Implementation of a self-administered questionnaire to detect lung carcinogens

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Background	Between 10 and 20% of lung cancers are of occupational origin. Screening for occupational risk factors is part of the diagnostic workup. A self-administered questionnaire to detect lung carcinogens of occupational origin, the RECAP questionnaire, was drawn up and validated with a view to limiting under-declaration of lung cancer as an occupational disease (OD).
Aims	Optimal administration conditions were investigated, to facilitate systematic use in the management of patients admitted to hospital with lung cancer.
Methods	The various care pathways of lung cancer patients were first studied in two centres, to identify the health-care professionals involved in medical management, the various care sites and the stages of treatment. A focus group of health-care professionals was set up, and semi-directive interviews were conducted with 24 patients.
Results	Caregivers tended to suggest that a physician or nurse should present the RECAP questionnaire, whereas patients rather chose non-caregiver staff, seeing the undertaking as being 'administrative' in nature. Some caregivers and patients thought the questionnaire should not be administered at the outset of treatment, due to the psychological trauma entailed by diagnosis. Administration during chemotherapy was recommended by patients, as they are more freely available at that time, and by caregivers, who thought patients better able to pay attention then.
Conclusions	The study highlighted patients' lack of information on how lung cancer can be recognized as an OD. Implementing the RECAP questionnaire should facilitate patients' claims for insurance cover for lung cancer as an OD.
Key words	Lung carcinogen detection; self-administered questionnaire.

Introduction

In 2012, there were 448 618 new cases of lung cancer and 388 203 deaths from lung cancer in Europe [1]. In 2015, there were 221 200 new cases and 158 040 deaths in the USA. Lung cancer is the leading cause of death from cancer in the world, with 1.69 million deaths in 2015 [2].

The greatest risk factor is smoking. However, in 2000, it was estimated that 10% of lung cancer deaths in males (88 000 deaths) and 5% in females (14 300 deaths) worldwide could be attributed to exposure to occupational lung carcinogens as identified by Driscoll *et al.* [3]: asbestos, arsenic, beryllium, cadmium, chromium VI, bis(chloromethyl)ether, nickel, polycyclic aromatic

hydrocarbons and silica. In France, classification as an occupational disease (OD) is based on OD tables specifying carcinogen exposure. Eleven lung carcinogens are listed in the French OD tables, but most cancers recognized as ODs implicate asbestos [4]. Occupational lung cancer is under-declared in France, as in other European countries, notably due to the difficulty of detecting occupational aetiology, and physicians' lack of awareness of occupational respiratory carcinogens, and of the importance of OD status for patients and their beneficiaries in terms of national health insurance cover [4–6]. Failure to screen for exposure to lung carcinogens represents a loss of opportunity for the patients, who will not have the coverage to which OD should give title. Identification of occupations potentially involving lung carcinogen

Key learning points

What is already known about this subject:

- Between 10 and 20% of lung cancers are of occupational origin.
- Occupational lung cancer is under-declared notably due to the difficulty of detecting occupational aetiology.
- Failure to screen for exposure to lung carcinogens represents a loss of opportunity for the patients, who will not have the coverage to which occupational disease should give title.

What this study adds:

- A self-administered questionnaire to detect lung carcinogens of occupational origin, the RECAP questionnaire, was drawn up and validated with a view to limiting under-declaration of lung cancer as an occupational disease.
- Optimal administration conditions were investigated, to facilitate systematic use in the management of patients admitted to hospital with lung cancer.

What impact this may have on practice, policy or procedure:

- Implementing the questionnaire should help reduce under-declaration of lung cancer as an occupational disease.
- The questionnaire should be systematically included in new patients' files and could be administered at any point along the pathway except right at the beginning, at diagnosis or first consultation.

exposure could also reinforce policies to prevent employee exposure to such substances and improve information on the means of self-protection.

In a previous study, a short easy-to-use self-administered questionnaire, RECAP (*Repérage des Agents Cancérigènes du Poumon*), was drawn up by oncologist-pneumologists and occupational physicians, covering situations of exposure to proven and probable lung carcinogens [7]. Understanding and acceptability were assessed in 15 lung cancer patients; validity and reliability were assessed in 70 lung cancer patients against a semi-directive questionnaire as gold standard. Sensitivity was 0.85 and specificity 0.87. Concordance between responses on the two questionnaires was 86%, with a kappa coefficient of 0.695 [0.52–0.87]. Mean self-administration time was 3.1 min (versus 8.12 min to administer the gold standard questionnaire) [7]. Systematic use of RECAP in lung cancer patients could simplify and accelerate the identification of possible occupational exposure to lung carcinogens and thus facilitate applications for OD status.

In the present study, optimal administration conditions were investigated, to facilitate systematic use in the management of patients admitted to hospital with lung cancer.

Methods

This qualitative study comprised two phases; focus groups with hospital health-care professionals and semi-directive patient interviews.

As a preliminary, lung cancer patient care pathways were studied in the University Hospital Centre of Saint Etienne and in the Lucien Neuwirth Cancer Institute, to identify the health-care professionals involved in lung cancer patient management, the various care sites and

the stages of treatment. The focus group comprised volunteers after staff were informed about the study. Participants were given clear and intelligible prior information regarding the project, and signed a consent form. Verbal exchanges during focus group meetings were recorded.

During the meetings, participants discussed:

- whether they preferred having RECAP administered to all lung cancer patients who had been in salaried work;
- the best point along the care pathway to introduce the RECAP questionnaire and the best place for administration.

The target population comprised lung cancer patients, including retired workers, treated in two French health-care centres: the Saint-Etienne University Hospital Centre and the Lucien Neuwirth Cancer Institute. Inclusion criteria comprised:

- primary lung cancer;
- insurance cover by the general and/or agricultural French national health insurance schemes;
- ability to understand French;
- having filled out the RECAP questionnaire. The RECAP questionnaire included 29 questions on prior occupational exposure including former jobs concerning asbestos, arsenic, bis(chloromethyl) ether, chromium derivatives, polycyclic aromatic hydrocarbons, nickel derivatives, radioactive dust or gas, on iron-mining, cadmium and crystalline silica [7].

Exclusion criteria comprised:

- lung cancer already recognized as occupational;
- receiving invalidity benefit for lung cancer under the French national health insurance scheme;

- without insurance cover by the general and/or agricultural French national health insurance schemes.

Eligible patients were provided with clearly understandable information on the study protocol and objectives. Written informed consent was obtained before inclusion. The information document specified that individual interviews would be recorded to facilitate transcription, and that data would be anonymized.

Patients' age, gender and socio-occupational category were collected. The interview was conducted following a guide.

The objective was to interview 20 eligible patients.

The patients and the focus groups were questioned on:

- Theme 1: The difficulties in understanding or filling out the questionnaire
- Theme 2: The reasons for the RECAP questionnaire being implemented
- Theme 3: The category of hospital staff best placed to contribute to detecting occupational cancer
- Theme 4: The best point along the care pathway of lung cancer patients

Interview analysis

Focus groups were recorded in December 2015. The semi-directive interviews were recorded in May 2016. The semi-directive interviews were analysed after transcription. Data were anonymized. Transverse and comparative analysis of thematic content was performed.

IRB approval was secured, and the study was registered with the French data protection commission (CNIL) for computer processing of the socio-occupational and medical data (number 14.297). Approval by the 'Ethics Committee' was obtained before starting the study (number IORG0007394).

Results

From interviews with doctors working in two health-care centre facilities, we had identified the health-care professional encountered along the care pathway: doctors, nurses, caregiver and administrative staff. We offered to organize focus groups within two health-care centre facilities by interviewing the health-care professional encountered along the care pathway. But, in a health-care centre, a few doctors did not want to participate in the study. They thought it was unnecessary to organize focus groups, because doctors should hand the questionnaire RECAP to patients. Also, only one focus group could be set up, in one of the two study centres, due to poor staff availability. It comprised one oncologist, one head nurse, one staff nurse and one nurse as coordinator. Three patients declined to participate in semi-directive patient interviews; 24 patients (6 female, 18 male) agreed.

Patients' mean age was 65 years (Table 1). Eleven patients were treated at the Saint Etienne Hospital and 13 at the Lucien Neuwirth Cancer Institute. The RECAP questionnaire revealed possible occupational exposure to at least one carcinogen in 13 patients.

Theme 1: The difficulties in understanding or filling out the questionnaire

The participants of focus group did not identify any obstacles to systematic administration, be it for health-care professionals or for patients, with the exception of socially disadvantaged patients, who would doubtless need help in filling out the questionnaire. All patients reported no difficulties in understanding or filling out the questionnaire, and self-administration time was not considered excessive (Table 2).

Theme 2: The reasons for the RECAP questionnaire being implemented

Participants of focus group suggested the questionnaire should be systematically included in new patients' files and given out in consultation during the first or second course of chemotherapy. Fifteen out of 24 patients thought it useful for the questionnaire to be delivered systematically to all lung cancer patients; among the reasons given were:

- the interest of looking for the cause of the cancer (9 of the 24 patients)
- an interest for research (5 of the 24 patients)
- a way of raising awareness for the prevention of occupational lung cancer and identifying occupational risk situations (3 of the 24 patients)
- for compensation and payment when the lung cancer is recognized as an OD (3 of the 24 patients)
- as a means of determining the prevalence of occupational lung cancer (2 of the 24 patients)

Patients identified no particular obstacles to using the RECAP questionnaire systematically.

Theme 3: The category of hospital staff best placed to contribute to detecting occupational cancer

The participants of focus group suggested the oncologist or, if not possible, a nurse are health-care professionals suitable for presenting the questionnaire. Regarding optimal means of administering the questionnaire along the care pathway, patients mentioned numerous kinds of health-care professional encountered along the care pathway: caregivers, administrative staff, and also social workers. The questionnaire seemed to be seen more as an administrative procedure, not necessarily to be delivered by caregivers, who, for many patients, are busy enough already (Table 2).

Table 1. Socio-occupational characteristics of included patients

Patients	Gender	Age	Last job	Potential lung carcinogens exposition
Patient 1	Male	60 years	Worker in the chromium plating industry	Chromium
Patient 2	Female	67 years	Cleaning worker	Not exposed
Patient 3	Male	75 years	Metalworking	Asbestos
Patient 4	Male	57 years	Building trades worker	Asbestos
Patient 5	Male	70 years	Mechanics	Asbestos
Patient 6	Male	74 years	Railwayman	Not exposed
Patient 7	Male	67 years	Delivery driver	Not exposed
Patient 8	Female	54 years	Cook	Not exposed
Patient 9	Male	74 years	Building trades worker	Asbestos
Patient 10	Male	68 years	Building trades worker	Asbestos
Patient 11	Male	Not documented	Technician	Asbestos
Patient 12	Male	67 years	Worker	Asbestos
Patient 13	Male	63 years	Plumber/heating specialist	Asbestos
Patient 14	Male	69 years	Worker	Asbestos
Patient 15	Female	54 years	Not documented	Not exposed
Patient 16	Male	59 years	Employee	Not exposed
Patient 17	Male	62 years	Building and related trades worker	Asbestos
Patient 18	Male	78 years	Building and related trades worker	Asbestos
Patient 19	Female	65 years	Social worker	Not exposed
Patient 20	Female	63 years	Not documented	Not exposed
Patient 21	Male	72 years	Building and related trades worker	Asbestos
Patient 22	Male	63 years	Worker	Not exposed
Patient 23	Male	68 years	Food processing and related trades worker	Not exposed
Patient 24	Female	54 years	Furniture painter	Not exposed

Theme 4: The best point along the care pathway of lung cancer patients

The participants of focus group thought the questionnaire could be administered at any point along the pathway except right at the beginning, at diagnosis or first consultation, when the patient is in a state of shock and already has a lot of information to 'take in' and so is not in a position to 'hear what's being asked'. Patients did not specify any particular place as being suitable for questionnaire administration, but 11 patients stressed that they were free during chemotherapy. Regarding the best time to fill out the RECAP questionnaire, two patients suggested avoiding the beginning of treatment (Table 2).

Discussion

The interviews with 24 patients confirmed the acceptability of filling out the RECAP questionnaire for patients and its ease of use, as explored in the previous study [7].

Neither patients nor care-staff mentioned any obstacles to implementing the RECAP questionnaire. Care-staff felt certain patients would certainly need help in filling it out. However, the previous study, drawing up and validating the RECAP questionnaire as a screening tool for occupational lung carcinogens, showed very good

acceptability and good understanding on the part of patients of diverse socio-occupational backgrounds [7].

Concerning administration conditions in the care pathway, opinions differed between patients and caregivers as to who should present the questionnaire to the patient. There may have been bias in the responses of those who were participants in the focus group since only a single doctor and three nurses were present. But some doctors, among those who had refused to participate in this study, had underlined that the questionnaire should be presented by a doctor. Caregivers thought the oncologist or, if not possible, a nurse, whereas patients mentioned many different professions encountered along the pathway: care-staff, administrative personnel and social workers; non-caregiving staff were considered as questionnaire delivery was seen as an administrative task, and caregivers were seen as being busy enough already. This difference may have been due to patients not realizing that screening for occupational and non-occupational risk factors needs to be included in the diagnostic workup.

Regarding the best time to present the questionnaire to the patient, caregivers and certain patients thought that the beginning of treatment should be avoided. The diagnosis was described by caregivers and some patients as a source of psychological trauma. According to Desportes and Spire, delivering the diagnosis of cancer causes the patient 'fear, anxiety, stupor, despair, anger'

Table 2. Major study themes and example quotes

Themes	Theme description	Example patients' quotes	Example focus groups' quotes
Theme 1	The difficulties in understanding or filling out the questionnaire	Quote 3: 'It was very clear'; Quote 19: 'To me, it was clear, succinct and precise'; Quote 23: 'It's very quick'.	'Sometimes, it is necessary to require somebody help to fill out the questionnaire because of patients difficulties in reading'.
Theme 2	The patients' reasons for the RECAP questionnaire being implemented: <ul style="list-style-type: none"> – looking for the cause of the cancer – an interest for research – prevention of occupational lung cancer – for compensation and payment – determining the prevalence of occupational lung cancer 	Quote 8: 'Because it's true we'd like to know why this cancer started, following what? We have an awful lot of questions'; Quote 15: 'It's very important for the future. Because it's true, not right now, but in 10, 15 years, people maybe won't have cancer thanks to these things'; Quote 13: 'For all these professions to progress, to avoid illnesses. For everything to get better. Me, I think you've got to look for all this information in the companies, from the start. It's not once you're ill that...'; Quote 3: 'That at least they get something back when they've worked all their lives, and they say okay I've got this disease but all the same with something for me'; Quote 3: 'And then the aim is statistics too. To know exactly which jobs are affected'.	
Theme 3	The category of hospital staff best placed to contribute to detecting occupational cancer	Quote 11: 'Well, anyone. The secretary... Giving a paper, that's nothing'; Quote 8: 'A care assistant. I don't think you need a nurse – the care assistants I think are quite enough. And also we have very good relations – they have very good contact with the patients'.	'We could ask it to nurses, and to nursing assistants. During consultation, it can be handed by the practitioner to the patients'.
Theme 4	The best point along the care pathway of lung cancer patients	Quote 14: 'I haven't any idea... At what moment, well, like here we're just waiting quietly so it's a good time. It's very good'; Quote 10: 'Here's good, I've got the time. So here's good, it's a good time'; Quote 8: 'Because already at the beginning you have to handle the shock, so all that stuff just then it doesn't interest us, but it's later on we try to understand'; Quote 18: 'Not at the first consultation, because I'd say we're overwhelmed by something else and haven't got time. There's a lot of information. You're told you've got lung cancer, it shakes you up a bit. And you wonder where it came from'.	'At the beginning, the patient had to face a lot of information. He should not think believe that it is another stuff to fill; it must be able to know what you want it to understand'.

[8]. Hureaux describes it as a major trauma and a break in the path of life [9]. For some patients in the present study, the waiting periods in chemotherapy leave them freer to fill out the questionnaire. For some patients, this was a matter of having more time, whereas for caregivers it was more a question of the patients having greater attention capacity once the moment of diagnosis had passed.

The study also highlighted patients' reasons for the RECAP questionnaire being implemented.

- Nine of the 24 patients mentioned the interest of determining the cause of the cancer. According to Colombier, patients' search for meaning in the origin of their disease can be seen as an attempt to absorb the shock and thus begin a narrative account of the trauma

[10]. According to Taylor, the search for meaning in what is being experienced is an attempt to understand what the disease symbolizes in the patient's life; such beliefs have an adaptive aspect, inasmuch as they seek to grasp, explain and gain control over the situation [11].

- Contributing to prevention by identifying factors for cancer is another reason for screening for occupational exposure to lung carcinogens highlighted by Britel *et al.* in a qualitative study, and mentioned by three patients in the present series [12].
- Screening for occupational risk factors for lung cancer is part of the diagnostic workup and responds to patients' questions about the origin of their disease.

The present qualitative study, based on a focus group of health-care professionals and semi-directive interviews with

lung cancer patients, collected proposals for optimal conditions for delivering the RECAP questionnaire, including it within the hospital care pathway. Implementing the questionnaire should help reduce under-declaration of lung cancer as an OD. It should be accompanied by information supplied by the health-care professional to the patient regarding ODs and the associated compensation procedures, so that patients can understand and decide to undertake a request for recognition of their lung cancer as an OD.

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Competing interests

F.C. is:

- President of the commission 'Evaluation, Strategy and prospective' French High Council for Public Health.
- Vice president, French National League Against Cancer.
- Member of the scientific advisory board, French National Agency for Prevention and Health Promotion (INPES) vice president of the French Cancer League.

The other authors report non-conflict of interests.

References

1. Lung – estimated mortality, all ages: both sexes. Crude and age-standardised rates per 100,000. Cumulative risk [0-74], percent GLOBOCAN 2012, IARC-3.2.2016 [Internet]. [cited 22 January 2016]. http://globocan.iarc.fr/old/summary_table_site-html.asp?selection=15110&title=Lung&sex=0&type=1&window=1&europe=4&build=6&sort=0&submit=%C2%A0Execute%C2%A0.
2. WHO | Cancer [Internet]. WHO. [cited 15 November 2017]. <http://www.who.int/mediacentre/factsheets/fs297/en/>.
3. Driscoll T, Nelson DI, Steenland K, Leigh J, Concha-Barrientos M, Fingerhut M, Prüss-Üstün A. The global burden of disease due to occupational carcinogens. *Am J Ind Med* 2005;**48**:419–431.
4. Les maladies professionnelles – Brochure – INRS [Internet]. [cited 22 January 2016]. <http://www.inrs.fr/media.html?refINRS=ED%20835>.
5. Rapport De claMP-FR-impr-44pages_Mise en page 1 - Rapport_DeclarationMP_EUROGIP_102F.pdf [Internet]. [cited 22 January 2016]. http://www.eurogip.fr/images/publications/2015/Rapport_DeclarationMP_EUROGIP_102F.pdf.
6. E questionnaire-25-34.qxd:maquette 2007 - eDossier-sante-2.pdf [Internet]. [cited 3 February 2016]. <http://splf.fr/wp-content/uploads/2014/08/eDossier-sante-2.pdf>.
7. Péliissier C, Dutertre V, Fournel P *et al.* Design and validation of a self-administered questionnaire as an aid to detection of occupational exposure to lung carcinogens. *Public Health* 2017;**143**:44–51.
8. Desportes G, Spire A. Cancer : l'annonce du diagnostic. *Temps Mod* 2007;**642**:207–216.
9. Hureauux J. Place de l'annonce dans la prise en charge des patients souffrant de cancer. *Méd Nucl* 2013;**37**:305–309.
10. Colombier M du. Une entrée en terre étrangère: le travail psychique de la maladie chez les patients atteints de cancer. *Cliniques* 2011;**2**:108–122.
11. Taylor SE. Adjustment to threatening events: a theory of cognitive adaptation. *Am Psychol* 1983;**38**:1161–1173.
12. Britel M, Pérol O, Conceição SBD *et al.* Moteurs et freins à la reconnaissance en maladie professionnelle des patients atteints de cancers bronchiques: une étude psychosociale. *Sante Publique* 2017;**29**:569–578.