



# “Feelings are facts”: Illness perceptions in patients with lung cancer

M.A. Hoogerwerf <sup>a,\*</sup>, M.K. Ninaber <sup>b</sup>, L.N.A. Willems <sup>b</sup>, A.A. Kaptein <sup>a</sup>

<sup>a</sup> Department of Medical Psychology, Leiden University Medical Center, PO Box 9600, LUMC, J-9-079, 2300 RC Leiden, The Netherlands

<sup>b</sup> Department of Respiratory Medicine, Leiden University Medical Center, PO Box 9600, 2300 RC Leiden, The Netherlands

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## Summary

Given the high degree of psychosocial problems in patients with lung cancer, quality medical care would benefit from exploring and addressing and providing potential solutions for these problems.

Patients with recently diagnosed non-small-cell lung cancer filled out a questionnaire that assessed illness perceptions and made a drawing of how they perceived their diseased lungs look. They also participated in an interview about the impact of lung cancer in their lives.

Scores on the Brief Illness Perception Questionnaire indicated that patients score low on ‘concern’, ‘emotional response’ and ‘timeline’, indicating they hope to be cured from lung cancer. Patients drew the tumor larger than it is on the chest radiograph. The drawings are moderately accurate representations of the patients’ lungs. In the interviews patients often expressed their hopes of being cured and how thinking positively would help. Patients who made a more accurate drawing of their lungs had less optimistic views about their prognosis. These views are more in line with the prognosis their physician would give them. However, few patients made an accurate drawing.

This study contributes to a better insight into what patients believe and feel about their disease. Suggestions for taking patient perceptions into account are provided.

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\* Corresponding author. Tel.: +31 6 10838564; fax: +31 71 524 8123.  
E-mail address: [m.hoogerwerf@umail.leidenuniv.nl](mailto:m.hoogerwerf@umail.leidenuniv.nl) (M.A. Hoogerwerf).

## Introduction

Cancer is a highly disruptive disease with great impact on patients' lives. Due to the relatively poor prognosis and the invasive and disruptive treatment, patients with lung cancer report higher levels of distress than patients with other types of cancer.<sup>1</sup> They report a high number of unmet needs in psychosocial care and high levels of anxiety and depression.<sup>2</sup> Research shows how attention to psychosocial needs can diminish symptoms and anxiety.<sup>3,4</sup> Because the incidence and mortality from lung cancer remain high<sup>5,6</sup> and curative treatment is not available in many cases, quality of life is extra important in treating patients with lung cancer.

For medical professionals, realising how patients experience their disease may be instrumental in giving the best possible care. One way to examine the beliefs of patients about their illness is through investigating illness perceptions. In the Self-Regulation Model, Leventhal et al.<sup>7</sup> describe that in response to a health threat, patients form perceptions about that perceived threat. Patients will also form a coping plan to deal with the consequences of the health threat or illness.<sup>8</sup> The illness perceptions can be divided into two categories: cognitive and emotional, with the following dimensions: consequences (the influence on the patient's life), timeline (how long the illness will last), control (both personal and treatment control), identity (the complaints attributed to the illness), concern, coherence (can the patient make sense of the illness), emotional response, and cause. Illness perceptions drive coping, illness behaviour and, therefore, outcome of medical and psychosocial care.<sup>9,10</sup> It is crucial to note that illness perceptions are most likely to be not 'objectively' correct. Leaving aside the issue of what 'medically correct' is, illness perceptions reflect the emotional and cognitive response of people to a complaint, a symptom, or an illness. People are motivated to act by these 'subjective' representations of what is happening in their body, and what medical management does to it. This offers a chance to influence adherence, self-management and outcome via studying and addressing these illness perceptions.<sup>11–13</sup> Hirsch et al.<sup>14</sup> and Lutgendorf and Sood.<sup>15</sup> have also demonstrated how illness perceptions and psychological influences impact health outcomes in patients with cancer, thereby underlining the importance of integrating patients' subjective views into standard clinical care.

Illness perceptions can be assessed with questionnaires (e.g. B-IPQ, IPQ-R) or open interviews. Illness perceptions can also be identified in patient's stories, for instance through weblogs or personal accounts written by patients or family, and in novels (for example Julia Glass – Three Junes, Alice Elliot Dark – Watch the animals). A third and relatively new way of assessing illness perceptions is the use of drawings. Reynolds et al. have demonstrated that drawings made by patients after a myocardial infarction are good predictors of their physical and psychological status afterwards<sup>16</sup> Similar results have been found in patients with headaches, vestibular schwannoma and SLE.<sup>17–19</sup>

There have been several earlier studies into illness perceptions in lung cancer patients. Kaptein et al. have compared illness perceptions and quality of life in Dutch and Japanese patients.<sup>8</sup> Other studies have focused on smoking

behaviour and cause attribution.<sup>20,21</sup> Several studies have used qualitative interview techniques to identify important themes after a diagnosis of lung cancer.<sup>22,23</sup> This study is the first to use drawings to investigate illness perceptions in lung cancer patients. Also, it is the first study to combine drawings, an illness perceptions questionnaire and interviews in a sample of patients with non-small-cell lung cancer. Given the paucity of research about illness perceptions in patients with lung cancer, this study is exploratory in its nature. It investigates (a) the illness perceptions patients with lung cancer hold, (b) the associations between these perceptions and scores on a validated measure that assesses illness perceptions (B-IPQ), and (c) the associations between illness perceptions as reflected in drawings and B-IPQ scores, and the chest X-ray which depicts the tumour.

## Patients and methods

Patients were recruited from the out-patient clinic of the department of Respiratory Medicine of the Leiden University Medical Center. Included were patients with non-small-cell lung cancer (NSCLC), any stage, who spoke sufficient Dutch or English to complete the interview, were physically well enough to sustain the interview, who had had at least one appointment with a treating physician after the diagnosis was made, and who were receiving or were going to receive some form of treatment. Patients were excluded if they had a medical education. Written informed consent was obtained from all patients. Tumor stage, pathology and the chest radiograph at time of diagnosis were obtained from the medical files after patients' written consent.

At the start of the interview, information about marital status, level of education and smoking status was collected. Patients were then asked to make a drawing of what they imagined their diseased lungs look like. They were also asked to fill out the Brief Illness Perception Questionnaire (B-IPQ). This is a questionnaire consisting of 8 questions measuring 8 dimensions of illness perceptions on a scale from 0 to 10, and an open question about what the patient considers to be the causes of the illness.<sup>24</sup> To gain a more detailed picture, the researcher asked the patients to explain their answers. Patients' answers were tagged down in keywords. These keywords were later categorised and counted. Afterwards, patients were invited to discuss further issues that had not previously been discussed but that they felt to be important too.

The drawings were analysed using ImageJ software.<sup>25</sup> The size of the tumor was measured and the proportions between tumor and lung were calculated. Measurements were done by two assessors. Agreement between measurements was assessed with a Bland Altman plot. Measurements that did not fit within  $\pm 2SD$  were discussed and consensus was reached between the assessors. In the chest radiographs, the size of the tumor and the lung were measured using the same procedure.

The drawings were analysed by defining three categories of importance: correctness of the shape of the lung, size of the tumor, and level of detail. These aspects were subsequently scored by each researcher individually as high or low for level of detail, correct or incorrect for shape of the lungs, and

location of the tumor. The researchers were three of the four authors of this article: a medical student, a pulmonary physician and a psychologist specialised in illness perceptions. This choice of researcher ensured that the drawings were assessed regarding both the clinical and psychological aspects. The kappa value for inter-observer reliability was 0.553.

The scores of the three researchers were averaged to create one score for each category.

The mean scores on the B-IPQ were calculated. The explanations given by the patients were categorised and scored.

Descriptive statistics were performed for the patient characteristics. Correlation between outcomes was assessed with Spearman's rank correlation coefficient. All calculations were done using PASW SPSS version 18.

The research project was approved by the Medical Ethics Committee of the Leiden University Medical Center.

## Results

Twelve patients were included. Patient characteristics are given in Table 1.

### Drawings

One patient was not able to make the drawing. She was feeling unwell during the interview and could not sit up straight to complete a drawing. She did complete the questionnaire and interview. Three drawings were rated as

high in detail, 8 as low. Location of the tumor was judged to be correct in 4 drawings, shape was rated as correct in 5. The interval between observing the chest X-ray and making the drawing was found not to have an effect on the accuracy and level of detail of the drawing.

The drawings of the diseased lung measured on average 19.03 cm<sup>2</sup> (range 5.42–53.58). The mean percentage of space within the lung drawing taken by the tumor was 10.98% (0.55–28.24). The mean percentage of the tumor on the chest radiograph was 5.91% (0.63–15.30). The mean ratio between these two measurements was 2.37 (0.52–9.95). Six patients drew the tumor over twice the size it is on the chest X-ray.

Three patients' drawings and their chest X-rays are included (see Fig. 1). Illustration 1A shows the drawing and chest radiograph of a 76-year old retired plumber who wanted to know everything about his illness. He had looked very carefully at his chest X-ray and made a very accurate drawing, depicting his lungs before and after treatment. Illustration 1B shows the drawings and chest X-ray of a 58-year old engineer. He has drawn the tumors in his lungs and the metastasis in his head. Illustration 1C shows the drawing of a 74-year old lady. The tumor is in the same location as in the lateral chest radiograph, but the drawing is made as seen from the front.

### B-IPQ

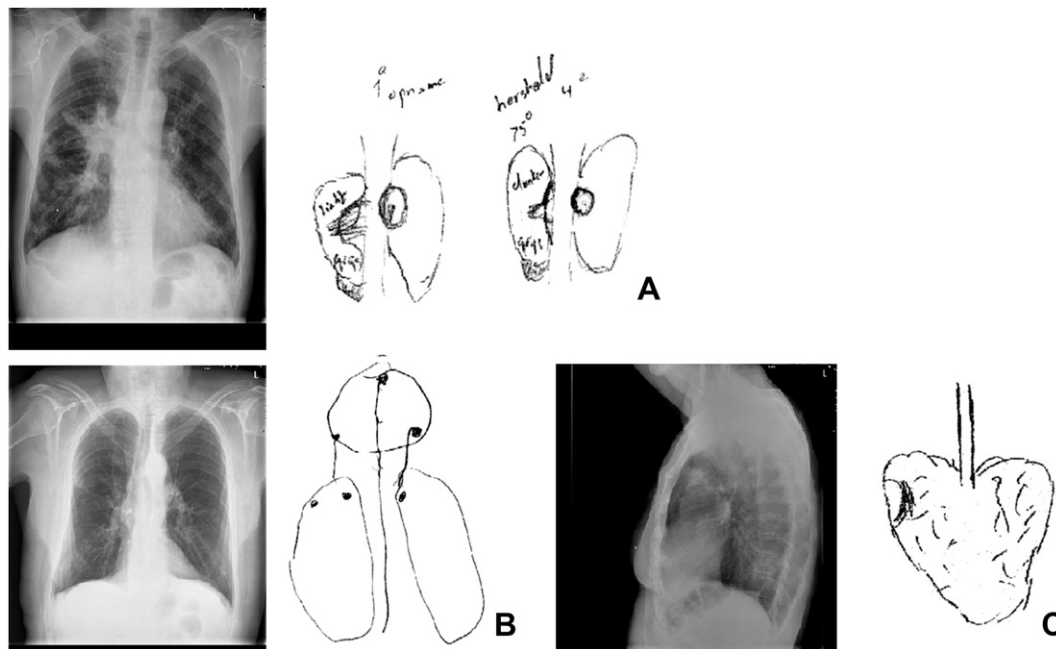
The average scores on the B-IPQ dimensions are displayed in Table 2. Most scores are moderate, between 5 and 7. Treatment control scores highest (7.50). Scores around 5 on 'emotional response' and 'concern' indicate that patients are not highly emotional or worried. Scores on the B-IPQ dimensions for melanoma, diabetes type 2, SLE and in a previous study in lung cancer patients are included in the table.<sup>7,23,26</sup> Patients in this study answered lower on 'concern' and higher on 'personal control' than in a previous study in patients with NSCLC. Patients with diabetes type 2 or SLE score higher on timeline. Coherence is significantly higher in melanoma patients and identity is lower. Most named causes for lung carcinoma were smoking ( $n = 6$ ) and bad luck ( $n = 4$ ). Other causes mentioned were hard work, stress, genes and familiar disposition, nutrition and working with chemicals. Two patients said that they had "no idea" what caused their disease.

### Interview

The explanations given during the interview are categorised in Table 3. Of the 12 patients, four patients answered they cannot be cured and will die of their disease, whereas four clearly expressed their hope to be cured. Most patients are convinced that being positive helps in being cured or doing better during chemotherapy. Only one patient answered that he knew the treatment would not cure him. In half of the patients, their physical complaints were caused mainly by the chemotherapy, according to the patients. Four patients said they were not worried about the disease. "I'm not worried. I'll worry when I have to. Keeping positive is better for my peace of mind." Those who were concerned worried about letting go of their family or the pain their

**Table 1** Patient characteristics.

Characteristic	Patients ( $n = 12$ )
Gender	
Male	5
Female	7
Age (years)	
Median (range)	70 (52–88)
Histology	
Squamous	7
Adeno	4
Large cell	1
Stage	
I	2
III	3
IV	7
Treatment modality	
Surgery	3
Hemotherapy	11
Radiation therapy	7
Smoking status	
Current smoker	3
Former smoker	8
Never smoked	1
Years smoked	
Median (range)	30 (0–66)
Education	
Primary school	2
Vocational training	5
Secondary education	3
Higher education	2



**Figure 1** Left: X-thorax, made before treatment Right: Patient drawing Illustration 1A: Patient drawing left: 1e opname = first admission, licht grijs = light grey Patient drawing right: hersteld = recovered, 4e = after fourth chemo, donker grijs = dark grey.

family experienced, and about how the disease would develop and what would happen to them. "I'm not worried about me, when I die everything is taken care of. I do worry about letting go of my family, of my wife. I would have loved to grow old together". Patients often wondered 'why me?' Often, they did not understand why this happened to them. "Of course I don't understand. Who can understand bad luck?" When asked for other things patients found important to discuss, most mentioned the health care system. Generally, they thought the medical staff was very friendly. The patients would like their physician to have more attention for the psychological and social consequences and their fears and to understand that waiting can be very tormenting. "Waiting in the waiting room is killing, especially when the doctor is running late." They also mentioned that lung cancer seemed worse than other types of cancer, because of the unfavourable prognosis and the association with

smoking. "Lung cancer is worse than for instance bowel cancer. You could have prevented this."

**Associations between B-IPQ, drawings and interview**

Because of the small sample size, statistical analyses are limited to a few correlations.

There is a statistically significant correlation between the accuracy of the drawing and the answer to the B-IPQ dimension 'timeline': the higher the score on timeline, the higher the accuracy of the drawing. Also, patients with a more accurate drawing expressed less hope of being cured by the treatment. This illustrates that patients with a more accurate drawings were less optimistic about their chances of being cured from the disease.

**Table 2** Scores on the B-IPQ dimensions (means and standard deviations), compared with other patient samples. Differences are computed with current sample (n = 12) as reference sample.

B-IPQ dimension	Mean ± SD				
	Lung cancer N = 12	Lung cancer <sup>17</sup> N = 24	Melanoma <sup>27</sup> N = 120	DM2 <sup>11</sup> N = 119	SLE <sup>10</sup> N = 32
Consequences	6.67 ± 2.61	7.50 ± 2.86	4.74 ± 3.00*	4.7 ± 2.9*	6.5 ± 2.3
Timeline	7.17 ± 2.41	6.13 ± 2.70	5.78 ± 3.56	9.2 ± 1.9*	9.2 ± 1.8*
Personal control	6.50 ± 1.93	3.88 ± 3.60*	6.61 ± 2.79	6.7 ± 2.3	5.6 ± 2.7
Treatment control	7.50 ± 1.88	6.82 ± 2.59	7.93 ± 2.12	8.0 ± 2.3	8.4 ± 1.6
Identity	5.92 ± 2.61	3.70 ± 3.05	2.23 ± 2.62*	4.6 ± 2.8	6.0 ± 2.6
Concern	5.50 ± 2.91	7.83 ± 2.63*	5.42 ± 3.21	7.0 ± 3.1	5.8 ± 2.7
Coherence	5.33 ± 3.75	5.58 ± 3.45	8.08 ± 2.21*	7.9 ± 2.3*	6.8 ± 2.6
Emotional response	4.67 ± 2.74	5.21 ± 3.09	4.37 ± 2.91	4.3 ± 3.3	5.8 ± 2.7

\*p < 0.05.

**Table 3** Patient interview.

Dimension	Answers (no. of patients)
Consequences	Restrictions <sup>7</sup> Letting go of family No future anymore Making last arrangements Betrayed by body Positive consequence: attention of family and friends <sup>2</sup>
Timeline	Cannot be cured <sup>4</sup> Hope to be cured <sup>4</sup> The doctor's says I've got this much chance <sup>2</sup> The disease can bloom every moment <sup>2</sup> No idea <sup>2</sup>
Personal control	Positive attitude helps <sup>8</sup> Can do little yourself <sup>3</sup>
Treatment control	I noticed or saw on the x-rays that treatment helps <sup>6</sup> I hope it helps this much <sup>3</sup> Won't cure me
Identity	Complaints mostly due to treatment <sup>6</sup> Fatigue <sup>5</sup> Shortness of breath <sup>3</sup> Difficulties while walking <sup>3</sup> Pain <sup>3</sup> Coughing <sup>2</sup> None <sup>2</sup> Difficulty sleeping Nausea
Concern	Letting go of family, worries about family <sup>4</sup> Don't worry <sup>4</sup> What will happen to me <sup>2</sup> There is no cure You have to put faith in what doctors do
Coherence	Don't understand why this happened to me, why me? <sup>6</sup> I want to know everything <sup>2</sup> Just happens to you, nothing to be understood It's a mysterious illness
Emotional response	Just happens, go on as usual <sup>5</sup> Fear <sup>4</sup> Sadness <sup>2</sup> Anger <sup>2</sup> Keeping busy helps <sup>2</sup>
Other	Very friendly medical staff <sup>5</sup> Worse than other types of cancer, brought this on yourself <sup>3</sup> Waiting for treatment or appointments with the doctor is very hard <sup>3</sup> Important that doctors explain things and are open to patients <sup>3</sup> Doctor only interested in medical issues, would like to talk about non-medical issues <sup>2</sup> Difficult the GP left this so long I feel like a number in hospital

When looking at the interviews and drawings it appears there is a connection between size of the drawing and worries. Patients with larger drawings of the tumour generally commented that they were more worried and felt that their disease would last longer.

## Discussion

### Major findings

This study illustrates the beliefs of patients with lung cancer and the degree of accuracy of their views on the tumor in their lungs.

The patient drawings are moderately accurate. There are large differences between patients: some draw an almost perfect copy of the chest radiograph whereas some drawings are far removed from the actual situation. In six out of eleven drawings, the tumor is drawn twice the size it is on the chest X-ray. This could be due to the assignment of drawing the lungs as imagined with the tumor in it. It could also show that patients tend to 'blow up' the tumor in their head because of the very substantial influence it has on their lives. In patients with heart failure a larger drawing of the heart was associated with higher levels of heart-specific anxiety.<sup>16</sup> In our study, patients who drew a large tumor appeared to be more worried and answered that their disease would last longer or their entire life. At the time of diagnosis, patients were shown their chest radiograph and their physician made a drawing for them as well. Some patients had seen repeated control chest radiograph. The interval between seeing the chest X-ray and making the drawing varied between three months and one week. There was no relation between the duration of the interval and the accuracy of the drawing. Most drawings are not consistent with the chest radiograph or the doctor's view, reflected in the scores on location of the tumor and shape of the lungs.

There are several surprising outcomes in the B-IPQ scores. The score on 'concern' is relatively low. Lung cancer is a very serious disease with an unfavourable prognosis. Patients would be expected to worry a lot. The same goes for the score on emotional response. Furthermore, patients score their illness as lasting 7.17 out of 10. This score is significant, because the highest score is 'this disease will last the rest of my life'. Patients who gave this answer acknowledged that they would die from lung cancer. Patients who gave answers lower on the scale hoped they would eventually be cured or did not dare to face that they would die from lung cancer. Denial could influence these outcomes: patients may well know how serious their illness is but may be afraid to admit this.

In this study, there was no evidence that patient's perceptions influenced their treatment trajectory or self-care. Patients with unrealistic optimistic expectations did not express less willingness to be treated or worse self-care. On the contrary, it appears from the interviews that patients who have more hopes to be cured, also have more faith in the treatment, because they expect it will cure them. However, this was not systematically studied and can only be concluded based on impressions from the interview.



Patients with more accurate drawings were less optimistic about their disease and had a perception of their illness and prognosis that is more like that of their physician. Most oncologists and pulmonologists would acknowledge that it is very likely that the patients will die from their disease. The 5-year survival rate of lung cancer is 50% for stage IA and drops to 2% for stage IV.<sup>27</sup> This is not in line with what patients hope for: many express their hopes that they will be cured, even though they have been diagnosed with stage III or IV NSCLC. This mechanism has been described by Salander et al. (1999) as 'disavowal': self-deception in the face of an accurate perception, as a way to cope with their diagnosis and treatment.<sup>28</sup> This can also be brought about by doctors: The described in her thesis how patients can hold on to the smallest hope in the expressions of their physicians.<sup>29</sup>

### Comparison with the literature

Other studies have found the same effect of denying the severity of the illness or denying smoking as a cause for lung cancer.<sup>20,29</sup> Berterö et al. described that patients generally want to go on as usual and adapt themselves to be able to do this.<sup>21</sup> The patients in our study also frequently mentioned they want to go on as usual. They find that the physical restrictions influence their lives the most and they do not want to let the disease affect them too much emotionally. That would interfere with going on as usual.

The B-IPQ has been used in a previous study in NSCLC patients.<sup>8</sup> This earlier study showed a lower score on 'personal control' and a higher score on 'concern' compared with the current sample. The patients in our study were interviewed earlier in the disease process. The score on 'personal control' has been shown to decrease in time after diagnosis.<sup>21</sup> The comparison between B-IPQ scores shows that lung cancer is not perceived as a chronic disease like SLE or diabetes mellitus. Patients said they would either die from the disease or be cured. For both melanoma and lung cancer an important causal factor is known, but patients with melanoma report a higher coherence. This is consistent with the remarks of the lung cancer patients about lung cancer as a 'mysterious illness' and 'worse than other types of cancer'. Melanoma is also more visible than lung cancer, which may make it less of a mystery. Furthermore, lung cancer is often discovered in a more advanced stage which may influence coherence.

### Limitations

Because of the small number of patients, this study cannot assess the values of the drawings accurately. There are some associations found, but statistics are not completely reliable in such a small study. In order to assess the value of drawings more accurately, studies in larger patient groups are needed. Furthermore, the outcomes may be biased through selection bias. Those patients who did not want to talk about their illness may experience more concern and emotional effects of the disease which makes them unwilling to talk about it. Also, patients who were severely ill appeared to be less willing to participate in the study,

which may have caused a selection bias towards healthier patients.

Age could have been a confounder in this study, as elderly patients could have resigned more easily to their disease and would therefore have been less concerned. However, the level of concern was not observed to have any relation with age and was spread randomly between the ages.

### Research implications and clinical implications

Although this is a pilot study, several important features are found. This warrants research in a larger group of patients in order to validate these findings. Furthermore, it is clinically very relevant to know how patients' perceptions influence their treatment trajectory and self-care. This was not systematically addressed in this study. Drawings have shown to be a good way of researching illness perceptions. They can hold valuable information about how the patients feel about their illness. If more research is done into drawings and their meaning, they might be a valuable addition to clinical practice.

Patients' illness perceptions are not always in line with what their physician thinks. This may be a reflection of patients' coping styles or a lack of understanding between doctor and patient. It is important to address these differences in order to provide the best possible care, because illness perceptions influence illness behaviour and expectations. Patients should hold realistic views of their prognosis to be prepared for what might come. On the other hand, hope is very important for patients to sustain the diagnosis and the demanding treatment.<sup>30</sup> It is the physician's task to navigate between these two ends and to find the right balance for each patient between keeping up patients' spirits but also correcting views that are simply wrong. Denial has been shown to have a protective effect on psychological and social outcomes in patients,<sup>31</sup> but isn't it important for patients to know what is coming to them? This question is vital in care for patients with lung cancer. In other diseases, there has been extensive research into how to influence patient perceptions to obtain the best outcomes. Skinner et al. have investigated the influence of illness representations on clinical outcomes<sup>13</sup> and Petrie et al. have initiated the first studies how changing illness perceptions can change patient outcomes in patients with asthma and myocardial infarction.<sup>32,33</sup> That kind of research is needed in lung cancer patients too. Furthermore, in this study, patients expressed they would like their physician to pay more attention to their psychosocial issues. The questions of the B-IPQ and the production of a drawing can be a useful tool in doing so. Furthermore, early palliative care has shown to improve quality of life and survival in lung cancer patients.<sup>34</sup> These findings emphasise the importance of a complete treatment with attention to biomedical, palliative and psychological care.

### Conflict of interest statement

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