Lung Cancer Europe

5th LuCE REPORT ON LUNG CANCER

Psychological and social impact of lung cancer

Lung Cancer Europe

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5th

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November 2020

LuCE

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WELCOME TO THE 5th EDITION OF THE LuCE REPORT

This is an annual initiative led by lung cancer patient organisations, with the purpose of raising awareness regarding the main challenges faced by people impacted by this disease across Europe.

People impacted by lung cancer face significant emotional and societal challenges. We, as a community, must work together to implement changes to help improve their quality of life.

Many faces, one voice.

The impact on quality of life can be significant with a profound effect on emotional, social and spiritual well-being.

Lung cancer is the biggest cancer killer worldwide. In Europe, there are 470,000 new diagnoses and more than 380,000 lung cancer deaths every year[1]. One in five of all cancer deaths in Europe are due to lung cancer. Raising awareness, screening, early detection and access to treatment and clinical trials remain essential to improve outcomes. The pathway from presentation to diagnosis and treatment through to survivorship issues can be bewildering and complex. As such, there is a wealth of information available on the symptoms of lung cancer and the physical side effects of treatments, whether radical or palliative in intent.

The aim of our 5th LuCE report is to get a better understanding of the psychological and social impact of lung cancer, not only for people with the disease but also for those in a caregiving capacity. Caregivers (family members and friends) provide physical, practical and emotional support on a daily or as-needed basis. This can include a range of responsibilities including helping manage symptoms and side effects, giving medications, providing transport to and supporting hospital appointments, assisting with meals, household chores and finances. Although the focus of caregivers is the person they are caring for, it is important for caregivers to also have access to support.

People with lung cancer often have multiple symptoms simultaneously related both to the primary disease and treatment(s). The impact on quality of life can be significant with a profound effect on emotional, social and spiritual well-being. Our lives and healthcare systems have of course changed during 2020 due to the impact of COVID-19. We have all experienced the challenges of coronavirus, but lung cancer does not wait for a pandemic to pass. The importance of addressing the psychological and social impact of a lung cancer diagnosis is therefore even more complex. In order to provide a holistic approach to the care of all of those impacted by lung cancer, access to appropriate support is essential regardless of geographical location or socio-economic status.

Lavinia Magee

Patient advocate and nurse consultant. Board member of Lung Cancer Europe (LuCE)

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1. About this report

LuCE is an organisation committed to people impacted by lung cancer. Formed by patients, caregivers and advocates, LuCE promotes a patient-centered and multidisciplinary approach to healthcare delivery. Our goals are to promote early diagnosis and the best possible treatment, and to ensure essential supportive services and resources are available when needed throughout the entire lung cancer pathway.

Implementing a multidisciplinary patient centred approach requires an understanding in relation to which spheres of life are impacted by a lung cancer diagnosis. On the one hand, this involves supporting the role of healthcare professionals in empowering people to cope with the needs that arise throughout the care pathway. Patient-centered care is about focusing on the needs of the person, rather than the needs of the healthcare system. This requires understanding peoples´ experience and identifying their needs and priorities.

As part of the lung cancer community, we are aware of the significant impacts in quality of life brought by the diagnosis of this disease. With improved outcomes, concerns regarding quality of life has gained attention among the scientific and medical community. Nowadays, there is a clearer understanding that this includes physical, emotional, functional, and social wellbeing. Lung cancer is a disease with high unmet need in these areas. Studies suggest that people affected by lung cancer experience greater emotional distress than people with other cancers, due to poorer prognosis and health outcomes, and increased feelings of guilt and stigma[2-3].

This report on the ´Psychological and social impact of lung cancer´ is a descriptive social research analysis exploring the major emotional and social issues experienced by people impacted by lung cancer in Europe. The purpose of this report is to raise awareness of the high emotional and social issues related to this disease, as reported directly by patients and caregivers. The findings of this report stress the need to implement a more friendly, more accessible, and more holistic approach to healthcare services.

1.1. RESEARCH OBJECTIVES

- To explore the psychosocial impact of lung cancer for patients and caregivers by centring on four main spheres: emotional wellbeing, impact on daily life, impact on family and loved ones, and consequences on work and finances.

- To explore the experiences and opinions in relation to patient care and support offered by healthcare professionals, family and loved ones, patient associations and non-profit organisations.

- To identify areas which must be improved in order to enhance psychosocial support for people affected by lung cancer, and reduce the burden caused by the disease.

1.2. METHODOLOGY

LITERATURE REVIEW

A comprehensive literature search of the PubMed database was conducted between February and March 2020, with search terms concentrating on psychosocial impact of lung cancer on patients and caregivers.

Previous findings reported in the literature were used to aid in the design of an online survey for people impacted by lung cancer (patients and caregivers) and a set of questions for qualitative interviews with specialists. A list of references is provided at the end of the report.

QUALITATIVE INTERVIEWS

We conducted 10 interviews with people involved in the lung cancer community from 8 European countries between May and June 2020. The purpose was to improve our understanding of the main challenges regarding the psychological impact of lung cancer on patients and caregivers, and to identify opportunities in healthcare services, which could help to address unmet needs. The questionnaire can be accessed at https://www.lungcancereurope.eu/2020/10/15/5th-edition-of-the-luce-report/. Names and affiliations of experts interviewed are as follows:

1. **Dearbhaile Collins.** Consultant Medical oncologist, Cork University Hospital (Ireland).

2. **Dégi László Csaba.** Social worker. Associate Professor and PhD Advisor at the Babes-Boyai University. Member of the Committee for Social Work and Support in Oncology at the Romanian Ministry of Health. (Romania).

3. **Bernard Gaspar.** Patient advocate. President of Asociación Española de Afectados de Cáncer de Pulmón (Spain).

4. **Günter Kranz.** Patient advocate. Member of Bundesverband Selbsthilfe Lungenkrebs e.V. (Germany).

5. **Isabelle Lebrocquy.** Patient advocate. Founder and Director of oPuce. Initiator of Dutch Governmental Plan of Action for Cancer and Work (The Netherlands).

6. **Debra Montague.** Patient advocate.

Founder of ALK Positive UK (The United Kingdom).

7. **Maria Vittoria Pacchiana.** Psychotherapist and psycho-oncologist. San Luigi Gonzaga Hospital, Orbassano-Turin. Member of WALCE onlus (Italy).

8. **Patricia Pugh.** Counsellor/Psychotherapist. Services manager at ARC Cancer Support Centres (Ireland).

9. **Kirsi Roos.** Oncology Nurse. Cancer Society of Southern Finland (Finland).

10. **Joanna Vick**. Lung cancer clinical nurse specialist. Royal Marsden Hospital (The United Kingdom).

ONLINE SURVEY FOR PATIENTS AND CAREGIVERS

Survey design

A survey containing 40 open and closed questions were drafted in conjunction with Fundación MÁS QUE IDEAS (Spain), and reviewed by experts in the field. The objective of this survey was to explore patients' and caregivers´ experiences about the emotional and social impact of lung cancer, and to identify the main barriers to accessing care in these areas. The survey was open to people affected by lung cancer (patients and caregivers). It was confidential and it did not include questions relating to personal information.

Data was collected through a self-filled online survey through the "Surveymonkey®" platform. While this tool is widely used, it does give rise to certain limitations, such as difficulties in reaching certain types of participants (i.e. those who do not have internet access or are not regular internet users). Also, the average time to complete this survey was 15-20 minutes, and this can mean that participants are less likely to stay engaged for the duration of the survey. This resulted in a number of participants not completing all the survey questions.

The survey was translated into 12 languages: Dutch, English, Finish, French, German, Greek, Hebrew, Italian, Latvian, Polish, Romanian, Slovenian and Spanish. The English version of the questionnaire can be accessed at the following link: **https://www.lungcancereurope.eu/2020/10/15/5th-edition-of-the-luce-report/.**

Survey dissemination

The survey was active from May 20th until June 25th 2020. It was disseminated through the communication channels of LuCE and LuCE members, including websites, direct email and social media channels. The main routes of dissemination were patient associations, non-governmental organisations (NGOs) and patient advocates, so it is logical to deduce that many of the people who participated had previous contacts with these support organisations (34.9% of respondents stated that they had received support from organisations).

Finally, this survey was delivered during the COVID-19 pandemic, which brought with it a range of additional issues and problems for people living with cancer. This may have resulted in modified responses, due to the increased anxiety, physical isolation and health repercussions that COVID-19 may have brought to the people surveyed.

Data analysis

A quality control check of the data was performed to identify and delete invalid answers (Refer to `General characteristics´). Data generated from the different language versions were integrated together using SurveyMonkey® analytic tools. Open questions were translated into English, aggregated and standardised into a single curated data set. National comparisons were performed only when there were more than 15 participants per country.

Finally, data from qualitative interviews, online surveys and the literature review, were combined to create a draft of this report, which was reviewed by LuCE, Fundación MÁS QUE IDEAS, and the experts interviewed. A finalised version of the report was then prepared.

1.3. GENERAL SURVEY CHARACTERISTICS

Participant characteristics

The total number of respondents was 786. However, 227 were disqualified due to (a) were neither patients nor caregivers (n=123); (b) completed the sociodemographic questions only (n=98); (c) did not reside in the WHO European region (n=6). Therefore, **the final sample size was 559 people.**

The majority of the participants were patients (65.3%), female (75.4%), and between 55-64 years of age (39.7%). This female over-representation is slightly higher in caregivers

(78.9%) compared to patients (73.5%). This bias should be considered when interpreting the data, as literature shows significant gender differences in the distress levels reported by people with lung cancer, with studies showing that women exhibit higher overall psychological impact than men[4-5]. The median age at diagnosis of this disease is 70 years[6], therefore the average age of participants in this survey was significantly younger.

The leading respondents came from France (22%), Spain (11.3%), Denmark (10.9%) and Italy (10%). Caregivers accounted for 34.7% of participants (relatives or a friend of the person with lung cancer). Caregivers tended to be younger and female.

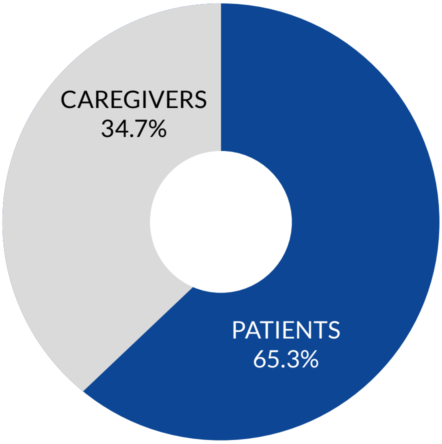

FIGURE 1: Sample distribution: patients and caregivers. (n=559)

Patients

Women: 73.5%
Men: 26.5%

Caregivers

Women: 78.9%
Men: 21.1%

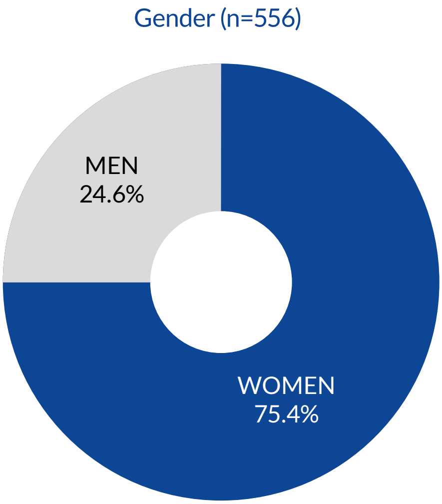

FIGURE 2: Gender distribution of survey respondents.

Country	Total	Patients	Caregivers
France	123 (22%)	102	21
Spain	63 (11.3%)	35	28
Denmark	61 (10.9%)	45	16
Italy	56 (10%)	32	24
The Netherlands	54 (9.7%)	39	15
Greece	44 (7.9%)	16	28
The United Kingdom	28 (5%)	19	9
Poland	23 (4.1%)	9	14
Sweden	22 (3.9%)	20	2
Finland	21 (3.8%)	18	3
Germany	17 (3%)	17	0
Latvia	15 (2.7%)	3	12
Slovenia	10 (1.8%)	4	6
Romania	9 (1.6%)	1	8
Israel	6 (1.1%)	2	4
Ireland	4 (0.7%)	1	3
Belgium	3 (0.5%)	2	1
	559 (100%)	365	194

TABLE 1. Country of residence of survey respondents.

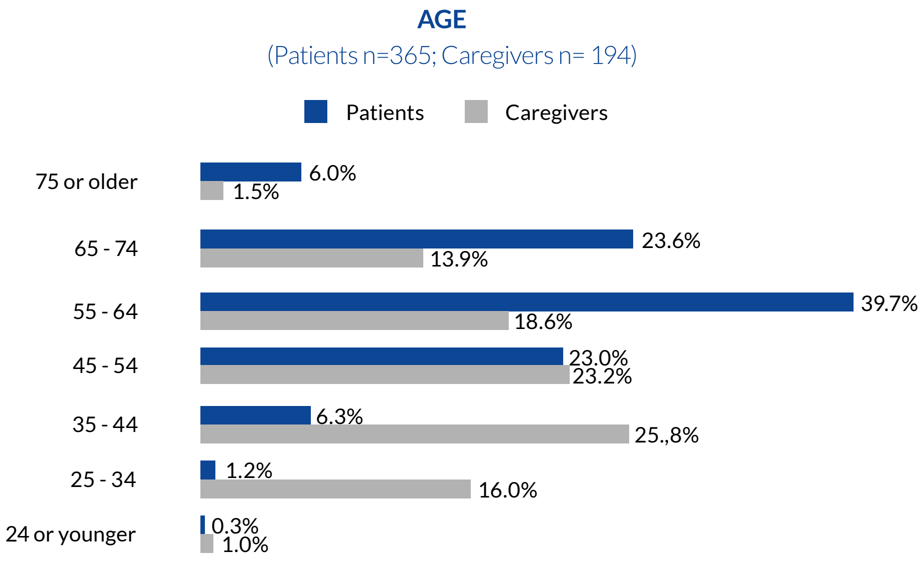

FIGURE 3. Age distribution of survey respondents.

Lung cancer characteristics

Patient responses: 59.9% were diagnosed with ´non-small cell lung cancer - adenocarcinoma´ followed by ´small cell lung cancer´ (8.0%). 6.4% were unaware of what type of lung cancer they were diagnosed with.

Half of respondents (49.2%) had Stage IV disease and 5.8% did not know the stage of their disease. The majority of patients (37.3%) were diagnosed between 1-3 years ago, followed by 3-5 years ago (23.1%), and around half of patients (47.8%) stated that they had received treatment, but their disease was still present.

Caregiver responses: When asked about the type of lung cancer their relative/friend was diagnosed with, 42.5% selected ´non-small cell lung cancer - adenocarcinoma´ and 13.0% answered ´small cell lung cancer´. 17.6% of caregivers did not know the type of lung cancer their loved one was diagnosed with.

57.2% of caregivers said that their loved one was diagnosed with Stage IV disease and 8.3% were unaware of the stage of the disease. According to 40.4% of caregivers, lung cancer was diagnosed between 1-3 years ago, and 47.4% answered that patients had received treatment, but the disease was still present at the time of completing this survey.

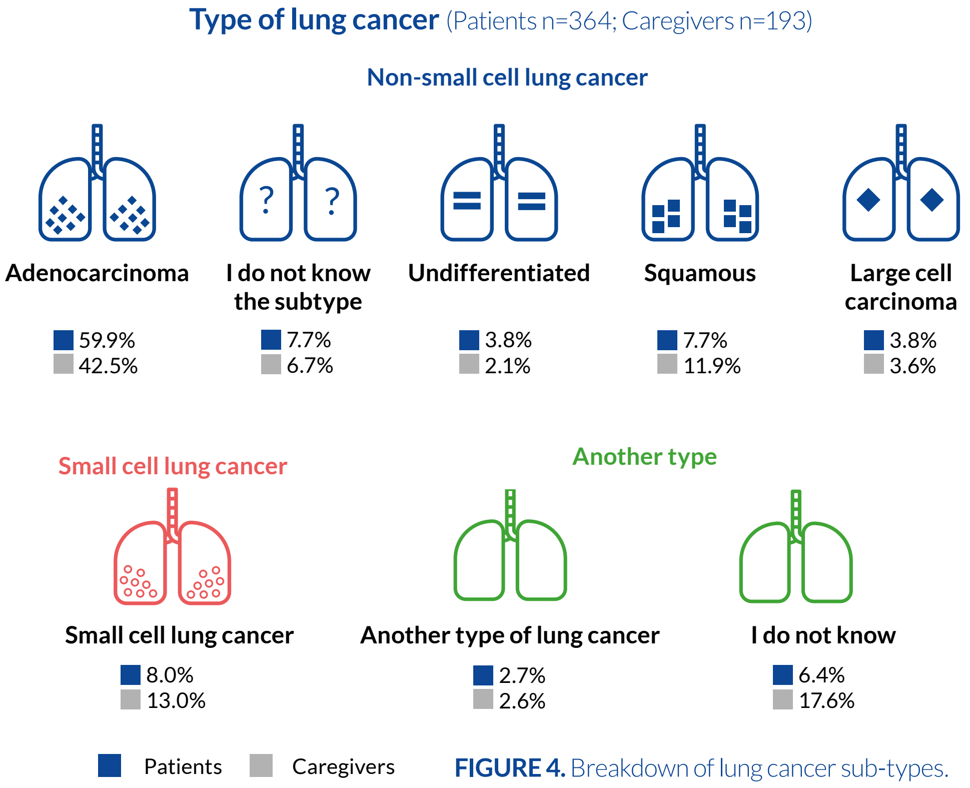

FIGURE 4. Breakdown of lung cancer sub-types.

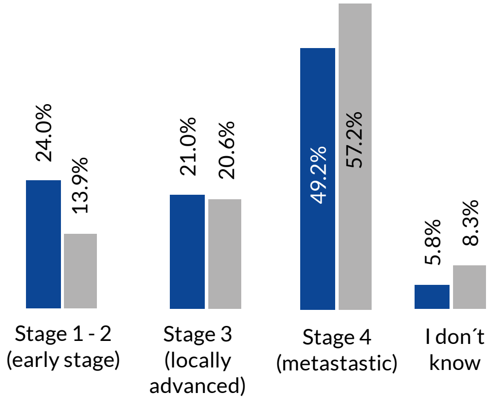

FIGURE 5. Stage of lung cancer.

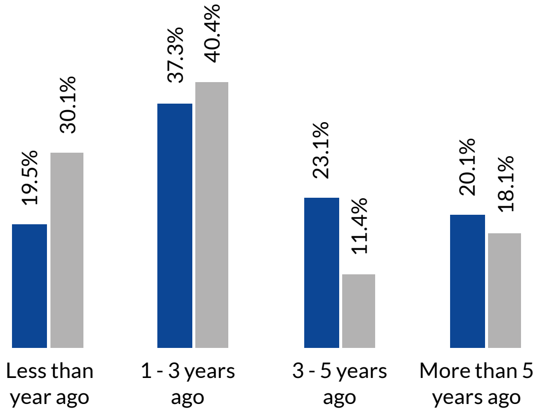

FIGURE 6. Time from diagnosis.

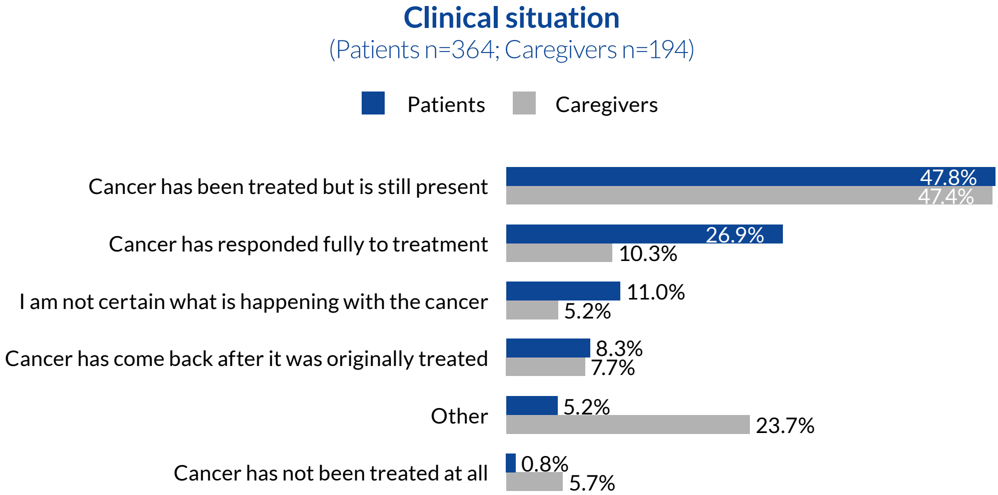

FIGURE 7. Clinical situation according to survey respondents.

2. Results

Although the landscape of lung cancer treatment is changing rapidly, survival and quality of life remains poor compared to other cancers, as the disease is typically diagnosed late. Lung cancer itself as well as the treatments given can produce severe symptoms and side effects that decrease the person's quality of life and this also has an impact on the family and social dynamic. The goal with any treatment is to live longer, however, it must not have a negative impact on quality of life. Therefore, it is so important to understand the impact of this disease on patients´ and caregivers´ lives.

One of the first questions asked to participants related to the negative effects that lung cancer had produced in four main spheres of their lives:

- Independence (housework, daily activities, social life, work)
- Emotional wellbeing
- Family
- Future expectations (not related to the illness)

According to participants, lung cancer negatively impacted all these spheres and **caregivers reported higher impact levels than patients.** This difference is especially remarkable in relation to emotional wellbeing (+0.66). Overall, **the greatest impact is on emotional wellbeing,** especially for caregivers. The main area identified among patients is in regard to the family sphere.

To what degree has each of the following been negatively affected because of lung cancer? (n=557)

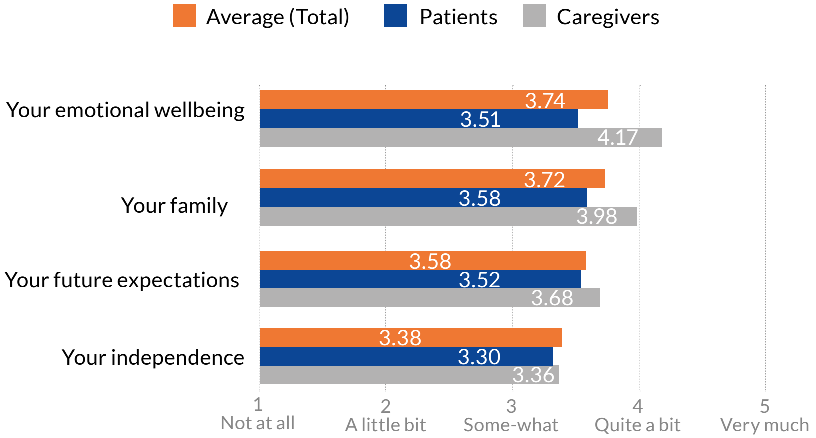

FIGURE 8. Spheres affected by lung cancer.

- **Emotional wellbeing:** 77.2% of caregivers and 52.5% of patients answered that their emotional wellbeing had been negatively affected by `*quite a bit/very much*´. Data per country show a higher psychological impact reported by respondents from France (both patients and caregivers) and the Netherlands (patients only)(NOTE 1). On the other hand, we found that patients from Greece, Denmark, Italy, and Germany reported less impact on their emotional wellbeing. (NOTE 2) There were no significant differences per country in the responses of caregivers. Remember that national comparisons were performed only when there were more than 15 valid answers per country (number of responses per country is outlined in Table 1).

- **Family:** 70.8% of caregivers and 60.0% of patients acknowledged that their family had been negatively affected by `*quite a bit/very much*´. This was even more impactful than their own emotional wellbeing, according to patients´ responses. The results show more negative impact in France (both patients and caregivers), the United Kingdom (patients only) and the Netherlands (patients only). (NOTE 3) Less impact at family level is reported in patients from Greece, Germany, and Denmark, and in caregivers from Italy. (NOTE 4)

- **Future expectations:** 58.6% of caregivers and 54.8% of patients answered that the impact on their future expectations was `*quite a bit/very much*´. These issues were particularly highlighted by participants from France (both patients and caregivers), the United Kingdom (patients only) and Finland (caregivers only). (NOTE 5) Participants who reported less impact on the future came from Germany (patients only), Denmark (both patients and caregivers), Greece (patients only) and Spain (caregivers only). (NOTE 6)

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[1] Patients from France = 4.12 (+0.61 from the average); Caregivers from France = 4.62 (+0.45 from the average); Patients from the Netherlands = 3.77 (+0.26 from the average).

[2] Patients from Greece = 2.73 (-0.78 from the average); Patients from Denmark = 2.93 (-0.58 from the average); Patients from Italy = 2.94 (-0.57 from the average); Patients from Germany = 3.00 (-0.51 from the average).

[3] Patients from France = 4.18 (+0.61 from the average); Caregivers from France = 4.57 (+0.59 from the average); Patients from the United Kingdom = 3.84 (+0.27 from the average); Patients from the Netherlands = 3.78 (+0.21 from the average).

[4] Patients from Greece = 2.87 (-0.71 from the average); Patients from Germany = 2.94 (-0.64 from the average); Patients from Denmark = 3.07 (-0.51 from the average); Caregivers from Italy = 3.58 (-0.40 from the average).

[5] Patients from the United Kingdom = 3.89 (+0.37 from the average); Patients from France = 3.87 (+0.35 from the average); Caregivers from France = 4.00 (+0.32 from the average); Patients from Finland = 4.00 (+0.32 from the average).

[6] Patients from Germany = 2.88 (-0.64 from the average); Patients from Denmark = 2.91 (-0.61 from the average); Caregivers from Denmark = 3.07 (-0.61 from the average); Patients from Greece = 3.06 (-0.46 from the average); Caregivers from Spain = 3.37 (-0.31 from the average).

- **Independence:** 49.2% of caregivers and 51.6% of patients said that lung cancer negatively affected their independence `*quite a bit/very much*´. Those who reported the highest levels of impact were respondents from France (both patients and caregivers) (NOTE 7) and the lowest levels of impact were registered in people from Denmark (both patients and caregivers), Italy (both patients and caregivers), and Greece (patients only). (NOTE 8)

THESE FIRST RESULTS SHOW A SIGNIFICANT AND MULTIDIMENSIONAL IMPACT ON QUALITY OF LIFE IN PEOPLE AFFECTED BY LUNG CANCER, WITH GREATEST IMPACTS REPORTED BY CAREGIVERS. IN THE FOLLOWING SECTIONS WE LOOK INTO THIS IMPACT, EXPLORING CAUSES AND CONSEQUENCES IN MORE DETAIL.

2.1. PSYCHOLOGICAL IMPACT

a) Emotions and feelings

In terms of emotional impact and feelings associated with lung cancer, patients and caregivers reported the same main four main feelings that caused them discomfort. More than half of the people surveyed recognized how these feelings had deeply affected their quality of life in terms of:

- **Uncertainty**
- **Sadness**
- **Anxiety**
- **Fear**

When analyzing the prevalence of these feelings, we find that more caregivers felt sadness, anxiety, fear, anger, frustration, and hopelessness than patients. However, more patients reported vulnerability, loneliness, reduced self-esteem, guilt, and shame.

2 out of 10 respondents have felt guilty because of lung cancer. Other studies have shown that self-blame is much higher in lung cancer compared to other types of cancer, because of the stigma associated with smoking (active or passive)[7-8].

The experts consulted also felt that these emotions are common for patients and caregivers and that the **intensity of some feelings is especially high at the time of**

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[7] Patients from France =4.08 (+0.69 from the average); Caregivers from France = 3.95 (+0.59 from the average).

[8] Patients from Denmark = 2.69 (-0.70 from the average); Caregivers from Demark = 2.69 1 (-0.67 from the average); Patients from Italy = 2.72 (-0.67 from the average); Caregivers from Italy = 2.96 (-0.40 from the average); Patients from Greece = 2.88 (-0.51 from the average).

diagnosis and when the disease is progressing. Lung cancer is still seen as a death sentence by many and this can cause uncertainty, sadness, anxiety, and fear. People require time and support to deal with the diagnosis and prognosis. Also, the diagnosis can be accompanied by feelings of frustration, anger, and guilt. At the following stages, experts pointed out how feelings can be related to diverse factors, such as treatment options, family, quality of life, work, or finances.

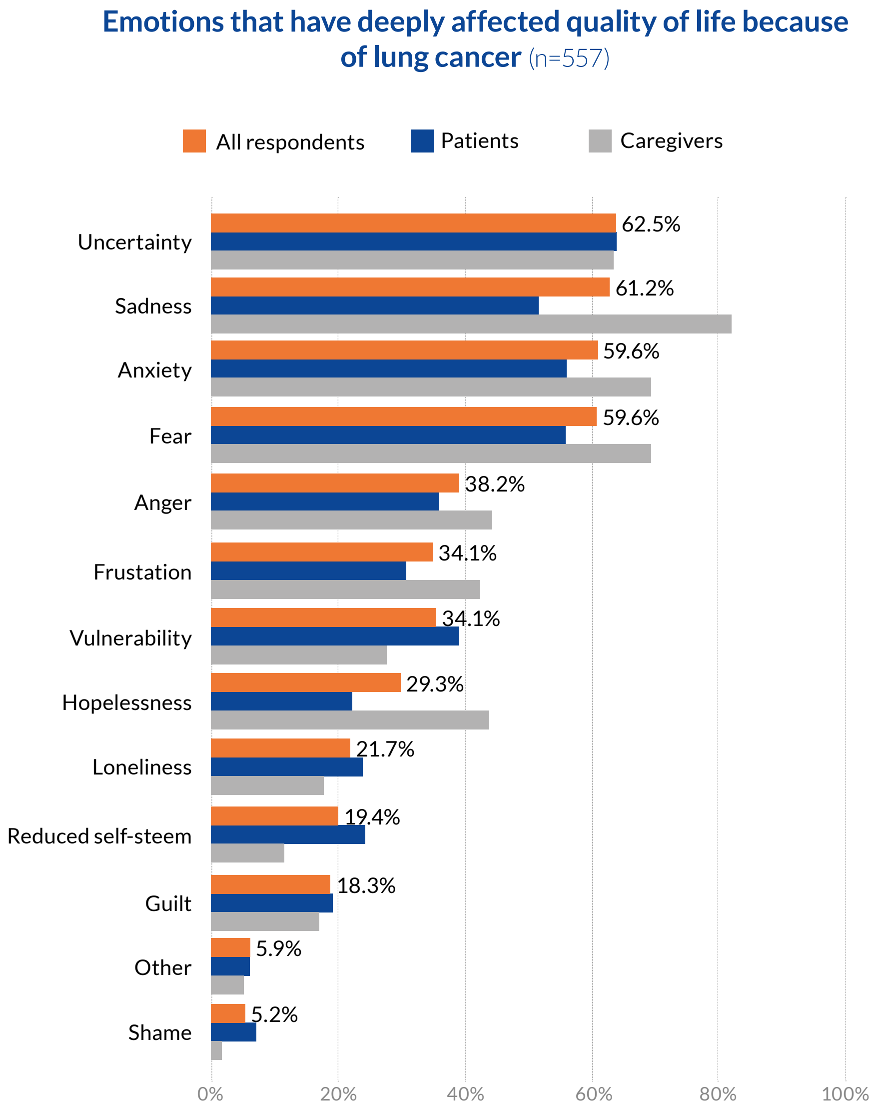


FIGURE 9. Emotions that affected quality of life of respondents.

> *The diagnosis of lung cancer is still seen as a death sentence; everything seems to stop at the time of diagnosis before the treatment cycles start. Patients are concerned about their livelihood and economic matters, especially if they are still of working age. They also ponder topics like: How do I cope with the illness, how do I cope with treatments, how do I tell my close ones, how will my co-workers and others react, do I have to comfort others or hide my illness?*
>
> *(Kirsi Roos, nurse, Finland)*

The **emotional burden** of lung cancer is so high that 8 out of the 10 experts agreed that **it is greater than other types of cancer, which is mainly due to high comorbidities, poor prognosis, and stigma.**

- **Prognosis:**
    - *Lung cancer can often be very complex and can have a significant impact on life expectancy creating huge amount of anxiety and stress. Patients need a lot of psychological care when they are given a poor prognosis with shortened life expectancy (Patricia Pugh, counsellor/psychotherapist, Ireland).*
    - *Lungs are vital organs; I think they cause more anxiety than other types of cancer. Patients usually suffer because they can only think of the imminent and painful death they may suffer. When people are diagnosed with lung cancer, they are usually aware of the prognosis, which adds to this anxiety (Günter Kranz, patient advocate, Germany).*
- **Comorbidities.**
    - *I think lung cancer has a bigger impact because patients are aware that the treatment is going to be hard. Their biggest worry is how long they are going to live (Isabelle Lebrocquy, patient advocate, the Netherlands).*
    - *They also know that the disease itself and the side effects of the treatment reduce the quality of life a lot, and all this has a strong emotional impact on the patients and their families (Maria Vittoria Pacchiana, psycho-oncologist, Italy).*

- Stigma:
    - *I think it does have a greater impact because it is easier to feel empathy for patients with other types of cancer. Lung cancer patients live with the stigma that they brought the illness upon themselves (Debra Montague, patient advocate, the United Kingdom).*
    - *At the beginning of 2000 in the USA they found that the amount of distress is higher for lung cancer patients and that if it has metastasis it nearly doubles. The most important factors were related to stigma and depression (Dégi László Csaba, social worker, Romania).*

What are the main emotional barriers reported by ***patients*** with lung cancer?

We asked participants an open question to provide the opportunity to explain their main emotional challenges so that we could understand their psychological distress better. The responses from patients were analyzed and categorized into 12 domains. The following are the six most reported:

Difficulties in managing emotions

25.2% of responses mentioned feelings that affect their emotional wellbeing, but they did not explain what caused them. According to their responses, the most difficult feelings to manage were fear, anxiety, anger, uncertainty, loneliness, and hopelessness.

- *Maintain a balanced state of mood, overcome fear and negative thoughts, fight anxiety and uncertainty.*
- *Invisibility, a roller coaste r of hope and despair.*
- *I can no longer manage my stress, repercussions on my sleep and anxieties.*
- *Loss of confidence and fear is blocking my ability to move forward.*
- *The constant insecurity and sometimes grief.*

Coping with the deterioration in quality of life

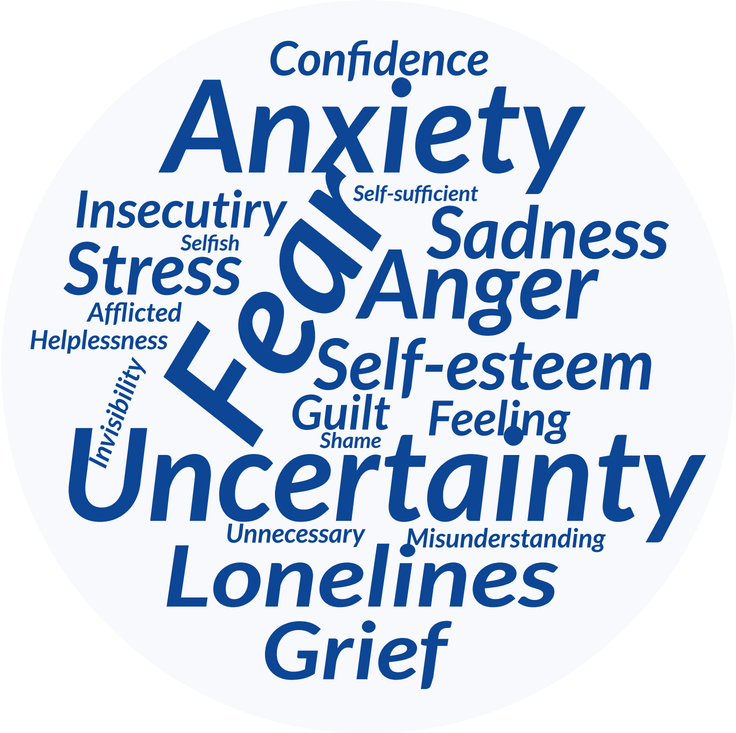
18.8% of responses mentioned that the main emotional challenges were directly related to the symptoms and side effects of lung cancer and treatments, especially in terms of fatigue/weakness and physical impairment.

- *Shortness of breath and fear of contagion of diseases.*
- *Weakness, lack of strength to perform everyday activities.*
- *The physical fragility due to the treatments leads me to have an attitude, less vigorous and therefore in daily life, in different situations I have to rely on the help of others, something I was not used to.*
- *My mobility is very limited, I quickly lose my patience, I can no longer concentrate so well, I get tired much faster.*
- *Frustration because of physical defects.*

Worries about death

17.5% of responses included emotions related to the feeling of near death. Their worries are explained by the implications on their families, fear of suffering and sadness about the possible limited available time.

- *I feel like I have a death sentence on me.*
- *Sadness and anxiety: not knowing how much I have left, what exactly awaits me, how I will end.*
- *How to end a life and how to say goodbye to family and friends.*
- *To think that I will not see my granddaughters grow.*
- *Getting used to the idea of being near death.*



Dealing with impact on family

17.2% of responses mentioned the consequences of lung cancer in the family as a top emotional challenge. When speaking about family members, most of the patients mentioned their partners, sons/daughters, and grandsons/granddaughters.

- *The effect it has on my family and my three teenage children. It is so hard to think about them losing their mother and the grief of not being with them is so terrible.*
- *The challenge of minimizing my uncertainty about the disease so as not to worry the family.*
- *Possible repercussions at the family level: genetic and emotional aspects.*
- *Reduced ability to care for the family.*

Facing social consequences

12.3% of responses included references to work, finances, and social relationships. The most common challenge was related to the impact of lung cancer on their jobs.

- *I lost my identity because I couldn't continue working. My job was a big part of who I was. My workmates do not hear. Many of my friends do not hear.*
- *Fear of unemployment, financial ruin.*
- *Inferior because I do not contribute to the community of having a job. And what others think of me.*
- *Significant difficulties returning to work, feelings of failure, depression.*
- *The public interference in my life: the health sector, job centres, etc.*

Uncertainty about the future

11.0% of the responses expressed feelings associated with an uncertain future and how this affects their daily life and plans.

- *Anxiety for not knowing what the future holds.*
- *Illness does not allow you to make future plans, and this creates sadness, discomfort, and anger.*
- *Can only make very short-term projects.*
- *The anxiety of the future, very difficult to make decisions.*
- *Overcome fear at first, then uncertainty over the future.*

We categorized additional responses into six other domains: the impact on daily activities (9.7%), attitudes and relationships with others (5.2%), worsening health (2.3%), concerns about medical tests (2.3%), issues related with medical information (1.9%), and issues related with healthcare systems (1.9%).(NOTE 9)

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[9] 8.1% of responses were not categorized because they did not answer the question.

What are the main emotional barriers reported by ***caregivers?***

Caregivers also answered an open question about the emotional barriers they faced after their loved one's diagnosis. We categorized responses into 12 domains (different from patient responses) and these are the six most reported:

Difficulties in managing emotions

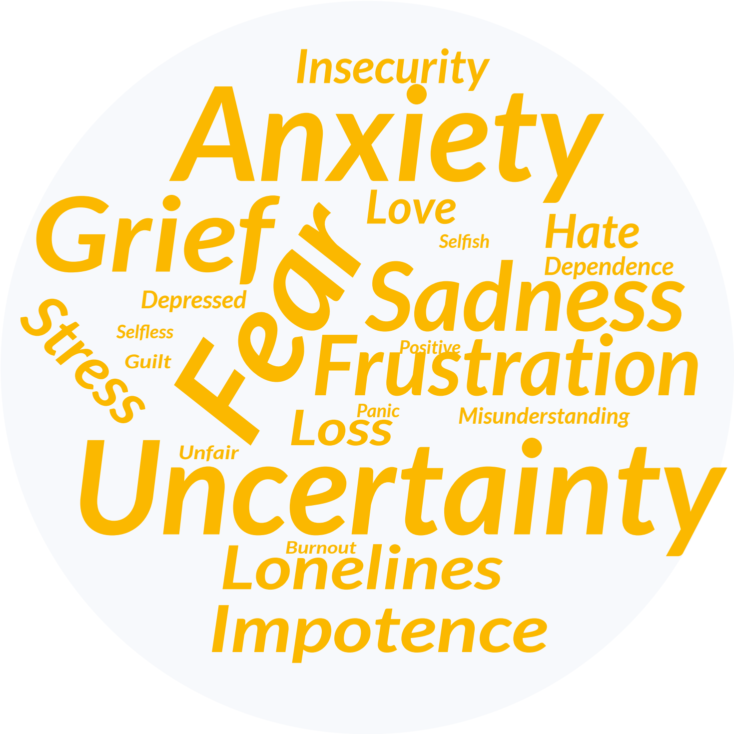
41.5% of responses do not mention the cause of such barriers, but detailed specific emotions that negatively affected their quality of life and were complicated to manage. They mainly specified feelings of fear, uncertainty, anxiety, sadness, grief and helplessness.

- *Fear and uncertainty are always there.*
- *I'm almost always anxious.*
- *Sense of helplessness and sadness, especially in the first years of illness.*
- *The anxiety resulting from my closest friend's diagnosis of lung cancer.*
- *Sadness that this is happening to the person that I love.*

Concerns about patient quality of life

14.5% of responses mentioned specific worries regarding the patient's wellbeing, both physically and emotionally.

- *Sadness and anxiety, especially when he is unwell, has pain or tells us that the treatment is not working.*
- *Seeing the patient suffer and weaken.*
- *To see the fear and sadness in his eyes...*
- *Fear and anxiety that my loved one will suffer a lot of pain.*
- *To witness the physical degradation, to accept the disease.*



Feelings about the person dying

13.8% of responses included emotions related to the patient's death and end of life.

- *The limitation of our horizons; at times of growth, death is getting closer. Plus, the occasional anxiety about the final stage of the disease.*
- *First, the real fear of losing my sister to this serious illness.*
- *The powerlessness in the face of this disease, the fear that he will die, the speed of the disease, not knowing what tomorrow will be.*
- *Fear and anxiety of losing a loved one and frustration at feeling helpless.*
- *Sadness, depression because the cancer was not curable.*

Worries about the care

12.3% of responses included feelings associated with caregiving, in terms of frustration or not knowing how to support.

- *It frustrates me not being able to make my partner happy. Seeing how she struggles to recover, doing everything she is told is good and still does not improve.*
- *Uncertainty about what to do about the disease and as a caregiver.*
- *Being able to accompany him calmly.*
- *Fear, pity, pain, shame that I didn't know how to help her, anxiety...*
- *Guilt over not having the time to be more present and relieve my mother.*

Uncertainty about future

11.9% of caregivers´ responses pointed out how the uncertain future had contributed to high emotional discomfort.

- *I do not know the follow-up; I cannot know the course of the disease.*
- *The uncertainty of the near future regarding our life as a couple.*
- *The vision of the future is very uncertain.*
- *Uncertainty. We do not know what's next. We do not know how everything will evolve.*
- *Not being able to plan to far ahead.*

Fear of health worsening

6.9% of responses mentioned emotional difficulties in facing the possible worsening of patients' health.

- *The fear of it coming back.*
- *Paralyzing fear, mom is not being treated because of the coronavirus,*
- *The anxiety for the development of the treatment, if it will be successful.*
- *Fear that the disease will reappear after each treatment.*

We categorized additional responses into six other domains: impact on other family members (5.7%), social consequences (5.0%), issues related with healthcare systems (4.4%), issues related with medical information (3.1%), impact on own daily activities (1.9%), and concern about own health (1.3%).(NOTE 10)

b) Worries

What patients and caregivers feel along the disease journey is associated with certain worries and concerns about things that happen or may happen in their lives. The literature review showed that the emotional distress in people affected by lung cancer can be caused by many different issues related not only to the disease but also to other worries and fears[9]. Participants in this survey were asked about a number of these issues, which are included in Figure 10 (Note: some categories are different for patients and caregivers). These categories have been corroborated in the participants' responses when they were asked about the main emotional barriers (previous section).

Caregivers reported having experienced much more worries than patients. There are three top worries amongst caregivers: death, disease progression, and pain and suffering. Patients also experienced these worries however, they stated that the impact on family and relatives was their main worry after diagnosis. Looking at Figure 11, we found that around 90% of caregivers reported having great concerns about the patient´s death and disease progression, but this percentage is much lower in patients: 50.7% (worry about own death) and 62.7% (worry about disease progression), respectively. Also, it is remarkable that **three out of four caregivers had been highly worried about how to offer emotional support and care to patients.**

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[10] 6.3% of responses were not categorized because they did not answer the question.

To what degree you have worried about the following issues?

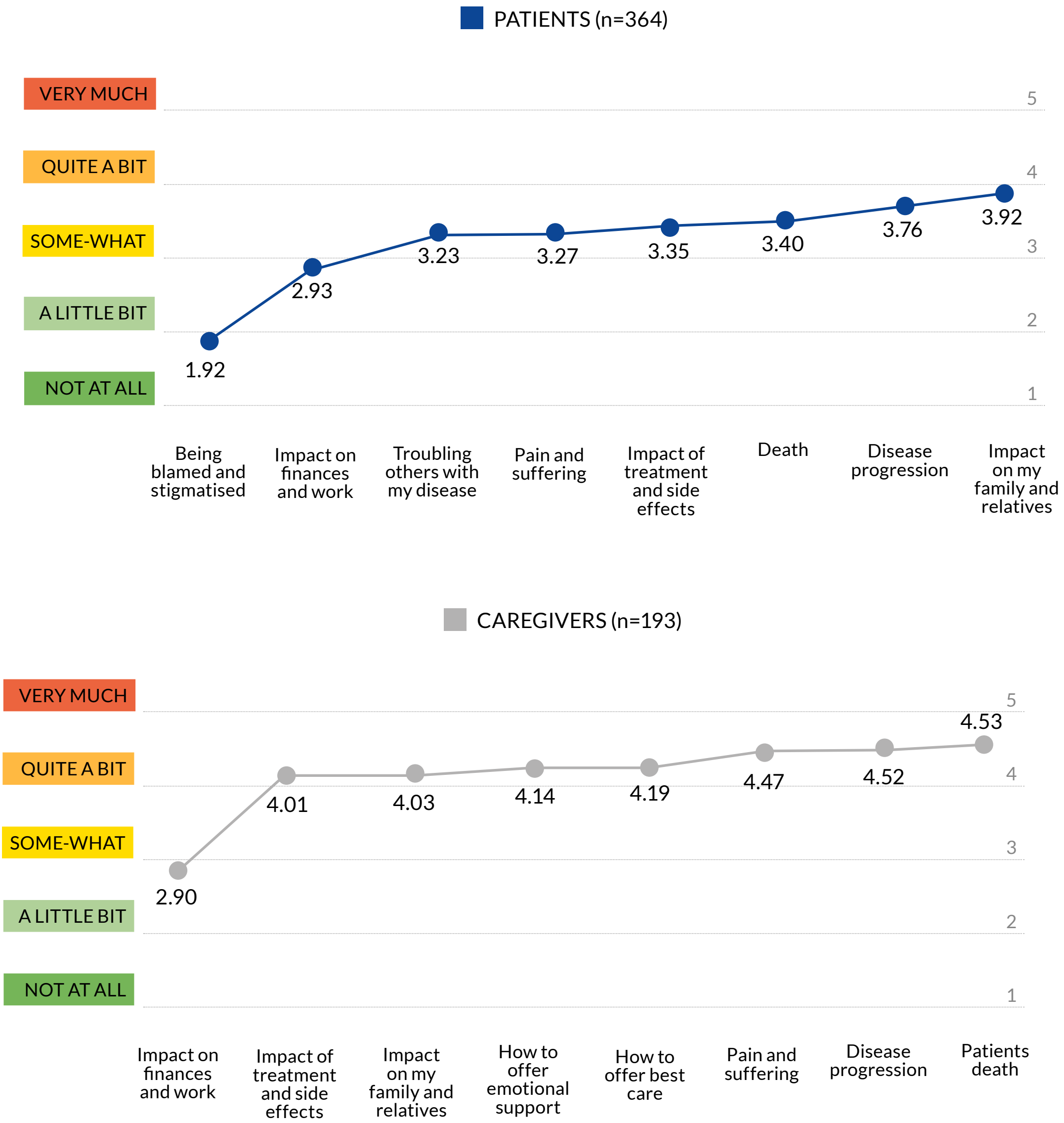
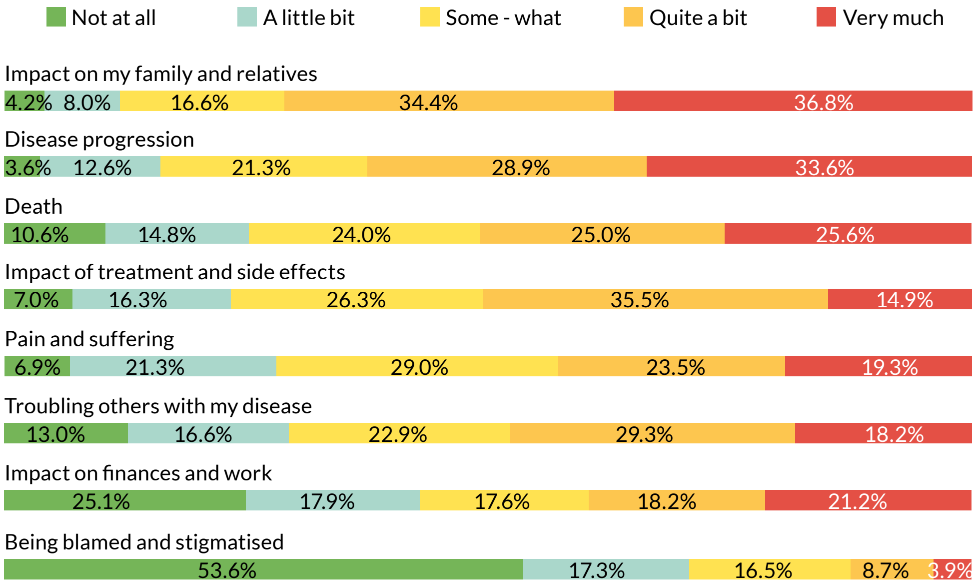


FIGURE 10. Worries after diagnosis (rate average).

PATIENTS

To what degree you have worried about the following issues? (n=364)



CAREGIVERS

To what degree you have worried about the following issues? (n=193)

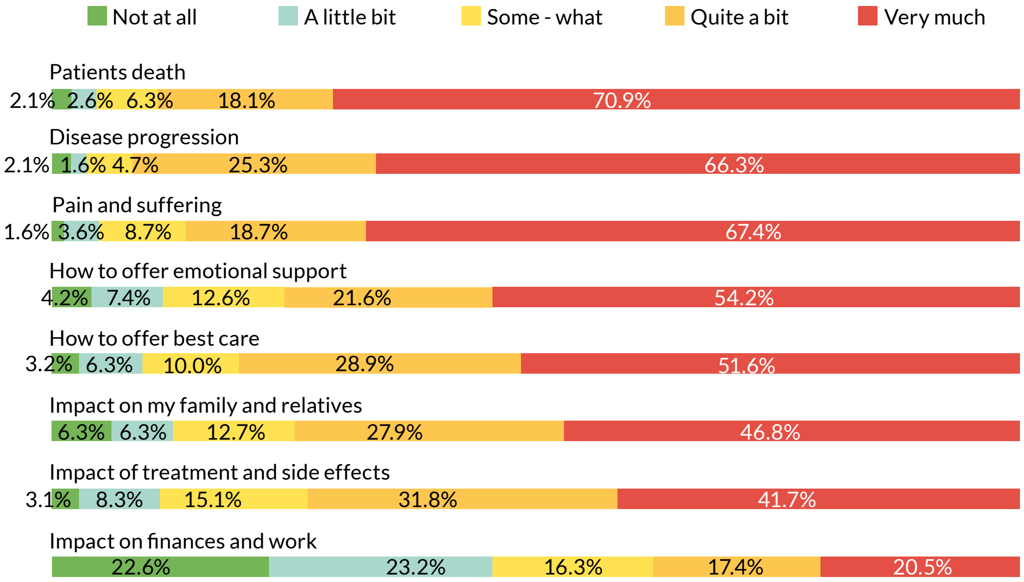


FIGURE 11. Worries after diagnosis (%).

c) Depression

Depression is a mental disorder characterized by persistent sadness and a lack of interest or pleasure in previously rewarding or enjoyable activities (definition by World Health Organization). Symptoms can vary from mild to severe and can include disturbed sleep and appetite, tiredness and poor concentration. Having depression is associated with reduced quality of life, decreased adherence to treatment, greater mortality, increased healthcare costs and worse satisfaction with care[10].

Depression is known to be a substantial issue in people with cancer, especially those with more severe symptoms or functional limitation[11], and its prevalence is higher in this population than in the general population. However, despite many years of research, the prevalence of depression in patients with cancer is still subject to much debate[12], because most published work has relied on depression symptom screening methods rather than diagnostic instruments[13]. Caregivers can also be affected by depression and some studies suggest that they have even higher levels of depression than patients[14-15].

Our results show that the **rate of a depression diagnosis is much higher in patients than the caregivers surveyed:** 18.4% of patients and 7.8% of caregivers. Although some were diagnosed with this mental disorder before lung cancer, the whole prevalence of depression among patients show that **2 out of 10 are dealing with lung cancer and depression at the same time.** Depression is one of the leading causes of disability and contributes to the global burden of lung cancer.

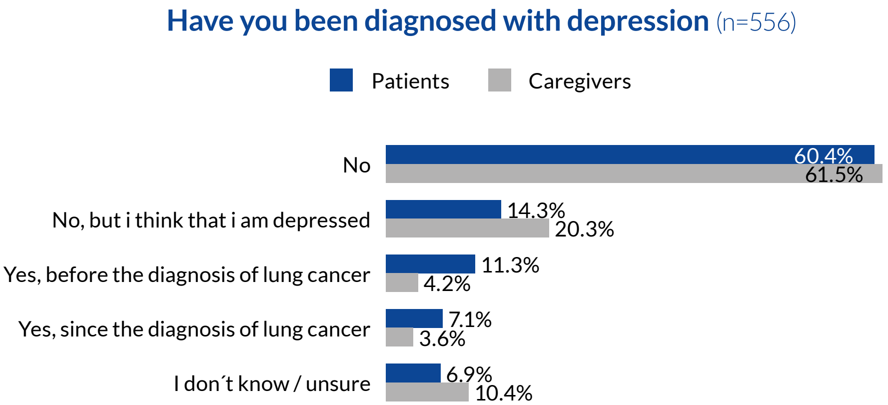


FIGURE 12. Diagnosis of depression (%).

On the other hand, we need to consider that there could be other hidden cases of depression. Despite not having been diagnosed with depression, **20.3% of caregivers and 14.3% of patients thought that they were depressed.** This means that they identified depressive symptomatology that should be addressed by healthcare professionals. Furthermore, 10.4% of caregivers and 6.9% of patients surveyed were unsure if they had been diagnosed with depression.

> *It seems to me that I no longer have myself, or that I am disappearing behind the disease. I feel fragmented and shared between the doctors and my loved ones. My cancer is not me, but the doctors take care of my cancer and my family is afraid of the effects of my cancer. My neighbours themselves are only worried about my cancer.*
> (Patient)

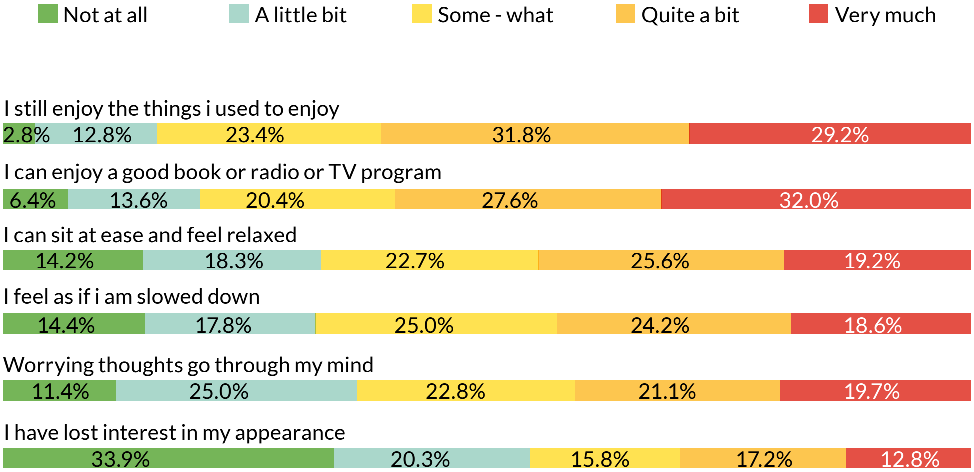
To explore reported depressive or anxiety symptomatology, the participants were asked if they had some worries and if they had felt capable of enjoying things and if they had felt relaxed during the previous week. The answers suggest a mood disorder in many patients and caregivers:

- Around 1 out of 4 caregivers reported an inability to enjoy anything during the previous week.
- 53.6% of caregivers and 40.8% of patients affirmed that worrying thoughts had gone through their mind frequently.
- 50.9% of caregivers and 32.5% of patients answered that they had barely felt relaxed.
- 46.8% of patients and 33.0% of caregivers felt slowed down.
- 30.0% of patients and 21.8% of caregivers recognized having lost interest in their appearance (quite a bit/very much).

PATIENTS

In the past week, please indicate to what degree you have felt the following

(n=364)



CAREGIVERS

In the past week, please indicate to what degree you have felt the following

(n=180)

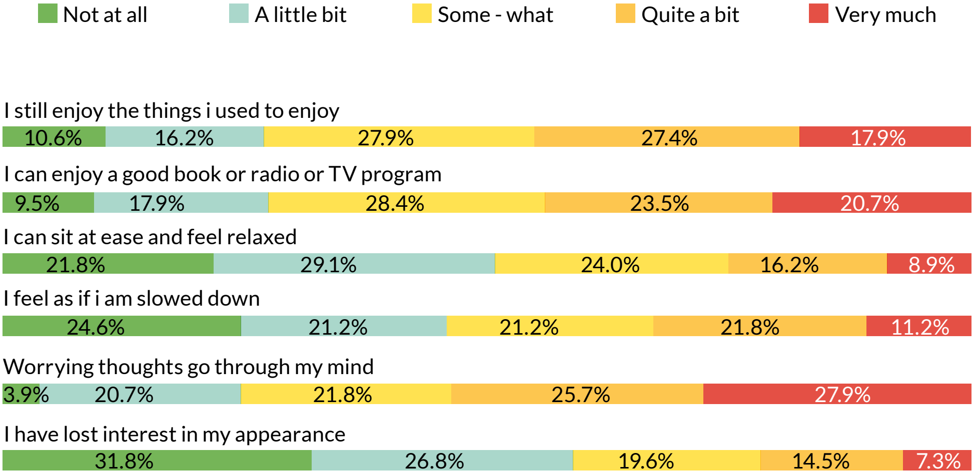


FIGURE 13. Anxiety and depressive symptomatology.

We identified two main healthcare challenges regarding depression: Firstly, identifying hidden cases of depression and getting an early diagnosis; secondly, getting access to medical and/or psychological treatment for all people diagnosed with depression. According to our survey, **1 out of 4 people with lung cancer and a diagnosis of depression stated that they had not received treatment to deal with it.**

We do not know why they did not receive help, but other studies suggest some challenges in caring for people affected by cancer and depression:

- Cancer specialists are not usually trained in mental health[16];
- Uncertainty whether the traditional treatments (anti-depressant medication and psychological treatments such as cognitive behavioural and interpersonal therapies) are also effective in depressed cancer patients[17];
- Lack of support services for depression (often absent or underdeveloped in low- and middle-income countries)[18].

Have you recived any treatment to help with your depression? (n=81)

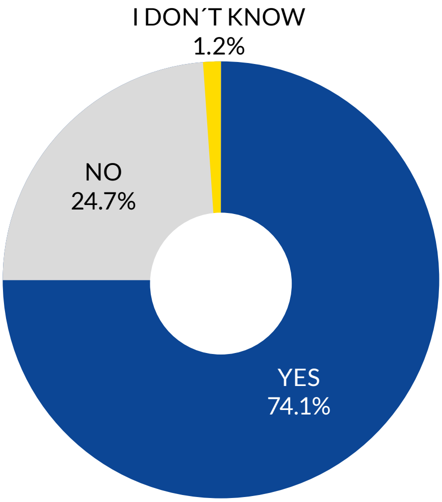


FIGURE 14: Depression: access to treatment.

d) Stigma

The connection between smoking and lung cancer, and the public perceptions of smoking as a behavioural choice, rather than an addiction, partly explain the stigma associated with this disease. Some studies report that people with lung cancer have found themselves alienated from family, friends, and society due to the consequences of smoking[19].

According to a survey by Global Lung Cancer Coalition, one in five (21%) people agreed that they have less sympathy for people with lung cancer than other forms of cancer[20]. This research also showed that there is a statistically significant correlation between those countries with lower cigarette consumption and higher proportions of people agreeing that they have less sympathy for people with lung cancer.

The stigma that affects patients with lung cancer is mostly associated with smoking, but there is another negative connotation shared with all types of cancer. Socially, to some, cancer still means dying and suffering. This is caused by the language used when speaking about cancer and the images used to portray it, and this can affect the way that patients and caregivers deal with the disease.

Literature shows how **stigma is associated with negative psychosocial outcomes[21]**, and it is related to diagnostic delays, limited use of psychosocial support services and low enrolment in clinical trials[22-23]. Stigma-related consequences vary from distress and depression to decreased disclosure to others, or less engagement in care and adherence to treatment[21].

> *There is a stigma associated with all types of cancer. In general terms it's related to the fact that the public opinion around cancer is that it's a fatal disease and that it means dying. Recently innovation is growing fast, but people don't know about it. That's why the general idea about cancer hasn't changed for years.*
> *(Isabelle Lebrocquy, patient advocate, the Netherlands)*

According to our survey, **46.4% of patients acknowledged having had concerns about being blamed and stigmatized** (see Figure 11). Exploring the nature of stigma requires differentiating between internalized and perceived stigma[24], and the consequences in patients' behaviour.

- **Perceived stigma (felt stigma)**

This concerns the reaction, negative appraisals and devaluation from others (family, friends, healthcare teams, and society in general). In terms of perceived stigma around people living with lung cancer, results about patients´ and caregivers´ experiences are very similar, with slightly higher scores in caregivers´ responses. Notice that these were asked about the perceived stigma against patients, not against caregivers.

More than 80% of survey respondents confirmed they were asked if the patients smoked when they learned about the lung cancer diagnosis, and this happened frequently in most of the cases (more than a half answered *'quite a bit/very much´*). Experts interviewed highlighted how this type of question reinforces feelings of shame or guilt in both patients and caregivers (as these could also have been smokers or may feel guilty because of not having helped them to quit smoking).

The participants also confirmed some stigmatizing attitudes and behaviours from others, such as **considering the patient as responsible for getting lung cancer** (mentioned by 30.9% of patients and 41.2% of caregivers) or **judging the patient negatively** for having this disease (experienced by 28.2% of patients; 24.0% of caregivers). These attitudes could be behind some discriminatory behaviours that people with lung cancer suffer, and may explain why **around 20% of people surveyed affirmed that some people had treated the patient poorly** because of having this disease (mentioned by 22.9% of patients; 19.8% of caregivers).

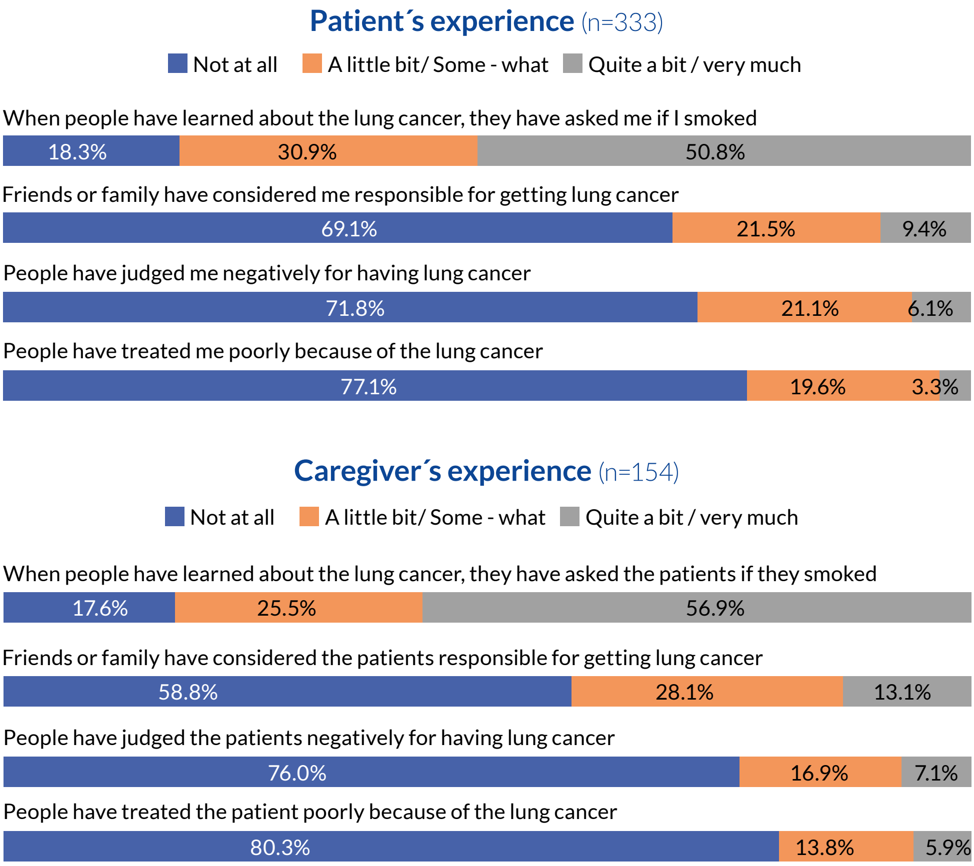


FIGURE 15: Percived stigma.

> *The immediate thought that goes through every single person's mind when they hear of someone who's got lung cancer is ´Oh, I didn't know you smoked?´ This is not the same question they would ask to a breast cancer patient, for example.*
> (Debra Montague, patient advocate, the United Kingdom)

Reviewing data collected per country, we find that patients from France and Greece reported much higher impact in the four items of perceived stigma. In contrast, patients from Italy, the Netherlands, and Denmark reported much less impact from felt stigma compared to other countries.

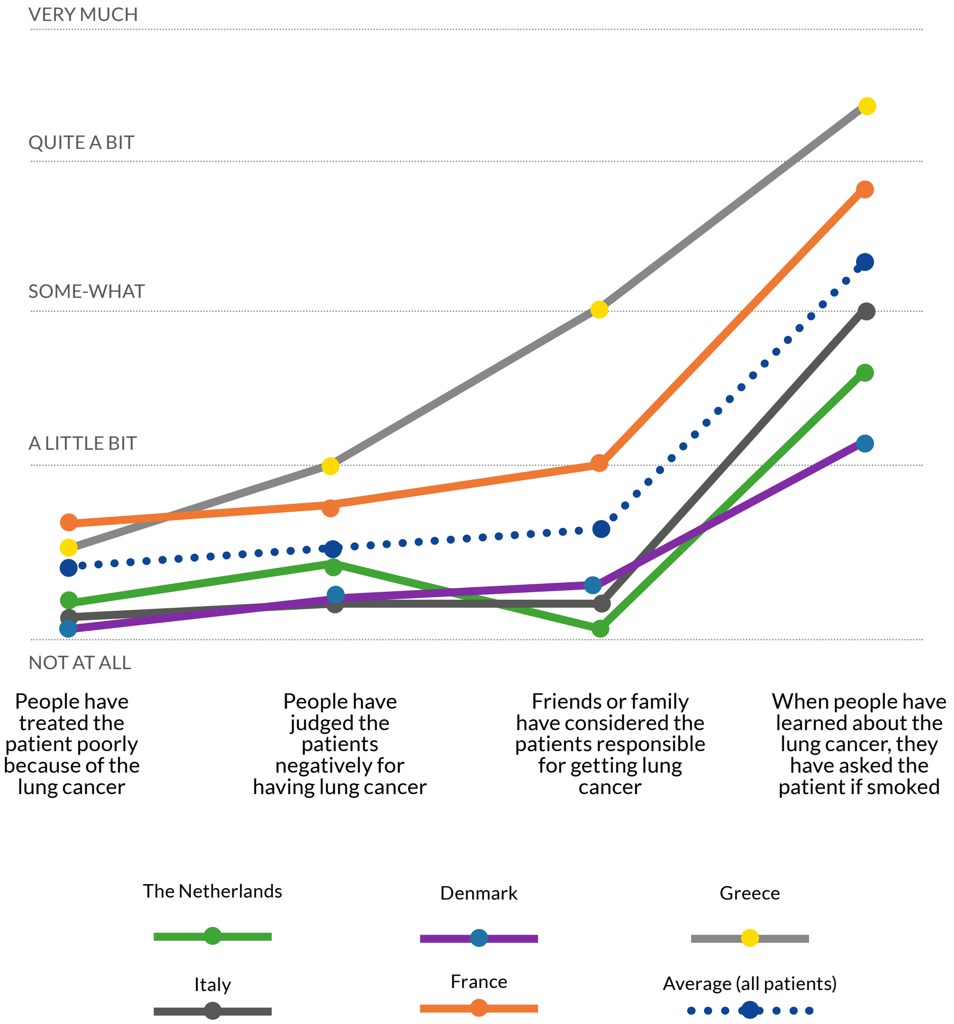


FIGURE 15. Perceived stigma (countries).

- **Internalized stigma (self-stigma)**

This is characterized by self-blame, guilt, shame, anger, and regret. Although less than 20% of the people surveyed reported feelings of guilt (Figure 9), this percentage increased considerably when they were asked specifically about self-blame and regret for having lung cancer. These feelings were stronger in patients than caregivers. Table 2 shows that 66.7% of patients surveyed stated that they had thought at times that their previous behaviour had contributed to the diagnosis, and **52.4% had at times felt guilty because of lung cancer.** Additionally, **2 out of 10 patients acknowledged feeling guilt frequently.**

Stigma and self-blame in caregivers can happen too, and more than 35% acknowledged having feelings of guilt; this is especially a burden for around 10%, who experienced these feelings quite often.

	NOT AT ALL		A LITTLE BIT / SOMEWHAT		QUITE A BIT / VERY MUCH	
	Patients	Caregivers	Patients	Caregivers	Patients	Caregivers
I have felt guilty about having lung cancer	47.6%	62.9%	31.5%	26.4%	20.9%	10.7%
I have thought that my past behaviour contributed to the lung cancer	33.3%	63.4%	36.0%	24.2%	30.7%	12.4%

TABLE 2. Internalized self-stigma.

- **Consequences of stigma**

The survey participants reported some consequences of stigma on patient disclosure about their lung cancer. Caregivers perceived a worse impact on patients than the patients themselves. **More than half of patients affirmed that they had been careful when speaking about the disease** (caregivers' perceptions rose to 69.5%) and recognized having stopped spending time with some people (a similar percentage was recorded in caregivers' responses). Furthermore, around **1 out of 3 patients admitted to having**

preferred to keep their cancer a secret at times, and this figure was much higher when caregivers were asked: 45.8% answered that the patient had sometimes kept the disease a secret. Finally, **around 30% of patients had at times regretted telling some people about their lung cancer.**

> *Church and friends initially asked if I smoked upon my diagnosis. Consistently, a condescending 'oh' from others we tell of the lung cancer diagnosis.*
> (Patient)

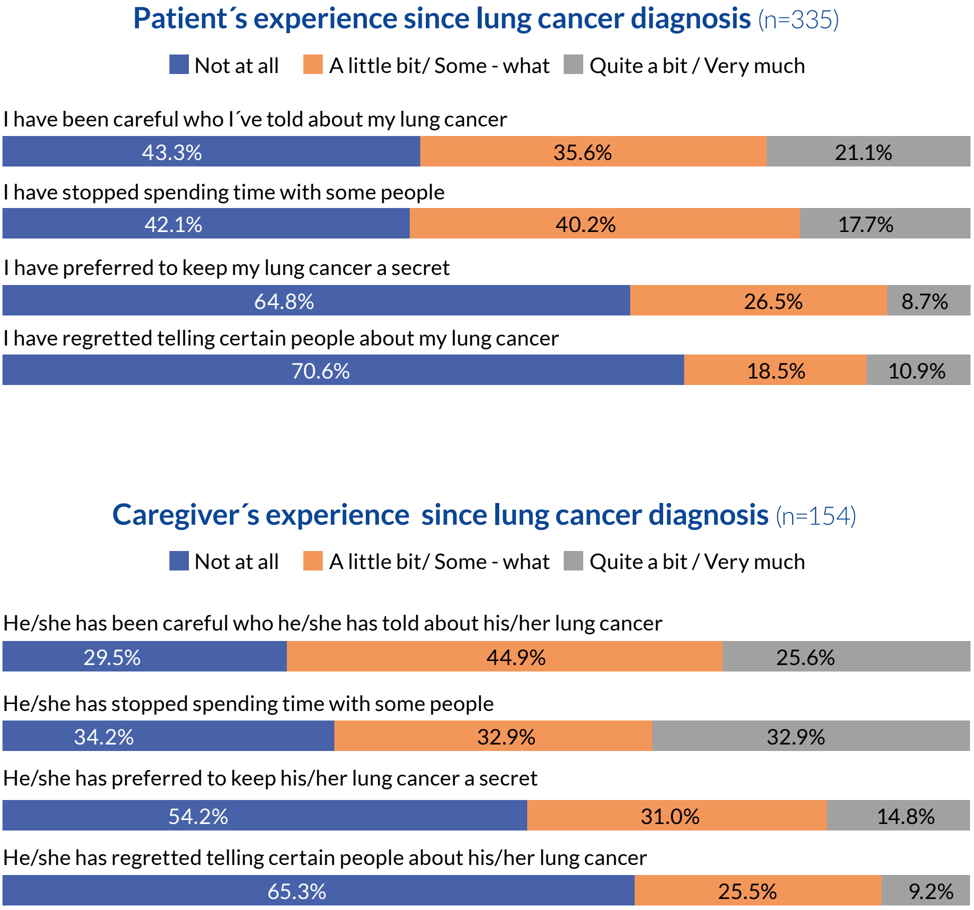


FIGURE 16: Stigma consequences.

How to reduce stigma?

- Educate the public about lung cancer. The greater the knowledge of the disease, the less the stigma will be.
- Inform the public that anyone can get lung cancer.
- Ensure that all patients are treated and supported equally.
- Stop the perpetuation of stigma through the use of stigmatizing language and images used to portray the disease.

There is also, in relation to the stigma around it, the fact that other cancers, such as breast and prostate, seem to evoke more empathy. It seems that there is a lot less support and awareness with lung cancer than with other types of cancer. Lung cancer is often seen as a diagnosis to be ashamed of.

Joanna Vick, nurse, the United Kingdom

e) Resilience

Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats, or significant sources of stress. Despite substantial distress that is associated with a cancer diagnosis and treatment, many people with cancer manifest remarkable resilience, and some studies have shown that overcoming cancer and treatment can be an opportunity for personal growth and satisfaction with oneself when coping with disease-related demands[25].

Resilience is associated with protective attributes and personal characteristics that promote successful adaptation to cancer, including, among others, meaning and purpose in life, a sense of coherence, optimism, positive emotions, self-esteem, self-efficacy, cognitive flexibility, coping, social support, and spirituality[26-27].

In the context of this report, we have not delved into resilience in people affected by lung cancer, but we have wanted to know if they had experienced some positive feelings regarding three issues that may suggest personal growth and satisfaction with themselves when coping with this disease (see Figure 17).

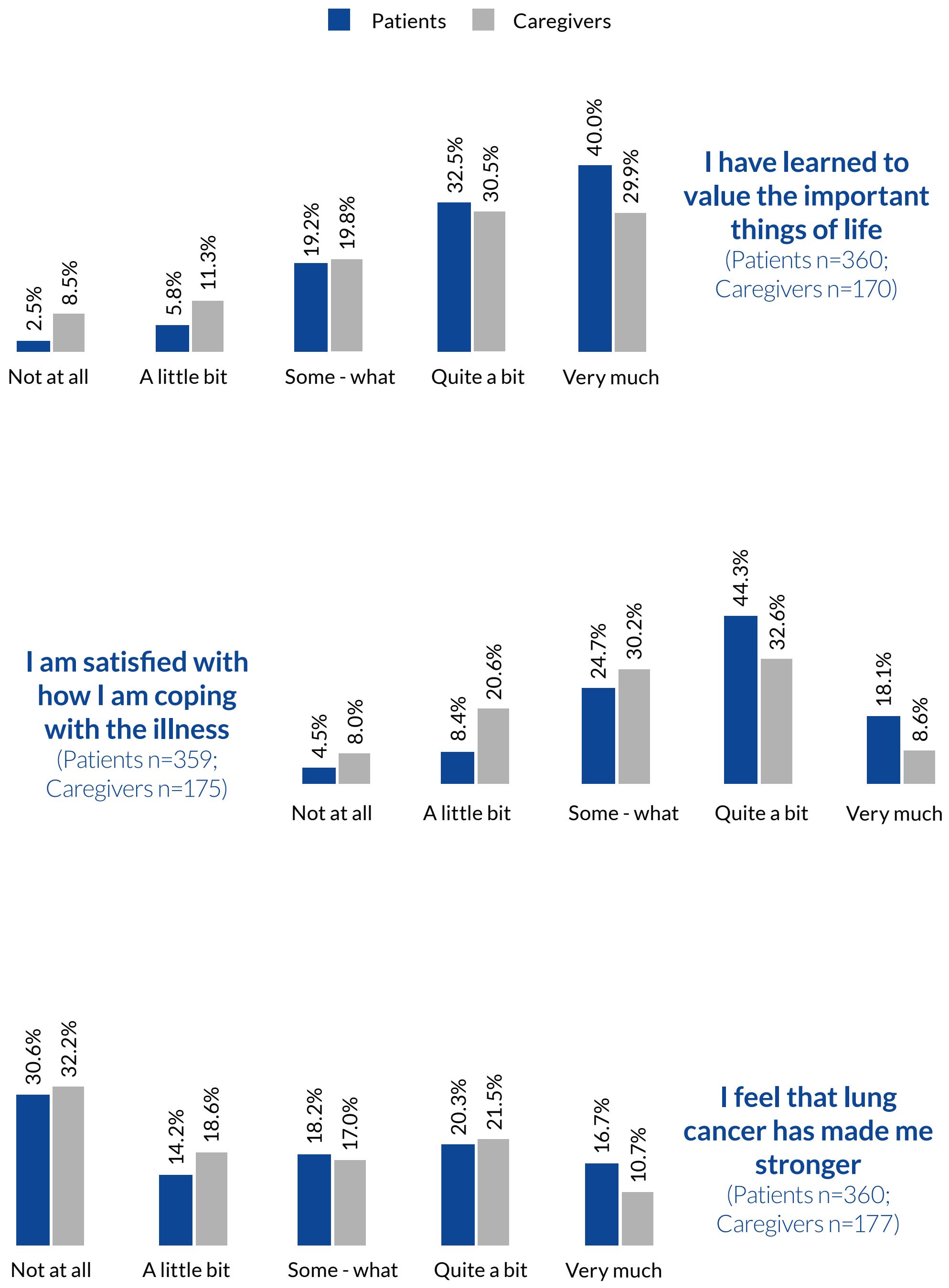
- Not all patients and caregivers react to adversary in the same way, with some more resilient than others. According to our survey, around 3 out of 4 **patients affirmed that they had learnt to value the important things of life** (72.5%), and this was also reported by 60.4% of caregivers.

- On the other hand, **most patients (62.4%) were satisfied with how they were coping with the illness. However, caregiver responses showed different results.** 41.2% of them said they were satisfied and 28.6% reported little or no satisfaction.

- Finally, we found differences in results when asking if lung cancer made them stronger. 37.0% of patients answered `*quite a bit/very much*´, while 44.2% of patients said ´*Not at all/A little bit* ´. These differences were also found in caregivers. 32.2% of them stated that they felt stronger, while 50.8% said they did not.

In general, life looks different. It is only for loan and sometimes short. We have to enjoy each other and the family. (Patient)

I devoted myself more to my family, to the education of my children. I appreciate more of the little joys of life. I stopped taking everything for granted and I generally enjoy life as much as possible. (Patient)



I have learned to value the important things of life (Patients n=360; Caregivers n=170)

I am satisfied with how I am coping with the illness (Patients n=359; Caregivers n=175)

I feel that lung cancer has made me stronger (Patients n=360; Caregivers n=177)

FIGURE 17. Resilience.

2.2. IMPACT ON DAILY LIFE

a) Physical limitations: symptoms and side effects

Thanks to treatment advances in lung cancer, survival has increased for many patients. However, while people with lung cancer are living longer, they are also living with symptoms and treatment side effects that deeply affect their wellbeing and daily quality of life. There is a critical need to understand the patient and caregiver experiences and perspectives regarding their needs in terms of the impact of side effects on quality of life.

According to our research, **fatigue, breathlessness, and pain are the side effects that most deeply affect wellbeing.**

1. Fatigue is the most commonly reported symptom by patients with lung cancer. In response to the open question `What side effects or symptoms have impacted your quality of life the most?´, 47% of patients mentioned fatigue/weakness/tiredness/lack of energy. These data coincide with other research which has shown that cancer-related fatigue (CRF) is present during the entire course of the disease, resulting in the impairment of both day-to-day living and overall quality of life[28-29].

This fatigue is usually defined in literature as more severe, more persistent and more debilitating than 'normal' fatigue caused by lack of sleep or over-exertion, and is not relieved by adequate sleep or rest[30]. It is caused by multifactorial causes, such as comorbidities, nutritional status, medications, or reduction of physical activity. Fatigue belongs to the symptom cluster of pain, depression, and insomnia, but they are typically treated as separate, although they may have common biological mechanisms[31].

What side effects or symptoms have impacted your quality of life the most?
(Patients n=230)

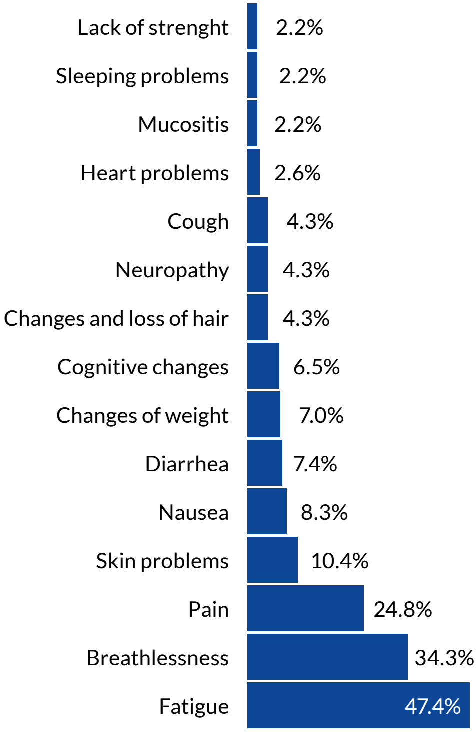


FIGURE 18. Side effects reported by patients.

2. The second side effect most reported by patients was shortness of breath, which is also related to fatigue and lack of performance. Breathlessness was identified by 34.3% of patients, who stated how this affects their lifestyle and their ability to carry out day-to-day routines.

> *The shortness of breath and impediments derived from the treatment do not allow me to do the physical exercise that I want or to go to all the places that my friends go to, or to do all the things that I did before.* (Patient)

> *Dyspnoea made it unimaginably difficult for me to walk.* (Patient)

3. Likewise, **pain is also identified as one of the symptoms with the greatest impact on their quality of life.** Of those who answered this question, 24.8% of patients wrote that pain had deeply affected their lives and they identified many different body locations such as spine, head, muscles, joints, chest, back, arms, shoulders, and feet. Pain is one of the symptoms of lung cancer, it is common following surgery and can also be caused by other treatments. It produces a significant limitation in the quality of life of many patients, even when there are pain relief medications and other pain control options.

Pain is the side effect that had most impacted their quality of life, according to caregivers. 27.5% of caregivers who reported side effects of symptoms mentioned pain (17.6% reported fatigue and breathlessness).

> *Pain in both arms and shoulders. There is so much I can't do, like dress myself in what I want instead of oversize clothes, clean myself in a normal way. I have problems to fix a lot of things in my home because I can't reach things without pain. It also makes me sleep very badly because I have to get up and walk every two hours at night.* (Patient)

> *Initially, I suffered bad pain in my back as a direct result of the tumour but also in my ribs and legs as an indirect effect. I ended up in hospital as the pain was not being addressed. I received good treatment and I am no longer on pain relief and have no pain. The pain impacted my life significantly, both before diagnosis and while waiting for treatment to start.* (Patient)

4. Other side effects and symptoms reported by a significant percentage of patients were: skin problems(NOTE 11) (10.4%), nausea (8.3%), diarrhea (7.4%), weight changes (7.0%), cognitive changes(NOTE 12) (6.5%), loss of and changes in hair (4.3%), peripheral neuropathy (NOTE 13) (4.3%), and coughing (4.3%).

b) Daily life activities

Symptoms and adverse effects caused by lung cancer and treatments can impact on patients´ engagement in moderate and strenuous daily or leisure activities, especially when they have medical comorbidities[32]. Also, poorer performance status has been linked to depressive symptomatology and emotional distress in patients with lung cancer[33]. Some studies suggest that lung cancer is associated with higher disease burden, more physical hardship and greater symptom distress than other cancer types[34].

Difficulties in daily life because of lung cancer
(Patients n=330; Caregivers n=151)

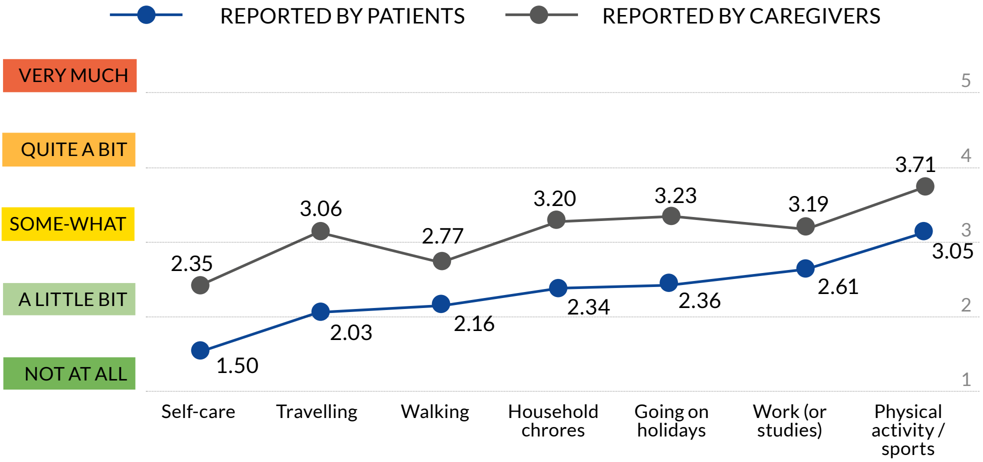


FIGURE 19. Difficulties in daily life (average rates).

Our survey shows that **most of the patients surveyed reported impairments in physical and role functioning,** affecting their status and performance. This was corroborated by caregivers, who were asked about difficulties that patients had.

As Figure 19 shows, **caregivers reported a higher impact from lung cancer in patients´ daily lives than the patients themselves. The impairments most frequent were difficulties with physical activity and sports, with work (or studies), and going on holidays.**

[11] Rash, dry skin, eczema, shingles. [12] Lack of memory, lack of concentration. [13] Tingling or numbness in hands or feet.

Analyzing data per country, we find that **patients from Greece, Sweden, and France reported the most negative levels of impact** on daily life activities. In contrast, the least impact was reported by patients from Italy, Denmark and Germany.(NOTE 14)

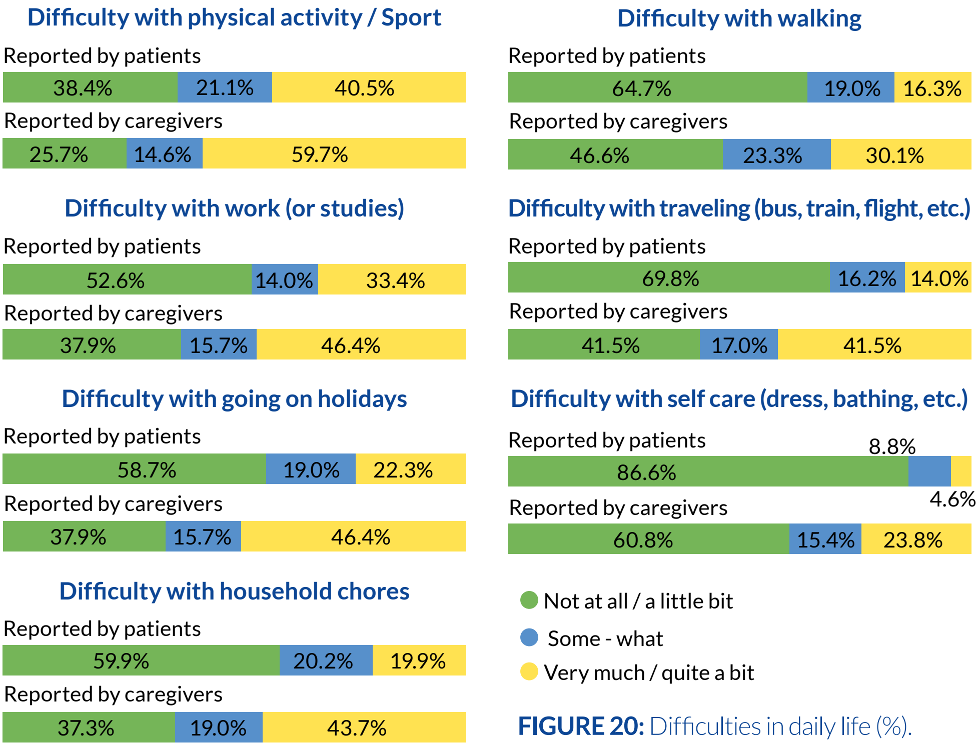


FIGURE 20: Difficulties in daily life (%).

61.5% of patients have difficulties with physical activity, and almost one half acknowledge difficulty with work (or studies).

At least 1 out of 3 patients reported difficulties with going on holidays, household chores, walking and travelling (bus, train, flight, etc.). Finally, 13.4% of patients acknowledged having had problems with self-care.

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[14] Patients´ responses average: 2.29. Greece (2.72); Sweden (2.54); France (2.48); The United Kingdom (2.41); Spain (2.37); The Netherlands (2.21); Finland (2.17); Germany (1.98); Italy (1.91); Denmark (1.91).

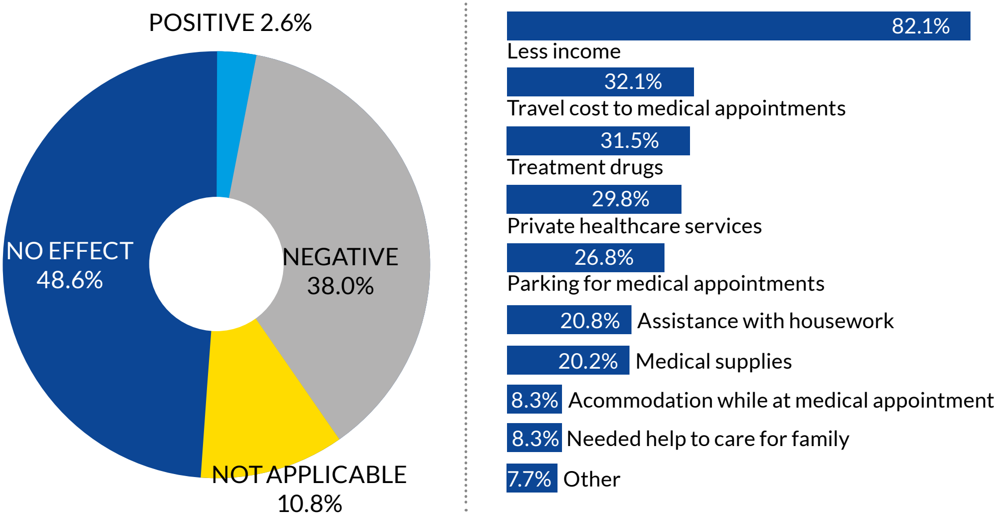
c) Financial impact

Around 4 out of 10 participants **(38.0%) confirmed that there was a negative impact from lung cancer on their household's financial situation.** Caregivers reported negative financial consequences at very similar rates to patients.

The **main reason reported by people who stated a negative impact was less income** (82.1%), but costs related to lung cancer should not be underestimated. Around 30% of cases of negative impact was because of travel costs to medical appointments (32.1%), treatment costs (31.5%), and private healthcare services (29.8%).

We find some relevant differences between patients and caregivers. The patients consulted reported much more economic impact because of reduction of income (88.3% *vs.* 66.7%), and caregivers reported a major impact on costs, especially on travel costs (23.3% *vs.* 54.2%) and parking expenses (20.0% *vs.* 43.8%).

The experts consulted also stated the lack of resources and services to address these financial needs. According to them, there are very few options, and even in countries where there are grants or subsidies, economic help, extensive social coverage and health insurance or social workers available, these resources are very limited, insufficient, and unknown by many people. We also need to pay attention to caregivers, who reported financial impact on themselves because they could not combine caregiving with work (or looking for a job).


Impact of lung cancer in household financial situation (n=492)

Reason why lung cancer impacted their household financial situation (n=168)

FIGURE 21. Impact on the financial situation.

The most important problem there is in relation to economic resources is caregivers. Most of them have to stay at home and take care of patients, which means they can't get a job and therefore are not earning any money. There are no public grants for them.
(Dégi László Csaba, social worker, Romania)

In Holland if you lose your job you also lose the pension. This is usually a very big concern for our patients, as they usually have a big responsibility in terms of economic support for their families.
(Isabelle Lebrocquiy, patient advocate, the Netherlands)

We have no official support service for families. Everything is developed by charities and even then, they are very poor and under-resourced. Therefore, we urgently need funding for these services. In addition to this there is definitely a difference depending on where do you geographically live. The resources are different if you live in the countryside or in the city and if you have access to one hospital or another.
(Dearbhaile Collins, medical oncologist, Ireland)

d) Work impact

38.1% of people surveyed reported a negative impact from lung cancer in the work situation of someone in their house. An interpretation of this data should consider that 24.7% of respondents (29.6% of patients; 15.4% of caregivers) were over 65 years old when they completed the survey, so we assume that many of them did not work at the time of diagnosis. This means that the impact of lung cancer on their work situation is presumably higher than 38.5%, since this is based on the total population surveyed, not the population that was working at the time of diagnosis.

This impact is a consequence of the disease journey, which includes living with symptoms such as fatigue or pain that affect the patient´s ability to work, length of hospital stays, frequent medical consultations, psychological disorders, and so on. From those who stated a negative impact, **55.7% selected as the main reason the inability to work, and the other two main causes are time off work** (23.2%) and early retirement (21.1%).

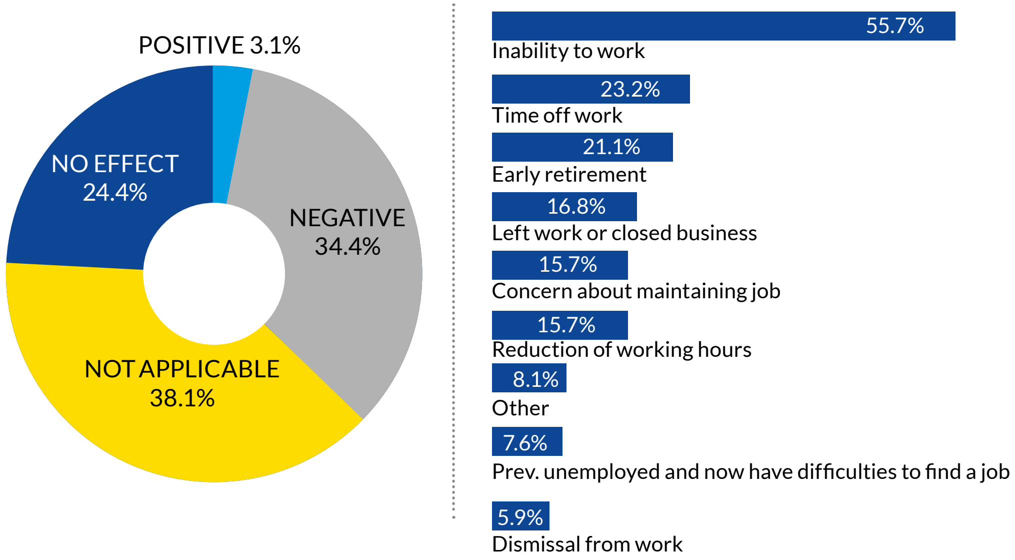
Literature shows that work situations may also be affected by other causes, such as job discrimination, difficulties regarding relationships with coworkers or job changes[35]. Issues regarding personal attitudes at work have been also highlighted by some people surveyed (e.g.: *`I had conflicts and lack of compassion at the time of temporary leave´*; *`I could not resume full time and it did not suit my boss´*; *`Look of others very negative´*).

Reviewing data per country, **Spain had the most negative data.** 59.3% of people surveyed from Spain reported a negative impact from lung cancer on their household work situation. This figure is more than 20 points over the average of all responses (38.1%). On the other hand, **people from Denmark reported a lesser impact** (22.2%), being the country with more positive results in this field.

> *I reduced my commitment and involvement; I need the assistance of my collaborators.*
> (Patient)

> *I am dedicated to computer programming, it is difficult for me to concentrate, I have reduced the number of hours and clients, with the consequent reduction in income.*
> (Caregiver)

> *I had to ask for leave to attend to my sister.*
> (Caregiver)


Impact of lung cancer in the work situation of you or of someone in your house (n=491)

Reasons why lung cancer impacted their household work situation (n=185)

FIGURE 22. Impact in the work situation.

e) Family and loved ones

From this study, data suggests that a lung cancer diagnosis affects family and loved ones. Family members have to face some emotional and social challenges, since diagnosis and their day-to-day lives can be seriously affected because of lung cancer.

Once again, when asked about difficulties they had observed in other family members, caregivers reported a higher number of psychosocial repercussions than patients. Around half of caregivers identified high emotional impact on one or more of the members (54.1%), physical tiredness (48.9%), changes in behaviour (47.7%), and changes in physical appearance (47.4%). The patients surveyed also reported, as the **most frequent repercussion, the high psychological impact** on a family member (49.2%), but the other options got much less responses. The results suggest that **patients and caregivers ranked differently the prevalence of some difficulties experienced by their family members, especially changes in behaviour** (patients 18.5%; caregivers 47.4%), **overload of responsibilities** (patients 15.1%; caregivers 39.1%), and **changes in their physical appearance** (patients 11.7%; caregivers 22.6%). Another significant item is that around **4 out of 10 participants reported overprotective attitudes.**

What are the main emotional and social difficulties that you have observed in your family members since the lung cancer diagnosis? (n=325 Patients; 132 Caregivers)

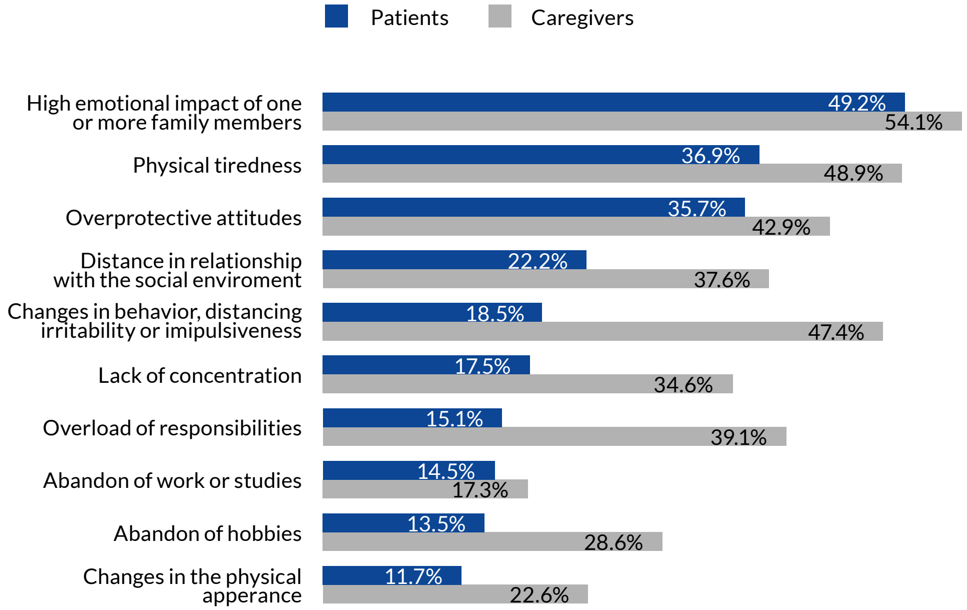


FIGURE 23. Difficulties in family members.

Lung cancer can impact family dynamics and routines, as well as the social environment around patients and caregivers. As Figure 24 shows, changes in family routines and plans are common in most people affected by lung cancer. **7 out of 10 acknowledged that they needed to make some changes in their family after diagnosis** in order to adapt to their new situation. Proportionally, more caregivers have reported changes at family level than patients, but this difference is not significant (67.2% of patients *vs.* 72.6% of caregivers).

Survey participants who had confirmed changes in their family dynamics were asked in an open question what specific changes were made. These are the six main changes reported:

- **Changes in daily routines:** mainly due to the physical impact of lung cancer, medical appointments, and stopping working.
  - *The disease required a systematic adaptation of the schedules according to the treatments, the consultations, the blood tests, the scans, or MRI. But it is also necessary to adapt to the physical capacities, which result in shorter and shorter walks, fatigue during meetings with friends etc. (Caregiver)*
  - *Many changes, not being able to do everything as before, now I have to find strategies to get by in everyday life when I try hard, I have severe pain and, tiredness... (Patient)*
  - *My lovely and helpful husband/support has taken over most practical tasks with house, garden, and cottage, as I have no surplus strength to manage much more. This also applies to daily shopping, which I especially miss, and it also gives me a poor conscience. (Patient)*
  - *I no longer work because of the diagnosis, which has meant a complete lifestyle change and total change of routines. Much of the change is positive! (Caregiver)*
  - *We have made a new distribution of the work assignments in our home. (Patient)*
  - *I spend most of the day at home taking care of her. I've quit work so I can take care of her. (Caregiver)*

Have you made changes to your family routines and plans since the lung cancer diagnosis? (n=519)

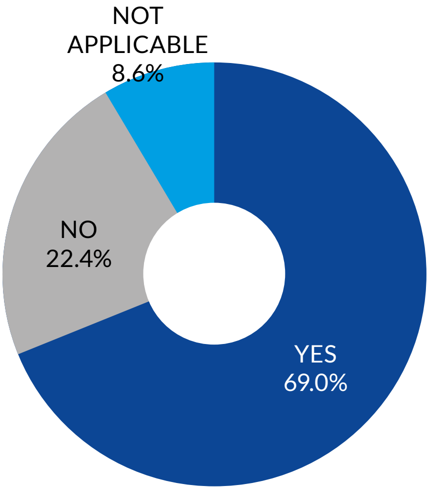


FIGURE 24. Changes on family routines.

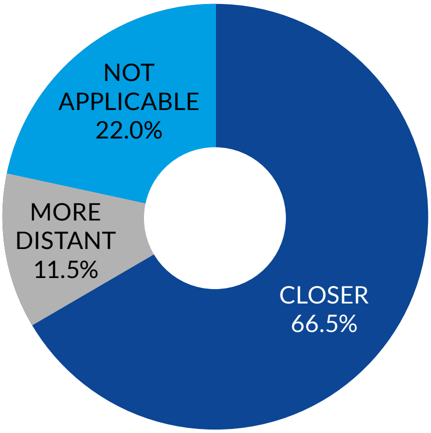
- **Less social and family interaction:**
    - *Given the circumstances, we almost entirely dedicate ourselves to care. We have abandoned social life completely. (Caregiver)*
    - *Hardly see my family other than my son and girlfriend. (Patient)*
    - *Less social gatherings, especially at night, due to tiredness or not being around other smokers. In summer less social life to avoid skin problems due to the sun. (Patient)*
    - *The time for each other within our own family has also been considerably reduced. (Caregiver)*
    - *My children hardly see him anymore, my father just wants to be in bed and when they see him, he is always angry and does not treat them well. (Caregiver)*
    - *Lack of energy determines how often we can do social activities. (Patient)*
- **Changes on plans:**
    - *Not planning too far into the future. Holidays - we never know if we can go on one or where it will be appropriate to go. It affects my teenage children's plans too - they are more hesitant about leaving me or going away and my daughter has struggled with the separation of going to university. (Patient)*
    - *I no longer need to plan my days weeks in advance. Whatever plans I do have need to fit around medical appointments so sometimes I have less flexibility than I used to have, as I want to be there and support him. (Caregiver)*
    - *I postponed works and projects. (Caregiver)*
    - *Plan ahead that activities will take a little longer than previously. (Patient)*
    - *We live day by day without far-reaching plans for the future. (Caregiver)*
- **New healthy habits:**
    - *I changed my eating habits and those of the family: more vegetables cooked in olive oil, very little sugar, less meat. We are doing more walks. (Patient)*

  - *No smoking in my home, moderate alcohol consumption, change of diet to vegetables, recreation through movement. (Caregiver)*
  - *After treatment, I radically changed my lifestyle. A lot of physical activity, diet, I avoid stressful events, as calm a life as possible. (Caregiver)*
  - *Healthy lifestyle: Eating habits, a lot of physical activity, walking, I avoid stressful situations, I simplify everything, (Patient)*
  - *We are more attentive to food and healthy things to do. (Patient)*
- **Family members moving in together:**
  - *We have adapted my house so that my mother can live with us. (Caregiver)*
  - *I now live with my mother so she can help me out with the household and my kids. (Patient)*
  - *Moved in with my mother for 18 months and now my sister is taking her turn and living with her. (Caregiver)*
  - *My husband and I moved in with my mother who is sick and now we all live together, with our little daughter too. (Caregiver)*
- **More social and family interaction:**
  - *I see my family more often; our relationship has become more intimate. (Patient)*
  - *I spend more time with my mother. (Caregiver)*
  - *Free time is largely dedicated to the family. (Caregiver)*
  - *I decided to stay home from work and be closer to the family. (Patient)*

These changes can cause conflicts with family members, however **66.5% of people surveyed confirmed that their family had a closer relationship afterwards,** compared to before the lung cancer diagnosis. However, **1 out of 10 people reported a more distant relationship** with family members. Closer relationships have been more reported by patients and caregivers from Spain (81.8%; 85.2%) and patients from Italy (84.4%).

Asked about their circle of friends (Figure 26), we found that **46.3% of patients and 42.9% of caregivers stated that they had experienced closer friendships** since diagnosis. In contrast, similar, but slightly lower, percentages of participants reported distance from some friendships (42.1% of patients and 38.6% of caregivers).

1 out of 3 patients said that they had met new friends and 1 out of 4 patients and caregivers perceived a lack of understanding and empathy in their circle of friends.



Do you think that you have a closer or more distant relationship with your family since lung cancer diagnosis? (n=492)

FIGURE 25. Relationship with family.

What implications has the disease had in your circle of friends?
(Patients n=328; Caregivers n=140)

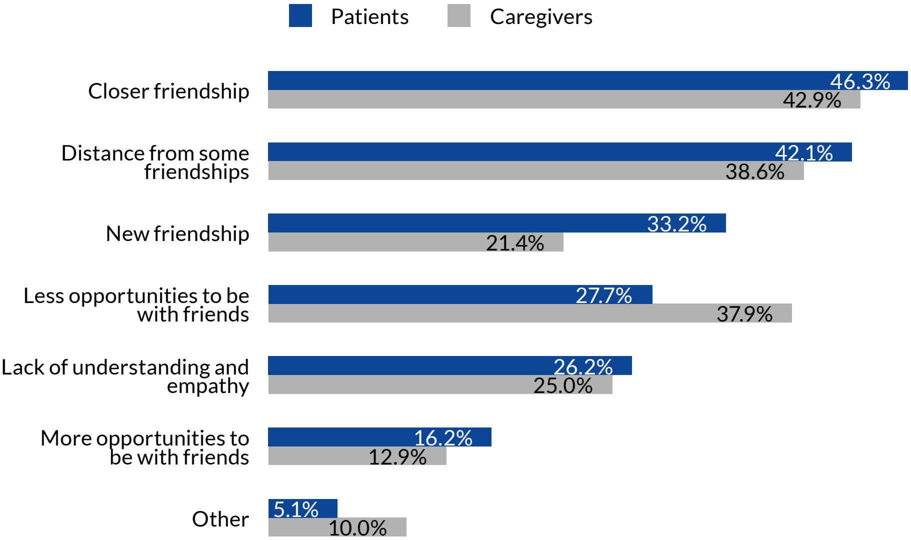


FIGURE 26. Implications in circle of friends.

UNDERSTANDING IMPACTS ON CIRCLES OF FRIENDS

I left some friends because it was evident that only by seeing me they became sad. (Patient)

Since I have been following my sister, I certainly have little if any social life. I tend to isolate myself a lot because it is difficult to talk about the disease with others, because I perceive that it is difficult for others to really understand the problem and I find that there is little empathy and a lot of superficiality. (Caregiver)

We subordinated our lifestyle to the patient and tried to spend every moment with him. (Caregiver)

Less personal time and for friends, lifestyle adapted in part to the patient. (Caregiver)

Friends withdrew during the illness because they could not handle it; I can no longer pursue certain leisure activities and hobbies, such as playing bowling, playing darts, swimming no longer works that way; I have a lot of restrictions, but also got to know a lot of new people and those affected, with whom you can exchange ideas and give tips. (Patient)

Sometimes difficult to make colleagues understand that we are more fragile than them, especially in this period of the Covid-19 pandemic, without wanting to go into detail about our illness. (Patient)

I lost contact with some friends. Other friendships grew stronger (again). (Patient)

I didn't have a social life anymore. Patient care involves many limitations. (Caregiver)

My schedule has been "FREE" reduced, now I know who my friends are and I am VERY LUCKY. (Patient)

Some friends and family have found it difficult to cope with and this has affected my relationships with them. (Patient)

As he is relatively fit, we are able to socialize, but I feel our conversations with friends inevitably turn to his illness and I can often feel like a 'spare part'. (Caregiver)

Many friends are lost, but new ones have come. Many people do not know how to deal with cancer sufferers. (Patient)

2.3. SUPPORTIVE CARE

Given the poor outcomes traditionally associated with lung cancer, understanding the experience and needs of patients and caregivers regarding the supportive care they have received is necessary to explore how to improve the provision of support to this population. As mentioned in this report, they have numerous challenges regarding physical health, daily life, and emotional wellbeing. The following data are presented about their assessment regarding the care they received from healthcare teams, family/ friends, and patient associations/non-profit organisations.

a) Healthcare teams

Lung cancer is linked with high associated comorbidity, which considerably reduces a patient´s quality of life[36]. Information and access to a multidisciplinary health team is a key element to get a better quality of life. We must also pay attention to the wellbeing of caregivers. Their lives also experience important changes after diagnosis, and they often experience feelings of sadness, anxiety, fear, or ire. However, they usually do not receive any support from healthcare[37].

The patients and caregivers surveyed confirmed that they were far from the position of having support of allied health care professionals to face multiple needs that they both have had to deal with since diagnosis. Table 3 shows that **only a minority of them acknowledged accessing any of these supportive professionals.** A deeper analysis should explore why this happens. Different reasons could be behind this limited access: lack of these resources, underutilization of referrals to supportive care services, lack of discussion about these concerns during healthcare visits, insufficient awareness about the value of this care from professionals among patients, caregivers, and healthcare teams.

Have you been supported by any of the following professionals in relation to the lung cancer diagnosis?

	Patients (n=318)			
	Yes	No, but I would have benefited from it	No, but I have not needed it	Unsure
Psychologist	35.3%	20.2%	39.7%	4.8%
Dietitian/nutritionist	24.3%	24.3%	46.6%	4.8%
Physiotherapist	23.4%	17.8%	50.3%	8.5%
Social worker	14.3%	9.6%	70.8%	5.3%
Palliative care team	9.3%	6.0%	76.3%	8.4%
Psychiatrist	6.1%	10.5%	75.5%	7.9%
Lawyer	4.0%	8.8%	80.8%	6.4%

	Caregivers (n=142)			
	Yes	No, but I would have benefited from it	No, but I have not needed it	Unsure
Psychologist	24.5%	41.7%	29.5%	4.3%
Dietitian/nutritionist	21.0%	30.4%	45.7%	2.9%
Physiotherapist	15.7%	20.9%	59.0%	4.4%
Social worker	9.8%	23.5%	62.1%	4.6%
Palliative care team	31,3%	20.6%	43.5%	4.6%
Psychiatrist	5.9%	21.5%	66.7%	5.9%
Lawyer	3.8%	12.0%	78.2%	6.0%

TABLE 3. Access to multidisciplinary care.

It is relevant to mention that 8.9% of all participants said that they had accessed private healthcare services (psychologists, physiotherapy, dietitians, nutritionists, etc.), so this should be considered when interpreting data from Table 3. Not all patients and caregivers who accessed these services did so through the public national health system. As mentioned before, private services were the fourth main reason why lung cancer negatively impacted on the financial situation of some participants (see Figure 21).

- **Psychological support.** Data from Table 3 show that the integration of psychosocial professionals in the disease journey is one of the main challenges in healthcare. **Improving access to psychologists is crucial for patients (20.2% would have needed it) and especially for caregivers (41.7% would have benefited from it).**

9 out of 10 experts consulted reported that **access to psychosocial professionals in healthcare was not enough.**(NOTE 15) Some of the challenges identified are the lack of public funding for these services, the perceptions and attitudes towards psychological support, the lack of knowledge about the existence of this resource and the disparity between regions. The consequences are that many people do not ask for it, others do not have the possibility to receive this support (if not available, they may not afford a private consultation) and others need to wait for a long time to get access.

The waiting list to access them is getting longer every day. People with severe psychiatric diseases usually go first on the list and us, as cancer patients, are the last ones.
(Debra Montague, patient advocate, the United Kingdom)

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[15] Question: Do you think that the access to psychosocial professionals in healthcare is enough? Responses: Not at all (7); A little bit (2); Somewhat (0); Quite a bit (0); Very much (1)

In Germany there is a widespread opinion that psychology is only needed when you have a mental disease.
(Günter Kranz, patient advocate, Germany)

The discovery of the disease is frightening, and it generates uncertainties, fears, and anxiety in our patients, which arises from the loss of control over their lives. Also, a very difficult moment for patients is during disease progression, because patients usually lose hope and confidence in the treatment. Both times are good for emotional support.
(Maria VittoriaPacchiana, psycho-oncologist, Italy)

It is necessary to inform and to educate health professionals and patients regarding palliative care units, and to eliminate the idea that they are only useful at the end of life.
(Bernard Gaspar, patient advocate, Spain)

Psychological support should be available throughout the whole process. From the perspective of the experts interviewed for this report, this is a **priority in two stages of great emotional distress for patients and caregivers: during diagnosis and during disease progression.**

- **Palliative care.** Only **9.3% of patients answered that they had received palliative care.** This low percentage could mean limited access to this service or certain misunderstandings about the term `palliative care´. Palliative care is especially important in lung cancer, as around 80% of patients have Stage IIIB or IV at the time of diagnosis. The finding that 76.3% of patients have affirmed that they would not have needed it when they had previously reported serious symptoms and side effects, as well as significant psychosocial impacts, may suggest that there is a lack of knowledge about the importance of early access to palliative care to improve quality of life.

Asked whether palliative care units in healthcare were enough, most experts consulted answered that they were insufficient.(NOTE 16) One of the main barriers identified was the **lack of staff and the restrictive inclusion criteria** in these units, which makes it difficult to refer patients. Also, experts pointed out that palliative care is not well integrated in the patient journey and only offered at the end of life. There is a **stigma attached to the word `palliative´,** in a way that it means end of life for many people. It is urgent to explain that palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual

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[16] Question: Do you think that the support provided by palliative care units in healthcare is enough? Responses: Not at all (3 responses); A little bit (2 responses); Somewhat (3 responses); Quite a bit (1 response); Very much (1 response)

(definition by World Health Organization). Therefore, it is to refer patients to these units as soon as possible to reduce the disease burden for both patients and caregivers. The third challenge identified is related to the **need for raising awareness about the value of palliative care units to emotionally support** patients and caregivers, not just for symptom management.

> *Palliative care should be introduced earlier during diagnosis and integrated with oncological treatment.*
> (Joanna Vick, nurse, the United Kingdom)

- **Social support.** Although social workers can help patients and caregivers to reduce the functional, work and financial impact of lung cancer, relatively **few participants expressed an interest in social counselling** (14.3% of patients and 9.8% of caregivers), which can suggest a lack of understanding about these professionals. Social workers are usually under-resourced in cancer care, even when they are available in some hospitals. They are also present in social services units, but these services are usually associated with other social problems.

> *We routinely refer our patients to palliative care, but most of the times palliative care only focuses on symptoms and not on the emotional support. Nevertheless, they are very helpful, but are also very under-resourced.*
> (Dearbhaile Collins, medical oncologist, Ireland)

- **Assistance of other healthcare professionals.** One important challenge in accessing supportive care is regarding dietitian/nutritionist support. Around 1 out of 4 patients and caregivers expressed interest in receiving this service. People receiving cancer treatment are at nutritional risk and may have eating problems and other gastrointestinal difficulties (nausea and diarrhea were mentioned by participants as two of the side effects of a higher impact on quality of life), but only 24.3% of patients surveyed received specialized dietary advice and nutritional counselling.

> *There are social workers at hospitals, but many patients and carers are not aware of their services. There should be more guidance at hospitals about what services are available and how to reach these.*
> (Kirsi Roos, nurse, Finland)

On the other hand, we found similar rates regarding access to physiotherapists. Although 61.5% of patients surveyed had difficulties with physical activities and 33.4% reported shortness of breath as one of the side effects that most deeply affected their lives, only 23.4% had been supported by physiotherapists. On the other hand, 17.9% acknowledged that they would have needed it. Some studies have showed how exercise interventions reduce morbidity in lung cancer, helping to prevent deterioration and maximize or restore physical status prior to, during, and following treatment[38].

There are social workers at hospitals, but many patients and carers are not aware of their services. There should be more guidance at hospitals about what services are available and how to reach these. (Kirsi Roos, nurse, Finland)

Once we know which professionals have cared for patients and caregivers, let´s see what specific supportive care needs they reported. As shown in Figure 27, caregivers reported more unmet needs than patients. According to their responses, improving healthcare requires prioritizing resources to address the following five unmet needs:

- Psychological needs, according to 41.4% of respondents.
- Symptoms control and management, according to 40.7% of respondents.
- Impact on family, according to 32.5% of respondents.
- Rehabilitation and exercise, according to 30.6% of respondents.
- Physical daily living needs, according to 26.8% of participants.

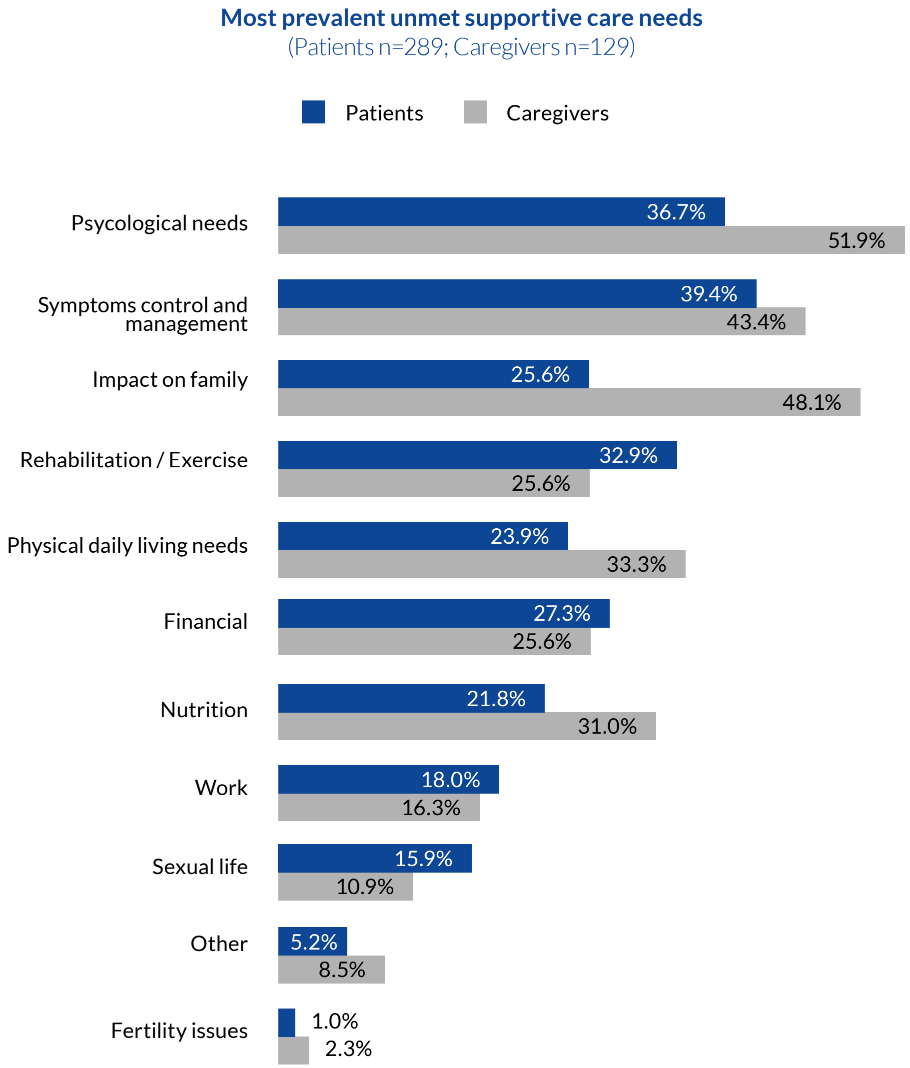

FIGURE 27. Unmet supportive care needs.

Beyond the access to care, we also explored how patients and caregivers valued the assistance they received from healthcare teams. The participants were asked to report their feelings about their experiences with their healthcare team regarding two issues: the emotional support received and their communication skills.

More than half of patients and caregivers said that the emotional support received by healthcare professionals was deficient. Only 30.6% of patients and 20.4% of caregivers showed satisfaction with the support received in this area or said there was no need for this service.

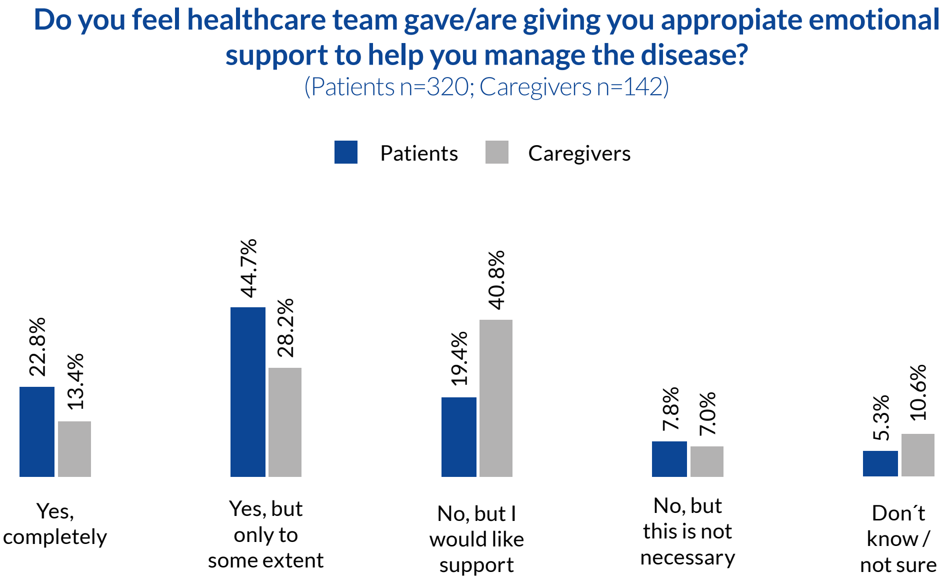

FIGURE 28. Emotional support from healthcare team.

According to most of the experts interviewed for this report, both oncologists and nurses are aware of the psychosocial consequences of lung cancer in patients and caregivers (they reported that nurses are more aware than oncologists)(NOTE 17), so limited resources are the main barrier to provide better emotional care. In this sense, they suggested the need to integrate multidisciplinary teams, digital resources, and patient organisations in cancer care. Furthermore, they highlighted the importance of spending more time during doctor appointments and improving healthcare professionals' communication skills.

There should be enough time at the healthcare unit to explain the diagnosis, planned treatment, and what will be done to make patients feel and get better. This would create a supportive and safe atmosphere and trust for the health care provider. On the other hand, the emotional impact could be reduced if professionals were trained in communication skills to identify psychosocial needs, to know how to offer good emotional support, and to educate and empower patients and caregivers to get them involved in their own care.

In response to this issue, **the survey participants valued the communication with their healthcare in a positive way, the level of satisfaction being higher among patients than caregivers.**(NOTE 18) 78.1% of patients thought this communication was positive/very positive, while this proportion fell to 65.9% in caregivers (Figure 29).

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[17] 6 out of 10 experts say oncologists are *quite a bit/very much* aware of it. 9 out of 10 said that in relation to nurses.

[18] Patients: 4.14; Caregivers: 3.80 (Rated from 1 `Very negative´ to 5 ´Very positive´)

Improving communication between patients/caregivers and healthcare teams would help in the early identification of supportive needs, which would be associated with better management of physical functioning, emotional wellbeing, and health-care satisfaction[39]. Furthermore, good patient-provider communication is associated with lower levels of lung cancer stigma[40], as some patients reported experiencing perceived stigma from medical providers[41]. Improve communication skills is a potentially fruitful area for intervention to reduce the stigma. It is urgent to raise awareness among healthcare professionals about how to speak with people impacted by lung cancer so that they avoid stigmatizing language.

Analyzing data per country, we identified the following countries where communication is more positively valued: Poland, the United Kingdom, the Netherlands, France and Spain.(NOTE 19) In contrast, Greece, Germany, Sweden and Finland are awarded lower rates regarding healthcare communications skills.(NOTE 20)

> *Patients want to know about their illness, and everything related to the treatment. This has resulted in oncologists being able to listen more to the patient, with more confidence, which has provided oncologists with a better idea of the patients' psychological health.*
> *(Bernard Gaspar, patient advocate, Spain)*

> *More and more oncologists are referring people for psychological care following a cancer diagnosis. Nowadays they are constantly receiving feedback from counsellors and centres, so they are informed about how patients are affected. It's a continuous collaboration, sharing of information and communication.*
> *(Patricia Pugh, counsellor/ psychotherapist, Ireland)*

How do you value the communication woth your physicians and healthcare team along the disease journey?
(Patients n=316; Caregivers n=139)

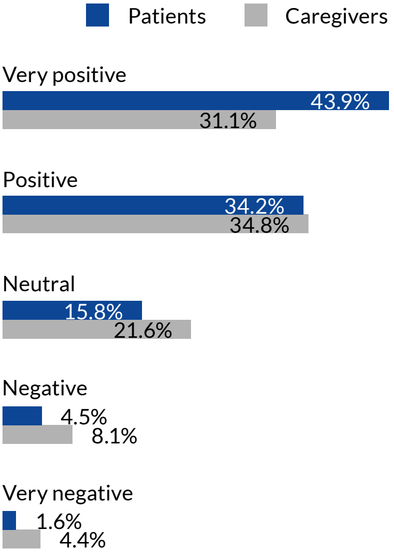

FIGURE 29. Communication with healthcare team.

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[19] Average rate 4.03 – Poland 4.50; UK 4.36; the Netherlands 4.2; France 4.19; Spain 4.18.

[20] Average rate 4.03 – Greece 3.71; Germany 3.73; Finland 3.73; Sweden 3.83.

After years of shortcuts, there are very few nurses in the clinics. Patients often deal with temporary workers who can't put themselves in the patient's shoes. They face every three days a new doctor and a new nurse who know very little about them.
(Günter Kranz, patient advocate, Germany)

I think physicians are aware, but they are not prioritizing psychological needs, which they should do. They sometimes only talk about the disease and not about the person.
(Dégi László Csaba, social worker, Romania)

b) Patient associations and non-profit organisations (NGOs)

The roles of **patient organisations and NGOs have become more and more active** in recent years. They can help the patient and caregiver engage more effectively with their care team and in their own care and provide psychosocial support to improve their quality of life. However, these entities are still unknown in our society. As a result, many patients and caregivers do not get involved with them.

Have you received support from a patient organisation or an NGO?
(n=478)

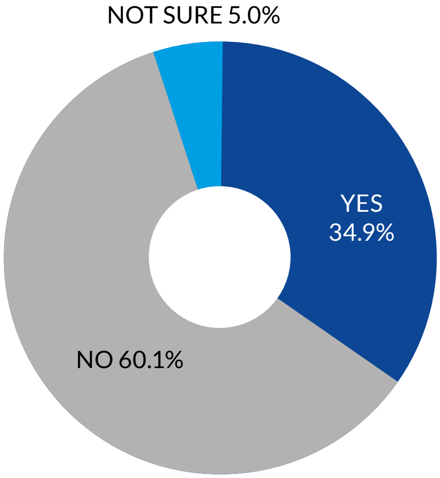

FIGURE 30. Support from patient organisation.

34.9% of people surveyed had received support from a patient organisation or an NGO. **This resource has been used by more patients (38.2%) than caregivers (27.5%).** We should assume that these percentages are even smaller in the general lung cancer population, because this survey has been promoted and delivered by patient associations and NGOs.

The factor that was more useful for people who received this support was information about the disease and treatments, especially for caregivers (70.5%). Secondly, they valued the contact with other patients and caregivers. It is remarkable that this is much more valued by patients (64.5%) than caregivers (40.9%).

The third common way that these organisations supported patients and caregivers was though access to professionals, such as psychologists, social workers, nurses, lawyers, etc. **Only 1.6% of people who received support from patient organisations and NGO answered *´It did not help´*.**

	All (n=168)	Patients	Caregivers
Information about the disease and treatments	64.3%	62.1%	70.5%
Contact with other patients and caregivers	58.3%	64.5%	40.9%
Access to professionals	45.2%	44.4%	47.7%
Healthy habits	28.6%	28.6%	29.5%
Leisure activities	20.2%	23.4%	11.4%

TABLE 4. How patient organisations and NGO helped.

Participants who did not receive support from these entities were asked why in an open question. It is remarkable that 17.0% did not know why they did not receive support from patient organisations. Our hypothesis is that they do not know about them or how to contact them. Also, around 10% of responses showed a clear lack of knowledge about these organisations (10.4%) or answered that they had not been informed (9.3%), so **there is a wide patient/caregiver population we need to reach out to in order to offer our support** and services.

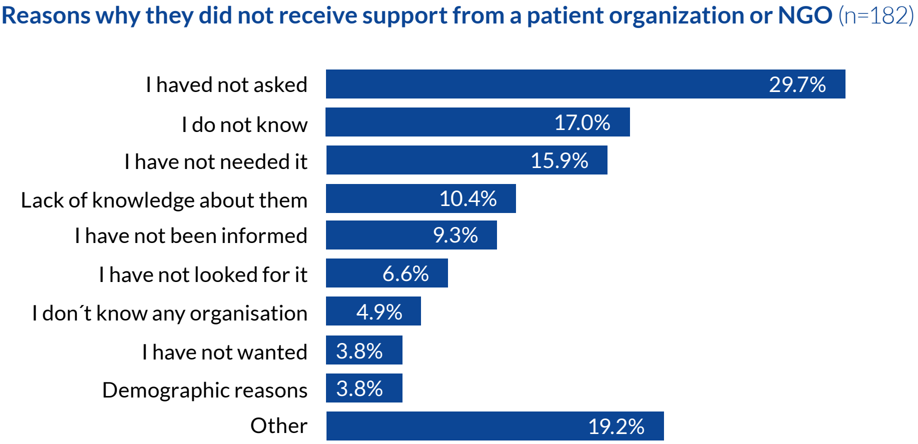

FIGURE 31. Reasons why they did not get support from patient organisation.

As we highlighted in previous reports, **one of our challenges as a community is to get more people involved in advocacy** to support people affected by lung cancer. LuCE is working to make the patient advocacy community stronger, but the mortality rates, the disease burden and the stigma associated with the disease are barriers to the involvement of many patients in these organisations.

Due to the limited resources (human and financial) of these organisations, experts consulted for this research identified some services and resources that patient associations and non-profit organisations should prioritize in order to offer the best care to patients and caregivers such as increase psychological support services, collaborate with other organisations and work with hospital centres so that more people are signposted to patient organisations.

> *A very important thing that NGOs should focus on is collecting the data. Make sure they can prove what you are saying with the right data. It's very important to collect national and international data, and therefore the collaboration with other NGOs is very important.* (Isabelle Lebrocquy, patient advocate, the Netherlands)

> *The first thing they should prioritize is making it easier for patients to access information; they can easily provide it through paper, electronic, or audiovisual content* (Maria Vittoria Pacchiana, psycho-oncologist, Italy)

Why didn´t patients and caregivers receive support from patient organisations?

- *I do not know where to apply, no one has informed me. (Patient)*
- *Because I did not take any steps to receive specific support. (Caregiver)*
- *No group towards my home and I received no contact from an organisation. (Patient)*
- *Because no one told me about a patient organisation. I had to look for it myself. (Patient)*
- *No idea. Is it in a Facebook group in which experiences are shared? Do not really know what options there are. Doctors had no information about this. (Patient)*
- *No idea, it was not offered, and I was not told where to go for it. (Caregiver)*
- *Because I really do not know how it works and how they can help me. The patient went to ask the social worker about the laboral inability, and he did not know how to help. (Caregiver)*
- *The offer of support has always been focused on my husband. I know I can ask for support and from where but feel if I did that my husband would feel guilty that I needed it. (Caregiver)*

c) Family and friends

Family members of patients with lung cancer are an essential part of care and have a significant impact on their wellbeing. Similarly, caregivers have multidimensional needs that must be recognized, and they require optimal support from other family members as well. Family members are the main source of informal support and they play an important role in patient and caregiver self-efficacy and adjustment[42].

The **majority of people surveyed were satisfied with the support received by their family,** and this satisfaction was **higher among patients than caregivers.** From 1 (not all satisfied) to 4 (very satisfied), the average rate in patients was 3.43, while it was 3.22 in caregivers.

In the same way, both patients and caregivers stated **satisfaction with the support received by their friends, but here the level of satisfaction is lower** and, once again, caregivers felt less satisfaction than patients. While the average rate in patients is 3.11, the rate in caregivers was 2.96. In this matter, it is important to remember some data previously shown in this report. 42.1% of patients and 38.6% of caregivers noticed distance from some friends, and 26.2% of patients and 25.0% of caregivers felt a lack of understanding and empathy from some friendships (see Figure 26). These could be some of the reasons to explain why **around 25% of people surveyed do not feel much satisfaction with the support received by their friends.**

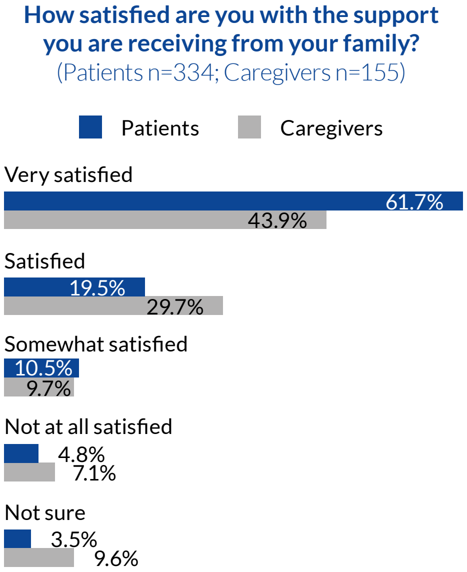
How satisfied are you with the support you are receiving from your family?
(Patients n=334; Caregivers n=155)

FIGURE 32. Satisfaction with support from family.

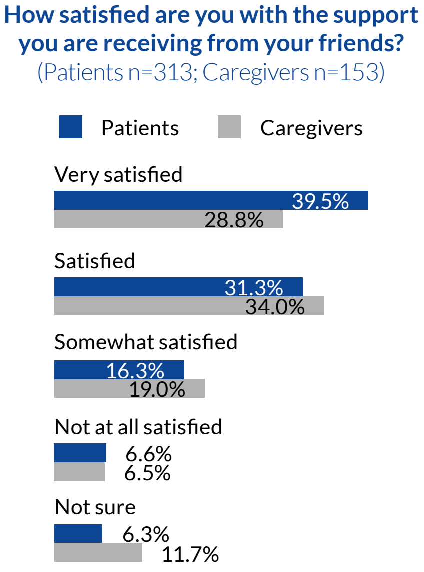
How satisfied are you with the support you are receiving from your friends?
(Patients n=313; Caregivers n=153)

FIGURE 33. Satisfaction with support from friends.

Despite these positive results in the level of support satisfaction, we found some significant results when asked about the availability of this help from family and friends. **25.2% of patients surveyed do not have anyone to help them with daily chores** and 36.0% only *some/a little of the time*. There is also a lack of emotional support to patients. **21.9% of them do not count on anyone to receive this support ever, or only a *little of the time*,** and 20.3% only *some of the time*.

Looking at caregivers, we find equally worrying data. **22.3% of caregivers do not have anyone around to help them with daily chores and 30.9% cannot count on anyone for emotional support for either** *none of the time* or *a little of the time*.

Therefore, even when people surveyed showed an overall good level of satisfaction with the care received, we found that a significant percentage of patients and caregivers did not feel fully supported by their loved ones. This interferes with the cognitive and emotional processing of the disease.

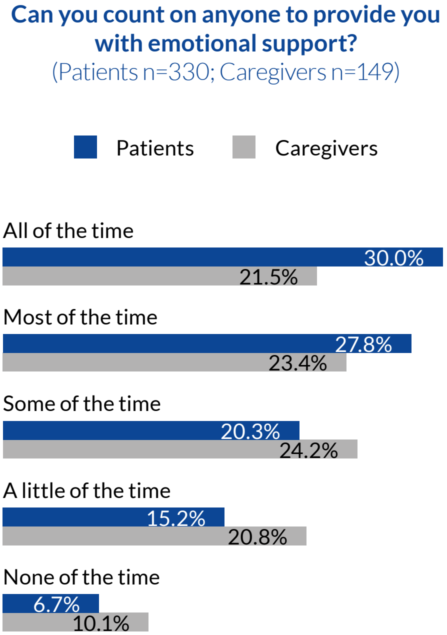

FIGURE 34. Informal emotional support.

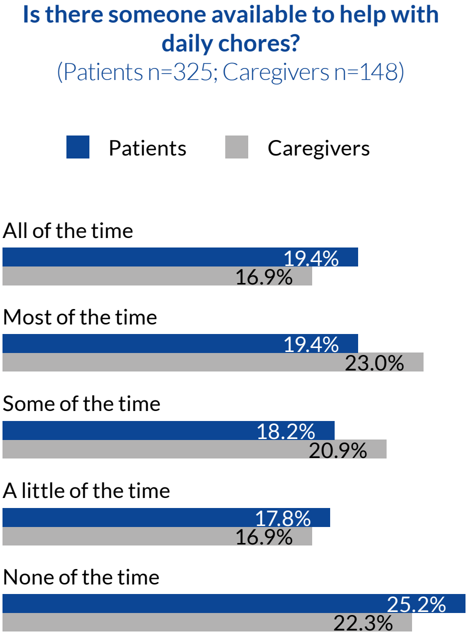

FIGURE 35. Availability of help for daily chores.

Coming together is a beginning, staying together is progress, and working together is success.

Henry Ford

3. Call to action

Provide integrated psychosocial services in the lung cancer care pathway

Improve quality of life for people impacted by lung cancer by delivering access to appropriate psychological and social services throughout the entire care pathway; tackle stigma through improved communication skills.

Increase awareness of patient organisations and NGOs

Encourage health services to signpost people impacted by this disease to patient organisations, NGOs and support centres; provide training to increase the number of people able to offer ‘peer to peer’ support.

Kiitos Umesc Hvala Kasih Todah
Diolch Sheun Mamnoon
Shnorhakalatiun Khopjaj Shokrum Spaas Mul
Gamsahapnida Ngiyabonga Gra Dhanyavaad Xie
Dank Takk Cam
Dakujem DawWaad Dhanyavaadaalu Kop Salamat Merci or al Go Grazie Faleminderit
Dhanyavad Dankie
Thank You Kun Kruthagnathalu
Arigatou
krap Or Dhonnobaad
Tack Gomapsupnida Kun ederim Asante
Gracias Nandree Blagodariya Fyrir Terima Euxaristo Shukriya Hain Dhan
Grazzi raibh Danke daa
Enkosi *dank*

Lung Cancer Europe

4. Acknowledgements

Seven years have passed since a group of patient advocates came together to create LuCE, in 2013. We wanted to give a voice to the needs and challenges that people affected by lung cancer have to deal with. Much work has been done since then, and we are very grateful to our collaborators and supporters, which has helped us grow these past years. We know, we have not walked this journey alone.

This report was possible thanks to the many people and organisations, who freely contributed their time to highlight the psychosocial needs of people impacted by lung cancer and caregivers.

We are indebted to each and every one of the **hundreds of people who completed the survey,** and shared their experience with us. We understand how difficult it is to speak about emotions and daily life with this disease. We hope that this report reflects your experiences as accurately as possible. Thank you for your generosity and time.

Thanks to all **the healthcare professionals who got involved in this project.** Thank you for recognising the importance of offering comprehensive support to people with lung cancer and caregivers in the physical, psychological, functional and social spheres. Thanks to the people who reviewed the survey and those who were interviewed. With everyone's support we have achieved a more accurate methodological approach, and a broader view of the most common psychological and social issues associated with lung cancer.

We also want to express our sincere gratitude to the following companies for supporting our organisation, and for their commitment to people impacted by lung cancer: **Amgen, AstraZeneca, Bayer, BluePrint Medicines, Boehringer Ingelheim, Bristol-Myers Squibb, Lilly, Merck, MSD, Novartis, Pfizer, Regeneron, Roche, Sanofi and Takeda.**

Thank you to **MÁS QUE IDEAS Foundation** for their continued support. This report would not have been possible without the key role they played in bringing this to fruition.

Lastly, **we want to give a special thank you to our members,** for their great support and involvement in this project. These organisations do a fantastic job nationwide, supporting people 365 days a year. We are very grateful that they recognize the value of working together at the European level to face challenges that we all share. These collaborative work efforts bring true meaning to the phrase `Alone we can do so little, together we can do so much´.

Lung Cancer Europe

5. About LuCE

LuCE is the voice of people affected by lung cancer, striving to make lung cancer an EU health priority, and supporting its' members to be effective and sustainable organisations. LuCE provides a European platform for already existing lung cancer patient advocacy groups and supports the establishment of national lung cancer patient groups in different European countries were such groups do not yet exist.

LuCE activities fall under three specific pillars, Education, Awareness and Advocacy, and our strategic objectives revolve around them:

1. Contribute to improve the **early diagnosis** of lung cancer
2. **Enhancing our network** by improving internal communication and engaging potential new members
3. Advocate for **equality of access** to treatment and care across Europe
4. Improve skills and **build capacity among our community** to increase the presence and relevance of lung cancer patient advocates
5. **Reduce the stigma** associated with lung cancer

Meet our team:

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Ewelina Szmytke
(Poland)
Vice-President

Regine Deniel Ihlen
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Treasurer

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Board member

Lavinia Magee
(UK)
Board member

Alfonso Aguarón
(Spain)
Project Manager

Charles Bisaillon
(Switzerland)
Communications Manager

ABOUT OUR MEMBERS

LuCE provides a platform for organisations and individuals working for people impacted by lung cancer. As of November 2020, there are 14 full members, 12 associate members and 4 individual members, representing 21 countries. We encourage you to learn more and support LuCE and our member organisations.

https://www.lungcancereurope.eu/about-luce/member-organisations/

FULL MEMBERS

Lélek-zet Egyesület

Patientforeningen Lungekræft
www.lungekraeft.com

Bundesverband Selbsthilfe Lungenkrebs e.V.
www.bundesverband-selbsthilfe-lungenkrebs.de

Women Against Lung Cancer in Europe
www.womenagainstlungcancer.eu

Associazione Insieme per i pazienti di Oncologia Polmonare IPOP ONLUS
www.associazione-ipop.org

Israel Lung Cancer Foundation
www.ilcf.org.il

Longkanker Nederland
www.longkankernederland.nl

Lungekreftforeningen
www.lungekreftforeningen.no

Stowarzyszenie Walki z Rakiem Pluca
www.rakpluca.org.pl
www.rakpluca.szczecin.pl

Asociación Española de Afectados de Cáncer de Pulmón
www.afectadoscancerdepulmon.com

Lungcancerförening
www.lungcancerforeningen.se

Pulmonale
www.pulmonale.pt

Lung Cancer Nursing UK (LCNUK)
www.lcnuk.org

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SuomenSyöpäpotilaat

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Patients en Reseau/Mon Reseau Cancer du Poumon

www.monreseau-cancerdupoumon.com

Landesverband Baden- Württemberg für Lungenkrebskranke und deren Angehörige e.V

www.lungenkrebs-bw.de

European School of Oncology (ESO)

www.eso.net

Dzivibas Koks

www.dzivibaskoks.lv

De L'air

www.assodelair.fr

K.E.F.I. of Athens – Association of Cancer Patients of Athens
www.anticancerath.gr

Community Health Association
www.facebook.com/pg
SanatatepentruComunitate

Društvo onkoloških bolnikov Slovenije
www.onkologija.org

Fundación MÁS QUE IDEAS
www.fundacionmasqueideas.org

European Thoracic Oncology Platform (ETOP)
www.etop-eu.org

Pembe Hanim
www.pembehanim.com.tr

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LuCE is the voice of patients with lung cancer, their families and survivors at a European level

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