



Emotional and social effects of lung cancer

Executive Summary

DESCRIPTION AND OBJECTIVES

The Report “Emotional and social effects of lung cancer” is a descriptive social research project. It employed a structured questionnaire to explore the main emotional and social repercussions of lung cancer in people diagnosed with this disease

in Spain. This research also seeks to know the experience of patients in relation to the care and support received and to identify population groups with greater emotional and social vulnerability, as a result of the diagnosis of lung cancer.

METHODOLOGY AND GENERAL CHARACTERISTICS

The technique used for data collection was a self-filled online survey through the “SurveyMonkey®” platform and it was active from April 11th to June 9th, 2019. The survey was confidential and it was aimed at people diagnosed with lung cancer (both in remission and with active disease). Before its dissemination, the survey was reviewed by a multidisciplinary expert panel comprising 12 people, representing the main scientific societies and patient associations for lung cancer in Spain.

A total of 211 people with lung cancer completed the online survey (sample error: +/- 6.86%). 40.3% of the respondents were diagnosed with adenocarcinoma non-small cell lung cancer and 22.7% of them had small cell lung cancer. These two are the most common sub-types represented in the survey. In this regard, it is remarkable that

11.8% were unaware of the type of lung cancer that had been diagnosed and 50.3% did not know if they had any associated genetic alteration. More than one half were people with metastatic disease (56.9%) at the time of completing the survey, and the treatments received were mainly chemotherapy (68.6%), radiotherapy (46.9%) and immunotherapy (36.5%). 76.7% of the respondents had active disease and 23.3% were in remission when responding to the questionnaire.

The percentage of women who answered the questionnaire was 57% of the total, compared to 42% of men (and 1% of “others”). The sample was weighted in order to avoid the conclusions of the study being biased by gender (Men: 70.4% – Women: 28.7%). The average age was 57.54 years, with 25 being the youngest and 86 the oldest (typical deviation: 11.15).

IMPACT ON DAILY LIFE

Lung cancer affects the future plans and daily lives of the people diagnosed. According to the respondents, the disease negatively affects their day-to-day activities (hobbies, routines, responsibilities, etc.) at a magnitude of 2.71 (from 0 to 5¹) and this rate increases to 3.22 when it refers to future plans. The magnitude of the repercussions is such that 1 in 4 people affirm that the impact of the disease on their daily life has been total (5: maximum score) and 34.5% stated that the disease has totally affected their future plans (5: maximum score). This impact is due, among other reasons, to coexisting with the symptoms and side effects of the disease and treatments, with a special emphasis on tiredness (3.22), pain (2.71), weight changes (2.58) and difficulty breathing (2.37)².

The coexistence with complications of a physical nature resulted in almost half of the patients (48.5%) claiming that they could not perform the basic activities of daily life without some help. The

main difficulties were physical exercise (38.8%), performing household chores (31.4%), travelling (25.8%) and remembering or concentrating (19.8%). The following variables influence the autonomy and daily lives of people with lung cancer:

- **Age:** the younger the age, the greater the involvement of the disease;
- **Gender:** lung cancer has a greater impact on the future plans of women;
- **Clinical situation:** lung cancer has a greater impact when metastases are present;
- **Level of studies:** the higher the level of studies, the lower the involvement of symptoms and side effects;
- **History of smoking:** lung cancer has a greater impact on non-smokers;
- **Place of residence:** lung cancer has a greater influence on those not resident in capital cities.

PSYCHOLOGICAL IMPACT

The impact of lung cancer on the emotional sphere is evident (3.07 in a range of 0 to 5³) and 23.1% patients affirmed that the affectation had been total (5: maximum score).

Age and gender influence the emotional type of repercussions. The disease has a greater emotional impact among women (they also have higher rates of depression). These impacts are statistically significant in terms of loneliness, the feeling of being judged and concern for physical image. Likewise, another variable with the capacity to influence has been identified: people who have never smoked have greater emotional repercussions.

Uncertainty is the most frequent psychological reaction in people with lung cancer (97.6%), the diagnostic process being the time of greatest emotional intensity, especially when receiving the news of the disease (52.4%). Another usual emotion

is fear; 94.6% of the participants said that they had experienced some type of fear, especially related to pain and suffering (57.5%) and death (50.4%). On the other hand, 94.3% of people identified some causative factor of sadness, especially due to the impact of the illness on loved ones (54.9%) and the future forecast (53.0%).

Stigma continues to be very marked in people with lung cancer, since 34.3% have experienced feelings of guilt, 21.6% have felt judged and 19.4% have felt shame for having the disease. For these reasons, 16.0% of patients hid the disease, with a more statistically significant proportion in men, in people who had not smoked and in people residing in provincial capitals and larger municipalities. Hiding the disease can also be related to the fact that 1 in 5 patients reported feeling bad as a result of the reactions of people around them.

IMPACT ON LOVED ONES

The impact at family level is less than in other areas (daily life, future plans and emotional state) but it is the main cause of sadness on the part of the patients.

In addition, there is a statistically significant difference in the impact at family level between people with localised and metastatic disease, with a higher

incidence among the latter. According to the people with lung cancer surveyed, the main symptoms experienced by family members were overprotection towards the patient (53.5%), responsibility overload (31.1%) and physical fatigue (28.4%).

On the other hand, the majority (90.9%) recognised changes in the family, including being a greater family union due to lung cancer (43.3%) and a high emotional impact on someone in the family (41.3%). It is relevant that the percentage of women who showed a greater family union was much higher than that of men (+ 25.8%). On the other hand, men more frequently experienced family distancing, compared to women (+ 20.0%).

Regarding relationships, 3 out of 4 patients with a partner stated that the relationship had been in some

way positively affected in the context of the disease, and more than half (56.4%) considered that the relationship had been reinforced after diagnosis. Men considered more than women that their relationship was strengthened after diagnosis (+ 17.3%).

It is worth noting that the couple was the main point of support more for men than for women, who were more likely to go to friends and family for support. The main negative impact of the illness was related to a reduction in intimacy and sexual activity. Six out of 10 patients (with or without a partner) had sexual difficulties. This problem was aggravated by the scarce health approach: 88.5% of those who said they had sexual difficulties had not turned to health professionals.

IMPACT ON FINANCE AND WORK

The majority of people with lung cancer (88.8%) did not work at the time of the survey. 79.9% of those who had continued working recognised difficulties in their work activity, especially with achieving their usual professional performance. The impact at work level also had an influence on the economic situation of the participants; in this sense, 45.9% of the patients affirmed that lung cancer had had a

negative or very negative impact at the financial level. The main causes of this were a reduction in income due to labor reasons (35.8%) and because they now receive a more reduced economic pension that the salary they received (34.2%), the expenses for transferring to the hospital (26.1%) and for the acquisition of new habits (24.3%).

SUPPORT RESOURCES

The respondents made a very positive assessment of the support received from family and friends. The vast majority (96.6%) had people in their environment to help them in daily activities (errands, shopping, household chores, etc.). In addition, family and relatives played an important role in emotional support: 76.6% claimed to have support at all times from family and loved ones, and 16.5% said that this was true on most occasions. The same happened (although with a smaller proportion) with the availability of people to talk to. In this sense, it is worth mentioning that 9.1% said that they only sometimes had someone to talk to, and 7.8% said never or almost never.

The negative counterpoint is found in formal or professional support resources. The high functional, social and emotional impact of lung cancer requires a multidisciplinary approach with the

participation of professionals from different disciplines. Despite this, the results show that only a minority of patients went to professionals in psychology (21.3%), social work (7.3%), psychiatry (7.4%) and physiotherapy (10.1%).

On the other hand, only 1 in 10 people claimed to have been treated by a palliative care unit, and it was found that there is a limited psychological and medical approach to complications of a sexual nature, since most of those who had had difficulties in this area had not gone to health professionals (88.5%).

Another underutilised resource is NGOs and patient associations, since 3 out of 4 people had not gone to these entities. This is mainly due to the fact that 61.8% did not know whether being in contact with an association or NGO would be useful in any way.

CALL TO ACTION

- Increase accessibility to support professionals to improve the quality of life and integration into multidisciplinary committees (social work, physiotherapy, sexology, psychology) and improve access to palliative care.
- Develop a social protection model that covers people with lung cancer with greater economic vulnerability.
- Make visible the role of NGOs and patient associations as support and information resources.
- Ensure that the messages from the health and social fields are transmitted to people with lung cancer in order to reduce stigma.

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If you would like to get the full Report (in Spanish) you can download it by accessing

www.fundacionmasqueideas.org

www.afectadoscancerdepulmon.com

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