

PREFACE



Lung cancer is the number 1 cause of cancer death and the most common cancer type worldwide. Unfortunately, its prognosis is poor and the available treatment modalities are limited. Because patients (and their loved ones) have to deal with such a bad prognosis within a short time period, learning to live with lung cancer and its treatment trajectory until the patient's death is particularly difficult as compared to other cancer types. Patients and their loved ones (informal caregivers) are confronted with a lot of (physical and mental) issues throughout the treatment trajectory and disease course. During this trajectory, the provision of optimal medical care is required. This does not only mean giving therapy, but it also includes offering adequate accompaniment and support to the patients and their caregivers. Various elements/aspects of care are comprised in this accompaniment, such as the promotion of a healthy lifestyle (smoking cessation), the supply of good medical information, the possibility of asking for a second opinion and having insight into the meaning and roles of caregivers to patients and the tensions related to their involvement. Good medical care and health care providers' accompaniment, with the supply of medical information of good quality as crucial element, facilitate the way patients and their caregivers cope with cancer and adjust their life to it, and result in improved disease acceptance and quality of life.

In this thesis we have investigated the above mentioned aspects/elements of medical care so as to gain more insight into the lung cancer patient's needs and life during the treatment trajectory and consequently contribute to the supply of optimized medical care, tailored to their needs.



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GENERAL INTRODUCTION AND OUTLINES OF THE THESIS



LUNG CANCER FACTS AND MEDICAL BACKGROUND

Epidemiology

Lung cancer is the most commonly diagnosed cancer type worldwide as well as the major cause of cancer mortality among men and women.(1) The Netherlands counted more than 21.000 lung cancer patients in 2011, with a number of 11.980 newly diagnosed cases and 10.695 lung cancer related deaths in 2010.(2)

Lung cancer types

Based on light microscopy, lung cancer is divided into two main types: non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC).(3) The majority of the patients are affected with NSCLC (80 to 89%),(3) which is further subdivided into adenocarcinoma, squamous cell carcinoma and large cell carcinoma. One of the well-known clinical differences between NSCLC and SCLC is the early dissemination of the latter, locally and to distant sites.(4)

Staging and prognosis

The tumor-node-metastases (TNM) system is an internationally used classification to determine the NSCLC stage (extent) and subsequently the therapeutic approach.(5) Tumors are categorized according to primary tumor characteristics (T), the presence or absence of regional lymph node involvement (N) and the presence or absence of distant metastases (M). The overall stage of lung cancer is then determined by the combination of the assigned T, N and M grades and ranges from in situ, to stage I (local disease) until stage IV (advanced disease). With a 5-year survival of 17.4%, the overall prognosis of NSCLC is very poor.(6) Each stage has a corresponding survival rate that shows a progressive decrease in the 5-year survival rate from 50% for stage IA to 2% for stage IV.(5) SCLC used to be classified based on the extent of the metastatic spread into limited and extensive disease, however, this was recently changed into TNM classification, like for NSCLC. (4) The survival rate of SCLC is poor as well, with a 5-year survival of 56% for stage IA and 0% for stage IV according the newest proposed classification.(4)

Causative factors and prevention

Smoking is a major causative factor of lung cancer. Ninety percent of patients with lung cancer are (former) smokers.(7) Other factors associated with lung cancer are exposure to environmental and occupational carcinogens (e.g. asbestos, arsenic, beryllium, diesel, nickel, silica, etc.).(8) Despite heightened awareness of the dangers of smoking and many attempts to influence public health,(9-12) promoting smoking cessation remains a great challenge in the Netherlands. Although death rates have recently started to decline among men, the death rates among women continue to rise, reflecting their smoking habits of the past decades.(3) It is therefore still needed to find strategies to stimulate and motivate smoking cessation. Screening programs for smoking related diseases may lead to heightened awareness of the risks of this habit and increased cessation rates among participants, as it has been shown by Ostroff et al. and Townsed et al.(13;14) These study results are promising but, given the limited number of similar studies and the increase of screening programs in practice, additional research remains highly necessary.(15)

THE MEANING OF LUNG CANCER: FROM A QUIET LIFE TO ENTERING (AND GOING THROUGH) THE TREATMENT TRAJECTORY

During life, each individual follows what is called a “life calendar”, defined as any plan involving the ordering of time and including the notion of going through different stages/phases to be negotiated at specific times along a trajectory (e.g. birth, going to school/university, first job, marriage, children, etc.).⁽¹⁶⁾ When someone is diagnosed with cancer for the first time, a new calendar within a new trajectory is being started, namely the illness calendar and the treatment trajectory. The treatment trajectory encompasses many different phases a person (to be) diagnosed with lung cancer usually will go through: the pre-diagnosis phase/phase of suspicion of lung cancer, the diagnostic phase, the disclosure of “bad news” by the (pulmonary) physician, the preparation for treatment, the treatment itself (including therapy, remission, relapse/recurrence, second-line treatment, etc.), the palliative phase and ultimately the phase of imminent death. Each phase along the treatment trajectory is associated with specific challenges to be dealt with, not only by the patient, but by his loved ones as well.⁽¹⁷⁾

The pre-diagnosis phase

Often (but not always), patients have been smoking for a while and remain asymptomatic for a long time.⁽⁷⁾ Then, they (may) unfortunately start to have symptoms and when the suspicion of lung cancer is being raised, they are sent to a pulmonologist for additional diagnostic investigations. This phase can be seen as the start of the treatment trajectory. As patients and their families frequently have to go to the hospital for various investigations and face an uncertain (but threatening) diagnosis, this phase is known to be as very stressful and hectic until the diagnosis is made.⁽¹⁸⁻¹⁹⁾

The disclosure of bad news

Once the investigations are completed, patients and their family must face a cancer type with one of the worst prognosis among all cancers and limited treatment options.^(1;5) Furthermore, lung cancer often already has reached an advanced stage at time of diagnosis,⁽⁵⁾ while patients frequently do not feel extremely ill or sick to death.⁽²⁰⁾ Therefore, they find it difficult to believe that they *really* have lung cancer.⁽²¹⁾ This unexpected diagnosis and its inevitable shortened life expectancy causes a huge disruption in the patient’s life calendar, threatening his future plans and expected life to be, causing an “existential crisis”.⁽¹⁷⁾ Patients and their loved ones are therefore intensely shocked. The distress they experience has been reported to be particularly intense as compared to other cancers from the moment of diagnosis and throughout the whole treatment trajectory.^(22;23) The diagnosis usually initiates the time that patients and their loved ones start to look for a way how to deal and come to terms with the diagnosis lung cancer and its treatment, a behavior called “coping”.

Coping with lung cancer

Coping, as originally defined by Folkman and Lazarus,⁽²⁴⁾ can be described as a reaction to an event occurring to an individual. That event is usually assessed as threatening to the individual’s

life or situation and prompts him/her to activate internal processes necessary to accommodate to that event, such as behavioral, cognitive and affective mechanisms, including coping. Lung cancer can therefore be seen as an event threatening the (newly diagnosed) patient's health and his own as well as his loved ones' future together. In other words, coping can be seen as dealing with existential matters of life and death, as well as a manner of negotiating and managing the new calendars (illness and treatment), added to the patient's and loved ones' life calendars on a daily basis.(16) Coping has different expressions in practice, e.g. experiencing feelings like anger, fear, helplessness and talking about it with someone, denial, taking care of the patient or looking for cancer related information.(24-26)

Looking for lung cancer related information

Once the diagnosis is known, lung cancer patients receive additional information about the disease from their health care provider and are being encouraged to start therapy within a short time period. The impact of hearing the diagnosis "lung cancer" is so huge, that it is difficult for them to understand and remember the total of detailed information given about the disease. (27;28) In addition, the information they receive is often complex, and might be confusing. (28-33) Furthermore, they have to prepare for the coming treatment and all the unknown things that is accompanying it. This prospect, combined with the received information, yields again a lot of distress to the newly diagnosed lung cancer patients and their loved ones.

It is known that (the suspicion of) a cancer diagnosis is an immediate reason for patients and their loved ones to look for cancer and investigations related information on the Internet, indicating they are in need of medical information.(34-38) Although they seem to have these needs as well, compared to other cancer patients, lung cancer patients have less a tendency to form patient organizations and provide their fellow sufferers with information related to illness and treatment or other issues.(39) Also, little is known about their specific information needs, while information is crucial for coping with cancer.(39;40) Patients who are well informed experience less psychological distress, are more satisfied with the care and information they receive, have more faith in their treating physician and treatment, and are more compliant to therapy.(36;41-43) Patients' satisfaction with received information is even associated with a better quality of life.(41) In the Netherlands, it was difficult to find accessible, comprehensible, reliable and up to date information about lung cancer in Dutch until 2003, when the Dutch Lung Cancer Information Center (DLIC) was launched. The booming use of the DLIC's website shortly after its creation uncovered the existence of a large, up till then unmet information need among the Dutch population, and made clear that the patient's loved ones had a special role in the information search and supply. The finding that the website's interactive webpage (where visitors can contact and ask questions to online lung specialists anonymously) was one of the most popular pages raised additional questions about lung cancer patients and their loved ones that needed to be answered.

A second opinion?

At the time of diagnosis, but also later on during treatment, for example time of recurrence, a patient may request a second opinion for reasons such as the wish for more explanation about the diagnosis, therapy and prognosis, the need for more information, dissatisfaction with

the communication and the quality of information as supplied by the treating physician and hope for another treatment advice and/or reassurance.(44-47) Usually, it is the pulmonologist who requests an expert colleague's opinion to confirm the diagnosis, or discuss the available treatment options in a later stage, once the patient has reached the limits of regular therapy or tried multiple treatment modalities.(48) Asking for a second opinion is a patient's right that is enshrined in the Dutch constitution and is covered by the general health insurance in the Netherlands.(49) The number of patient initiated second opinions has been increasing over the years,(45;50) but the outcomes and potential benefits of second opinions for lung cancer have never been investigated. Insight into the results of such common practice is necessary to evaluate whether this part of care has potentially any added value for lung cancer patients.

The role of caregivers during therapy

Once the start of therapy has been reached, patients' loved ones often become the patients' informal caregivers and provide them with support and care, as it has been described by various authors.(51;52) Caregivers intensively share with the patient's lung cancer experience and their welfare and quality of life (QoL) are connected with each other.(20;53-55) In addition, caregivers do a lot of practical things.(55) As patients and their caregivers go along the different phases of the treatment trajectory together, they try to learn how to live with lung cancer, its therapy and the patient's shortened life expectancy. Coping with lung cancer is difficult and can be accompanied by tensions and quarrels between patients and caregivers. These tensions may originate from the different needs patients and caregivers have or may be related to the burden of patient care experienced by the caregivers.(55-57) The unpredictability of the treatment trajectory often adds to the uncertainty and distress experienced. The number of studies about how patients and their caregivers cope *together* with lung cancer is limited, and these only highlight particular aspects of coping with lung cancer.(17;58-61) Examples are the experience of social constraints, communication about sexuality, behavior after the communication about imminent death, care provision needs, patterns of distress and wellbeing, specific coping strategies and key challenges in the care of the patient and these are mostly solely based upon the patient's or the caregiver's perspective.(17;58-61) The insight into coping with lung cancer therefore remains incomplete and partially unclear.

Towards the end of life

Progressively, patients and caregivers may find a way to cope with lung cancer and its trajectory together, but the extent to which disease acceptance and accommodation to the conditions of the treatment trajectory are reached, differs individually.(62;63)

Ultimately, they reach the end of the treatment trajectory and the patient's end of life. This last phase also has very specific challenges for patients and caregivers with regard to their own needs, decision making and the patient's death.(64;65)

THESIS AIM, OUTLINE AND RESEARCH QUESTIONS

The purpose of this thesis is to contribute to optimized care for the lung cancer patient and his caregivers, so as to give them tailored care in the near future. To achieve this goal, insight into the perspective of the lung cancer patient and his caregivers (including insight into their life and needs) during the treatment trajectory is crucial. Therefore we looked at various elements within the different phases patients and caregivers go through during the lung cancer trajectory, from the moment of being at risk for lung cancer (the so-called pre-phase) until the patient's death.

The influence of knowledge on smoking behavior [chapter 2]

The first aim was to investigate whether the knowledge/information of having premalignant/precancerous lesions could influence an individual's smoking behavior.

1. Does participation in a chemoprevention study for premalignant lesions influence smoking cessation?
2. Are participants with premalignant lesions more likely to quit smoking?
3. What are other factors associated with smoking cessation?

Information needs and seeking behavior [chapters 3-5]

The second aim was to explore the information needs and information seeking behavior of lung cancer patients and other persons involved with them, and their reasons to do so.

1. Are lung cancer patients looking for information on lung cancer on the Internet and the DLIC website in particular?
2. Are other persons from the patients' inner circle looking for information by the same means? Who are they?
3. What information are lung cancer patients and these caregivers specifically looking for on the Internet/DLIC website? What are their information needs?
4. Why are lung cancer patients and their loved ones (informal caregivers) seeking information and answers to their questions from the Internet and online lung specialists?

Second opinions [chapters 6-7]

The third aim was to gain more insight into the additional information provided on diagnosis and therapy by a second opinion and its potential impact on patients and patient outcomes.

1. What additional medical information results from a second opinion?
2. What are the consequences of a second opinion for the diagnosis and therapy of lung cancer patients (in terms of minor/major/neutral potential impact)?
3. What are the benefits of second opinions? Do lung cancer patient benefit from second opinions in terms of patient outcomes?

Coping with lung cancer [chapter 8]

The fourth aim was to explore how patients and their caregivers cope together with lung cancer during the treatment trajectory.

1. How do lung cancer patients and their caregivers live with lung cancer from the time of diagnosis and during the treatment trajectory? How do they cope together?
2. What is the meaning of the caregiver(s) to the patient? Do they have particular tasks or roles to fulfill?
3. What are the needs of patients and caregivers during the treatment trajectory?
4. Are there tensions between them? What are the causes of these tensions?

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THE FINDING OF PRE-MALIGNANT LESIONS IS NOT ASSOCIATED WITH SMOKING CESSATION IN CHEMOPREVENTION STUDY VOLUNTEERS

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ABSTRACT

Background and study aims: Screening programs for lung cancer may lead to a heightened awareness of the risks of smoking and enhance quitting. The aim of this study was to evaluate if the participation on a chemoprevention study for pre-malignant lesions, could influence smoking cessation.

Methods: Two hundred one volunteers, current (n=188) and former smokers (n=13) with more than 20 pack years, had been screened for the chemoprevention study. One hundred forty-six of the current smokers at time of chemoprevention study screening have been retrospectively interviewed about their smoking behavior ≥ 1 year after their first contact for the chemoprevention study. Structured questionnaires were used, and interviews were held by telephone. The quitters at the time of these first interviews were contacted again 4 years after the initial interview about their current smoking behavior.

Results: Of the 146 smoking volunteers, 83 were diagnosed with premalignant lesions of the bronchial mucosa and participated in the chemoprevention study, and 63 had no pre-malignant lesions and were not included in that study. The majority of participants were men: 87 (60%). The mean age of the participants was 52 ± 9 years, and the mean age at which volunteers started smoking was 15 ± 3 . Mean number of pack years was 47 ± 27 . Ten volunteers in the group without premalignant lesions and 19 in the group with pre-malignant lesions had quit smoking at time of the first interview. The smoking cessation rate of the total study group was 20%. Univariate logistic regression analysis demonstrated that smoking cessation was only significantly associated with male gender. No significant associations were found between smoking cessation and the finding of premalignant lesions, age, level of addiction, educational level, marital condition, history of cancer/pulmonary diseases, age at start smoking, previous attempts to quit smoking and motivation to quit smoking. Within the group of subjects who had quit smoking at the time of the first interview, 15 out of 29 persons who had stopped smoking at the time of the first interview, have reported that participation in the bronchoscopy screening and/or the trial, has been of major influence on their decision to stop smoking.

Conclusions: A smoking cessation rate of 20% has been found among volunteers for a chemopreventive trial investigating smoking-related premalignant lesions after almost 2 years after initial contact has been found. Volunteers experienced screening and trial participation as having influenced their smoking cessation. Smoking cessation was significantly associated with male gender, while the finding of premalignant lesions by bronchoscopy was not.

INTRODUCTION

Smoking is a major causative factor of cardiovascular disease and the most important cause of lung cancer.(1-3) Ninety percent of lung cancer patients are (former) smokers,(1) and in Europe, Japan and North America, between 87 and 91% of lung cancers in men, and between 57 and 86% of lung cancers in women, are attributable to smoking.(4-6)

Since cardiovascular diseases and lung cancer are among the most important causes of mortality in the western countries,(7;8) reduction of the number of smokers would be of great benefit for public health. Smoking cessation is the best preventive measure for these smoking-related diseases. Nevertheless, despite the knowledge that smoking is a harmful habit, multiple messages on cigarette boxes, anti-smoking campaigns, scientists' and doctors' warnings,(9-11) there are still many smokers,(12-14) and only a small percentage of smokers succeed to quit permanently. Despite a minor reduction in the number of smokers during the last decade, still around 25% of the adult population smoked in the Netherlands in 2007.(15) Furthermore, smoking cessation has proven to be extremely difficult to achieve. Even with counseling and nicotine replacement therapy, the success rate remains low.(16-18)

Another way to reduce smoking related mortality is secondary prevention, i.e. screening for smoking-related diseases. Screening for lung cancer with different screening modalities aims at detecting the disease at an early stage, so that treatment may be more effective. Screening for early-stage lung cancer may result in a high actuarial survival rate in selected volunteers,(19) but whether screening is truly effective still needs to be proven in (ongoing) randomized controlled trials (RCTs).(20)

Screening programs for smoking-related diseases may also lead to heightened awareness of the risks of smoking among participants and thus help reduce the number of smokers. On the other hand, it could be argued that smokers participating in a screening program are aware of the dangers of smoking and may get a false sense of security when results of screening do not demonstrate abnormalities, and cause them to lose their motivation to stop.

Some studies have shown that participants in computed tomography (CT) screening programs quit smoking more often when abnormal findings (usually of unknown significance) were present. Cessation rates were high.(21;22)

At the beginning of February 2002, a chemoprevention study was initiated at the VU University Medical Center (VUmc) and the Netherlands Cancer Institute (NKI) in Amsterdam, the Netherlands. Volunteers with at least 20 pack years of smoking were screened by bronchoscopy and when a pre-malignant lesion was present, enrolled in a double blind placebo-controlled phase II study.(23)

The goal of this study is to evaluate whether participating in the aforementioned study and the knowledge of the presence of premalignant lesions enhanced cessation rate. We hypothesized that volunteers who underwent screening by bronchoscopy and participated to the trial because they had premalignant lesions, were more likely to quit smoking than volunteers who did not.

PATIENTS AND METHODS

Subjects

Between February 2002 and October 2004, 201 current and former smokers were screened for a double blind randomized controlled trial of the inhalation corticosteroid fluticasone dipropionate to study its effect on bronchoscopically detected premalignant lesions in the bronchial mucosa.^(23;24) Volunteers were recruited by repeated advertisement in (local) newspapers, information folders at the VUMC hospital and NKI hospital or asked by their pulmonary physician of the VUMC or NKI hospital whether they wanted to participate.

Inclusion criteria for this chemoprevention study were healthy volunteers, current or former smokers, with a smoking history of over 20 pack years. Patients who had undergone treatment with curative intent of head and neck- or lung cancer of any stage and did not show any sign of recurrence on CT were also asked to participate. Exclusion criteria were serious comorbid disease, forced expiratory volume in 1 second (FEV₁) values below 1000 mL, or use of systemic or inhaled corticosteroids in the year before enrolment.

The inclusion criteria of this study were as follows: all volunteers who were screened by bronchoscopy for the aforementioned trial and smoked at the time of screening (t0). Exclusion criteria were also formulated: former smokers at t0 were excluded, because their decision to quit smoking was taken before their response to participate in the chemoprevention study. Volunteers who fulfilled inclusion criteria according to our data but seemed not to have undergone any bronchoscopy were excluded as well (see Figure 1: Flow Chart).

At least 1 year after the initial contact for screening for the fluticasone study (mean time period between initial contact and first interview was 21±7 months, time period of this contact for first interviews abbreviated as t1), we approached all persons who had undergone bronchoscopy and participated in the RCT and those who had undergone bronchoscopy but were not eligible for the chemoprevention trial because they had no premalignant lesions.

These volunteers received a letter from our institution and were approached by phone at least one week later. When the volunteers were reached by telephone, they were first asked whether they had received the letter announcing this study in continuation of the previous one. If not, explanation about this study was given, and volunteers were asked to participate. If they had received the letter, they would immediately be asked to participate. The volunteers were retrospectively interviewed by phone using standardized questionnaires regarding several issues including their smoking status. Usually, the interviews took place at the first telephone contact.

Around 4 years after the initial contact for screening for the fluticasone study (mean time period between initial contact and second interview was: 54±8 months), we approached once again, following the same strategy as mentioned previously, volunteers who were former smokers at t1, for a second retrospective, structured interviews by telephone regarding their present smoking status (at present time period, contact for second interviews, abbreviated as t2).

Interviews

The first interviews took place by telephone by BBMP and RMS, in the period of June 2005 until February 2006 (t1).

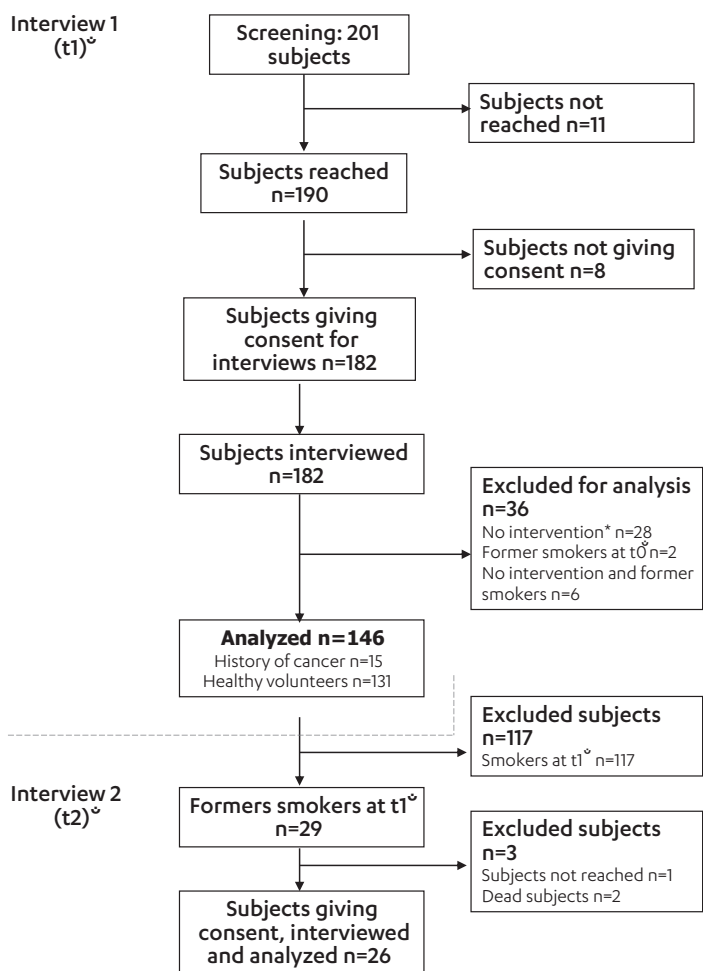


Figure 1: Flow chart of study volunteers. *No intervention: volunteers had received information only and were neither screened by bronchoscopy nor included in the trial. t0 is the time of screening for the Fluticasone study, time at which volunteers had neither started yet with investigations nor had undergone any bronchoscopy. t1 is the time of the first interviews and t2 the time of the second interviews.

The questionnaire contained 35 open- or multiple choice questions and statements concerning demographic data, level of education, medical history, motivation to participate in the fluticasone trial, smoking history, smoking behavior and subjective experience of burden by bronchoscopy (scale from 1 until 10, with 1: no burden at all, and 10: great burden).

Concerning their smoking behavior participants were asked: “Do you smoke at the moment?” If they answered “yes” they were asked, “How many cigarettes do you smoke in a day?” If “no” they were asked “To what extent did volunteering and/or participating in the fluticasone study make you quit smoking?” Participants could answer 1) not at all, 2) to some extent, or 3) to a major extent.

The second interviews with former smokers at t1 took place by telephone by RMS from June 2008 until August 2008 (t2), with a set of 7 questions derived from the first questionnaire to assess their smoking behavior once again and the influence of the fluticasone trial on their decision to quit smoking and to keep refraining from smoking.

Data on smoking cessation was based only on participants' answers to the interview questions.

Statistical Analysis

We performed descriptive analyses and we used χ^2 -tests and independent t-tests to identify differences in demographics between our study groups. Regression analysis was performed to analyze which factors were associated with smoking cessation.

All analyses were conducted using SPSS version 15.0.

RESULTS

Participant characteristics

Data of the 201 volunteers who had been screened for the chemoprevention study were at our disposal. Eleven subjects could not be reached, eight did not give their consent for the interviews, and 36 were excluded because they were former smokers at t0 and/or seemed to have not undergone any kind of intervention (bronchoscopy/trial participation). Ultimately, we interviewed 146 subjects for this smoking behavior study (see Figure 1: Flow Chart). The study participants have been divided into 2 groups (Table 1). Group 1 consisted of 63 subjects who were excluded from the RCT because they had no premalignant endobronchial lesions found at bronchoscopy, and group 2 consisted of 83 subjects who had participated in RCT because they fulfilled all inclusion criteria including the presence of premalignant endobronchial lesions.

The majority of participants were men: 87 (60%). There were significantly more males in the group with premalignant lesions. There were no significant differences in history of malignancies between the group with (n=11) and the group without premalignant lesions (n=4). The mean age of all participants was 52±9 years, and the mean age at which subjects started smoking was 15±3 years. Mean number of pack years was 47±27. At time of the first interview (t1), the mean number of cigarettes smoked per subject was 22±13/day, which is less than at time of screening for the fluticasone study t0 (27±13/day). The number of pack years and the number of cigarettes smoked per day at t0 was significantly higher in the group with premalignant lesions.

Smoking cessation

At the time of the first interview (t1), 10 subjects in the group without premalignant lesions and 19 in the group with premalignant lesions had quit smoking. The smoking cessation rates are 16% and 23%, respectively. The smoking cessation rate of the total study group was 20%.

Smoking cessation factors

Univariate logistic regression analysis (Table 2) demonstrated that smoking cessation was only significantly associated with male gender. Number of attempts to quit smoking in the

Table 1: Characteristics of study population

Item	Total (n=146)	Group 1 (n=63)	Group 2 (n=83)	P-value gr 1 vs.2
Demographics				
Gender (M/F)	87/59	31/32	56/27	0.026 [⊖]
Age in years (mean, SD)	52±9	52±9	53±9	0.702
Level of education (high vs. low)*	68/78	31/32	37/46	0.579
Marital condition (single/partner)	80/66	36/27	44/39	0.619
History of asthma and/or COPD (yes/no)	19/127	8/55	11/72	0.921
History of malignancy (yes/no)**	15/131	4/59	11/72	0.174
History of malignancy in the family (yes/no)	90/56	39/24	51/32	0.955
Location (VUmc/NKI)	61/85	23/40	38/45	0.260
Smoking habits				
Age start smoking in years (mean, SD)	15±3	15±3	14±3	0.067
Pack years (mean, SD)	47±27	38±17	55±30	0.007 [⊖]
Number of cigarettes per day at time (t0) [‡]	27±13	24±12	30±13	0.015 [⊖]
Current number of cigarettes per day if smoker***, at time of first interview (t1) [‡]	22±13	20±13	24±12	0.146
Previous attempts to quit smoking (yes/no)	119/27	52/11	67/16	0.779
Motives for trial participation				
Smoking cessation wish as reason for participation (yes/no)	52/94	26/37	26/57	0.260
Interest in current health as reason for participation (yes/no)	58/61	40/23	45/38	0.214
Other				
Burden of bronchoscopy**** (mean, SD)	6.0±2.5	5.6±2.6	6.2±2.4	0.127

Significant, p<0.05

* High education: University degree, Higher professional education. Low education: primary school, junior/senior high school, junior and senior secondary vocational education.

** In the group without pre-malignant lesions, no volunteer had suffered from smoking related cancers (lung, head and neck cancer) and 4 from other cancer types (1 lymphoma, 1 skin and 2 breast cancers). In the group with premalignant lesions 4 volunteers had suffered from head and neck cancer and 7 from other cancer types (1 lymphoma, 2 testis, 1 skin, 2 breast cancers and 1 unknown).

***Group without pre-malignant lesions: n=53 and group with pre-malignant lesions: n=64, total: n=117

****Experienced burden of bronchoscopy: 1=no burden at all and 10=great burden

In the group with pre-malignant lesions (n=62), one patient could not remember his/her experienced burden of bronchoscopy because of brain damage due to epilepsy.

[‡]t0 is the time of screening for the Fluticasone study, time at which volunteers had neither started yet with investigations nor had undergone any bronchoscopy. t1 is the time of the first interviews and t2 the time of the second interviews.

COPD, chronic obstructive pulmonary disease, NKI, Netherlands Cancer Institute, VUmc, VU University Medical Center, SD, standard deviation.

past tended to show an association with smoking cessation, but did not reach significance. The presence of premalignant lesions was not significantly associated with smoking cessation. Other factors of Table 2 did not show any significant associations with smoking cessation.

Bronchoscopy

Volunteers who underwent at least one bronchoscopy were asked to grade their subjective experience on a scale from 1 until 10 (with 1: no burden at all, and 10: great burden). Mean

Table 2: Univariate regression analysis

Variable	Odds Ratio	95% CI	P-value
Malignant lesions	1.573	0.674 – 3.637	0.295
Gender (female)	0.315	0.119 – 0.830	0.020**
Age in years	0.988	0.945 – 1.033	0.602
Pack-years	1.008	0.994 – 1.022	0.287
Educational level	1.089	0.482 – 2.458	0.838
Marital condition	1.387	0.614 – 3.132	0.432
History of cancer	1.542	0.453 – 5.246	0.488
History of asthma and/or COPD	1.088	0.332 – 3.564	0.889
History of cancer in family	1.023	0.443 – 2.363	0.958
Burden of bronchoscopy	1.000	0.848 – 1.180	1.000
Age at starting smoking	0.916	0.794 – 1.058	0.233
Cigarettes per day at screening	1.015	0.986 – 1.045	0.314
Smoking cessation wish as reason for participation	0.774	0.324 – 1.852	0.566
Interest in current health as reason for participation	0.719	0.318 – 1.628	0.429
Attempt to quit smoking	0.404	0.159 – 1.027	0.057*

*p<0.1

**p<0.05

CI, confidence interval, COPD, chronic obstructive pulmonary disease.

subjective experience in the group of former smokers at time of first interview was 6.0±2.2 and in the current smokers 6.0± 2.5. Mean subjective experience in group 1 (n=62, 1 person could not remember her experience with bronchoscopy) was 6.0±2.6 and 6.2±2.4 in group 2 (n=83). Independent *t* tests did not show any significant difference between participant groups and between former smokers and current smokers at time of the first interviews.

Opinions about trial influence

Within the group of subjects who had quit smoking at t1, 15 out of 29 subjects have reported screening with bronchoscopy and/or trial participation of a major influence on their decision for smoking cessation. One subject answered “do not know”, 9 answered “no influence” and 4 “some influence”. Among participants who had pre-malignant lesions, 74% (14 out of 19) considered participation in the trial as a major influence on their smoking behavior. The reported trial influence (n=28) (influence or no influence) on smoking cessation and the fact of having pre-malignant lesions or not, tended to show a relationship but did not reach significance with a chi-square test (p=0.097) (table 3).

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reported trial influence ($n = 28$) (influence or no influence) on smoking cessation and the fact of having premalignant lesions or not tended to show a relationship but did not reach significance with a χ^2 test ($p = 0.097$) (Table 3).

Table 3: Trial influence on smoking cessation per group

Trial Influence	Yes N(%)
Quitters after t0 at t1 [†]	
Total (n=28)	19 (68%)
Group 1 [⊖] (n=9)	4 (44%)*
Group 2 [⊕] (n=19)	15 (79%)*
Quitters at t1 reevaluated at t2 [‡]	
Total (n=19)	12 (63%)
Group 1 (n=7)	3 (43%)
Group 2 (n=12)	9 (75%)
Relapse smokers ^{**} at t2 [‡]	
Total (n=7)	4 (57%)
Group 1 (n=2)	0
Group 2 (n=5)	4 (80%)
Former and relapse smokers ^{**} at t2 [‡]	
Total (n=26)	16 (61%)
Group 1 (n=9)	3 (33%)**
Group 2 (n=17)	13 (77%)**

[⊖]Group 1: group without pre-malignant lesions
[⊕]Group 2: group with pre-malignant lesions
^{*} $p < 0.1$
^{**} $p < 0.05$
[†]t1 is the time of the first interviews and t2 the time of the second interviews
[‡]relapse smokers are volunteers who had quit smoking at t1 but smoked again at t2

Second interviews [t2]

Of the 29 subjects who were former smokers at the time of the first interview (t1), 26 subjects were interviewed again (see Figure 1: Flow Chart). One subject could not be reached and 2 subjects had died (causes of death: car accident and metastasized posterior tongue carcinoma). Of the subjects participating in the second interview ($n=26$), 19 (73%) (still) did not smoke at time of the second interview t2, this is 13% of our total study population, and gives smoking cessation rates of 11% for the group without premalignant lesions and 14% for the group with premalignant lesions.

Three of the “refrainers” had resumed smoking after a period of abstinence following trial participation, but had quit again at t2.

Of the total group of former smokers at t1 ($n=26$), 16 (62%) still considered the trial as an influencing factor on their smoking behavior. A χ^2 test between the reported trial influence (influence vs. no influence) and the fact of having pre-malignant lesions or not, showed a significant relationship at t2 ($p=0.046$), $p < 0.05$.

DISCUSSION

This quitting rate of 20% among volunteers for a chemopreventive trial after almost 2 years since initial contact was higher than what is normally found after active smoking campaigns among the general population,(12;25) although we must emphasize that we are looking at a selected study group and comparable to what was found in other studies aimed at screening for lung cancer by the use of CT scan screening: Townsend et al. 24-42% and Ostroff et al. 23%.(21;22)

There seemed to be an association between trial participation and smoking cessation since volunteers included in the trial showed a higher smoking cessation rate than volunteers excluded. The distinguishing factor between these 2 groups and determinant of trial inclusion was the finding of premalignant lesions at bronchoscopy. Because other studies had shown that having smoking-related diseases, experiencing smoking-related symptoms or having smoking-related damage resulted in higher smoking cessation rates,(26-28) we assumed that the supposed association between smoking cessation and the presence of premalignant lesions was reliable. However, this association was not statistically significant.

Of all known factors related with smoking cessation, only male gender was significant.(27;29) There was a trend of higher cessation rates if premalignant lesions were found, which is contrary to what one might expect as the level of addiction (indicated with pack years and number of cigarettes smoked per day) is associated with smoking behavior (29-31) and differed significantly in both groups at baseline. Other factors such as level of interest in quitting smoking, age of starting smoking, age of participant, education, marital status, history of cancer or lung diseases and previous attempts to quit smoking (25;27;29-31) were not significant. Small sample size might play an important role in these findings. We may be confronted with a low statistical power as a consequence of the retrospective study design.

Knowing that an initially strong motivation to quit smoking disappears quickly,(32) even in patients being diagnosed with cancer, one might expect that having premalignant lesions is not likely to be a very strong motivation to stop.

Because of its invasive character and reported patients' anxiety, fear of pain and breathing difficulties during bronchoscopy,(33) as well as the fear for cancer diagnosis following the diagnostic intervention,(34) we expected that the experience of bronchoscopy would affect a patient's smoking habits. Nevertheless, it is unlikely that the (unpleasant) experience of a bronchoscopy as a single factor is associated to quitting smoking in this study, because we have found no significant difference between the subjective burden of a bronchoscopy between former smokers at t1 and volunteers who never quit smoking. Smit et al. (35) and Scholte op Reimer et al. (36), also have found that despite a major smoking-related event, such as a pneumothorax or an acute myocardial infarction, many people continue to smoke.

Our study also has other limitations beside the number of participants. First, our results are based upon participants' answers. Participants may have given more socially acceptable answers about their smoking behavior out of shame for their addiction. Furthermore, we did not determine criteria to define the "former smoker" in unit of time (e.g. volunteers are classified as former smoker if they have refrained from smoking during 3 months). Thus, we can only trust participants' answers and consider them as former smokers if they have said so. Also, we only have contacted the volunteers who were former smokers at time of the first interview (t1) twice.

“Current smokers” at t1 have been contacted just once. As the smoking behavior of the smokers at time of first interviews is unknown for the second interviews, an underestimation of the smoking cessation is possible, although it seems improbable that smokers at t1 would have quit smoking at t2, considering that smoking cessation is very difficult to achieve despite motivation.(37) Fortunately, there is no indication that reassurance (informing a subject that no abnormalities were found), leads to more dangerous behavior (i.e. smoking). Participants of the group without premalignant lesions smoked less at t1 than at trial screening time (t0). The drop in persistent quitters between t1 and t2 confirms the need for prolonged support to prevent relapse.

CONCLUSIONS

We found a smoking cessation rate of 20% among volunteers for a chemoprevention trial investigating smoking-related premalignant lesions almost 2 years after initial contact. Volunteers experienced screening and trial participation as influencing smoking cessation. Smoking cessation was significantly associated with male gender while the finding of premalignant lesions by bronchoscopy was not.

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3

A WEBSITE ON LUNG CANCER: WHO ARE THE USERS AND WHAT ARE THEY LOOKING FOR?

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ABSTRACT

Purpose: The Dutch Lung Cancer Information Center launched the Web site www.longkanker.info in November 2003. The purpose of this article is to describe the launching of the Web site, its development, the type of visitors to the Web site, what they were looking for, and whether they found what they requested.

Methods: Supervised by a panel (pulmonologists, patients, communication specialists), a large amount of material about lung cancer has been collected and edited into accessible language by health care providers, and the Web site has been divided into special categories following the different stages that lung cancer patients, relatives, and health care providers go through during the illness. The Web site is updated regularly. Search engines have been used to check the position of the Web site as a "hit." Pulmonologists have been informed about the founding of the Web site, and all lung cancer outpatient clinics in The Netherlands have received posters, folders, and cards to inform their patients. Visitor numbers, page views, and

visitor numbers per page view have been registered continuously. Visitor satisfaction polls were placed in the second half of 2004 and the second half of 2005.

Results: The Web site appeared as first hit when using search engines immediately after launching it. Half of the visitors came to the Web site via search engines or links found at other sites. The number of visitors started at 4600 in the first month, doubled in the next months, and reached 18,000 per month 2 years after its launch. The number of visited pages increased to 87,000 per month, with an average number of five pages per visitor. Thirty percent of the visitors return within the same month. The most popular pages are interactive pages with the overview of all questions to "ask the doctor" at the top with forum messages, survival figures of all form of lung cancer, and information about the disease. The first satisfaction poll obtained 650 respondents and the second 382. The visitors to the Web site are caregivers (57%), patients (8%), and others (students, people fearing lung cancer). Of the visitors, 895 found what they were looking for, and the satisfaction is the highest among nurses and caregivers (91% and 95%, respectively) and the lowest among physicians and patients (85% and 83%).

Conclusions: Given the number of visitors to the lung cancer Web site, it can be concluded that there is a great need for additional information among patients and caregivers. The launched Web site www.longkanker.info has reached its goal of providing a dependable source of information about lung cancer and satisfying its visitors.

INTRODUCTION

In this day and age it is inevitable that patients and their caregivers look to the Internet as an important source of information. This information is regarded by patients and caregivers as complementary to and not as a replacement of the consultations with physicians.(1;2) More study is needed to find out how this complementariness can be optimized. Despite careful and extensive information given by physicians, patients and their caregivers still seem to have a lot of unanswered questions once they get home. There is a clear need for additional sources of information to obtain information once patients have left the doctor's office. Websites dedicated to making good information accessible on specific disease areas may play an important role in this.

As shown by several references in this paper, the Internet is a major and growing source of health information. Everyday 12.5 million searches for health-related topics are done on the Internet. In 2001, one third of Europeans used the Internet to get health information.(3) Since the early days of Internet use, mainstream providers of health care information have often initially been slow to develop sites, whereas independent organizations and individuals are quick to offer health care information and products of varying degrees of quality, honesty and safety.(4) For many disease areas patient organizations exist that provide information on the disease, the treatment and other relevant issues, and advocate on patients' behalf.

Of all common cancers, lung cancer has the worst prognosis. The five-year survival for lung cancer patients is less than 15 %.(5) In the Netherlands it is 10-15% (6) with the annual mortality exceeding the mortality rates of colon cancer and breast cancer combined.(7-9) Every year in the Netherlands over 9.000 people are diagnosed with lung cancer.(7)

One would expect that for a common and serious disease such as lung cancer a strong national or international patient organization would exist; however initiatives to start this have just begun. Remarkably, physicians and survivors, not patients themselves, start these initiatives. Apparently lung cancer patients do not have a tendency to organize. This is most likely due to the poor prognosis, the high morbidity of lung cancer patients and the relatively older age of the lung cancer patients. Of all 5-year age cohorts of patients with lung cancer the highest numbers are found between 60 and 75.(7) Before 2003, it was difficult for patients and caregivers to find easily accessible and comprehensible information on lung cancer. Although there was ample information available on the Internet, it was difficult to assess whether it was up-to date and reliable. Moreover, most information was in English. Therefore, the Lung Cancer Information Center (in Dutch: Longkanker Informatie Centrum) was launched in 2003 with its first important action to establish a website providing up-to-date and reliable information for lung cancer patients and their relatives. In this report, we describe this website and evaluate the experience obtained during the first two years.

METHODS

The organization has invested considerably in forging relationships with pulmonologists, as they play a central role in the treatment of lung cancer patients in the Netherlands. The initial support for a patient organization among pulmonologists was measured beforehand by a questionnaire. Of the respondents, 97% (n=29) indicated they would find a Web site with completely accurate information for patients relevant.(10) Pulmonologists are continuously kept involved in the

organization through seats on the board and the advisory committee. Other participants of the board and advisory committee are laypeople, including patients, and communication specialists. A pharmaceutical company provided a grant to cover the start-up costs of the organization. Additional sponsors were attracted immediately to avoid the risks of single sponsorship. By the time the Web site went online, the organization had a total of eight sponsors. The agreements of the sponsoring are fully in line with the organization's sponsoring policy that was derived from the policies of the Long Term Medical Conditions Alliance in the United Kingdom.(11) There is no pharmaceutical representation on the editorial board or advisory committee nor any influence on the contents of the information on the Web site, new topics, or source of information.

A large amount of material on lung cancer was collected and edited to be made accessible for laypeople. All information was written by an experienced pulmonologist (J.F.) and reviewed by Dutch lung cancer and communication experts. Changes in information go through the same process. Except for the professional secretary, all people involved in the board of the foundation and the advisory committee are volunteers who receive no income for their efforts. The information on the website follows the stages lung cancer patients and their caregivers go through, and the questions they elicit: 'What is lung cancer? What diagnostic tests are used? What are the treatment option? Should I choose treatment? What to do when the lung cancer cannot be treated anymore? The Web site is accessible for people with different levels of education and interest. Related to type of information, a few layers were built in to enable specifically interested people to get, with somewhat more effort, the required information without overwhelming others with too much information. The medical information is based on recent publications and guidelines on lung cancer. This is regularly updated. The texts were written by pulmonologists, nurses and others closely involved with lung cancer and revised by the board and advisory committee. All pulmonologists and relevant medical associations were informed by mailings about the foundation and the Web site. Additionally, all lung cancer outpatient clinics in the Netherlands received posters, folders and credit card-size cards to give to their patients. A service directly related to the Web site was the possibility to ask questions online to a pulmonologist with specific interest and training in lung cancer.

The website has been registered with all relevant search engines. The number of visitors, number of page views, and the number of visitors per page are recorded continuously.

In the second half of 2004 and the second half of 2005 a "visitor satisfaction poll" was placed on the Web site for several months. To prevent bias as much as possible, one of 10 visitors at random was asked to participate. Questions related to type of visitor and whether the information sought was actually found had to be answered.

RESULTS

Immediately after launch the Web site appeared as first hit when Googling 'longkanker' (lung cancer in Dutch).

Visitors

In December 2003, the first month after launch, there were 4,611 unique visitors. In January 2004, the number of visitors rose sharply to 8,500 and then remained stable for several months.

It subsequently started to rise again to around 12,000 per month and continued to rise to around 18,000 visitors per month after two years.

The number of page views rose to more than 87,000 per month. The average number of visited pages per visitor remained relatively constant at around five. By comparing the number of unique visitors with the number of visits, it can be deduced that over 30% of visitors returns within the same month.

Top ten visited pages

The interactive pages are the most popular ones (see Table 1). At the top of the list the pages belonging to the 'ask the doctor' service can be found. Here patients' and caregivers' questions are answered by a pulmonologist within 48 hours. On this page, an average of three to four questions per day are asked. At this moment, more than 1,800 questions and answers can be found on the Web site. The forum, where visitors can exchange experiences, is well visited, but only after 1.5 year visitors began contributing to the forum on a regular basis. The general information on different types of lung cancer also ranks highly. Noteworthy is the high ranking of the page on survival figures. This page is deliberately placed on a deeper level (to allow people to make a conscious choice about whether they want to view these figures). However, it seems there is a great need for information on survival among the visitors.

Table 1: Top ten visited pages, November 2005

	Number of visitors of this page	Description page content	URL (address)
1	12,568	Overview of all questions 'Ask the doctor'	www.longkanker.info/faq/alles.asp
2	10,616	Homepage	www.longkanker.info/index.asp
3	10,258	All forum messages	www.longkanker.info/forum/toast.asp
4	6,099	Opening page 'Ask the doctor'	www.longkanker.info/faq/overzicht.asp
5	3,072	Information on NSCLC	www.longkanker.info/longkanker/nietkleincellig.asp
6	2,224	Survival figures of all forms of lung cancer	www.longkanker.info/longkanker/overleving.asp
7	2,161	Information on early detection of symptoms	www.longkanker.info/voorkomen/reageren.asp
8	2,054	Information on mesothelioma	www.longkanker.info/longkanker/mesotheliom.asp
9	1,728	Information on SLCL	www.longkanker.info/longkanker/kleincellig.asp
10	1,688	Pdf of folder on early detection of symptoms	www.longkanker.info/pdf/LIC_symptoom.pdf

NSCLC, non-small cell lung cancer, SCLC, small-cell lung cancer

Referrers and search engines

Approximately half of the visitors arrives at www.longkanker.info via search engines or links found at another site. The total number visitors in 2004 was 108,746 of which 45,956 came through search engines such as Google and the Dutch search engine Ilse, 6,894 arrived through links on other Web sites. The effect of the November as lung cancer month can also be seen. For instance, in November 2004, 656 visitors came from a Web site for general practitioners on which a news item was placed covering the lung cancer Web site.

Visitors Satisfaction Poll

The first poll obtained 650 respondents, the second 382. As the results were remarkably consistent, the data from both polls were pooled. The results give an impression of the type of visitors attending the Web site (see Table 2). Eight percent of visitors are patients. Cautiously extrapolated to the average number of visitors, this means an annual number of 800 patients per month (the prevalence of lung cancer in the Netherlands is approximately 12.500). Worth noticing is the high number of caregivers among the visitors, i.e., 57% of respondents. The category 'other' is also relatively large. Most likely this category comprises of students and people fearing they have lung cancer.

Eighty-nine percent of the visitors said they found what they were looking for (Table 3). The satisfaction is highest among nurses (95%) and caregivers (91%) and lowest among physicians (85%) and patients (83%). What people indicate to have missed on the Web site varied widely from a desire for more pictures to more information on recovery after surgery.

Table 2: Type of Visitors to the Web site

Type of Visitors	% of responders	Extrapolated to an average of 10,000 visitors per month
Patient (n=84)	8	800
Caregiver (n=590)	57	5,700
Physician (n=20)	2	200
Nurse (n=77)	8	800
Other (n=262)	25	2,500
Total (n=1033)	100	10,000

Table 3: Type of Visitors and Satisfaction with Information

Type of Visitor	Found	Not Found	% Found
Patient (n=84)	70	14	83
Caregiver (n=590)	538	52	91
Physician (n=20)	17	3	85
Nurse (n=77)	73	4	95
Other (n=262)	224	38	86
Total (n=1,033)	922 (89%)	111 (11%)	89

DISCUSSION

Number of visitors

Two years of experience with this lung cancer website clearly shows that there is a large need for additional information among patients and caregivers. As the language of the website is Dutch, visitors of the website are likely to be inhabitants of areas where Dutch is the common language (Netherlands and Flanders, Belgium) with a population of around 20 million. For

these people, there is no language barrier. Eight thousand to 18,000 visitors per month gives an indication of how great the need is.

The Netherlands offers in general high-quality health care facilities and adequately educated physicians. Despite this, much additional information seems to be needed than what is offered during normal consultations with the doctor. Lung cancer patients and their relatives in the Netherlands are not unique in the way they search the Internet for additional information.

In the U.S. Health Styles Survey, 35% of survey participants reported using the Internet in search of health-related information. The Web sites visited most often were health information portals, government agencies, and nonprofit organizations. The reasons reported for accessing the Internet in this study are that the health information is clear and easy to find and use.(12)

Individuals looking for information on the Internet are significantly more likely to be younger, have higher incomes and more educated than people who use other sources of information. Considering that recent studies have shown that older adults are the fastest growing group of internet users,(13) it may well be that in the future the age gap between offline and online searchers will decrease.(14) This may be specifically true for health information seekers because individuals aged between 40 and 59 are found to be most likely to look for health information on the Web.(15) The number of visitors to Web sites such as the one described here is therefore likely to increase with more and more patients and their caregivers having access to the Internet and looking for health information. From an unpublished pilot study with extensive interviews of 30 Web site visitors, our impression that today's lung cancer patients often fear seeing what is written about their disease and therefore ask relatives and caregivers to get the information was confirmed.

Satisfaction with Internet as source of information

Although the way the Internet poll was done might result in a biased population completing the questionnaire, we think that the comparable results from both polls, the way in which these were done, together with the outcome, have prevented this as much as possible.

Based on the results of the two polls placed on the Web site, one may conclude that this disease-specific site supplies the large majority of visitors (89%) with the information they are looking for. Probably the strong involvement of both physicians and patients generates reliable and comprehensible information. Access to reliable disease information on the Internet has been associated with reduced anxiety,(2) increased feelings of self-efficacy, and decreases in utilization of ambulatory care.(16) Almost half (48%) of health information seekers report the Internet helps them to take better care of themselves.(17) Two-thirds (67%) of adults say that the Internet has helped them to better understand "health issues".(18;19)

Internet users are very satisfied with the information they find on the Internet. Compared with information from other non-physician information sources, breast cancer patients reported to be most satisfied with the information they found on the Internet (89%). These patients were considerably less satisfied with information from television (46%), newspapers (52%), magazines (58%), and radio (60%). Of these patients, 92% felt that acquiring information through Internet empowered them to make decisions about their health, and 91% said it helped them to talk to their physician, ask him or her questions and arrive at a 'partnership' with their physician.(20) Why patients are more dissatisfied than caregivers is unclear; a possible reason might be the unpleasant

confrontation with the poor outcome of lung cancer in general. In-depth interviews with a number of patients and caregivers confirm the fear of being informed of the bad prognosis for many patients, with no prospects of cure or long-term stabilization (manuscript in preparation). Although the information on the Web site is based on Dutch guidelines, the aim of the Web site is not to overtake the role of the patients' physician. For controversial issues and changes in standards of treatment, e.g., treatment of locally advanced disease, the patient needs to discuss this specifically with his or her physician.

Worries

Despite these positive feelings about the Internet, some breast cancer users also felt that the amount of information could be overwhelming (31%), that the Internet made them aware of conflicting medical information (76%) and that the information on the web confused them as to the right course of treatment (27%).(20) Eighty-one percent of people found it easy to find information they rated to be of high quality; 72%, however, was very or somewhat concerned about the quality of Internet information. Thirty-five percent of searchers feel they are excellent or very good at appraising whether Internet information is of high quality. Therefore it seems valuable for patients and caregivers to be able to provide them with the address of one or more Web sites that provide high-quality information. Half of our visitors arrive at the Web site through search engines and links from other Web sites. That means that the other half arrives by directly typing in the Web site address. That indicates that people already know the address, either from previous visits or by referrals from other people. The Web site is very often referred to by physicians and nurses. This gives patients peace of mind about the quality of information, and it gives physicians peace of mind about the other sources of information his or her patients use.

Caregivers

Although it is impossible to verify whether the type of visitors, as indicated by the visitor, is correct, we think that the random order in which visitors were chosen to complete the poll and the comparable results of the two successive polls make it likely that the potential bias is small. We found that more than half (57%) of our visitors are caregivers of patients, compared with 8% of visitors being patients. Caregivers seem to have different types of motivation when looking for information: getting the information for themselves, providing the patient with information, and preparing for doctor's visits or trying to make sense of what the doctor has said. These findings concur with other findings in the literature. Based on a meta-analysis of 24 published surveys Eysenbach (2) estimates that in the developed world, about 39% of persons with cancer are using the Internet. 15% (21) to 20% of cancer patients are indirect users, i.e., they use the Internet through caregivers. These patients ask caregivers (such as partners, children, friends) to find the information for them instead of searching themselves. Many indirect users become direct users over time.(22) Basch et al. report that 60% of cancer patients' caregivers use the internet.(23)

What the doctors think

Most physicians see the accessibility of health information through the Internet as a positive development which increases the level of understanding information,(24-26) but an important

minority (9% in one study) thought that it has, in fact, worsened the patient–physician relationship because patients challenge their physicians’ authority, patients’ requests are not always appropriate for their health, and patients take up their time with information they bring to consultations.(27) Murray et al. (26) found that of the 3,209 respondents in their study, most people (71%) who took information to the physician do so because they want his or her opinion rather than a specific intervention. The effect of bringing in the information was usually positive as long as the physician had sufficient communication skills and did not appear challenged. Patients perceived that the physicians reacted positively in 67% of cases, neutrally in 27% and negatively in only 7%. However, 15% of respondents reported that their physician had “acted challenged” when they brought the information in. Of patients who took the information in to the consultation with their physician, 71% said they did so because they wanted their physicians opinion about the information, not because they wanted a specific intervention such as a test or a referral. The data in this study do not support concerns that health information on the Internet currently results in many requests for inappropriate care. Moreover, most patients apparently accepted physician judgments that requested interventions were not appropriate.(26)

There has been concern that patients may start using the Internet as a diagnostic tool, delaying or forgoing medical intervention.(16) The evidence suggests, however, that the Internet can actually encourage people to seek help from a health care professional,(28) or at the very least, has no effect on healthcare use.(18) It appears that many patients are arming themselves with information from multiple sources including both health care providers and the Internet. Indeed, 78% of people who used the Internet for health information reported feeling better about information they had received from their health care provider because of what they found online.(19)

The reason for the degree of dissatisfaction among the small number of physicians in the polls is unclear; the Web site was not started as important source of information for physicians as they often seek other information than patients and have, in general, access to in-depth information from many other sources. A potential improvement is adding to the Web site a link to the Web site of the Dutch pulmonologists with information on treatment trials for lung cancer patients.

CONCLUSION

The goal of the website www.longkanker.info has been to provide a dependable source of information to people with lung cancer and their caregivers. Although the percentage of patients among the visitors is relatively small, extrapolating this into numbers indicates that a substantial number of the patients has visited the Web site. Furthermore, the use of the Web site by relatives makes that a large number of lung cancer patients has now direct or indirect access to this information and we think that our goal has been reached.

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4

WEBSITE VISITORS ASKING QUESTIONS ONLINE TO LUNG CANCER SPECIALISTS: WHAT DO THEY WANT TO KNOW?

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ABSTRACT

Background: In 2003 the Dutch Lung Cancer Information Center (Longkanker Informatie Centrum) launched a website containing information on lung cancer accessible to anyone.(1)

Objective: Our study aim was to inventorize the information needs of the visitors of this website by analyzing the questions they asked the lung cancer specialists in the websites interactive section "Ask the Physician".

Methods: The first 2000 questions posted up until May 2006 have been classified by visitors' wish, type of required information, identity, gender, and phase during treatment course.

Results: Our results show that 1893 (1158/1893, 61%) of the questions were asked by a loved one/ caregiver and (239/1893,13%) by patients. 1 out of 3 questions was asked by a daughter/grand-daughter. Most questions concerned specific information on lung cancer and lung cancer course (817/1893, 43%). The most inquired specific information topics were therapy side effects, diagnostics, general information on lung cancer, and regular therapy. Furthermore, questioners wanted to verify their own doctor's information (122/1893, 6%), a diagnosis (267/1893, 14%), and a prognosis (204/1893, 11%).

Conclusions: Lung cancer patients and their caregivers asked the most questions in the interactive website section. The most frequently requested information was more detailed information. These include specific information on lung cancer (regular therapy, diagnostics, and disease symptoms), verification of what the doctor has said, diagnosis, and prognosis. Most of the requested information could have been obtained from treating specialists, indicating that current information supply to lung cancer patients and their caregivers may not be matching their needs sufficiently. The further implementation of an online dialogue with lung cancer specialists might be a solution.

INTRODUCTION

The internet has changed the position of patients within the healthcare system. Currently, the internet is widely used as a resource for health related information.(2-5) Ybarra et al.(6) have reported a percentage of 73% Internet use among Americans, of whom 56% reported using the Internet as a resource for health information. A few health care providers already utilize the potential of the Internet (7-10) such as, the “emaildoctor”.(11) However, these physicians are still forerunners and not disease specific specialists, possibly making information superficial and not up-to-date, resulting in resistance against these practices among medical specialists. As a result of an initiative of doctors, patients, nurses, and other professionals involved with lung cancer, the Dutch Lung Cancer Information Center (DLIC) was founded. There were not a lot of information available on lung cancer in the Netherlands and lung cancer patient groups were poorly organized.(12)

This center is meant for lung cancer patients, their relatives or loved ones, and people seeking information about lung cancer. The center of the activities of DLIC is the website.(1) Since its launch in 2003, the DLIC website has been visited very often and has reached a steady number of 20,000 visitors per month. The number of monthly visitors are striking, considering that lung cancer incidence and prevalence respectively are around 10,500 and 14,000 per year in the Netherlands.(13,14) Results from our previous study have shown that caregivers of lung cancer patients are the largest group of visitors of the website.(12)

Deducted from the total number of visitors and visitor type,(12) around 1,600 patients and 11,800 caregivers visit the DLIC website each month.(13)

The most popular page of the DLIC website is the interactive section “Ask the Physician”, which was launched in March 2004.(15) Through this web page, visitors can ask lung cancer specialists specific questions about lung cancer. Since the launch of this interactive web page 7 years ago, approximately 6,400 questions have been posted. Furthermore, around 500 people per day visit the section “Ask the Physician” to read these questions and their answers.

The large number of questions in the section “Ask the physician” indicates that website questioners, presumably lung cancer patients and their caregivers, are in need of information on lung cancer. Studying these questions might give more insight into the identity of these specific visitors and in their information needs. It is important to define these needs as it might help defining guidelines for a better way of addressing lung cancer information by treating specialists. There are many studies published about looking for health related information on the internet, but we did not find any studies addressing online interaction between questioners and lung cancer specialists. The aim of this study was to classify the asked questions posed on the DLIC website into categories so as to give an overview of the types of persons who visit the website and their information needs.

METHODS

Overview

The main objective of the DLIC for answering questions in the interactive section “Ask the Physician” is to give support to questioners, clarify, and indicate where possibilities can be found with their own specialist. If lifestyle advices or smoking were mentioned by questioners, smoking was systematically

discouraged, while exercise and a healthy diet were encouraged. Diagnoses were never stipulated, initial opinions were not challenged, and no other treatment suggestions were made.

Every time new visitors used the interactive section to ask a question, they had to fill in a form and give their name and email address. Each form and each question with the matching answer have been carefully read retrospectively by our team members (RMS and CL). After reading, categories were deducted from the form/question/answer according to their content and set in a database. If it was impossible to determine any of the categories of the visitors, items were classified as unknown. The questions have been categorized into the next items determined by our research group (see Table 1).

Analysis

The first 2000 questions asked until May 2006 on the webpage "Ask the Physician" [1] have been imported to a Microsoft Access database and then categorized and analysed according above mentioned items.

Ethics Approval

According to Dutch law, this study does not need approval by an ethical review board.

RESULTS

General

Since its launch in March 2004, the webpage "Ask the Physician" has been widely visited. Data on the numbers of visitors, page views, questioners, questions, lung cancer incidence, and prevalence in the Netherlands are not shown in current manuscript but are available on request. During our defined study period (March 2004-May 2006), 2000 questions have been asked by 1200 people. Because one person asked 107 questions on her own, and the information seeking behavior of this person was not likely to be representative for the majority of questioners using the interactive webpage. This person was excluded.

Eighty percent (1199/1893, 80%) of the people who asked questions on the interactive webpage asked one question. The rest (694/1893, 20%) asked one or more additional questions. Around 1% of the people asked more than 10 questions. In total 1893 questions have been analysed.

Who Asks Questions?

Tables 2 and 3 give the demographics of the persons asking questions on the webpage. The majority of questions were asked by caregivers of lung cancer patients (1158/1893, 61%). Thirteen percent (243/1893, 13%) of all the questions were asked by patients. Of the total study group around one third (849/1893, 33%) of questions were asked by daughters and granddaughters. The category "unknown" has been applied when demographics of the questioners could not be found.

Regarding the percentages of questions asked by caregivers and lung cancer patients, caregivers asked 4.8 times more questions than patients in a period of 27 months. This means that 212 questions were asked by caregivers per 100 patients per year.

Table 1: Categories

Categories	Possible outcomes
Questioner identity	<ul style="list-style-type: none"> Student Patient Caregiver: child/grandchild, partner, other family members, no family Person who fears lung cancer Other Unknown
Gender	<ul style="list-style-type: none"> Male Female
Phase of illness/phase in lung cancer procedure	<ul style="list-style-type: none"> Before diagnosis-symptoms only Before diagnosis-after X-ray After diagnosis Time of choosing therapy after surgery During therapy After therapy After healing or recovery Terminal stage After death Other Unknown
Type of information requested	<ul style="list-style-type: none"> Specific information on lung cancer or lung cancer therapy Diagnosis Prognosis Treatment advice Explanation of doctor's words Terminology questions Help with a choice Lifestyle advice Help with essay/paper Other Unknown
Specific information: specific information topics	<ul style="list-style-type: none"> Lung cancer information in general Therapy side effects Symptoms of disease Regular therapy Alternative therapy Experimental therapy Diagnostics Lung cancer prevention Disease progression Other

Table 2: Questioner's identity type

Questioner identity (n questions=1893)	n	%
Caregiver	1158	61.17
Patient	243	12.84
Person who fears lung cancer	239	12.63
Student	55	2.91
Other	30	1.58
Unknown	168	8.87

Table 3: Questioner's identity type by gender

Category		n	%
Gender (n questions=1893)	male	415	21.92
	female	1225	64.71
	unknown	253	13.37
Gender of patients (n=243)	male	66	27.2
	female	144	59.3
	unknown	33	13.6
Gender of caregivers: male, female, unknown (n = 1158)	male	190	16.41
	female	835	72.11
	unknown	133	11.49
Children/grandchildren (n=849)	male	123	14.49
	female	622	73.26
	unknown	104	12.25
Partner (n=180)	male	48	26.67
	female	126	70.00
	unknown	6	3.33
Other family members (n=83)	male	11	13.25
	female	55	66.27
	unknown	17	20.48
No family (n=46)	male	8	17.39
	female	32	69.57
	unknown	6	13.04

Moment of Asking Questions

All questions asked by patients and caregivers (n=1394) were asked at different phases during lung cancer procedure. Most questions arose during therapy (376/1394, 27%), after therapy

(223/1394, 16%) and after diagnosis (209/1394, 15%). Questions were also asked at terminal stage of illness (125/1394, 9%), before diagnosis after the first X-ray (112/1394, 8%), and after surgery (98/1394, 7%)

What Did the Visitors Ask?

Table 4 provides an overview of the wanted information by questioners. Patients (n=243) requested specific information (122/243, 50%), wanted to verify doctor's information (25/243, 10%) and a diagnosis (20/243, 8%) or a prognosis (19/243, 8%) in the most cases. Other questioners (n=1650) wanted specific information (695/1650, 42%), a diagnosis (247/1650, 15%), a prognosis (185/1650, 11%) and to verify doctor's information (97/1650, 6%).

The category "verify doctor's information" means that a questioner checked whether the information given by the specialist was true: *"the doctor has told me that I can choose between chemotherapy and radiotherapy as therapy, is this true?"* The category "clarify doctor's explanation" means that the questioner wanted an explanation of what the specialist had said: *"My father has lung cancer and will be treated with chemotherapy. The doctor has said that with treatment my father has 30% chance. What does he mean?"* The category "unknown" has been applied when the purpose of the questions was unclear or unknown.

Table 4: What was asked in the first instance: topics, patients, and other questioners

Topics	Patients (n=243) n (%)	Other questioners (n=1650) n (%)	Total group (n=1893) n (%)
Specific information	122 (50.2)	695 (42.12)	817 (43.16)
Verify doctor's information	25 (10.3)	97 (5.88)	122 (6.44)
Diagnosis	20 (8.2)	247 (14.97)	267 (14.10)
Prognosis	19 (7.8)	185 (11.21)	204 (10.78)
Treatment advice	14 (5.8)	85 (5.15)	99 (5.23)
Other	11 (4.5)	69 (4.18)	80 (4.23)
Terminology	10 (4.1)	66 (4.00)	76 (4.01)
Clarify doctor's explanation	7 (2.9)	71 (4.30)	78 (4.12)
Advice, references	6 (2.5)	36 (2.18)	42 (2.22)
Help with a choice	4 (1.6)	19 (1.15)	23 (1.22)
Lifestyle advice	3 (1.2)	30 (1.82)	33 (1.74)
Unknown	2 (0.8)	3 (0.18)	5 (0.26)
Help with essay/paper	0 (0.0%)	47 (32.85)	47 (2.48)

Specific Information Topics on Lung Cancer and Lung Cancer Therapy

In the case of questions regarding specific information, the number of topics asked exceeds the number of requests for information on lung cancer and lung cancer therapy (Tables 4 and Table 5) because questions generally contained several topics people wanted to know about.

When patients wanted specific information, the most frequently discussed topics were (see Table 5) therapy side-effects (29/145, 20%), diagnostics (28/145, 19%), regular therapy (26/145, 18%), experimental therapy (15/145, 10%) and disease symptoms (14/145, 10%).

When other questioners requested specific information, the most frequently asked questions were about therapy (196/931, 21%), general information on lung cancer (140/931, 15%), diagnostics (113/931, 12%), disease symptoms (109/931, 12%), therapy side effects (100/931, 11%) and disease course (102/931, 11%).

Table 5: Topics of required specific information on lung cancer and lung cancer therapy, patients, and other questioners

Topics of specific information	Patients (n=145) n (%)	Other questioners (n=931) n (%)
Therapy side-effects	29 (20.0)	100 (10.7)
Diagnostics	28 (19.3)	113 (12.1)
Regular therapy	26 (17.9)	196 (21.1)
Experimental therapy	15 (10.3)	50 (5.4)
Disease symptoms	14 (9.7)	109 (11.7)
What can it be?	11 (7.6)	52 (5.6)
Disease course	9 (6.2)	102 (11.0)
General information on lung cancer	7 (4.8)	140 (15.0)
Other	5 (3.4)	51 (5.5)
Alternative therapy	1 (0.7)	6 (0.6)
Lung cancer prevention	0 (0.0)	12 (1.3)

DISCUSSION

Principal findings

In this study, we looked at information that was requested from online lung cancer specialists by visitors of the DLIC website. Most questions were asked by lung cancer patients and their caregivers (especially daughter and granddaughter). There are many studies published about looking for health related information on the internet, but studies about asking specific questions to online (lung) specialists are rare. This distinguishes our present study. Our study results show that most frequently requested information was more detailed information about lung cancer (such as regular therapy, diagnostics, and disease symptoms), verification of doctor's words, diagnosis and prognosis. This kind of information could have been obtained from treating physicians, implying that the supplied information to lung cancer patients and their caregivers may be insufficient with regard to their needs. Beside this, the impressive number of questions asked on the website indicates that patients and caregivers are willing to participate in online dialogues with specialists.

Before comparing our results with data from other studies, it should be mentioned that we have chosen to analyse all questions regardless if they were from one person or a different one. Since the number of persons who asked more than 1 question is substantial (20%), this may have influenced our results. An argument for our approach is that each question was different and was asked during different phases of the lung cancer procedure. Each question should thus be considered as one item regardless of who asked it.

Similarities and differences between our results and other study results can be seen. We found that 61% (1158/1893) of the questions were asked by caregivers. The result confirms our

observations in our previous study (12) and other studies that a large percentage of caregivers use the Internet. Norum et al. (16) reported that 60% of patients' partners used internet and Ybarra et al. (17) found that support seekers were significantly more likely to be patients' caregivers.

In our study, 13% (243/1893) of the questions were asked by patients. Studies of Fleisher et al. (18) and Mold et al. (19) stated that 15 to 20% of patients in their study were *indirect* internet users. Miles et al. (20) gave a percentage of 24%. Our results are different and add to existing study data because present study gives the percentage of patients who are *direct* internet users. Furthermore, our study group only included lung cancer patients. According to Eysenbach's study, only 16% of all information seeking cancer patients was a lung cancer patient, (21) which is more comparable to our findings. This relatively low percentage of lung cancer patients looking for information and asking questions online could be explained by differences in gender, age, and socio-economic status. The majority of questioners were young women and the biggest group of questioners was a daughter or granddaughter. Women look for health related information on the Internet more often than men and a younger age is associated with a greater internet use. (4,16,21-30) It is known that lung cancer patients usually are elderly males of low social levels. This is associated with a limited tendency to use the internet. (31) Although data on age and gender of all patients who asked questions on the website were not completely available, we assume that the Dutch lung cancer patients do not differ from lung cancer patients elsewhere and thus go on the internet less often than their female caregivers. Additionally, lung cancer patients' strategies to look for medical information differ from other cancer patients. They are more likely to be passive in seeking information than other cancer patients. (32) Thus, they will ask their caregivers to look for information for them and look less actively themselves. In this manner, a lot of lung cancer patients were getting information from the DLIC website indirectly.

Considering the number of visitors per year attending the website and the number of questions asked by caregivers and lung cancer patients, the question rises whether present results are representative for the total website visiting population of caregivers and lung cancer patients. According to our data, about 212 questions are being asked by caregivers per 100 patients per year for the 14,000 annual cases in the Netherlands. The number of visitors of the DLIC website per year appears relatively larger than the number of questions asked. A plausible explanation for this fact may be that many visitors already found the answers to their questions in the websites general information or in the questions in the section "Ask the physician". Another explanation may be that visitors solely visited the website to look for information and that some of them may not dare to ask questions. If we compare present results with the poll "visitor identity" we had performed in our previous study, (12) the percentages of lung cancer patients and caregivers correspond well with each other. Thus, questions asked by visitors on the website are quite representative for the total visitor population.

Our study found that most information seeking behavior occurred during therapy, after therapy, and after diagnosis. Other studies show similar results, indicating that most patients seek explanatory information just after their diagnosis and before starting treatment; or just after diagnosis (49%) or during treatment (31%). (33,34)

Information seekers had specific questions. Most of them wanted specialized information about a specific topic concerning lung cancer, a diagnosis, a prognosis, or to verify doctor's

information. The most frequently asked topics of specific information about lung cancer in present study were regular therapy, diagnostics, general information about lung cancer, therapy side effects and disease symptoms. A number of studies investigated the most wanted information topics by internet users, and found that information related to treatment (80%), (35) information about a condition, symptoms, advice about symptoms and treatment,(36) information on cancer screening/diagnosis, support services, psychosocial issues, and general cancer site information,(37) were the most wanted topics. Rutten et al.,(38) found that the most frequent information needs of cancer patients were information on treatment (38.1%), specific on cancer (12.8%), rehabilitation (12.2%), and prognosis (10.8%).

It is noteworthy that patients of our study were more interested in trials and side effects than the other questioners, who were mostly caregivers.

Further Research

Given the questions on the webpage “ask the Physician” and the fact that most answers could have been obtained from the treating physician/specialist, it could be concluded that for many of these lung cancer patients and caregivers visiting the website, information given during specialist consultations was unclear, insufficient, not well understood or not well remembered. This has also been mentioned in several studies.(39-41) However, since we do not know whether caregivers asking questions on the website were actually present during consultations with treating physicians, we cannot conclude that the given information was indeed unclear and insufficient to patients or to them. Neither can we conclude that the information was not given, not well understood, or not well remembered because we were not present during consultations as well. Submission of a question does not necessarily indicate that information has not been provided. We do not know what information has been given. Beside this, investigators in a recent study have found age and prognosis to be predictive for poor information recall in cancer patients.(42) Patients and caregivers may have had difficulties to remember medical information. Additionally, the information needs of lung cancer patients differ from their caregivers’, as illustrated by our study. Nevertheless, as noticeable in our results, 8% (151/1893) of the questions concerned an explanation of doctor’s words or terminology, indicating that a (small) part of the information given by treating specialists is actually not clear. Also the large number of questions on the website still is a signal that the medical information supply of lung cancer patients and their caregivers does not completely match their information needs. This phenomenon is an interesting indication that lung cancer patients and their caregivers are open and willing to participate in online dialogues with treating specialists. In our previous study,(12) we already showed with a visitor satisfaction poll that the majority of visitors were very positive about the usefulness of the website and its interactive page. Thus, we suggest an adaptation, and hopefully subsequently possible amelioration of the medical information supply to lung cancer patients and their caregivers. Suggestions for improvement could be to survey repeatedly about the information needs of lung cancer patients and their caregivers, giving printed or written information to patients and caregivers,(43-45) encouraging email contact and online dialogue with specialists for questions,(9,10) directing to reliable internet sources of information for complementary information,(12) and repeat the information given during consultations.

Further research is needed to explore the reasons why lung cancer patients and their caregivers turn to online lung specialists for information. The importance and role of caregivers during treatment should also be investigated since they appear to be involved in the information supply of lung cancer patients in present study.

CONCLUSIONS

Lung cancer patients and their caregivers asked most questions in the interactive section of the DLIC website. The most frequently requested information was more detailed and specific information about lung cancer (regular therapy, diagnostics and disease symptoms), verification of what the doctor has said, diagnosis, and prognosis. Most of the requested information could have been obtained from treating specialists, indicating that the information supply of lung cancer patients and their caregivers may not be matching their needs sufficiently. Since lung cancer patients and caregivers seem to be appreciating and willing to use online interactive dialogue with lung cancer specialists, further implementation of such dialogue might be a solution.

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5

WHY DO PATIENTS AND CAREGIVERS SEEK ANSWERS FROM THE INTERNET AND ONLINE LUNG SPECIALISTS? A QUALITATIVE STUDY

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ABSTRACT

Background: Since its launch in 2003, the Dutch Lung Cancer Information Center's (DLIC) website has become increasingly popular. The most popular page of the website is the section "Ask the Physician", where visitors can ask an online lung specialist questions anonymously and receive an answer quickly. Most questions were not only asked by lung cancer patients but also by their informal caregivers. Most questions concerned specific information about lung cancer.

Objective: Our goal was to explore the reasons why lung cancer patients and caregivers search the Internet for information and ask online lung specialists questions on the DLIC's interactive page, "Ask the Physician", rather than consulting with their own specialist.

Methods: This research consisted of a qualitative study with semistructured telephone interviews about medical information-seeking behavior (eg, information needs, reasons for querying online specialists). The sample comprised 5 lung cancer patients and 20 caregivers who posed a question on the interactive page of the DLIC website.

Results: Respondents used the Internet and the DLIC website to look for lung cancer-related information (general/specific to their personal situation) and to cope with cancer. They tried to achieve a better understanding of the information given by their own specialist and wanted to be prepared for the treatment trajectory and disease course. This mode of information supply helped them cope and gave them emotional support. The interactive webpage was also used as a second opinion. The absence of face-to-face contact made respondents feel freer to ask for any kind of information. By being able to pose a question instantly and receiving a relatively quick reply from the online specialist to urgent questions, respondents felt an easing of their anxiety as they did not have to wait until the next consultation with their own specialist.

Conclusions: The DLIC website with its interactive page is a valuable complementary mode of information supply and supportive care for lung cancer patients and caregivers.

Abbreviations

DLIC: Dutch Lung Cancer Information Center

NSCLC: non-small cell lung cancer

SCLC: small cell lung cancer

INTRODUCTION

Lung cancer is the second most common type of cancer and the most common cause of cancer deaths in both men and women in Europe and the United States.(1,2) The Netherlands counted approximately 14,000 lung cancer patients in 2002. This number increased to more than 21,000 in 2011.(3) In 2003, the Dutch Lung Cancer Information Center (DLIC) was established. Its purpose was to give simple, accessible, and evidence-based information on lung cancer through its website,(4) as well as support, and to unite lung cancer patients and their caregivers.(5) The unique quality of the DLIC is that it was set up at the national level and broadly supported by both health care professionals and patient groups. Following its creation, a special section was added to its website—an interactive webpage, called “Ask the physician”, where visitors could anonymously ask an online lung specialist questions and receive an answer within 48 hours.(6) It was after some scepticism from the lung specialists involved in the website’s management and content that this new section was launched.(6)

Since its launch, the DLIC website has become increasingly popular and has reached a steady number of 25,000 unique visitors per month.(5-7) Surprisingly, the most popular page of the website is the “Ask the Physician” page. Our study group has previously investigated who was visiting the interactive webpage and what the information visitors were looking for.(6,8) Seventy-four percent of the questions (n=1893) were not only asked by lung cancer patients (13%) but also in large numbers by their informal caregivers (61%, e.g., family, friends, and loved ones). Most questions (43%) concerned specific and general information about lung cancer. Furthermore, verification of information given by patients’ own specialists was sought, for example, the overall survival rate of lung cancer or specific therapeutic advice.

This impressive number of caregivers visiting the DLIC website, next to lung cancer patients, and their use of the online experts piqued our interest. Literature shows that a cancer diagnosis is an immediate reason for an increase in Internet use by patients and their families to obtain medical information, next to unmet information needs.(9-13) Looking for information seems to be an important and frequent task for caregivers, next to other activities, such as patient care, supporting and facilitating medical consultations, and aiding in information recall.(14-16) Also, physicians have limited consultation time and are not statutorily obliged to address or inform caregivers as they are patients, although such an approach is recommended.(17,18). Furthermore, consultations addressing multiple persons require high communication skills and are thus difficult. It is therefore plausible to think that unmet information needs underlie the above mentioned Internet use. However, if we look at the total picture, many elements and motives for these Internet searches remain unclear to us, especially with regard to caregivers of lung cancer patients in particular and the patients themselves. Why are there so many caregivers of lung cancer patients looking for information and consulting the DLIC online lung specialists? Why do they address the online specialists instead of the patient’s own specialist? Are there differences between caregivers and patients with regard to their motives when seeking information and their needs?

In comparison to other groups of patients, lung cancer patients and their caregivers are more vulnerable because the patients are facing a much shortened life expectancy. They need more special attention from health care providers. As the quality of life, psychological adjustment to

the disease, risk of appraisal, anxiety, and depression of cancer patients and their caregivers are affected by barriers and failures in information supply and communication from health care providers,(19-21) it is crucial that this vulnerable group receive information meeting their needs, especially because these needs differ throughout the cancer trajectory.(22) Adequate information supply is considered to be a part of good medical care and support. To provide appropriate care to lung cancer patients and their caregivers, it is important to explore their information-seeking behavior in order to gain more insight into their needs and indications for better communication modes and a tailored information supply. Therefore, we conducted a qualitative interview study with telephone interviews to explore the reasons why caregivers and lung cancer patients search the Internet for information and ask the DLIC online lung specialists additional questions about lung cancer, next to face-to-face consultations with their own treating specialists.

METHODS

Design

We conducted a qualitative, exploratory study consisting of semistructured telephone interviews with visitors to the DLIC website who asked the online lung specialist a question on the "Ask the Physician" webpage. This study was approved by the local medical ethics committee of the VU University Medical Center, Amsterdam.

Procedures and Participants

Recruitment took place between August 2005 and April 2006. All consecutive visitors who asked the online lung specialists a question on the interactive page of the DLIC website were invited to participate in our study. After submission of a question, an online (digital) confirmation window would pop up with Dutch text, containing an invitation for participation in our study and an explanation about its purpose and the telephone interviews to be held. If visitors wished to participate, they were asked to complete an online form with their name, phone number, and home and email address in order to be contacted. After completion of the form, visitors could click on the button "send". If they did not wish to participate, they could just close the pop-up window.

Within 3 weeks, visitors who had given their online consent for study participation were contacted by email or phone by CL (a communication expert and expert interviewer with no prior relationship to the study respondents). CL gave them additional information and checked whether participants were fluent Dutch speakers. When CL contacted the volunteers by phone and oral participation consent was given, they were either interviewed immediately, or a later appointment was made. If CL contacted them by email, written participation consent was given and an appointment was made for a future telephone interview.

Of the 84 persons who had agreed to participation online, 43 individuals could not be reached, 4 asked to postpone the interview but never contacted CL again, and 7 refused participation after initially having been interested (4 were due to the patient's death/current poor condition, and 3 gave no reason). Ultimately, 30 participants were interviewed on their motives for looking for information on the Internet and asking questions on the DLIC "Ask the physician" webpage. Of the

30 participants, 5 were patients with a lung tumor, 20 were caregivers of lung cancer patients, and 5 did not have cancer (one lung patient and 4 individuals who feared that they had lung cancer). Since we were interested only in cancer patients with a lung tumor and their caregivers, we analyzed only the 25 respondents with cancer. The ratio of patients and caregivers (5:20) is not balanced but is in accordance with the population of visitors of the interactive webpage, as we have reported in other papers.^(6,8) One patient had small cell lung cancer (SCLC), three had non-small cell lung cancer (NSCLC), and one probably had breast cancer with lung metastases. The patients had a median age of 52 years (range 44-62). The majority of caregivers were women, most of them daughters and partners, with a median age of 39 years (range 21-58) (see Table 1 for more details on participants).

Interviews

A topic list was made to prepare the interviews. Main topics were Internet use, information needs and supply, reasons to use the Internet, reasons to query the online lung specialists on the DLIC website, and reasons not to. The topic list was completed with personal information about demographics and disease. Sample questions asked during the interviews are listed in Textbox 1.

Textbox 1. Sample interview questions

Questions

- When did you start looking for information on the Internet?
 - Why did you look for information on the Internet?
 - What role does the Internet play in information supply?
 - What role does the caregiver play in information supply?
 - Why did you ask a question on the interactive page of the DLIC website?
 - What did you ask? What did you want to know?
 - Was the answer to your question satisfactory? Was it useful? Why?
 - At which moment during the lung cancer procedure did you have the greatest information needs?
 - Why did you not ask the (patient's) treating physician your question?
 - Is it different to ask a question through the Internet/by email? Why? How so?
 - What is your opinion about the possibility of asking an online physician questions on a website?
 - What is your opinion about the possibility of asking your treating physician questions by email?
 - What is your opinion about the possibility of asking a nurse questions by email?
 - Would you like to communicate with the (patient's) treating physician by email?
 - What would be the value of such communication?
-

The semi-structured telephone interviews were conducted by CL. Participants were encouraged to talk freely until all topics were discussed. The duration range of an interview was 20-90 minutes. All interviews were written down verbatim with pen and paper, put into orthographic transcripts, and then subsequently typed into MS Word documents directly after interview termination (these MS Word documents will be referred to as "interview transcripts").

Table 1: Study population characteristics and Internet use (n=25)

a	Gender M/F	Age, years	Diagnosis patient ^b	Previous Internet use ^b	Education ^c	Caregiver type	Current therapy
P1	F	44	Metastasized BC	No	HE	-	Palliative therapy
P2	M	62	NSCLC I/II	Yes	HE	-	Adjuvant chemo
P3	F	50	SCLC ED	Yes	LE	-	Palliative chemo
P4	M	52	NSCLC SU	Yes	LE	-	Palliative chemo
P5	F	52	NSCLC I/II	Yes	HE	-	Adjuvant chemo
CG1	F	57	NSCLC IV	Yes	HE	Partner	Palliative therapy
CG2	F	36	NSCLC IV	Yes	LE	Daughter	Deceased 6 weeks before
CG3	F	45	NSCLC IV	Yes	HE	Partner	Deceased 3 months before
CG4	F	52	NSCLC I/II	Yes	HE	Partner	After surgery, no adjuvant chemo
CG5	F	39	Mesothelioma	Yes	HE	Daughter	Terminal phase
CG6	F	39	SCLC LD	No	HE	Daughter	No current therapy, chemoradiation 1 year before
CG7	F	33	LC SU	Yes	LE	Daughter	Palliative chemo
CG8	F	51	NSCLC IV	Yes	LE	Partner	No current therapy, palliative chemo 6 months before
CG9	F	32	LC SU	Yes	LE	Daughter	After diagnostics and diagnosis
CG10	F	26	LC SU	Yes	HE	Niece	Deceased
CG11	M	22	Mesothelioma	Yes	LE	Nephew	Therapy unknown 6 months after diagnosis
CG12	F	42	LC IV	N/A	LE	Daughter	Palliative therapy
CG13	M	58	LC IV	Yes	LE	Partner	Palliative therapy (radiotherapy)
CG14	F	38	LC IV	Yes	LE	Sister	Palliative therapy
CG15	F	21	NSCLC I/II	Yes	HE	Daughter	No current therapy, surgery 1 year before
CG16	M	28	SCLC SU	Yes	HE	Son	Therapy unknown 3 months after diagnosis
CG17	M	36	LC IV	Yes	HE	Partner	Palliative chemo
CG18	M	35	LC IV	N/A	HE	Son	Palliative therapy
CG19	F	41	Mesothelioma	Yes	HE	Daughter	Deceased recently
CG20	F	44	LC SU/ metastases BC	Yes	LE	Daughter	Therapy unknown during diagnostics

^aP=patient, CG=caregiver.

^bBC=breast cancer, NSCLC=non-small cell lung cancer, IV=stage IV, SCLC=small cell lung cancer, ED=extensive disease, SU=stage unknown, I/II=stage I or II, LD=limited disease, LC=lung cancer type unknown.

^cHE=high education (university, academy, college level), LE=low education (primary school, high school, intermediate vocational training).

During transcription into MS Word documents, CL would already start to classify interview passages according to their content and the questions listed in Textbox 1 (topic list based). Apart from the interview transcripts, sometimes CL wrote notes with her impressions on the respondents' ideas during the interviews, which she attached as a memo to the interview transcripts. Occasionally she also copied interesting quotes from her email correspondence with the participants as field notes into the interview transcripts.

Analysis

Researchers RMS and MJW used a thematic approach in the analysis of the transcripts (n=25). (23) After familiarization with the data by reading it repeatedly and carefully, we made a summary of each interview and started initial coding of the transcripts. To facilitate coding, organizing, collecting, and selecting data from the interview transcripts, we used MaxQDA version 10.(24) After numerous meetings focusing on understanding the collected data and correct interpretation, we determined potential themes first and then sorted and collated the (initial) codes according to them. Hence, we looked at the participant's Internet use first, to further determine when they started to surf the Internet and to assess their information needs. After this, we focused on identifying and classifying the reasons why participants surfed the Internet and posed questions to online lung specialists instead of their own specialist. Grouping this information, we made an initial thematic map.

After review of the potential themes for coherence, we refined these themes, identified new themes, and recoded some data extracts. This refinement led to the identification of similarities and discrepancies between participants with regards to the sought-after information. The newly identified themes were found to be the beneficial effects of looking for information for participants, the presence of tensions between patients and caregivers provoked by the Internet search, and perspectives about the use of email with the patient's specialist. After recoding the data extracts according to the refined and new themes, we reviewed the entire dataset again and discussed the generated main themes conscientiously and critically for coherence, consistency, robustness, and representativeness (23,25) in order to develop a final thematic map.

RESULTS

Starting to Surf the Internet

All respondents, except for 1 patient and 3 caregivers, reported using the Internet on a regular basis. They had access to Internet at home and used it for daily activities such as checking their email, banking, or looking for different types of information. They reported that the lung cancer diagnosis specifically urged them to seek information and ask the online lung experts lung cancer-related questions. Their diagnosis had a great impact on their lives, as they were facing lung cancer, its (future) treatment trajectory, and ultimately the shortened life expectancy of the patient. Therefore, they felt the need for additional information to learn how to deal with the situation by any means.

Both patients and caregivers also mentioned that they surfed the Internet again at specific moments later during the lung cancer treatment trajectory, such as during chemotherapy, at the appearance of new symptoms or disease progression, or when having to make a choice

between two treatment options. These moments also meant a change in their current vulnerable balance, which pushed them to search for information again.

I have been told a lot at the hospital, but everything goes so fast, you hear a lot of terms, and you just do not know anything [...] First, I looked at the tumor types and how everything would go during surgery. After that, I looked again when it was recommended for me to have chemotherapy. [P2]

Patients and caregivers mentioned that their need to seek information often arose once they had time to rest and think about what they had been told, often at a time when their questions could not directly be answered by the treating specialist anymore: “Once you have come home, you have forgotten half of what you have been told, which is exactly the moment you would want to ask something.” [CG8, partner]

What are Respondents Looking For and Why?

Respondents reported searching for lung cancer–related information in general but also information specific to their personal situation. An illustration of the information search of caregiver Sylvia (fictitious name), describing what she was looking for and why, is given in Textbox 2.

Apart from feeling the need to gather general information in order to be better informed and have a better understanding of the disease, respondents wanted to be prepared for future consultations, future course of disease, and treatment trajectory. They also felt the need for specific information regarding practical matters or emotional support directly related to their individual condition in order to help face current or short-term situations. Examples are practical

Textbox 2. Caregiver Sylvia

Sylvia (fictitious name) is the 36-year-old daughter of a lower educated male patient of 72 years old. At time of the interview, Sylvia’s father had died a week earlier. He had been diagnosed with metastasized lung cancer 7 weeks prior.

I started looking [for information] 2 weeks after the definitive diagnosis of lung cancer with brain metastases had been made. I searched the Internet because I wanted to know the prognosis and what different types of lung cancer there were. Once I started, I kept on going. I also wrote something on the forum of the DLIC website and I got some reactions; it was very nice. It may sound strange, but it is nice to know that there are many people who are dealing with the same thing. At the hospital they don’t have much time for you. You can see them thinking “Yes, you have cancer, I have explained everything, now get on with it”. Then you come home and the questions arise [...] and you think “I want to ask the question now”. But if you call the doctor, you get the secretary who says “the doctor is not here, he is with a patient. When do you have an appointment? Next week? You can ask your questions then”. But this way a question that feels urgent to you remains unanswered. This is one of the reasons why I turned to the Internet and by stumbling across the DLIC website, [...] I found everything I was looking for. This website is incredible. I can stay on the site for hours [...] When I came back to the treating physician after the diagnosis, I asked him “what kind of lung cancer is it, small cell, non–small cell? What are the advantages and disadvantages of giving therapy?” You should have seen his face wondering how I knew all of that. Actually, I have only ever asked the online expert one question: “if someone has metastasized cancer, why is not it possible to operate on the lungs and brain and just remove the cancer from both sites?” I received a satisfactory answer. Although it was just as I thought, it was still nice to get confirmation. And you never know, perhaps the Internet expert will say there are still possibilities or new therapies. Even if it is not the case, it is still nice to have been able to ask. I think it is excellent to be able to ask a question of the DLIC online expert and to get an answer so quickly because it has prevented several sleepless nights.

matters during the treatment trajectory and finding emotional support through contact with fellow sufferers (see Table 2). Ultimately, all respondents expressed that the main goal of their information search was to find support as they were dealing with lung cancer. Textbox 3 also gives an illustration of patient Mary's (fictive name) information search and her search motives.

Textbox 3. Patient Mary

Mary (fictitious name) was a 44-year-old highly educated, married patient. She was diagnosed with breast cancer metastasized to the lungs. After a period of stable regression, she was receiving palliative therapy at time of the interview. She was very pleased with Internet as mode of information supply and the DLIC interactive webpage, but she emphasized that she did not want eHealth to become a substitute for visual contact with treating specialists in the future.

After the diagnosis, I hit rock bottom. A neighbor, who is a nurse, brought me a lot of pamphlets. This helped me back on top and gave me the feeling that I should do something. At that point [1 month after the diagnosis], I started to study the folders and the Internet. I wanted to come to grips with the situation and also get the feeling that I had a rough plan for my treatment. The Internet has played an important role in terms of information supply. I am a member of a private mailing group where we exchange a lot of information. One of the group members made me aware of the DLIC website and that questions were being answered there. Early on, I would see my doctor first and after that I would go online looking for the things he had suggested, verifying whether there were no other possibilities. But there came a point when I felt I needed to take charge of the situation instead of just following him passively. I wanted to get ahead of the game, so now I started looking for information before every new hospital appointment, so that I could come well prepared. I researched every possible thing: what I had, what I would get, what possible alternative or experimental therapies there were, things about pain control for later during the process, you name it. I have accepted the disease and I see myself as a kind of research project. I think it is good to be well informed. It gives you the feeling that you have control over your disease and your treatment.

Differences Between Patients and Caregivers

Although patients and caregivers reported searching for general information as well as information specific to the individual condition, their searches differed with regard to quantity and content (see Textboxes 2 and 3). Patients searched for a minimal amount of general background information and focused specifically on their individual current condition. They aimed to get more information about symptoms and therapy, together with practical information for the coming disease course and consultations. Not all of the patients seemed to want to gather information about the last moments of life, although they were perfectly aware of their shortened life expectancy. Patients especially said they were searching (among other things) for hope by contacting fellow sufferers and/or looking for a confirmation of the accuracy of their diagnosis and chosen management. This made them feel supported (see Textbox 3). On the contrary, caregivers expressed the need to collect a lot of general information of any kind (see Textbox 2). An element they mentioned with regard to the available information on the Internet was the difficulty of understanding or interpreting online information correctly, as they were lacking a doctor's knowledge and felt overwhelmed by the vast amount of information given. Caregivers also wanted to be informed more frequently about the patients' end of life and prognosis in particular. Furthermore, they reported looking for information specific to their personal situation in order to feel supported. Like the patients, caregivers said that their quest for (emotional) support consisted of (among others) searching for hope and

Table 2: Needs of respondents

General information needs	
Background information on lung cancer	Epidemiology, lung cancer types
Diagnosis	
Therapy	Regular, experimental, alternative
Diagnostics	Investigations types and explanation about it
Disease course/end of life/prognosis	Life expectancy, (overall) survival per stage, what to expect at the end of life, suffocation
Information sources/literature	DLIC website, websites specialized on experimental therapy
Individual information needs	
Managing personal situation	Help with a choice: postoperative chemotherapy, radiotherapy or not
Managing personal health or mental condition	Explanation and/or treatment of symptoms or side effects (eg, own neurological problems or insensibility after surgery), preparation for coming treatment (eg, what is going to happen during surgery), analgesia, what can this symptom be?
Managing emotions	Search for hope, confirmation, reassurance, emotional support, compassion, consolation, contact with fellow sufferers/ comparable experiences, expert's verification/2 nd opinion, moments of panics and uncertainty
Managing daily life	Lifestyle advices, hospital bills, food supplements, hospice
Managing practical aspects of treatment trajectory	Eg, explanation of medical terms/terminology like stable disease or "adenocarcinoma", meaning of laboratory/imaging results specific to patient, organizing euthanasia

reassurance/confirmation of medical information, contact with other fellow sufferers (by direct contact or by reading their stories) and with the online expert (see Table 2).

Why Not Ask Their Own Treating Specialist?

Numerous reasons were mentioned for using the Internet and asking the online expert questions in particular, rather than addressing their own treating specialist. Respondents said they did not want to ask their own specialist. They mentioned being ashamed about discussing personal matters or indecencies within the context of a consultation. They also did not wish to disturb or burden their own specialist because he or she was (supposed to be) very busy. Especially caregivers were convinced of being a burden to the specialist as they were "only a caregiver anyway".

There are a lot of things that I wouldn't discuss with the lung specialist. For example, a big part of his lung has been removed and when we caress each other, he has no feeling in that part of his skin. He does not feel my touch. He says that it feels alien, as though it's not part of his own body. Then we asked ourselves "will it remain that way?" But you do not ask the lung specialist those kind of things when he is looking at the chest X-ray very seriously. [CG4, partner]

And you do not bother the specialist by calling him at the hospital, because surely he has better things to do. [P3]

Respondents had the feeling of not being able to ask a question or request information. They experienced barriers in their contact with their own specialist because they felt he or she

had no time during and between consultations. They experienced the specialist not being open to questions: “The communication at the hospital was dramatically bad” and “We have a kind of reticence to ask our treating specialist questions. They do not like it when you ask a question.” [CG6, child]

Following the suggestion of the DLIC, I brought a list of questions for my specialist. You could see him thinking “Not another one with a list...” Specialists are always in a hurry. They do not even have time for a proper discussion with you. I have seen 4 different pulmonologists, and when you walk into the consultation room, they would all still be reading your medical record at the same time. [P2]

Patients as well as caregivers appreciated the convenience of using the Internet and the DLIC website because of its 24-hour accessibility and its anonymity. This made them feel freer to ask the online lung experts for any kind of information and helped them express their feelings better. They felt less anxiety as they were able to pose a question instantly, receive a reply from the online specialist to urgent questions within a short space of time, and not have to wait until the next consultation with their treating specialist. This was especially the case for caregivers as, for example, one of them said that the patient had a follow-up appointment every 3 months but that she could surf the Internet every day. Furthermore, respondents appreciated the expertise and open-minded, kind, and empathic attitude of the online lung experts.

I think it's fantastic. It is anonymous and it's great to ask your questions to someone who's competent in the field [...] I was looking for someone independent [...] Although he [the online expert] is an outsider, he knows what he is talking about. [P2]

I think it is very good to be able to ask a physician questions online. It's a smaller step to take than calling or talking to your treating specialist. [CG9, child]

His style (of the online expert) is really nice, not disapproving. He is very kind and always says something like “I wish you good luck” or “I hope it will be all right”. [CG1]

Reasons Not to Use the Internet

Patients and caregivers mentioned that sometimes they postponed or stopped their Internet search, for instance, because the information they encountered was too much. Not searching helped them to stay positive. Other respondents felt that they had collected enough information after a period of time and therefore deliberately quit the information search, knowing they were avoiding confrontation with the disease sometimes.

No, at the beginning, I did not look for information. The disease, it was not about me, it was as if it was about someone else [...] I must say that I am not on the Internet very often anymore, because a lot of people die there. It is too much for me [...] and makes me feel depressed. You need to feel there is still a light at the end of the tunnel. [P3]

I went looking for information after my husband passed away, not during his illness though. It does not make you feel happy and I wanted to stay positive, so it does not help if you read these unpleasant things on the Internet. [CG3, partner]

I think I should not read too much about lung cancer anymore. Now that the disease has gone, it's time to move on. I have got the feeling that I have just recovered from a heavy illness myself and that at long last I am finally fit enough to get up and go again. Yes, perhaps I am avoiding thinking about all that is lost. [P2]

Tensions

Both patients and caregivers also talked about the occurrence of tensions when meeting their own information needs by searching the Internet. Specifically caregivers realized that their needs were not always the same as the patients and experienced difficulties in dealing with the information they had collected. They felt torn by the dilemma of disclosing sensitive information or hiding it from the patients, as they wanted to protect them from (unwelcome) confrontations. For example, one caregiver said that he did not share the death of someone from his mailing group as he thought that this would be too much to handle for the patient.

There are things that I do not tell him, because I do not want to worry him [...] It is difficult because sometimes, when we are at the doctor's, I would like to know things, such as the life expectancy, but I am reluctant to ask, because I do not want my father to hear it. [CG12]

Well...Actually I have kept information from him when he was very unwell and we did not know yet whether he could be operated. At the time, my son and I looked for the 5-year survival rate and decided we should not tell him. Once he was home again after the operation, he was looking at a very old medical encyclopedia that we never use. Then he said "Do you know what the 5 years survival of lung cancer is?" I said I did and in reply he asked me why I had never told him. He was upset at first, but he understood. [CG4, partner]

Email Contact With Their Own Treating Specialist or an Oncology Nurse

All patients were very positive when being explicitly asked about their opinion on the opportunity to have email contact with their own specialist for questions. Caregivers, however, had more reservations as they felt embarrassed contacting the treating specialist (as being *only* caregivers) and were afraid that the specialists might be overwhelmed by emails. Respondents also reacted positively about having email contact with an oncology nurse in order to obtain medical information and ask questions, on the condition that she or he had to specialize in lung cancer. One caregiver mentioned the very useful assistance of an oncology nurse as a constant and accessible contact point for support and information during the whole treatment trajectory.

DISCUSSION

Principal Findings

The present study adds knowledge on the information-seeking behavior of lung cancer patients and their caregivers during the lung cancer treatment trajectory and their reasons for doing so. Strikingly, the majority of respondents were caregivers. Our findings show the coping strategies of caregivers and patients towards managing lung cancer. They searched the Internet and asked online DLIC lung experts questions because they wanted lung cancer-related information and

help in coping with the disease practically and emotionally. This happened repeatedly during the whole treatment trajectory. This search helped the respondents to deal with lung cancer in a better way. It permitted them to gain a better understanding, be prepared (for the treatment trajectory and the disease course), feel free to search and ask for information, express feelings, be relieved of anxiety, feel emotionally supported, and regain control. This confirms that information is essential and beneficial for coping with cancer for both patients and caregivers and that caregivers are actively involved in information search and supply.(14,26) Furthermore, the information needs of caregivers differed from those of patients.

Lung cancer patients and their caregivers searched the Internet in order to deal with lung cancer and their personal situation. The perspective of the coping theory can be applied to explain the respondents' behavior.(27) When events occur in a subject's life, the subject is prompted to activate internal processes necessary to accommodate that event (e.g., behavioral, cognitive, and affective mechanisms, including coping). It is known that anxiety, anger, fear, helplessness, and depressive feelings are frequently experienced after a cancer diagnosis.(28) The study respondents experienced such distress at diagnosis and other key points of the treatment trajectory that provoked a change in their lives, therefore posing a threat, challenge, or harm to them personally. Subsequently they tried to manage this distress by means of coping, through searching the Internet and turning to online lung experts for lung cancer-related information. Information is essential for coping with cancer, and new media (e.g., the Internet, online cancer communities, mailing groups, etc.) are crucial today for the dissemination of information. (14,26) Hence, our respondents are used to searching new media for information. Still, the choice of the Internet and online experts versus the patient's treating specialist remains intriguing. Caregivers particularly had a greater tendency to search the Internet. This may be related to the serious nature of lung cancer, as the gravity of a disease urges people to seek additional information.(14) Also, when facing a life-threatening disease, cancer patients and family members often want confirmation of information, despite good communication with health care providers and adequate information supply.(29,30) Furthermore, Ong et al. (31) and other investigators (32-35) found that patients and caregivers are often unsatisfied with the communication or the information given to them in medical settings. These issues were also observed in present study results. Apart from this, the practical advantages of the Internet and the availability and attitude of the online experts moved the respondents toward this medium. Respondents were not only looking for general lung cancer-related information but also information specific to their own situation. Soothill et al. (36,37) reported the need for "universal" and "personal" information among cancer patients and caregivers, helping them to cope with cancer, such as managing daily life or emotions. Searching for these two types of information was beneficial for the study respondents. Although similarities in the information search of patients and caregivers were observed, important differences were noticed too. Caregivers were inclined to look more extensively (in terms of quantity) for information than patients, and the content of the information found differed too. This trend was recognizable from the literature. Caregivers, of lung cancer patients in particular, show high participation rates in online cancer communities.(14) Compared to patients, they also have a higher tendency to look for information than providing it to other caregivers and patients, and they are more inclined to participate in emotional support exchange.(6,8,14) Moreover, lung cancer

patients and caregivers have different information needs;(38) caregivers tend to have more unmet needs and concerns than patients.(36,37) This could originate from the caregivers' perception of themselves as being helpless observers, their lesser involvement with health care providers, or the patients' underreporting of concerns and unmet needs.(39) It also seems that information seeking is a typical activity for caregivers, as lung cancer patients are often too ill to do it themselves.(14) Interestingly, most caregivers among our respondents were (young) women. Women typically participate more in mail groups and supportive communication than men and seem to search or care more about information (provision) than men.(14,40,41)

Thus, it is important to recognize the caregivers' needs as well as those of patient, since caregivers play a critical role in sustaining the cancer patient, and their ability to nurture and support the patient may be compromised in case of unmet needs.(42,43) This may have serious implications for both the patients' and caregivers' psychological state and coping. Further investigations on this topic are therefore needed.

As seen in our results, trying to meet one's own information needs can also be accompanied by difficulties and/or tensions. Confrontation with threatening or negative disease information can be of great impact on the well-being of patients and caregivers.(11,44) This may subsequently lead to the total abortion of the information search, the avoidance of confrontation with the "sensitive" information in particular, or concealing it from loved ones or patients, with all its possible consequences on the psychological state of those involved. This dilemma between wanting to meet information needs and protecting oneself or another have often been described in literature as the origin of conflicts and communication problems between caregivers and patients.(45-47) A balance between these two elements must therefore be achieved to maintain psychological well-being. Solutions to reach such a balance may not only be ceasing the information search temporarily, but also consulting reliable and clearly categorized sources of information and discussing the tensions with the concerned persons or with someone who might be of help. The possibility of obtaining or discussing information directly with the treating physician or a specialized oncology nurse should be considered.

Study Limitations

Since we performed a cross-sectional study with an interview at one single point during the lung cancer treatment trajectory, it is possible that we have missed information on the respondents' needs, as we did not follow them over time. Nonetheless, respondents described different moments during lung cancer treatment. The quality of a person's information needs is constant over time even though the quantity of the needed information may show a slight decrease.(48,49) It is therefore reasonable to assume that our results paint a reliable picture of the information needs and other reasons why respondents surfed the Internet.

Another limitation is the fact that all interviews were held by phone and were not audio recorded. Also, CL started to classify interview passages shortly after their transcription. This may have led to bias and to information loss during the simultaneous transcription of the interviews. However, since CL is an expert interviewer used to collecting information in this particular manner, it seems less probable that data were lost. Furthermore, the classification of interview passages took place according to the questions CL asked during the interviews (see Textbox 1), reducing bias.

Because data collection took place a few years ago, changes in habits of Internet users and DLIC website visitors may have occurred over time, next to changes in website availabilities. The relevance of our findings may also be questionable. However, we know that Internet health searches have become much more commonplace.⁽⁵⁰⁾ Additionally, internal reports of the DLIC website have shown that the number of visitors each month and the visitors' identity remained the same over time.⁽⁷⁾ The interactive webpage still remains a very popular page of the website, and the number of questions is still increasing. Questions concerning general information on lung cancer as well as information on personal matters are still being asked. The website availabilities have not really changed, and its homepage shows only a few additions since its launch (e.g., animation, links to new blogs, and a visitor's poll). We can therefore assume that the reported findings are still relevant and representative for the population we investigated. A final question to address is whether our study sample is representative of the investigated population, as ultimately a sample of 25 respondents was interviewed despite the far larger number of persons interested. Persons who never surf the Internet were also anticipatorily excluded. The respondents' distribution is, however, in accordance with the population visiting the DLIC website.^(6,8) Moreover, patients and caregivers who never surf the Internet were not the target of this present study. Additionally, we showed in previous studies that many website visitors only read the webpage "Ask the physician" without asking questions. This group of visitors may be represented by the group of respondents who were interested in participating but were never interviewed. Another argument for the respondents' representativeness is the reaching of saturation of data and themes after multiple readings of the interviews.

Practical Implications

Our study results have numerous practical implications for the care of patients and their caregivers during the lung cancer treatment trajectory. Caregivers represented the majority of respondents looking for information and indicated they needed help coping with lung cancer. However, they often felt unable to address the patient's treating specialist. Since the well-being of patients and caregivers are connected, special emphasis must be given to the often neglected experience and needs of caregivers.^(51,52) In practice, this might simply be solved by addressing caregivers' needs during consultations. In case of difficulties, lack of time, or objections from the treating specialists, workshops directed towards communicating with multiple persons and managing consultation time might help. Moreover, appointments additional to regular consultations are possible, as well as the implementation of support groups and information events focusing on the patient-caregiver unit. Extensive research on these possible interventions should be done prior to any implementation. The experiences, needs, and the role of caregivers during lung cancer treatment require further investigation. Both patients and caregivers searched the Internet and the DLIC website broadly for additional information on lung cancer. It can therefore be concluded that there is a demand for such a service, although it was not considered a potential replacement for live consultations with the treating specialists. The positive effects on the respondents' coping and their level of satisfaction, however, show that use of such services is favorable. They should therefore be promoted as *additional* information supply sources and be part of good medical care. To prevent the use

of unreliable information sources, treating specialists might refer patients and caregivers to reliable and objective websites (with online experts). James et al. have already reported evidence supporting this approach as being (surprisingly) a wish of both patients and caregivers.(53)

Next to referral to a specialized oncology nurse for additional information and support, the development of direct personal email contact with the nurse or with the treating specialist may also be considered, for those reluctant to use the Internet and consult online experts. There are, of course, barriers and advantages to such communication modes.(54) Barriers might be the lack of Internet access and peer pressure, as well as the absence of training or ability to use email and concerns about junk mail, privacy, and security.(54) Advantages are numerous, such as speed, efficiency, and productivity,(54) and, as illustrated in our study results, satisfaction and relief of anxiety among patients and caregivers. The specialists' and nurses' perceptions and the feasibility of direct email contact should nevertheless first be investigated before future implementation.

CONCLUSIONS

Lung cancer patients and especially their caregivers use the Internet and the interactive webpage of the DLIC website because they want additional information on top of what they have received from their treating specialists. The information search also helps them to cope with lung cancer. The Internet and the DLIC's interactive page are therefore valuable complementary modes of information supply. Because the DLIC online expert is not able to answer patient-specific questions, using email contact between patients/caregivers and treating specialists or specialized oncology nurses might be considered in case of urgent questions, next to referring them to reliable sources of information.

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6

LUNG CANCER PATIENTS BENEFIT FROM SECOND OPINIONS BY IMPROVEMENT OF DIAGNOSIS AND THERAPY

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ABSTRACT

Purpose: To collect data from the initial evaluation of patients referred for a second opinion to a specialist pulmonary oncology clinic and compare these with the data of the re-evaluation (second opinion) conducted there to identify discrepancies in diagnosis, stage and therapeutic advice.

Methods: Demographics and disease characteristics of 188 patients referred between January 2005 to December 2009 were collected from medical records, next to therapeutic advice. The data of both initial and second evaluations were compared with each other.

Results: At time of referral, the (clinical/histopathological) diagnosis was known in 174 patients (92.6%) and the stage in 162 patients (86.2%). Forty-eight percent of the patients had received prior therapy and 73% a therapeutic advice. Next to data review, additional diagnostic procedures were performed in 68% of the patients. There were discrepancies between the initial and second opinion in diagnosis (17 patients, 9%), stage (24 patients, 13%) and therapeutic advice (70 patients, 37%). The second opinions led to a total of 91 discrepancies, 53 of these had a potential major impact on patient outcomes in terms of survival, morbidity and quality of life. For patients with advanced lung cancer, the results were similar but the number of changed stages, therapeutic advices and discrepancies with a potential impact on patient outcomes were slightly higher (15%, 40% and 51% respectively).

Conclusions: Lung cancer second opinions referrals led to significant discrepancies in diagnosis and therapeutic advice in a substantial number of patients. This might be translated in better (palliative) care.

INTRODUCTION

Although peer consultation between colleagues account for the majority of second opinion requests in daily oncology practice, (1) the phenomenon of patients asking a second opinion is not uncommon, because of the life-threatening character of the disease and potential mutilating and toxic treatment modalities. (2) Patients' main reasons to seek a second opinion are the wish for more information about the treatment options, hope for a different advice, confirmation and/or reassurance of the proposed therapeutic management, unfulfilled (information) needs (e.g. about diagnosis, treatment and prognosis) and previous negative experiences with their treating physicians. (2-4) The rapid expansion of information supply and seeking, due to the increasing use of Internet-based information sources and the growing autonomy of patients, has contributed to the increase of patient initiated second opinions. (1-4) According to Hewitt et al. in 1982, already 56% of 1500 cancer survivors had sought at least one second opinion. (5) Despite evidence of beneficial effects and probable financial advantages, the usefulness and value of patient initiated second opinions are often questioned though. (6-9)

Lung cancer is the most important cause of cancer related death among men and women worldwide, accounting for 1.38 million deaths annually. Facing a dismal prognosis and experiencing particularly intense distress as compared to other cancer patients, (10) lung cancer patients are very likely to request a second opinion. However, to the best of our knowledge, there are no reports available on the incidence and/or outcomes of lung cancer patient initiated second opinions. In the view of the current discussion on the usefulness of patient initiated second opinions, the growing wish of patients to do such requests and the expected increase of lung cancer incidence and management related costs, it is important to gain more insight into lung cancer patients initiated second opinions.

In present study, we retrospectively collected data from the initial evaluation of patients visiting a specialist pulmonary oncology clinic for a second opinion and compared these with the data of the re-evaluation conducted there, to identify discrepancies in diagnosis, stage and therapeutic advice.

METHODS

Settings

Generally in the Netherlands, when the diagnosis lung cancer is suspected, for instance after chest X-ray or hemoptysis, patients are usually referred to a team of pulmonologists at a nearby general or university. Additional staging diagnostics are performed there and the diagnosis is usually confirmed. Patients receive a therapeutic advice and therapy usually takes place in the same hospital. Although therapy often involves different disciplines (Pulmonology, Radiotherapy and Thoracic Surgery), the pulmonologist is usually the principal treating physician for patients. The therapeutic advice is formed in consultation with colleagues, in a multidisciplinary team (MDT).

If the diagnostic procedures fail, patients may be referred to a more specialised hospital to complete diagnosis and staging. Patients may also be referred for specific diagnostics or therapies not available in the referring hospital (e.g. EGFR mutation analysis, mediastinoscopy or stereotactic radiotherapy) or for a second opinion. Depending on the outcome of the referring consultation, patients are sent back or choose to stay at the specialist hospital.

The VU University Medical Center (VUmc) is a tertiary specialist pulmonary oncology center with a specialized MDT of experienced specialists (pulmonologists, radiotherapists and thoracic surgeons), equipped with advanced techniques for diagnosing and staging lung cancer (e.g. PET-CT-scans, mutation analysis facilities). Patients are discussed in the MDT weekly. Around 400 new patients are seen yearly from all over the country (from both urban and rural area), partly second opinions. Patients in this study came from 46 general and 6 university hospitals.

Study population

In the present study a patient initiated second opinion was defined as a consultation for re-evaluation of the patient's case, at his/her own request with or without the agreement of his/her treating pulmonary specialist. Due to the nature of the second opinions (*patient* initiated) and their timing (sometimes immediately after the first consultation at the original hospital), this implies that the evaluation in the first hospital was not always complete and subsequently a therapeutic advise had not always been given at time of presentation for the second opinion (see results). To prevent delay to start of treatment as much as possible, second opinions were always performed within one week after request. Available written reports and digital diagnostic imaging material were either brought by the patient at the visit or send by courier prior to the consultations.

All patients with the (probable) diagnosis lung cancer presenting to the pulmonary oncology outpatient clinic of the VUmc between January 2005 and December 2009, from outside its district and fulfilling the above mentioned second opinion definition were included in this retrospective medical charts study. In total 184 patients were included, of which 4 were referred twice, resulting in a study population of 188 cases.

Study end points

Primary and secondary outcomes

Medical information (e.g. prior therapy, current therapeutic advice) and the patients' and disease characteristics (diagnosis and UICC-6 TNM stage) were collected from the initial evaluation (referral) and the re-evaluation at the specialist center and compared. Discrepancies in (pathological or clinical) diagnosis, stage of disease and therapeutic advice were noted next to initiator of referral, additional diagnostic tests, trial inclusion and whether therapy was given at the specialist center or elsewhere.

Secondary end points

In the presence of discrepancies, a categorization of their potential impact on patient outcomes (in terms of survival, morbidity and quality of life) was developed based upon evidence based guidelines.⁽¹¹⁾ Three outcome categories were defined: discrepancies with potential major, minor and identical impact (see **Appendix I** for a more detailed description of the categories).

Statistical analysis

Descriptive analyses using chi-square tests to identify possible differences in second opinions were performed using SPSS version 20.0.

RESULTS

Patients characteristics

The majority of patients were male (57%) and the mean age at presentation was 59 (± 10 SD) years (see Table 1 for patients and disease characteristics). Males (n=108) were significantly ($p < 0.05$) older than females (n=80) with a mean age of 61 years versus 56 years respectively.

In 174 (93%) patients a pathological or clinical diagnosis and in 162 (86%) patients the stage was determined, 100 patients had received prior therapy (53%) and a therapeutic advice had been given to 150 patients (80%) at time of presentation. Most patients had an advanced stage (non-) small cell lung cancer.

For 12 patients with a known histopathological diagnosis, no stage was determined at time of referral (staging unknown: n=3; definite staging not completed/failed: n=9).

Table 1: Study population baseline characteristics (n=188)

	N(%)
Male	108 (57%)
Mean Age at presentation	59 (± 10.2 SD) years
Known prior data:	
- Diagnosis*	174 (93%)
- Stage	162 (86%)
- Therapy	233 (48%)
- Therapeutic advice	356 (73%)
Histopathological diagnosis lung cancers* (n=174):	
- Non-small cell lung cancer (NSCLC)**	151 (87%)
- Small-cell lung cancer (SCLC)	15 (9%)
- Lung cancer other type: carcinoid	1 (1%)
- Adenocarcinoma unknown primary	3 (2%)
- Mesothelioma	1 (1%)
- Large cell carcinoma unknown primary	2 (1%)
- Squamous cell carcinoma unknown primary	1 (1%)
Stage (n=162):	
- I/IA/IB	7(4%)/6(3%)/1(1%)
- II/IIA/IIB	5 (3%)/ 1 (1%)/4 (2%)
- III/IIIA/IIIB	39(22%)/15(9%)/24(14%)
- IV	95 (55%)
- Limited disease	4 (2%)
- Extensive disease	11 (6%)
- Other***	1 (1%)
-advanced lung cancer ^f	146 (78%)
-non-advanced lung cancer	42 (22%)

*The sub classification by Scagliotti et al., JCO 2008 was not used (36)

**NSCLC subtypes squamous cell-, large cell-, adenocarcinoma's and nos (non otherwise specified) together

***Other stage classification for mesothelioma

^fStages 3, 4 and extensive disease

Reviews and additional diagnostics

All available imaging material was reviewed next to the tissue of 56 (30%) patients. In 3 patients, the tissue was not of adequate quality for review analysis and in 5 patients it was inconclusive. Additional histopathological investigations and diagnostics were needed in 127 (68%) patients, including acquisition of tissue (74, 39%), EGFR mutation analysis (64, 34%), PET-/CT-/PET-CT-scans (78, 42%), and bronchoscopy (20, 11%). In 61 patients (33%) no additional diagnostic procedures nor a review of tissue were considered necessary.

Second opinions outcomes

Discrepancies in diagnosis and stage were found in 17 (9%) and in 24 patients (13%) respectively. Lung cancer was also *de novo* diagnosed in 14 patients (7%) and for 23 patients (12%) definite staging was completed (see Table 2).

In the therapy naïve patients (n=88), a larger number of discrepancies in diagnosis and stage were observed than in patients with prior therapy (n=100), and more *de novo* diagnoses and stages were determined ($p < 0.001$).

The consequences of discrepancies in diagnosis, stage and therapeutic intent following the second opinions are shown in Table 3. Changes occurred in NSCLC subtype (n=10), lung cancer type (n=1) and from lung cancer to infection (n=1). All 5 patients presenting with a carcinoma of unknown primary were diagnosed with lung cancer (NSCLC type).

Table 2: Outcomes after second opinion referral

	N (%) Total (n=188)	N (%) Prior therapy (n=100)	N(%) No prior therapy (n=88)	P-value [¤]
Diagnosis				
- Confirmed	157 (84%)	92 (92%)	65 (74%)	p = 0.002
- Changed	17 (9%)	6 (6%)	11 (12%)	
- No prior diagnosis*	14 (7%)	2 (2%)	12 (14%)	
Stage				
- Confirmed	138 (73%)	88 (88%)	50 (57%)	p < 0.001
- Changed	24 (13%)	8 (8%)	16 (18%)	
- No prior stage	23 (12%)	3 (3%)	20 (23%)	
- Unknown/no stage after 2 nd evaluation**	3 (2%)	1 (1%)	2 (2%)	
Therapeutic advice				
- Confirmed	75 (40%)	44 (44%)	31 (35%)	p = 0.452
- Changed	70 (37%)	32 (32%)	38 (43%)	
- No prior advice	38 (20%)	21 (21%)	17 (20%)	
- Unknown***	5 (3%)	3 (3%)	2 (2%)	

¤ P-value with Pearson chi-square tests

*1 patient did not have a pathology based prior diagnosis, this remained unchanged after the second evaluation. Patient has been treated without a pathology confirmed diagnosis.

**For 1 patient the diagnosis of recurrent NSCLC was changed to complication of therapy without any sign of recurrence (infection), no stage was therefore assigned. The stage of the other 2 patients was unknown at time of referral and remained unknown after the second evaluation.

***5 patients only received a diagnostic advice and no therapeutic advice

Table 3: Consequences of second opinions on diagnosis, stage and therapeutic intent

	N
Changes in diagnosis (n=17)	
- Lung cancer types:	
- SCLC → NSCLC	1
- Lung cancer subtypes:	
- NSCLC subtypes	10
- Lung cancer → benign condition (infection)	1
- Carcinoma of unknown origin:	
→ Lung cancer	5
Changes in stage (n=24)	
- Higher stage	
3 (A/B) → 4	5
3A → 3B	3
2B → 3 A/B	1
1A → 1B =1	1
- Lower stage	
4 → 3 A/B	6
3A/B → 2 A/B	1
3A/B → 1 A/B	3
4 → 1 A/B	3
- Other*	1
Changes in therapeutic intent after stage switch (n=25)	
- Palliative → curative	10
- Curative → palliative	5
- No change and other*	9

*One patient with a change in diagnosis from SCLC to NSCLC, other stage classification

The stage was changed in a higher stage (n=10), respectively a lower stage (n=13), when compared to initial staging. One patient switched from SCLC ED to NSCLC stage 4 (classified as *other* in Table 3) and no staging was determined for the last patient because he had an infection. The discrepancies in stage had consequences for the therapeutic intent, from palliative therapy to curative therapy (n=10) and vice versa (n=5). For 9 patients the therapeutic intent remained the same.

Therapeutic advice

The initial therapeutic advice was confirmed in 75 (40%) and changed in 70 patients (37%). The other 23% of the patients received for the first time a therapeutic or a diagnostic advice. The differences observed were not significant (see Table 2).

After the therapeutic advice of the specialist center, approximately one fifth of the patients (n=42, 22%) were included to receive therapy in a trial setting. Of the total population, 25 (13%) patients came with a request to be treated within a trial. This request was granted in 13. Trial inclusion was significantly higher in the group of patients who requested trial enrollment versus patients who did not ($p < 0.001$) and in the group with a changed therapeutic advice ($p < 0.001$). There were no significant differences with regard to trial enrollment when dividing the population according to prior therapy.

Most patients were treated at the specialist center (128 patients, 68%), 56 patients were referred back to their hospital. Of the remaining patients, 2 died before therapy initiation and 2 were discharged.

Discrepancies with potential consequences on patient outcomes

In total, 91 discrepancies were found after the second opinion, including changes in diagnosis, stage and therapeutic advice and were classified according to their potential impact on patient outcomes (minor, major and identical, see Appendix I). When multiple discrepancies were found in 1 patient, only the discrepancy with the most important potential impact was counted. For 53 patients (28% of the total population and 58 % of the group of patients with changes), the discrepancies had a potential major impact on patient outcomes, for 20 patients (22%) a potential minor impact and for 18 patients (20%) a potential identical impact. There were no significant differences in the number of discrepancies with potential major consequences between the group with a changed and unchanged therapeutic advice. The most frequent discrepancies with potential major consequences (n=53) concerned (in descending order of frequencies) a modification in diagnosis or stage (n=24), chemotherapy (n=10), mutation analysis (n=7), the resectability of a tumor (n=4), neo- or adjuvant modalities to surgery (n=3) and the switch from concurrent chemoradiation to chemotherapy (n=3)(see Table 4).

The general outcomes of second opinions for the patients with advanced lung cancer (as a subgroup of the total study population) are shown in Table 5 (more detailed data available on request).

DISCUSSION

Second opinions have proven to be of value for a number of different diseases, especially in oncology. (12-15) The percentages of discrepancies after a second opinion vary between 1% and 60%, depending on the disease and anatomic site, the nature and quality of pathological specimen (cytology or histopathology), the applied definition criteria for the changes (in diagnosis, stage or therapeutic advice), their clinical impact on therapy and/or prognosis and the patient population.(4;12-18)

Present study provides the very first report of patient initiated second opinions for lung cancer in a specialist center, which resulted in a substantial number of significant discrepancies in diagnosis, stage and therapeutic advice *after* the re-evaluation of patients' data. It shows that

Table 4: Nature of changes with potential major consequences (n=53)

	N(%)
Diagnosis and/or staging modification	24 (45%)
Decision to give chemotherapy or not	10 (19%)
Performing mutation analysis*	7 (13%)
Tumor resectability	4 (7%)
Adding neo/adjuvant modalities to surgery	3 (6%)
Switch from chemotherapy to concurrent chemoradiation (and eventually surgery) and vice versa	3 (6%)
Switch from radiotherapy to chemoradiation and vice versa	1 (2%)
Switch from radiotherapy to surgery	1 (2%)

*Mutation analysis on K-ras en EGFR-mutations

Table 5: Second opinion outcomes of patients with advanced* lung cancer (n=146)

	N(%)
Changes after the second opinion	
-in diagnosis	9 (6%)
NSCLC subtype	8
SCLC → NSCLC	1
-in stage	22 (15%)
Lower stage	13
Higher stage	8
ED** → 4	1
-in therapeutic advice	59 (40%)
Number of changes with potential consequences on patient outcomes	75 (51%)
Number of changes with potential major consequences on patient outcomes***	39 (27%)

*Stages 3, 4 and extensive disease

**From ED (extensive disease) to stage 4

***The most frequent changes with major potential impact on patient outcomes were (in descending order) a modification in diagnosis or stage, chemotherapy, mutation analysis, switch from concurrent chemoradiation to chemotherapy and the resectability of a tumor.

a patient initiated second opinion in a specialist center might have impact on the treatment (outcomes) of individual patients and is therefore -in this study especially with regard to the group of advanced lung cancer- of value.

Second opinions solely on lung cancer have never been investigated and in other reports with mixed/miscellaneous patient populations, the number of lung cancer cases was too limited to draw specific conclusions in this group.(3;14;15;19;20) Although it is difficult to compare present results with general second opinion data, it is striking that our percentages discrepancies and their potential impact on patient outcomes are higher than reported in literature. In addition, it is even more striking that our findings show such large percentages of discrepancies as they are the result of *patient* initiated second opinions. One would tend to think that, as patients refer themselves regardless of the probability to find a discrepancy, only a minor number of discrepancies would be found. Our findings demonstrate otherwise. There may be several explanations for our observations.

First of all, there might be a “pre-selection” of patients since younger females (compared to the lung cancer population) are slightly overrepresented in our study sample. They are in general more inclined to request a second opinion (2;4;21;22) and consequently, might be more inclined to urge their treating physicians to perform more additional diagnostic procedures and try more experimental and/or aggressive treatments. Still, this does not explain all findings, as the patients of this study received advice in accordance with current international guidelines.(11) Additionally, our study population seems representative since the geographical spread is rather homogenous and patients came from all over the country.

Second, the definitions we applied for a second opinion and a discrepancy are not identical to other authors'. Although some elements are similar,(15;20;22) e.g. a change from benign to malign or in stage; differences remain, such as the distinction between a potential major or minor impact (which may also be subject to change and personal preferences), lung cancer specific elements and the second opinion type (patient initiated).(23) The classification we used is nevertheless in

accordance with evidence based literature (see appendix) (11) and we have attempted to make the most complete definition of a (patient initiated) second opinion, consistent with our daily practice. Third, distinguishing malignancies from benign disease in the lung and the pleura is laborious and may have led to evaluation differences between different pathologists.(24;25) Specimen type (cytology versus histopathology) and inter- and intrarater variability play herein a role.(16;17) Important to note is the that second opinions were performed in a specialist center for thoracic oncology, where a team of trained and experienced specialists work, and diagnostic facilities, most up to date treatment options and possibilities for trial enrolment are present. Patients there were discussed in a specialized thoracic oncology MDT as well drawing conclusions was much more a team based advice, rather than a single specialist's opinion.(12;17;26-28) Training promotes earlier recognition of symptoms and disease,(27) and the second reviewer (e.g. pathologist) usually has more information than the referring physician.(23) Next to this, it is known that more discrepancies are found when patients are being referred from regional hospitals to academic centers.(17;20) The specialist approach resulted in the refinement of diagnosis and stage, the administration of "tailored" therapy and thus the increase of discrepancies between first and second opinions. This specialist approach is also reflected in the rather high number of additional diagnostic tests despite the availability of these tests and presence of material from referring hospitals and the fact that patients also had been discussed in MDT's there. This is probably due to several reasons. First, the second opinions were the patients' wish, regardless of the capacities, quality or availability of investigations already present in the referring hospitals. As some patients referred themselves before the definitive diagnosis, additional diagnostic tests were necessary. Next to this, it is very probable to think that when patients request a second opinion, they wish to have a as complete as possible diagnosis, including diverse diagnostic investigations. This needs to be in agreement with the "new" treating physician, naturally. Moreover, review of imaging and material was not always sufficient or adequate for staging, and some diagnostic procedures had failed at the referring hospitals. Additional investigations were therefore legitimate. Last, specific investigations more feasible at the specialist center (EBUS/EBUS mediated procedures, TBNA, mediastinal sampling, mutation analysis, etc.) were required. Based on the foregoing, it is probable that the large number of discrepancies we report are rather the result of the specialist approach than the patients' intuition. Nevertheless, our results show that patient initiated second opinions are meaningful and may be beneficial for patients in term of outcomes, even for patients with advanced cancer. It is therefore important to acknowledge and discuss the patients' feelings and perspective in case of a wish for a second opinion. Furthermore, taking the patient's request seriously often results in a beneficial/ advantageous situation for both patient and physician.(1-3,33-34)

Limitations

A possible limitation lies within our study design. The study is retrospective, requiring interpretations from the reviewers of the data.(3) In case of disagreement, consultation between the authors took place until complete agreement was reached.

Furthermore, some data were not retrievable. This is the case for follow-up data on the outcome of the advice after sending back patients to referring hospitals (n=56). However, the advice was

followed in most cases, which might indicate the trust of the patient and consequently the “referred back” physician in the given advice. Also due to the study design, it was impossible to measure any effect on survival or quality of life reflecting the value of the given advice.

The generalization of our data results may also pose a problem since the Dutch health care system differs from other countries. There are however many similar elements in the treatment trajectory and therapy since the Dutch treatment guidelines are based upon internal guidelines and literature.(11)

Further implications

The discussion on health care concentration and quality of care extends beyond any border. (29-33) Present study results seem to contribute to this discussion as being in its favour, but this subject goes beyond the scope of this study. Further research on physician initiated referrals are needed to compare with the patients’ and gain more insight into physicians’ second opinion referral patterns to tertiary centers.

We did not investigate the financial impact of second opinions either, as we were solely interested in the medical comparison of the first with the second opinion. The cost effectiveness of second opinions is conceivable, though.(6;7;7-9) It is difficult to generalize on the financial impact of second opinions based on our results, as there are several effects which might result in extra costs as well. Extra inevitable costs are those of consultation, review by pathologist and additional investigations in case of outdated or inconclusive initial tests. However for the latter, it is already questionable if additional investigations result in (more) evidence for therapy. In general, any improvement of therapy based on evidence should not be considered as extra costs. It should rather be considered as a saving, even if the prescribed drugs are much more expensive, for instance TKI’s (gefitinib, erlotinib) versus standard chemotherapy, as the patient receives more tailored therapy and unnecessary treatment options are being prevented. The newest web-based communication facilities such as teleconference might help reducing the costs and barriers and risks (such as delay in starting treatment) to second opinion consultations, limit their numbers and unburden centers.(18) Although we did not score the importance of the interviews and physical examination for the advice of the specialist center, a consultation by means of teleconference could have been enough for 61 (32.5%) patients in our study sample, as no additional diagnostics or examination were performed.

Next to the possible financial advantages and probable potential impact on patient outcomes, various researches have shown that patients are not only more self-confident but that they also have more confidence in their physician and therapy after a second opinion. They are more satisfied and understand their situation and illness better.(2-4;34)

Provided that the necessary health care facilities are available, we think second opinions should be incorporated in the guidelines for lung cancer like in the United Kingdom (<http://guidance.nice.org.uk/QS17>) and obtained before initiation of the first therapy as changes may have important consequences for the patient and the patient-physician relationship.(35;35)

The most important should be that colleagues feel comfortable about going in discussion with their patients about seeking a second opinion if the patient wishes to, and take this (well-considered) step together in order to put the quality of patient care at first.

CONCLUSIONS

Second opinions may lead to significant discrepancies in diagnosis and therapeutic advice in a substantial number of lung cancer patients and should therefore be an integral part of quality practice.

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7

**CASE REPORT SERIES:
BENEFITS OF A SECOND
OPINION FOR LUNG CANCER**

BENEFIT OF A SECOND OPINION FOR LUNG CANCER:
NO RECURRENT DISEASE, BUT INFECTION

Schook, RM; Smit, EF; Postmus, PE, Hartemink, KJ; Paul, AM

J Thorac Oncol. 2012 Aug;7[8]:e6-7

INTRODUCTION

Being faced with a dismal prognosis, whether initially or during follow-up, is for cancer patients frequently reason for a second opinion.(1) We present a remarkable example of the benefits that a second opinion may give.

CASE REPORT

A 46-year old female, received chemoradiotherapy with curative intent (first cycle cisplatinum 80 mg/m² and pemetrexed 500 mg/m²; second and third cycles cisplatinum 80 mg/m² and etoposide 100 mg/m² on days 1,2 and 3, concurrent with thoracic radiotherapy 33 x 2 Gy and prophylactic cranial irradiation as part of the Nederlandse Vereniging van Artsen voor Longziekten en Tuberculose, (NVALT)-11 trial) for stage IIIB adenocarcinoma of the right upper lobe. After 9 months, she presented with dyspnoea, wheezing and severe nonproductive cough. Positron emission tomography and computed tomography (PET-CT) scanning showed a cavitating lesion in the irradiated area in the right upper lobe and multiple fluorodeoxyglucose (FDG)-avid lesions in the right lung. These images were regarded as recurrent NSCLC, accompanied with an infectious component. For the latter, ciprofloxacin was given. The presumed diagnosis of tumor recurrence and the fatal prognosis were discussed with the patient and her husband. The step to seek a second opinion was initiated by the patient.

All data were reviewed and the CT scan repeated. The scan showed multiple nodules in both lungs, cavitation in the irradiated tumor area and an increase of fibrosis and stricture of the upper lobe bronchus (Figure 1, see Appendix II). The PET findings could be explained by an active infection in and around the cavitation without proven signs of tumor recurrence. Despite repeated antibiotic treatment the situation deteriorated with continuous cough, shortness of breath, weight loss and anaemia. Laboratory findings showed a C-reactive protein (CRP) of 257 mg/L and a normal white blood cell count ($9.6 \times 10^9/L$). To drain the cavity, an open window thoracostomy was performed and necrotic tissue was removed (Figure 2, see Appendix II). *Aspergillus fumigatus* was isolated in the pathological specimen and patient received postoperative antimicrobial and antifungal therapy. The patient's cough disappeared immediately and her condition improved considerably. Three months after thoracostomy, patient presented with a bleeding from the cavity. After gauze tamponade, the serratus anterior muscle was transposed into the cavity (Figure 3, see Appendix II). The postoperative course was uneventful and 15 months after her initial visit for a second opinion, there still are no signs of infection nor recurrent tumor. The patient resumed work.

Comment

High-dose radiotherapy results in damage of the circulation and may cause necrosis within the irradiated area.(2;3) Defence against infection will be limited and radiological changes in this area might therefore be due to effects of infection. Differential diagnosis between infection and tumor progression is extremely difficult, also because uptake of ¹⁸F-FDG is present in both situations. Treatment of infected necrosis in an irradiated area is difficult.(4) Surgical resection of the complete

area is risky due to the scarring and patients usually present in a poor general condition. A less hazardous procedure to open the cavity and evacuate the necrotic and infected tissue is preferable.

(5) After initial improvement, muscle flaps can be used to fill the cavity with healthy tissue.

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BENEFIT OF A SECOND OPINION FOR LUNG CANCER:
INTRAPULMONARY METASTASES
OR MULTIPLE PRIMARY TUMORS?

Ter Avest, MJ; Schook, RM; Postmus, PE; Grünberg, K; Ylstra, B; Paul, MA

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INTRODUCTION

The presence of bilateral pulmonary nodules in lung cancer usually means distant metastases (M1a).(1) We present an extraordinary example that challenges to look beyond this classification, and illustrates the potential benefits of a multidisciplinary re-evaluation in such a case.

CASE REPORT

A 70 years old male, former smoker and current marathon runner was diagnosed in September 2005 with a probable squamous cell carcinoma of the right upper lobe (RUL) with (possible) small satellite lesions, a nodule in the middle lobe (RML), and a nodular structure in the left upper lobe (LUL) on computed tomography (CT) scan and 18-fluorodeoxyglucose positron emission tomography (FDG-PET) scan. This was considered to be a primary lung cancer with intrapulmonary metastases (stage IV, histology confirmed). The patient received 6 cycles of chemotherapy doublet (cisplatin 150 mg on day 1 and gemcitabine 2000 mg on days 1 and 8) which resulted in a slight reduction in size of the lesion in the RUL, and a clear reduction of the lesion in the LUL, although the RML remained unchanged (Figure 1, see Appendix II). Eleven months later, the lesion in the RUL increased in size. A second opinion was arranged.

After reviewing all data and images with repeated PET and CT, the possibility of multiple primary tumors was considered. A video-assisted thoracoscopy (VATS), diagnostic wedge excision of the LUL, and a transthoracic biopsy of the RUL were performed, revealing two papillary adenocarcinomas. A wedge excision of the RML, a lobectomy of the RUL and mediastinal lymph-node dissection, showed a 1.8-cm diameter papillary adenocarcinoma of the LUL, a 3.3-cm diameter mixed papillary adenocarcinoma/adenocarcinoma in situ (AIS) of the RUL and a 1.1-cm diameter AIS of the RML, all radically resected. All nodes were negative. Array-comparative genomic hybridization (a-CGH) analysis revealed that all these lesions showed different patterns of gains and losses, consistent with three primary tumors (Figure 2, see Appendix II).(2)

In December 2007, a recurrence in the operation scar of the LUL and a new abnormality in the left lower lobe (LLL) were observed on CT scan, both 18-FDG-PET positive. Diagnostic wedge excisions of the LUL and LLL and a mediastinal lymph-node dissection were performed. Pathological examination showed two invasive papillary adenocarcinomas (LUL and LLL of 1.5 cm and 0.6 cm, respectively), with free resection margins, without lymph-node metastases. The post operative course was uneventful. There have been no signs of recurrence since and the patient is alive and well more than 6 years after the initial diagnosis.

COMMENT

The differentiation between intrapulmonary lung metastases and multiple synchronous primary lung cancers (MSPLC) may make the prospects for an individual completely different: treatment with either palliative or curative intent. Differentiation between the two requires histopathology and imaging. Separate primary lung tumors can easily be recognized when they are histologically different. In case of identical histological features, genetic analyses such as array-comparative genomic hybridization analysis (a-CGH analysis) may be useful in

the distinction between MSPLC and metastases.(2) Imaging techniques as 18-FDG-PET may be of help by calculating standardized uptake values (SUVs). SUVs (Δ SUV) of the tumors might differ more in patients with second primary tumors than in those with metastatic disease.(3) Furthermore the growth pattern, lobulized and spiculated aspect on CT may be of help.(4) An aggressive surgical approach is justified in patients with MSPLC, because node-negative disease, and the absence of distant metastases may result in survival rates comparable to patients with isolated lung cancers.(5) To avoid pulmonary insufficiency, limited surgical procedures are preferred. However, the resection must be complete.(2) Patients with MSPLC and node-negative disease should therefore be staged separately and if possible, treated as separate entities with curative intent.(6)

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BENEFIT OF A SECOND OPINION FOR LUNG CANCER:
NO METASTASIS TO THE KIDNEY BUT A SYNCHRONOUS
PRIMARY RENAL NEOPLASM

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ABSTRACT

Background: The finding of a renal mass on imaging is suggestive of metastatic non-small cell lung cancer in the presence of a lung tumor but can also have another origin.

Case Report: We describe the case of a patient diagnosed with stage IV lung cancer based on a renal metastasis. A second opinion including review of histopathological data and additional imaging followed by lung surgery and cryoablation of the kidney lesion revealed two tumors of different origins, non-small cell lung cancer and a renal cell carcinoma.

Discussion: The presence of a renal mass diagnosed on a CT scan in a patient with lung cancer is not always synonymous with metastatic disease. Confirmation of diagnosis by tissue sampling is mandatory, especially if a synchronous primary tumor is possible.

INTRODUCTION

The presence of metastatic non-small cell lung cancer (NSCLC) can be suspected by imaging. However, tissue sampling is required to confirm the diagnosis, especially if a synchronous primary tumor is possible. In this case report, we present a case with stage IV lung cancer based on a renal metastasis.

CASE REPORT

A 48-year-old female received palliative radiotherapy (30 Gy) directed to vertebrae Th9-Th12 and 4 cycles of chemotherapy [gemcitabin 1,200 mg/m² (on days 1 and 8), carboplatin 80 mg/m²] for an 18-FDG-PET avid, thyroid transcription factor-1 (TTF-1) positive adenocarcinoma of the right lower lobe invading the thoracic vertebrae 10, and an additional 18-FDG-PET negative lesion in the right kidney, cytology-confirmed adenocarcinoma, considered as a distant metastasis (cT4NxM1). Therapy resulted in a slight reduction of both lesions. Due to the determined stage (IV), an expectative approach was opted. The patient initiated a second opinion.

The patient's data were reviewed and additional 18-FDG-PET and CT scans were performed. Except for the presence of the lesion in the kidney, no signs of metastases were found. Therefore, the initial diagnosis was reconsidered as two primary tumors: an adenocarcinoma of the lung, stage IIIB (cT4N0M0) and an adenocarcinoma of the right kidney (cT1a). Two cycles of neo-adjuvant chemotherapy (cisplatin 80 mg/m², pemetrexed 500 mg/m² on days 1 and 21) were administered prior to lung surgery. Surprisingly, no tumor was found in the right lower lobe perioperatively. A hemi-corpectomy of Th10 and a resection of the processus transversus of Th10 and Th11 were performed, followed by spine stabilization.

With regard to the lesion of the right kidney, an expectative approach was agreed because of stable disease (no growth), its localization (in the mid pole of the kidney) and small size (2.3 cm). Eleven months later, cryoablation was ultimately performed because the patient insisted on removal of the tumor, which revealed a papillary renal cell carcinoma. The postoperative course was uneventful. The patient is doing well more than 6 years after the initial diagnosis.

DISCUSSION

This case report emphasizes the importance of differentiating a primary from metastatic disease when a renal mass is diagnosed on a CT scan in a patient with lung cancer. Although metastases to the kidneys are very uncommon,⁽¹⁾ differentiation between these two entities is crucial for further management and prognosis (palliative approach vs. curative intent).^(1, 2) On CT scan, a solitary metastasis to the kidney is more likely to be found in patients with higher tumor stage of the nonrenal malignancy or when other viscera are also affected.⁽¹⁾ Usually, the metastasis is an asymptomatic, small, endophytic, and solid mass.⁽¹⁾ The finding of a corresponding hotspot on FDG-PET scan is suggestive of a metastasis, even if it appears to be benign on CT.⁽³⁾ However, if the primary tumor is not FDG-avid, this might not be the case. The possibility of a primary renal neoplasm should also be considered, but with caution, since the low sensitivity of detection of FDG-PET scans.⁽³⁾ Histology obtained by percutaneous biopsy confirms or strengthens the diagnosis in case of small masses and doubts about performing a nephrectomy.⁽⁴⁾ If histology alone is not conclusive, immunohistochemistry is useful. TTF-1 is a typical marker for adenocarcinoma in the lung, while negative in primary renal neoplasms, as illustrated in figure 1 (see Appendix II).⁽⁵⁾ Once the diagnosis is confirmed, definitive therapy should follow. Patients with localized lung cancers may obtain long-term survival with surgery.⁽²⁾ In case of a primary renal neoplasm, surgery is the gold standard.⁽⁶⁾

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BENEFIT OF A SECOND OPINION FOR LUNG CANCER:
FROM METASTATIC DISEASE TO RESECTABLE LUNG
CANCER WITH SARCOID-LIKE REACTION

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ABSTRACT

Background: Mediastinal lymphadenopathy in combination with lung cancer is suggestive for lymph node metastases but can also have other origins.

Case report: We describe a patient diagnosed with stage IV lung cancer presenting with parenchymal lesions and enlarged mediastinal lymph nodes. A second opinion including FDG-PET scan review and a mediastinoscopy followed by surgery revealed tumor specimens originating from a single primary tumor with a sarcoid-like reaction in the mediastinal lymph nodes, changing the diagnosis from metastasized to resectable lung cancer.

Discussion: PET positive lesions are not always synonymous with metastatic disease in the presence of a malignant tumor. Conscientious review of FDG-PET scans and tissue sampling are therefore mandatory to determine definitive staging and subsequent interventions.

INTRODUCTION

Mediastinal lymphadenopathy in combination with lung cancer is suggestive for lymph node metastases. However, lymphadenopathy may have another cause which may result in a totally different diagnostic, therapeutic approach and prognosis.

CASE REPORT

A 75-year old male with COPD (Gold II) and a smoking history of 50 packyears underwent a CT-scan for an abdominal aortic aneurysm. Three parenchymal lesions were seen (LUL, LLL, RUL), as well as enlarged mediastinal lymph nodes. Subsequently, 18-FDG-PET images showed uptake in both lesions in the left hemi-thorax and intense multilevel bilateral mediastinal FDG uptake in lymph nodes. The 5 mm Ø lesion in the RUL showed no FDG avidity. Transthoracic needle biopsy of the Ø 3 cm lesion in the LUL revealed a squamous cell carcinoma. During the multidisciplinary discussion at the referring hospital, it was concluded that patient most probably had stage IV lung cancer with intrapulmonary and mediastinal metastases. The patient requested a second opinion.

At our expert center, histology and imaging were reviewed. The PET uptake of the mediastinum was quite characteristic for a sarcoid-like reaction (Figure 1, see Appendix II).(1;2) Based on images of the two parenchymal lesions in the left lung, synchronous primaries were considered. Mediastinoscopy was performed to exclude metastatic disease and histology confirmed a noncaseating granulomatous inflammation of the mediastinal lymph nodes without metastases (Figure 2, see Appendix II). Taking the patient's limited cardiac function and pulmonary reserve capacity into account, two wedge excisions of the lesions of the left lung and lymph node dissection were performed. The two resected tumor specimens were found to be originating from a single primary tumor, based upon morphology and immunohistochemistry: a 3 cm Ø undifferentiated large cell carcinoma of the LUL (R0) and a 0.6 cm Ø undifferentiated large cell carcinoma of the LLL (R1). The final pathological staging was therefore pT4N0M0R1. The patient was followed at regular intervals. Repeated CT-scans did not show any sign of recurrence, while

the enlarged lymph nodes did not change over time. Ultimately, almost 3 years after the initial second opinion the patient developed brain metastases and died.

COMMENT

This case illustrates the importance and need for accurate staging with the ultimate proof of histopathological findings, despite the current developments in sensitive non-invasive imaging technologies.

In the presence of a malignant tumor e.g. lung cancer, PET positive lesions are not always synonymous with metastatic disease. Conscientious review of FDG-PET scans is therefore mandatory. Sarcoid-like reactions in mediastinal lymph nodes can be recognized, showing a typical FDG uptake pattern.(1;2) The exclusion of other diseases presenting with mediastinal lymphadenopathy e.g. infectious or idiopathic, together with histopathological examination are ultimately required for an accurate diagnosis.

Granulomatous reaction is a primary reaction pattern to injury, which can also be observed along with a malignant tumor, both in adjacent tissues and regional lymph nodes as a local or more generalized immune response to cancer cells.(3;4) Another cause for a false positive PET scan, like anthracosis, was recently published.(5) Tissue sampling from both the tumor and the lymph nodes are mandatory and will determine definitive staging and subsequent interventions. To prevent clinical overstaging by underdiagnostics, extensive additional diagnostics based on histopathological findings are preferred.

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