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Perception of Lung Cancer among the General Population and Comparison with Other Cancers

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Introduction: To evaluate the perception of lung cancer in the general population to identify obstacles in patient–doctor communications.

Methods: A prospective nationwide survey was conducted using a questionnaire and lexical approaches given to 2200 healthy subjects selected within a representative polling database.

Results: Of the 1469 subjects eligible for full analysis, most were well informed regarding the epidemiological changes to lung cancer and the main risk factors. The overall survival of patients with lung cancer (32%) was overestimated, and the survival of patients with early stages of lung cancer was underestimated (52%). Lung cancer was identified as a severe disease (82%) with a worse prognosis than other cancers. Most of the population was aware of the main treatments available, except for targeted therapy. Using lexical analyses, we observed that a major proportion considered lung cancer to be a tobacco-induced, life-threatening disease that involved major treatment, and a minor proportion considered it to be an environmentally induced disease. Compared with breast cancer, lung cancer was characterized by a greater feeling of guilt and was more frequently associated with lifestyle.

Conclusions: We have identified knowledge gaps in the perception of lung cancer and have highlighted a need for a public information campaign on lung-cancer screening to promote the good survival rate from early-stage disease and the progress achieved with new therapeutic strategies.

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JM, JLP, NK, DB, and BM conceived the study and wrote and edited the manuscript. JM and BM collated and analyzed data. TF, NT, and DJ collated and analyzed data and edited the manuscript. JDM analyzed the data and edited the manuscript.

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Lung cancer is the most common cause of cancer-related deaths, and its prognosis remains poor, with an overall survival rate of less than 15%.[1] Lung cancer is a disease of high symptom burden and has major psychological impact. Psychological distress because of lung cancer is higher than that because of other cancers, and there are large unmet psychosocial concerns. As it is frequently associated with lifestyle, and particularly smoking, lung cancer is often socially represented as a self-inflicted disease.[2] Therefore, for the patient, a diagnosis of lung cancer is often associated with feelings of guilt and a high level of anxiety.[3]

These feelings are probably associated with delayed diagnosis and the fear of the inefficacy of some anticancer treatments. Because the majority of cases are diagnosed later, only around 20% of lung cancers are operable at the time of diagnosis, as clinical symptoms usually only appear at a later stage and are not specific. Moreover, delays between the first symptoms and a specialist visit, and then between the first visit and beginning treatment, are long,[4,5] often exceeding 2 months in France. Conventional front-line chemotherapies used in unselected patients reached a plateau of efficacy, which led to a pessimistic view of lung cancer in the late 1990s including within the general population, especially as other cancers, such as breast cancer or hematological malignancies, seemed to benefit from medical progress.[6]

However, lung-cancer management has evolved rapidly with the advent of new chemotherapies, the validation of maintenance treatment, the development of targeted drugs, improvements in surgery and radiotherapy in both early and locally advanced stages of this disease, and the greater potential interest in lung-cancer screening.[7–13] After years of very slow progress, these recent advances provide scope for a dramatic improvement in the perception of this disease by both patients and physicians. In clinical practice, medical staffs are often largely unaware of how the patient perceives and feels about their disease. One of the main sources of psychological distress that patients may experience is linked with social perceptions and the cultural context in which events take place.

Herein, we have evaluated perceptions of lung cancer in the general population to better anticipate fears or failures

that could alter physician–patient communications and delay lung-cancer screening and diagnosis. We have conducted (in France) a prospective observational survey of 2200 healthy subjects older than 18 years and collected data related to etiology, epidemiology, diagnosis (including screening), treatments, prognosis, and perceptions of lung cancer using lexical approaches.

PATIENTS AND METHODS

General Considerations

This prospective study was designed not only by an interdisciplinary group of oncologists involved in lung-cancer management, but also by chest physicians, general practitioners, and social psychologists not involved in lung-cancer treatment. The survey was conducted in France by Kantar Health, a market-research company. All data collected were anonymous, and the French Data Protection Authority (Commission Nationale Informatique et Libertés) was notified of the study (registration number: 117856). The research was conducted according to the relevant national and European laws, and professional guidelines. All participants enrolled in the study were informed of the objectives of the research, how the data would be used, and their right to withdraw their answers from the study.

Population

The general population was selected from the ACCESS SANTE permanent polling database, representative of the French population aged ≥18 years and living in France in June 2013. Its representativeness and the algorithms used in sample selection have been verified by experts from the National Institute for Statistics and Economic Studies (Institut National de la Statistique et des Etudes Economiques, France) and EUROSTAT (Europe). Subjects entered into this database were accrued in several ways (face-to-face interviews, phone calls, and e-mail invitation), in an attempt to reduce the possible risk of selection bias associated with a particular method.

The panelists participate in six to eight health surveys per year and receive nonmonetary incentives in return for their participation. The panel was composed of 20,000 households (including 53,000 individuals), selected according to standard sociodemographic and geographic criteria. The representativeness of the sample was assessed using the quota method, and computerized weighting was used according to the raking adjusted statistics method. To ascertain that the sample was representative of the overall national population, a weighting was applied based on five criteria: gender, age (five categories), socioprofessional status (eight categories), region (nine categories), and community size (five categories).

A self-administered questionnaire was posted to a selected representative sample of 2200 participants from the general public who were aged ≥18 years, using quota sampling.

Questionnaire

Questions were asked about age, gender, place of residence, smoking, socioeconomic characteristics (educational level and working status), and whether or not they had personally been in contact with someone who had experienced lung cancer. Also, questions regarding their knowledge of epidemiology, symptoms, treatment, prognosis, screening for lung cancer, and how they evaluated their own level of knowledge about lung cancer were asked.

Lexical Tests

At the beginning of the questionnaire, subjects were proposed a test of verbal association. They were asked to spontaneously associate five words with "lung cancer." The test was performed by 96% of the subjects (n = 1429) leading to a total of 7839 words. The lexical corpus was performed using the lexicometric-derived approach, called ALCESTE.[14] This procedure uses repeated, descending hierarchical clustering. It is a two-by-two matrix that compares how words co-occur (or not) in each extract and develops a classification tree that is descendant because the whole corpus is divided first into two main lexical classes according the greatest difference between the use of any two words. Then, for each of these two classes, the software redivides the text into two other different parts and continues this classification until the lexical classes become stable and autonomous.

Statistics

Results are expressed as percentages or means + standard deviations. Analyses were performed using CromX (SocioLogiciel, France). The p values less than 0.05 (two-sided tests) were considered statistically significant.

RESULTS

Demographic Characteristics

Of the 2200 people identified from the database, 1469 were eligible for the full analysis (Fig. 1). These 1469 people were representative of the whole population, and there was no selection bias because similar demographic characteristics were observed in both populations (see Supplemental Table, Supplemental Digital Content 1, http://links.lww.com/JTO/A752). In this population, 16% were current smokers, 27% were former smokers, and 57% were never-smokers. Forty percent had a close family member or friend with a history of lung cancer.

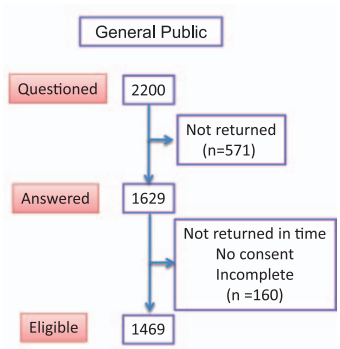

FIGURE 1. The CONSORT diagram.

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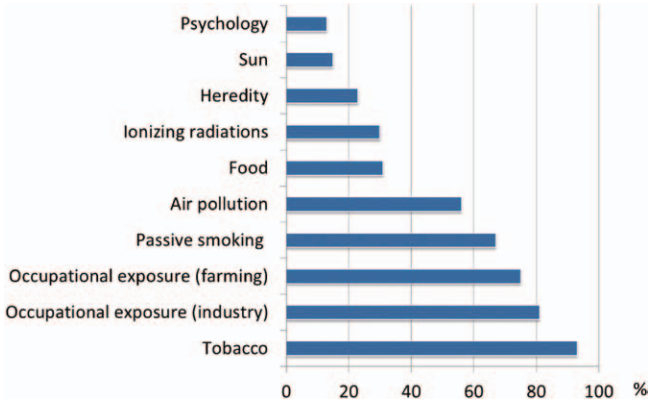

FIGURE 2. Beliefs about the causes of lung cancer (percentages of listed causes).

Knowledge of the Epidemiology and Risk Factors for Lung Cancer

The participants were asked about the epidemiological changes in the incidence of lung cancer over the past 10 years. Regarding the incidence of lung cancer in men, the response "the same" (the correct response), "higher," or "lower" was given by 40%, 47%, and 12% of the public, respectively. Most participants were familiar with the epidemiological changes in incidence in women: the correct response of "higher" was given by 75% of the participants.

The main beliefs on the causes of lung cancer, as a percentage of the listed causes, are summarized in Figure 2. The vast majority of participants were familiar with the role of active smoking (93%), whereas only two-thirds (67%) were aware of the role of passive smoking.

Of the 1469 participants, 22% considered themselves to be at risk of developing lung cancer (see Supplemental Table, Supplemental Digital Content 2, http://links.lww.com/JTO/A752). The perceived risk was significantly higher for smokers (62%) than for former smokers (21%) and never-smokers (6%) (p <0.001), for younger than for older subjects ($p = 0.006$), and for more men (26%) than women (19%, $p = 0.009$).

Knowledge of the Symptoms and Prognosis

The first question concerned the initial symptoms of the disease. We observed that 85% of the general population believed that symptoms are present in most cases. Lung cancer was considered a severe cancer by the vast majority (83%).

Participants were asked to give their opinion about five other cancers on a scale of 1 to 10: pancreatic cancer was considered severe (80% of the participants), whereas colorectal, breast, and prostate cancers were regarded as less serious (59%, 38%, and 36% of participants, respectively; Fig. 3*A*). We analyzed the data according to gender and found no differences in the perception of the seriousness of lung cancer between men and women, whereas differences were observed in the concept of seriousness of breast cancer, with women considering this more serious than men. We also analyzed the perception of cure rate of lung cancer and observed that 32% of the public think that lung cancer can be cured at any stage and 52% if diagnosed at an early stage (presented in the survey as "a very early stage"; Fig. 3*B*). The perceived cure rate for other cancers was higher for breast, prostate, and colorectal cancers and similar for pancreatic cancer (Fig. 3*B*).

Knowledge of Lung-Cancer Treatments

When lung-cancer treatments were listed and suggested to the participants, the best known were chemotherapy (91%), stopping smoking (90%), surgery (71%), radiotherapy (64%), treatment of symptoms (48%), targeted treatments (45%), and alternative therapies (15%; Fig. 4). When asked their opinion on the treatment of lung cancer, most participants thought that lung-cancer treatment required overnight hospitalization (74%), that treatment had to be administered by perfusion to be efficient (60%), that chemotherapy alone was sufficient

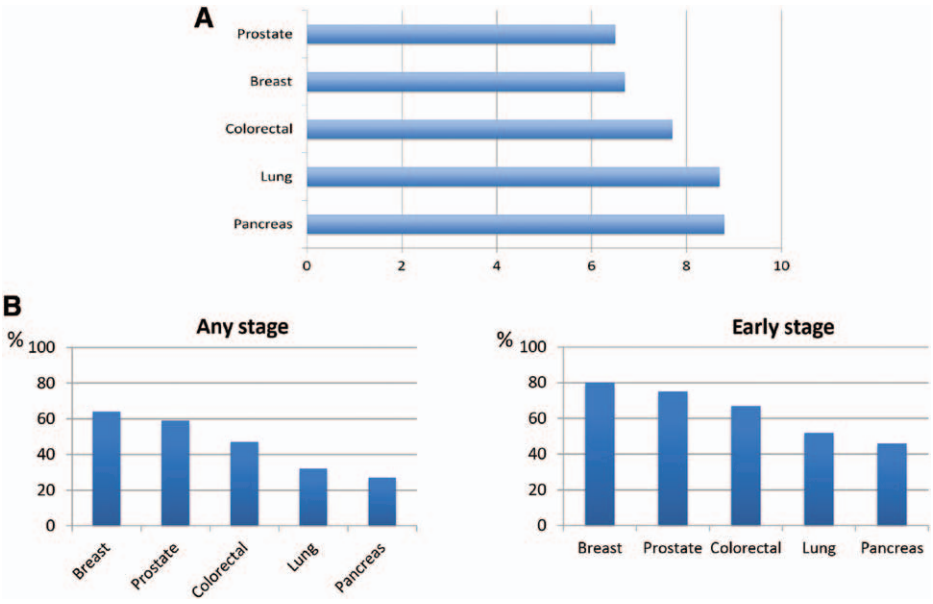

FIGURE 3. *A*, Assessing the gravity of five cancers. Answers to the question: "On a scale of 0–10, how would you rate the seriousness of these cancers?" *B*, Average percentage chance of a cure from five types of cancer at all stages (B-left panel) or at any one stage (B-right panel).

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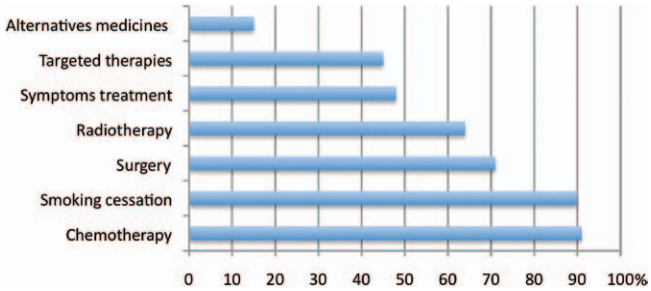

FIGURE 4. Knowledge of the main lung cancer treatments.

(44%), and 21% thought that alternative medicine could efficiently treat lung cancer (see Supplemental Fig., Supplemental Digital Content 3, http://links.lww.com/JTO/A752).

Perception of Lung Cancer: Lexical and Thematic Fields

Participants were invited to spontaneously associate their perceptions of lung cancer. Analysis of the 10 most frequent words in the lexical corpus (n = 7839 words, 5.4 per person) showed a tendency to associate the expression "lung cancer" with tobacco use ("cigarette," "smoking," and "tobacco" were cited 1017 times in total), a fatal disease ("death" was cited 535 times), pollution (n = 231), chemotherapy-based treatments (n = 337), and suffering. (n = 276). The main repertoires for the lexical corpus, deciphered by performing a descending hierarchical clustering and taking into account the sociodemographic profile of the subjects, are shown in Table 1. Briefly, from a thematic point of view, the corpus could be split into two main lexical repertoires. The major repertoire (85% of the corpus) brought out words, such as tobacco, associated with death (32.2%) or cure (25.3%), the color black and symptoms (cough, fatigue, shortness of breath). For the lexical field of "death," disease, hospital, and suffering were predominantly more associated by younger (18–34 years old) smokers, whereas lung, black color, and respiratory symptoms were chosen more by women aged 35–49 years. In the minor repertoire (15%), lung cancer was associated with risk factors (pollution, asbestos, chemical products, pesticides) and lifestyle (work, hygiene). This lexical field was preferentially responded to by the elderly and nonsmokers.

Perception of Lung Cancer: Comparison with Breast Cancer

Comparisons between perceptions of lung cancer and breast cancer demonstrated that breast cancer was significantly more frequently considered as a twist of fate, an injury, or an attack, whereas lung cancer was more frequently associated with the loss of autonomy or a punishment (Fig. 5).

DISCUSSION

Most of the studies published in this field are retrospective and focus on patients with lung cancer or medical students, but very few have included the general population.[15,16] Moreover, most published studies were performed at a time when patients with lung cancer had a very pessimistic outlook because of the absence of novel treatments.

The originality of our study is our screening of a large number of the general population at a crucial period when lung-cancer management is rapidly evolving. However, our study was restricted to the French population; thus, our conclusions cannot be fully extended to other countries. Nevertheless, we think that the perception of lung cancer in France, despite some specificities, is probably close to that in other developed countries, as epidemiologic and therapeutic changes have evolved similarly worldwide. One limitation of our study can be that the percentage of smokers (16%) is lower than the usually reported percentage of smokers in France (30%). This gap might be explained by the fact that nonsmokers are more likely to respond than smokers.

We have analyzed the perception of risk factors and epidemiology of lung cancer. Li et al.[17] showed that knowledge and beliefs about lung cancer varied significantly according to smoking status, never-smokers being the most knowledgeable about tobacco-related cancer risk. We found that the link of causality between lung cancer and smoking habits is well known in the general population. Nevertheless, we observed striking differences in the knowledge of other risk factors. The general population also appears to be aware of the potential carcinogenicity of occupational exposure, air pollution, and ionizing radiation. These risk factors have been extensively studied and are known to cause lung cancer, even if the relationship is weaker than those for active smoking.[18] Recently, the role of diesel particles has been reported to be a risk factor

TABLE 1. Lexical Field Analysis

	Main Words Chosen (% of the Total Corpus)	Three Most Significant Words (χ^2)	Significant Sociodemographic Variables
Lexical clusters	Death (32.2%)	Death (209), hospital (113), suffering (79.2)	Smokers, 18–34 yrs, professionally active
	Cure (25.3%)	Cure (93.8), hope (55), treatment (49.7)	Aged >65 yrs, non-active, low instruction level.
	Black (18%)	Breath (145), cough (62.5), lung (79.1)	Non-smokers, women, 35–49 yrs, active, high level of education, urban lifestyle
	Fatigue (9.5%)	Fatigue (228.4), radiotherapy (194), being out of breath (184.1)	Former smokers, rural lifestyle
	Pollution (15%)	Pollution (273.4), chemical product (198.2), asbestos (219)	Nonsmokers, men, aged >65 yrs, nonactive.

Ten most frequent words are as follows: death (n = 535), tobacco (n = 453), cigarettes (n = 426), chemotherapy (n = 337), disease (n = 283), suffering (n = 276), pollution (n = 231), pain (n = 193), smoking (n = 138), asbestos (n = 132). In total (tobacco, cigarettes, and smoking) n = 1017.

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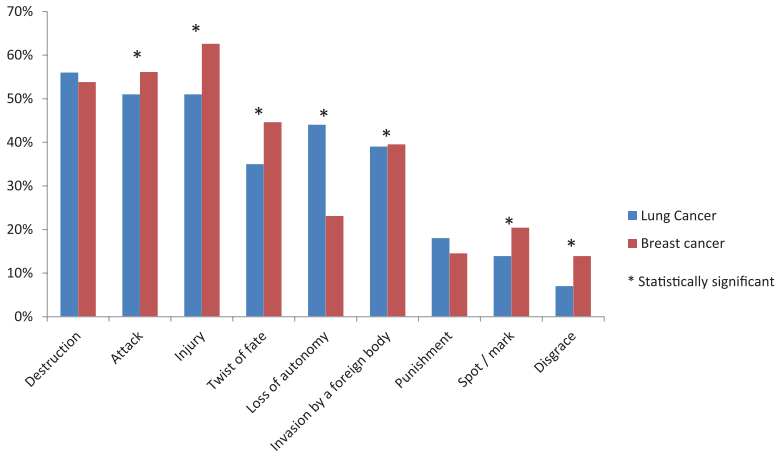

FIGURE 5. Comparison of how lung cancer and breast cancer feel to the patient. In response to the question "According to you, how does a patient with lung/breast cancer consider their disease?"

for lung cancer.[19] In contrast, few data support the role of food in lung carcinogenesis. However, a third of the general population cited alimentation as a risk factor, probably because of the recent literature that targets the general public more than physicians. The role of passive smoking was unknown by a third of the population, even though the role of passive smoking has been very well documented and is associated with 600,000 deaths worldwide every year, among which 21,400 are caused by lung cancer.[20]

Interestingly, smoking habits strongly influence the perception of the risk of lung cancer. As expected, the risk was perceived as significantly higher by smokers than by nonsmokers. In contrast, the risk was underestimated by former smokers. In summary, the general population appears to be aware of the main risk factors for lung cancer, but effort should be made to improve education that passive smoking is also a well-recognized risk factor.

We also analyzed the general public's knowledge of lung-cancer symptoms. Surprisingly, a large majority think that lung cancer is symptomatic in the early stages of the disease. There is probably confusion, as lung cancer is known to be symptomatic at a metastatic stage. Lung cancer is indeed known to be associated with the worst pain intensity and higher mean depression scores compared with that of other cancers.[21] This observation should be taken into account as lung-cancer screening has been validated by recent studies.[13] Effort should be made to convince the general population that lung cancer is not symptomatic in its early stages and that the best survival is observed with small asymptomatic lung cancer, which can benefit from surgery. It is well known that the efficiency of a screening program is directly related to public awareness and that a diagnosis performed before the onset of symptoms is associated with better survival.

We have entered a new and hopeful era in the treatment of lung cancer. In recent years, there have been some exciting developments in lung-cancer treatments, especially concerning improvements in surgery to treat early-stage patients (videothoracoscopy), alternative procedures for inoperable patients (stereotactic radiotherapy, thermoablation), new radiotherapeutic strategies (tomotherapy, gating, and intensity-modulated radiotherapy), and the development of new targeted drugs based on a better understanding of lung oncogenesis.[22] Awareness in the general public of these promising developments should change the pessimistic approach to lung cancer. Interestingly, although patients were aware of the main cancer treatments, e.g., surgery, radiotherapy, and chemotherapy, they had poor knowledge of the new tools in radiotherapy or of targeted agents. Effort in this area may help enroll more patients into clinical-research programs that are evaluating targeted drugs.

The perception of prognosis is a key issue in patient–doctor communication. Sagan et al. showed that patients with lung cancer perceive their disease more optimistically than medical personnel, but this study did not include healthy individuals from the general population. We also observed that the public overestimated the 5-year survival rate from lung cancer (32% compared with the actual survival rate of 15%).[16,23] Conversely, the public underestimated the rate of definitive cure by surgery for early-stage lung cancer.[24] Moreover, the high rate of cure at the early stages is the basis of the lung-cancer screening program. Rutten et al.[25] showed that only a minority of respondents (17%) correctly evaluated the prognosis of lung cancer, in contrast to colon and skin cancers. In a recent prospective study, 69% of patients with lung cancer believed that chemotherapy might be curative.[26]

According to the lexical approaches, the general population perceived lung cancer as a life-threatening disease associated with a high symptom burden: fatigue, cough, pain, and shortness of breath were cited frequently. Gralla et al.[27] noted that more than 80% of patients with lung cancer are affected by at least three symptoms (including the most common, e.g., pain, dyspnea, and fatigue). This explained the patient's social-function impairment and the contribution to intrusive thoughts (references to death, fatigue, symptoms). Another interesting finding was that lung cancer was more often associated with a loss of autonomy and was considered a punishment. Doctors should be aware of this, so that they can diminish this association. Patients' associations, which are less developed for lung cancer than for breast cancer, should also help patients and their families have a better perception of this disease. Therapeutic burden by itself also contributes to this social representation of the disease, probably because most of the general population is aware of the impact that a patient's treatment can have on daily life and possible changes in family and social status.

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In conclusion, our work may help to identify psychological obstacles in effective patient–doctor communications, to fill the knowledge gap in the perception of some aspects of this disease, and thus improve lung-cancer management. A large public information campaign concerning the potential benefits of lung-cancer screening, the good survival rate from early-stage disease, and the progress observed with new therapeutic strategies, such as targeted therapies, is needed.

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