

## Examining the relationship between symptoms watched in lung cancer patients and illness perception

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### Abstract

**Objective:** To examine the relationship between the symptom experience of lung cancer patients and their illness perception of the disease.

**Methods:** The descriptive and cross-sectional study was conducted from April to September 2015 at the Chemotherapy Treatment Centre of the Medicine Chest Diseases Clinic at the Ege University, Izmir, Turkey, and comprised lung cancer patients of either gender aged >18 years. Data was collected using a predesigned Patient Questionnaire as well as the standard Lung Cancer Symptom Scale, Illness Perception Questionnaire and Karnofsky Performance Scale. The patients' sociodemographic characteristics and data on their illness, the symptoms they experienced and the numerical and percentage distribution of the items on the illness perception scale, mean and standard deviation values were examined. Pearson Correlation analysis was used to examine the correlation between illness perception and Karnofsky Performance Scale scores and other variables.

**Results:** Of the 105 patients, 86(81.9%) were males, 86(81.9%) were married, 49(46.7%) were elementary school graduates, 101(96.2%) were unemployed, and 95(90.5%) were receiving chemotherapy. The overall mean age of the sample was 61.43±8.24 years, the period since diagnosis was 11.38±17.84 months, and the duration of chemotherapy was 4.28±2.37 months. The mean symptom burden score was 22.75±10.85 and the Lung Cancer Symptom Scale score was 22.75±10.85. The mean score of the type of illness domain was 5.53±2.12. The overall mean global quality of life score was 64.30±12.60.

**Conclusions:** As the symptom burden experienced by the lung cancer patients increased, their perception of the illness became more negative, and the longer the cyclical periods and the period of diagnosis, the patients' control over their illness decreased.

**Keywords:** Lung cancer, Perception of illness, Nurse. (JPMA 72: 634; 2022)

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### Introduction

Cancer is a multi-dimensional condition that brings about significant changes in the physical, psychological, social and spiritual aspects of an individual's life. It is a life experience that causes intense uncertainty during and after the treatment process as well as changes in an individual's psychosocial reality.<sup>1,2</sup> It has been found that depending upon the symptoms the patients experience, and with increased symptom load, their physical functions decrease significantly and quality of life (QOL) is adversely impacted.<sup>3,4</sup> Therefore, the illness perception is important, especially for cancer patients. Illness perception is the way an individual's beliefs and expectations regarding a medical condition or symptom reflect on the individual's life.<sup>5-9</sup>

Beyond having to face living with a serious and chronic

disease that has an impact on QOL, individuals with lung cancer perceive their illness as one that harbours uncertainty, pain and associated fears of a painful death, as well as feelings of guilt, abandonment and anxiety that leads to general chaos in their lives. The uncertainty of a prognosis may lead to a loss of self-efficacy and anxiety about the future.<sup>3,4,6</sup>

The current study was planned to examine the relationship between the symptoms observed in lung cancer patients and their illness perception.

### Subjects and Methods

The descriptive and cross-sectional study was conducted from April to September 2015 at the Day-care Chemotherapy Treatment Centre of the Medicine Chest Diseases Clinic at the Ege University, Izmir, Turkey. The centre is a tertiary facility having 8 beds, and serves between 8am and 5pm during which time, two nurses are responsible for the care of the patients. The centre serves about 400 individuals with lung cancer every year. After approval from the institutional ethics review committee, the sample size was calculated using G-Power calculator at 0.05 significance level and 80% power. The sample size

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was inflated by 5% to increase reliability.<sup>7</sup> The sample was raised using random sampling technique from among those who presented to the chemotherapy unit for treatment.

Those included were lung cancer patients of either gender aged >18 years who were able to speak and understand Turkish, were literate, had received a diagnosis of cancer 6 months prior, and were under treatment either in the shape of chemotherapy, radiotherapy or surgery. Patients who had rated 30% and below on the Karnofsky Performance Scale (KPS) were excluded. After taking informed consent from all the subjects, data was collected using a predesigned Patient Questionnaire (PQ) as well as the standard Lung Cancer Symptom Scale (LCSS), the Illness Perception Questionnaire (IPQ) and the KPS. The PQ was developed in the light of literature<sup>5-8</sup> and contained patient's sociodemographic and clinical data.

The LCSS determines the QOL of patients with lung cancer. It comprises 9 statements related to the major symptoms of loss of appetite, fatigue, cough, dyspnoea, haemoptysis and pain, with three summary questions on Symptomatic Distress, Impact of the Illness on Activity and Global QOL. The patients are asked to mark each symptom using visual analogue scales (VAS). Each response is marked along a 100mm horizontal line. Higher scores on the LCSS are negative, while lower scores are positive. A high symptom score indicates that symptoms are perceived by the patient to be highly negative. High scores given to the symptoms indicate that the patient experiences these symptoms intensely and they negatively affect the process. Low scores given to the symptoms indicate that the patient experiences these symptoms less frequently and they do not adversely affect the process. Past test re-test reliability indicated high patient reproducibility for 52 patients ( $r > 0.75$ ,  $P < 0.01$  for all items).<sup>10</sup> The scale's validity and reliability among Turkish patients is established with Cronbach alpha coefficient 0.75.<sup>11</sup>

The IPQ was developed in 1996 and was revised subsequently.<sup>12</sup> Its validity and reliability in the Turkish population has also been established.<sup>9</sup> The IPQ type of illness domain encompasses 14 commonly experienced symptoms. For each of these symptoms, the individuals are first asked if they had experienced it since the start of the illness and then whether they viewed it as related to the illness.

The IPQ perception of the illness domain comprises 38 statements that are rated on a five-point Likert scale. This domain has seven subdomains; timeline (acute/chronic),

consequences, personal control, treatment control, illness coherence, timeline (cyclical), and emotional representation. The IPQ causes of illness domain comprises 18 statements which are rated on a five-point Likert scale. There are four subscales related to the individuals' thoughts about the possible causes of the illness; psychological attributions, like stress or worry, family problems, personal traits, risk factors, like genetics, smoking, drinking, aging, immunity, like germs or virus, loss of body resistance, accident or chance, like accident, injury, bad luck, etc. The validity and reliability of the scale in the Turkish population have been established.<sup>9</sup>

The KPS is commonly used as an instrument to measure functional status in clinical oncology, with a score range of 0-100 related to functional ability.<sup>13</sup> KPS scores 90 and above signify good performance; the cut-off point for poor performance is 80 or below.

Data was collected by two researchers during face-to-face interviews in a suitable environment. Each interview lasted about 25 minutes.

The mean age, period of diagnosis, duration of chemotherapy, marital and education status, health status, employment status, income level mean  $\pm$  standard deviation (SD) values as well as frequencies and percentages were calculated as appropriate. Pearson Correlation analysis was used to examine the correlation between illness perception and KPS scores and other variables.  $P < 0.05$  was considered significant.

## Results

Of the 105 patients, 86(81.9%) were males, 86(81.9%) were married, 49(46.7%) were elementary school graduates, 101(96.2%) were unemployed, 105(100%) had health insurance, and 81(77.1%) had income status average. The overall mean age of the sample was  $61.43 \pm 8.24$  years, the period since diagnosis was

**Table-1:** Patients' Lung Cancer Symptom Scale (LCSS) scores (n=105).

LCSS sub-domains	Mean $\pm$ SD	Min-Max
Loss of appetite	49.33 $\pm$ 22.62	0-100
Fatigue	43.90 $\pm$ 21.77	0-100
Cough	12,28 $\pm$ 20,53	0-100
Dyspnoea	11.23 $\pm$ 21.10	0-100
Haemoptysis	2.66 $\pm$ 7.37	0-40
Pain	17.04 $\pm$ 18.23	0-50
Symptomatic distress	39.14 $\pm$ 9.51	0-70
Impact of the Illness on Activity	44.01 $\pm$ 16.97	0-100
Global Quality of Life	64.30 $\pm$ 12.60	2-90
Mean symptom burden score	22.75 $\pm$ 10.85	0-71.67
LCSS total score	31.55 $\pm$ 9.27	6.67-75.56

SD: Standard deviation.

**Table-2:** Patients' Illness Perception Questionnaire (IPQ) scores (n=105).

Subgroups	Mean±SD	Min - Max
Type of illness Perception of the illness Timeline (acute/chronic)	5.53 ± 2.12	0-10
Consequences	2.82 ± 0.56	1.83 - 4.83
Personal Control	3.44 ± 0.53	2.17 - 5.00
Treatment Control	3.37 ± 0.41	2.50 - 4.33
Illness Coherence	3.59 ± 0.37	2.60 - 4.80
Timeline (cyclical)	2.66 ± 0.59	1.20 - 4.60
Emotional Representation Causes of illness Psychological Attribution	3.22 ± 0.69	1.00 - 4.50
Risk Factors	4.22 ± 0.61	2.17 - 4.83
Immunity	2.23 ± 0.59	1.00 - 3.67
Accident or Chance	2.57 ± 0.54	1.00 - 4.00
	2.86 ± 0.94	1.00 - 4.67
	2.65 ± 0.53	1.00 - 4.00

SD: Standard deviation.

11.38±17.84 months, and the duration of chemotherapy was 4.28±2.37 months. The mean symptom burden score was 22.75±10.85 and the LCSS score was 22.75±10.85. The mean score of the type of illness domain was 5.53±2.12. The overall mean global QOL was 64.30±12.60.

Overall, 95(90.5%) patients were receiving chemotherapy; the 2nd cycle had been completed by 23(23.8%), the 3rd cycle by 18(19.0%) and the 6th or more cycles by 25(26.7%). Overall, 88(92.4%) expressed belief in the treatment. KPS score 100 was found in 37(35.2%), 90 in 53(50.5%) and 50-80 in 15(14.3%).

The patients' LCSS mean score was 31.55±9.27 (r: -0.404, p<0.005) (Table-1).

The mean IPQ score was 5.53 ±2.12 (r: -0.272, p<0.005) (Table-2). A positive, weakly significant correlation was found between identity and dyspnoea, pain, symptomatic distress, mean symptom burden score, and LCSS total score (p<0.05). A significant relationship was found between the timeline (acute/chronic) and the diagnosis period; a positive, weak and significant relationship between treatment control and the effect of disease on activity, LCSS total score and KPS; positive, weak, and significant relationship between timeline (cyclical) and the chemotherapy and diagnostic period; and a positive correlation between emotional representation and fatigue, shortness of breath, the effect of illness on activity, mean symptom burden score, LCSS total score, and KPS (p<0.05). When the disease was examined in terms of age and perception of its causes, it was seen that the older the patients and the longer the chemotherapy period, the less likely they were to attribute their disease to psychological causes (p<0.05). A negative and significant relationship was found between immunity and fatigue, LCSS total score and age (p<0.05). A positive and significant correlation was found between the mean symptom burden score and KPS, but there was a negative correlation between chance and shortness of breath along with a significantly positive correlation with KPS (p<0.05). No significant correlation was found between personal control, disease compliance and risk factors and other variables (p>0.05) (Table-3).

## Discussion

The diagnosis of lung cancer patients entailed the burden

**Table-3:** The relationship between some variables and Illness Perception Questionnaire (IPQ) subscale scores (n=105).

Variables	Illness Perception Questionnaire Sub-domains											
	Identity	Timeline (acute/chronic)	Consequences	Personal Control	Treatment Control	Illness Coherence	Timeline (cyclical)	Emotional Representation	Psychological Attribution	Risk Factors	Immunity	Accident or Chance
<b>LCSS</b>												
Loss of appetite	.092	-.083	.010	.127	.043	-.017	.135	.160	-.082	-.154	-.034	-.031
Fatigue	0.121	0.068	-0.052	0.085	0.183	0.012	0.004	.407*	-0.145	-0.15	-.232*	-0.151
Cough	0.124	0.149	-0.02	0.005	0.089	0.094	0.024	-.458*	0.109	0.022	-0.114	-0.085
Dyspnoea	.260*	0.114	0.08	0.028	0.095	0.08	0.059	.431*	0.051	0.013	-0.147	-0.222
Haemoptysis	0.062	-0.068	-0.082	0.031	-0.026	-0.168	-0.001	-0.129	-0.016	-0.095	-0.098	-0.019
Pain	.285*	.131	.000	.073	.087	.030	-.038	-.009	.069	-.048	-.106	-.047
Symptomatic distress	.232*	.115	.085	.087	.150	.063	.021	-.085	-.080	-.149	-.113	-.002
Impact of the Illness on Activity	.183	.167	.067	.026	.251*	.066	-.019	.304*	-.036	-.016	-.163	-.115
Global Quality of Life	-.082	-.135	-.095	.168	.170	.036	.008	-.229*	-.053	-.110	-.073	-.111
Mean symptom burden score	.282*	.107	-.003	.107	.156	.043	.064	.382*	-.009	-.116	.214*	-.176
LCSS total score	.272*	.110	.006	.124	.216*	.060	.050	.404*	-.031	-.127	-.224*	-.177
Karnofsky	-.065	.197*	-.097	-.153	-.275*	-.175	.102	.273*	.082	.173	.269*	.248*
Age	.048	-.072	.240*	-.021	.014	.124	-.095	.035	-.248*	-0.122	-.268*	-0.131
Duration of chemotherapy (month)	-.065	.175	.111	-.127	.010	.052	.197*	0.035	-.199*	-.152	-.149	.083
Period of diagnosis (month)	.057	.225*	.044	-.058	-.090	.052	.246*	.141	-.015	.026	.078	.007

\*p&lt;.005. LCSS: Lung Cancer Symptom Scal.

of treatment and adversely affected their QOL.<sup>7,14</sup> This may have been because 35.2% patients had received 1st or 2nd cycles of chemotherapy and the KPS score of 85.2% patients ranged 90-100. It is emphasised in the literature that the less the burden of symptoms experienced by a patient means the more positive is the patient's perception of the illness and the better is QOL.<sup>15</sup> Indeed, QOL scores of the participants was 64.3%. This finding is consistent with literature.<sup>7,8</sup> Similarly, in the current study, 49.33% participants exhibited loss of appetite, 43.9% complained of fatigue, and 39.14% reported a reduction in their ability to engage in daily activities. Kloot et al. pointed out that the symptoms the lung cancer patients experienced caused them to have a negative perception of their illness.<sup>7</sup> One of the highest scores the individuals in the current study exhibited on the LCSS was related to their symptomatic distress (39.14%, Table-1). This finding is consistent with literature.<sup>14,15</sup>

Illness perception refers to the beliefs and cognition that patients have about the disease.<sup>6-8</sup> A positive, weak significant correlation was found between the identity and dyspnoea, pain, symptomatic distress, symptom burden and LCSS overall scores (Table-3). It was determined that there is a relationship between the disease perception and the symptoms of the patients. Similar findings have been reported earlier.<sup>8,14</sup>

The emotional representation subscale score by type of illness was high at  $4.22 \pm 0.61$  (Table-2). This showed that the patients' perception of the illness constituted intense negative emotions. This is because lung cancer patients perceive that mortality rates associated with the illness are high and that curative treatment is not possible for everyone. It is therefore important for healthcare professionals to understand what patients go through and to be aware of patients' perceptions of the illness.<sup>6,7</sup> The current study found a positive correlation between emotional representation and fatigue, dyspnoea, the impact of the illness on activity, the mean symptom burden score, the LCSS total score and the KPS, and a negative and significant correlation in terms of the symptom of cough and global QOL. The high score in this dimension indicates extreme anxiety on the part of the individual about the illness and demonstrates the degree of negative impact. There are studies reporting similar findings.<sup>1,2,14</sup> Especially when the symptoms grew more severe and diversified, it was seen in a study that patients had a perception that "they would have to live with this illness for the rest of their lives" and that their rating in this context was the high score of 7.17 out of 10, with most of the patients stating that they perceived that they would die from lung cancer due to their symptoms and the

course of the illness.<sup>7</sup> The current study was consistent with that of Vollmann et al. which found a significant correlation between the timeline (acute/chronic) and the diagnosis period and that with a prolonged diagnostic period, with the patients believing that their illness was chronic and their control over the condition diminished with time.<sup>14,15</sup> The current findings were also similar to two other studies.<sup>7,8</sup>

A positive, weak and significant correlation was found in the current study between treatment control and the impact of the illness on activity, the LCSS total score and the KPS. The higher scores in this domain show that the individual has a positive perception that the illness will be taken under control with treatment. Furthermore, it was observed that 92.4% of the patients believed that the treatment would make them well. This finding is consistent with the literature.<sup>14</sup> Lung cancer patients described their disease as a "mystifying illness" and stress their belief that they will either die from it or be cured.<sup>6,7,14</sup> Our study supports this finding with patients' scores in the illness coherence subscale being low ( $2.66 \pm 0.59$ , Table-1). This result indicates that patients do not understand their illness and find it mysterious. The current study showed a weak but significant positive correlation between the timeline (cyclical) and the duration of chemotherapy and the period of diagnosis. The high score in this domain indicates that individuals believe the illness to be cyclical. These data were found to be compatible with the literature.<sup>14</sup>

We found a positive, weak but significant correlation between consequences and age as well. As patients got older, it was seen that they firmly believed that the illness had very serious consequences and they had a negative perception of the process. Also supporting this conclusion was that the older the patients were, as a result of the impact on their immune system, there was a positive and significant correlation between fatigue, LCSS overall scores, the mean symptom burden score and the KPS. This result may be interpreted to mean that with advancing age and the deterioration of the immune system, patients associated the symptoms they experienced with the illness and harboured negative thoughts. The findings of a study support these results.<sup>6</sup> On the other hand, a negative and significant correlation was determined between the psychological attribution subscale and age and the duration of chemotherapy. The fact that the mean age of the individuals in this study was high may be attributed to the extended length of their period of diagnosis. It is reported in literature that individuals' illness perceptions change over time, that becoming more informed about the illness and the

treatment makes a positive impact, and that a social web and the support of spouses play an important role in emotional perceptions.<sup>16</sup> While no significant correlation was found in the current study between the personal control subscale and risk factor variables ( $p>0.05$ ), a significantly negative correlation was found between accident or chance and dyspnoea, but a significantly positive correlation in terms of the KPS. This can be interpreted to mean that personal control had no impact on the symptoms experienced, and that the patients did not associate their illness with the risk factors related to lung cancer. When the patients' perceptions of the illness were reviewed, it was seen that the personal control score was lower compared to the other subscales. Similar findings have been reported in literature.<sup>14,15</sup>

The current study was conducted at a single centre, which was a limitation. In the light of the findings, it is recommended that knowing the perceptions of individuals about cancer before starting the treatment process is critical, and so is the identification of individual factors that may adversely affect this process. As a result of the evaluations, psychological counselling should be provided to the individual, if necessary. The patients and their families should be considered a whole during the treatment process and the participation of the family in the treatment should be ensured. Also, the functionality of psychological counselling services given to individuals and families receiving cancer treatment must be ensured. Finally, public awareness must be raised about cancer and its perceptions.

## Conclusion

Being aware of the illness perception of lung cancer patients has a positive impact on a patient's QOL. It is important for healthcare professionals to know a patient's perception of his/her illness so that they can prepare their patients for the future. This can contribute to ensuring treatment compliance.

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