting (12). The questionnaire was used in many

studies in various cultural and social areas around the world (i.e., 13-14) including Iran (15-16). The method of rating questions is based on the Goldberg recipe as Likert scale and the points are zero-zero one-one. The maximum and minimum scores for this questionnaire are 12 (maximum symptom load) and zero (minimum symptom load), respectively; higher scores indicate a worse health status (17) and scores above 5.5 show an abnormal condition (possibility of mental disorder) (18).

### Data Analysis

Data were analyzed using the Statistical Package for the Social Sciences (SPSS v.20). The average scores of the four sections of the questionnaire were calculated and compared using the student's t-test. Using the Chi-square test, the proportions of participants with GHQ scores greater than 5.5 were compared between males and females, as well as between patients and caregivers. The GHQ-12 total scores correlation was tested for total scores of QoL. Quantitative variables were presented as mean (SD). Type one error rate was defined as 0.05.

## RESULTS

Out of 71 caregivers participating in the study, 63.4% (N=45) were female. Meanwhile, 46.5% (N=33) of patients were female ( $P=0.043$ ). While the average age of caregivers was 38.7 years, it was 42.4 years in patients. Spouses of the patients were the main caregivers (34.8%, N=24). Also, 78.9% (N=56) of the caregivers were living with patients in

the same place. Furthermore, a quarter of the caregivers and almost a third of the patients had an academic degree (Table 1).

Both the caregivers and patients were compared according to the four constructs of the COH-QOL-family version questionnaire. In caregivers, the average score of physical wellbeing was  $6.12 \pm 1.95$ , whereas in patients, it was  $5.32 \pm 2.08$  ( $P=0.021$ ). In case of psychological wellbeing, the average score in caregivers was  $4.14 \pm 1.50$  and in patients was  $5.7 \pm 1.54$  ( $P=0.000$ ). We observed no significant differences between caregivers and patients in case of social concerns ( $4.62 \pm 1.50$  vs.  $4.90 \pm 1.74$ ) and spiritual wellbeing ( $7.03 \pm 1.17$  vs.  $7.2 \pm 1.53$ ) (Table 2).

Regarding the GHQ-12, the mean scores were 5.06 (2.5) and 4.17 (2.53) in caregivers and patients, respectively; the difference was statistically significant ( $P=0.04$ ). Furthermore, 43.5% (N=30) of caregivers had GHQ-12 score higher than 5.5; this figure in patients was 24.6% (N=17). Again, the difference was statically significant ( $P=0.02$ ).

The average scores of physical wellbeing, psychological wellbeing, social concerns, and spiritual wellbeing between high GHQ scores (possibility of mental disorders) and normal GHQ scores in patients were compared and all scores were statistically significant (Table 3).

The same comparison was performed between caregivers with high and normal GHQ scores, which was also significant except for spiritual health (Table 4).

Table 1. Characteristics of the study sample

		Caregivers N (%)	Patients N (%)	P-value
Gender	Male	26 (36.6)	38 (53.5)	0.043
	Female	45 (63.4)	33 (46.5)	
Age		$38.7 \pm 13$	$42.4 \pm 15.5$	NS
Relation with patient	Spouse	24 (34.8)	-	-
	Parents	11 (15.9)	-	-
	Sibling	15 (21.7)	-	-
	Children	19 (27.5)	-	-
	Diploma or lower	52 (74.3)	24 (70.6)	NS
	University level	18 (25.7)	10 (29.4)	
Living with patient	Yes	56 (78.9)	-	-
	No	15 (21.1)	-	-

**Table 2.** Comparison of patients and caregivers according to physical, psychological, and spiritual wellbeing and also social concerns

QOL Questionnaire Domains	Reliability	Caregivers X $\pm$ SD	Patients X $\pm$ SD	P – Value
Physical wellbeing	0.70	6.12 $\pm$ 1.95	5.32 $\pm$ 2.08	0.021
Psychological wellbeing	0.86	4.14 $\pm$ 1.50	5.7 $\pm$ 1.54	0.000
Social concerns	0.73	4.62 $\pm$ 1.50	4.90 $\pm$ 1.74	NS
Spiritual wellbeing	0.63	7.0 $\pm$ 1.26	7.06 $\pm$ 1.7	NS
Total	0.88			

**Table 3.** Comparing average score of 4 subscales of quality of life between those with high GHQ-12 (possibility of mental disorders) and low GHQ-12(Normal GHQ) score in patients

Subscale	Cut off 5.5 total GHQ	N	Mean	SD	P Value
Physical wellbeing	Normal GHQ	52	5.6100	1.99529	0.04300
	GHQ $\geq$ 5.5	17	4.4259	2.25100	
Psychological wellbeing	Normal GHQ	47	6.1665	1.42078	0.00000
	GHQ $\geq$ 5.5	17	4.3574	1.95006	
Social concern	Normal GHQ	44	5.3313	1.58335	0.00100
	GHQ $\geq$ 5.5	15	3.6668	1.59792	
Spiritual wellbeing	Normal GHQ	48	7.5021	1.41069	0.00600
	GHQ $\geq$ 5.5	15	6.2514	1.66225	

**Table 4.** Comparing average score of 4 subscales of quality of life between those with high GHQ-12(GHQ $\geq$ 5.5) and low GHQ-12 (GHQ $\leq$ 5.5) score in caregivers

Subscale	Cut off 5.5 total GHQ	N	Mean	SD	P Value
Physical wellbeing	Normal GHQ	39	6.5462	1.59014	0.23000
	GHQ $\geq$ 5.5	29	5.4600	2.25005	
Psychological wellbeing	Normal GHQ	37	4.6481	1.49908	0.03100
	GHQ $\geq$ 5.5	30	3.4179	1.20592	
Social concern	Normal GHQ	32	4.9778	1.48306	0.03100
	GHQ $\geq$ 5.5	26	4.1201	1.42181	
Spiritual wellbeing	Normal GHQ	38	6.9620	1.20075	NS
	GHQ $\geq$ 5.5	30	7.0810	1.19581	

The proportion of high GHQ-12 score was separately calculated and compared between males and females in the two groups. In the patient group, there was no statistically significant difference between males and females. However, in the caregiver group, the proportion was higher in females (23, 52.3%) than in males (7, 28) ( $P=0.05$ ) (Table 5). Regarding the possibility of mental disorders, the GHQ results showed no significant differences between male and female patients. However, the probability of acquiring mental disorders in female caregivers was two times higher than male caregivers ( $P=0.05$ ) (Table 5).

In addition, there was a negative correlation between GHQ-12 score and COH-QOL-family version questionnaire ( $r=-0.593$ ,  $P=0.000$ ).

**Table 5.** Comparison of proportion of high GHQ-12 score between men and women separately in patients and caregivers groups

		Normal GHQ N (%)	Abnormal GHQ N (%)	P-value
Patients	Male	27 (75)	9 (25)	NS
	Female	25 (75.8)	8 (24.2)	
Caregivers	Male	18 (72)	7 (28)	0.05
	Female	21 (47.7)	23 (52.3)	

## DISCUSSION

In this study we witnessed that due to the traditional family relationships in the Iranian society, most of the caregivers of thoracic cancer patients were their spouses or people living with them. This finding is similar to the results reported by Wittenberg et al. (19) and Grunfeld et al. (9). In addition, in our study, most of the caregivers were female, which is possibly due to the responsibilities assigned to women in Iranian culture. This result is in agreement with the study by Khanjari et al. (20).

Regarding the QoL, caregivers reported a higher physical wellbeing than patients. This is an expected result since thoracic cancer patients undergo surgery, chemotherapy, and other treatments which have serious complications. However, caring for a cancer patient has its own physical burden (i.e., helping patients in their usual daily activities, additional domestic duties, etc.). This finding supports the findings of other similar studies (9,21).

Evaluating psychological wellbeing revealed that caregivers had a higher level of vulnerability towards psychological disorders than patients. The most frequent disorders in the caregivers were anxiety and depression. Although it has been shown that thoracic cancer patients, due to their state of health, suffer from psychological disorders (22,23), the caregivers should not be neglected since the stressful situation of caring for another person is added to their personal distresses. Moreover, female caregivers were more likely to develop psychological disorders than the male caregivers. This is also in line with the study by Valeberg and Grov (24).

Our findings regarding social and spiritual wellbeing indicated no significant differences. It could be speculated that tight family bonds and religiosity of the Iranian society play a major role in this regard.

Comparison of the GHQ scores and the QoL measures revealed a reverse correlation between these two factors, which is significant from a statistical point of view. In other words, lower QoL results in higher vulnerability towards psychological disorders in the caregivers and thoracic cancer patients.

## Limitations

Factors such as the type of thoracic cancer, its survival rate, and whether it is curative or palliative can alternate the QoL and general health status of patients and caregivers. However, we did not consider these factors in our study.

## CONCLUSION

The findings of the current study demonstrated that family caregivers of thoracic cancer patients suffer from physical and psychological distress, sometimes even more than our patients. This fact highlights the important role of family caregivers in the process of approaching a patient with thoracic cancer.

Based on our findings, we recommend several measurements. First, on diagnosis, an informative session could be arranged for thoracic cancer patients and their caregivers to familiarize them with the disease and its effects on their lives, and also to provide them with problem solving skills. Second, healthcare staff and social workers are encouraged to provide the caregivers with interventional methods that enhance their coping strategies. Third, insurance companies should extend their coverage on thoracic cancer patients and their caregivers. Fourth, considering the increasing rate of chronic diseases, especially cancer among Iranian population which is getting older, prevention of physical, mental, and spiritual disorders in caregivers needs structural changes in the approach. Fifth, screening methods and early diagnosis of thoracic cancer seems to be essential not only because of its financial benefits, but also for its role in lowering the burden of the disease both for patients and their families.

## Limitations

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