

The Development of the Korean Lung Cancer Registry (KALC-R)

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Lung cancer is the most commonly diagnosed cancer and the leading cause of cancer-related deaths worldwide. Globally, there were an estimated 1.8 million new cases and 1.59 million deaths in 2012. In Korea, the incidence of lung cancer is increasing and 24,267 (47.6/100,000) patients with lung cancer were registered at the Korea Central Cancer Registry in 2015. Previous nationwide surveys of lung cancer were performed in 1998 by the Korean Academy of Tuberculosis and Respiratory Diseases and in 2007 by the Korean Association for Lung Cancer (KALC), but the studies faced difficulties in maintaining lung cancer registry because of limitations regarding the Private Information Protection Act. To produce unbiased and reliable epidemiological data, the KALC and Korean Central Cancer Registry developed a detailed lung cancer registry (KALC-R) data structure. Following a pilot survey of 489 lung cancer cases in 2013, about 10% of the sampled lung cancer cases from the Korea Central Cancer Registry are surveyed each year. With the analysis of detailed data from the KALC-R, an important epidemiological background for scientific research or policy development is expected to be generated.

Keywords: Lung Neoplasms; Registries; Smokers

Introduction

Lung cancer is the most commonly diagnosed cancer and the leading cause of cancer-related deaths worldwide. Globally, there were an estimated 1.8 million new cases and 1.59 million deaths in 2012. The highest incident rates are in North America, Europe, and East Asia. More than 600,000 new

cases are diagnosed each year in the United States, European Union, and Japan combined¹. In Korea, the incidence of lung cancer is increasing and 24,267 (47.6/100,000) patients with lung cancer were registered in the Korea Central Cancer Registry (KCCR) in 2015. Unbiased and reliable statistic data are needed not only for scientific research but also for government and company policy development.

Main Text

In Korea, a nationwide survey of lung cancer was first performed by the Korean Academy of Tuberculosis and Respiratory Diseases (KATRD) in 1998, in which histologically confirmed lung cancer patients (n=3,794) diagnosed in 1997 were retrospectively surveyed². Patient data were collected from 50 hospitals with more than 400 beds. Squamous cell carcinoma was the most frequent histologic type of lung cancer (44.7%), followed by adenocarcinoma (27.9%). Most of the patients were smokers (76.5%), including 89.8% of male patients. The proportion of squamous cell histology was attributed to the high rate of smoking, particularly unfiltered cigarettes.

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The second nationwide survey of lung cancer was conducted by the Korean Association for Lung Cancer (KALC) in 2007, reporting 8,788 patients diagnosed with lung cancer in 2005³. A web-based case reporting form was used to collect patient data from 64 hospitals (more than 400 beds). Adenocarcinoma was the most frequent histopathologic type (36.1%), followed by squamous cell carcinoma (32.1%), large cell carcinoma (1.5%), and small cell carcinoma (13.5%). Current smokers comprised 40.5% of the group, 30.6% were former smokers, and 28.9% had no smoking history. Of the male cancer patients, 87.3% were current or former smokers, while only 20.3% of the female cancer patients had a history of smoking.

The KALC next developed a web case record system for prospective registration of lung cancer cases by physicians. However, with the activation of the Personal Information Protection Act in 2014, difficulty in obtaining informed consent and the inability to store unique identifiers with other variables for registry hampered the maintenance of the lung cancer registry system. Another problem with a registration system organized by academic societies is the potential bias in selecting cases. As expected, cases with interest to physicians were more likely to be registered.

In contrast, the KCCR has an exclusion from the Private Information Protection Act for personal data collection and storage. Based on the International Classification of Disease 10th edition (ICD-10) coding system, patients with confirmed disease codes of C34 are being registered in KCCR. The KCCR data have an advantage in that they reflect the entire number of lung cancer cases; however, it also has weaknesses, such as incompleteness of data and a lack of detailed information required for scientific research. Indeed, the data structure of the KCCR has only 47 data fields such as demographic information, address, cancer codes, date of first hospital visit, and date and cause of death; thus, it cannot substitute for the need for a lung cancer registration system.

To produce unbiased and reliable epidemiological data related to lung cancer, the KALC and KCCR made a joint proposal to develop a lung cancer-specific registration system,

with the first meeting held in July 2015. Thereafter, members from the lung cancer registration committee of the KALC and KCCR met every two months to develop a new database structure for the lung cancer registry. The first version of the lung cancer registry (KALC-R) was developed in February 2016.

KALC-R has about 80 data fields comprising demographic data, symptoms, smoking history, lung function test results, histological findings, molecular study results, and first treatment (n=28). Fields with detailed clinical and pathologic TNM staging data (n=22) were developed in preparation for the future conversion to the eighth version of Union for International Cancer Control staging system⁴. For the treatment records, sheets for surgery (n=11), radiation treatment (n=9), and medical treatment (n=6) were developed to permit multiple sessions of treatments to be recorded in separate sheets of each treatment session. Lastly, recurrence and survival data fields were added (Table 1).

As the registration of data was going to be collected by health information managers of each hospital, an instruction booklet was developed and an educational program for health

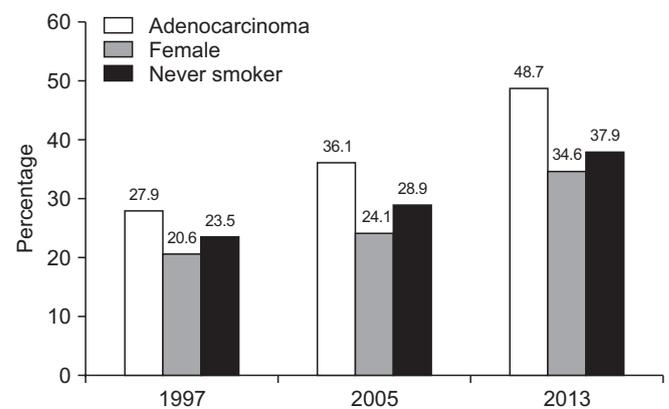


Figure 1. Comparison of the proportion of adenocarcinoma, female patients, and lung cancer patients who have never smoked, as viewed between the national surveys of 1997, 2005, and 2013.

Table 1. Abbreviated structure list of Korean Lung Cancer Registry

| | |
|---------------------|---|
| Key variables | Name of patient, national security number, name of hospital, hospital patient number |
| Basic demographic | Height, weight, chief complaints, symptoms, performance status score, smoking history |
| Pulmonary function | Forced vital capacity, forced expiratory volume in 1 second, diffusion capacity |
| Pathology | Date and methods of pathologic diagnosis, pathologic classification, driver mutations |
| TNM staging | T, N, M descriptors |
| Surgery | Location and number of tumor, date, purpose, name, extent, completeness, complication of surgery |
| Radiation treatment | Date, fraction dose, number, total dose, target, location, purpose, method of radiation treatment |
| Medical treatment | Date, cycles, purpose, name, and kinds of treatment |
| Survival | Completeness of treatment, date of recurrence/progression, and death |

information managers was offered in September 2016. The pilot survey was completed in December 2016 from seven university-affiliated hospitals and 12 cancer centers designated by government, resulting in a survey of 489 sampled cases diagnosed with lung cancer in 2013. The cases were selected through systematic sampling method using the stratification variables, including sex, age group, date of diagnosis, hospital, and Surveillance, Epidemiology, and End Results program (SEER) code.

In this issue of the journal, Kim et al.⁵ report the results of the pilot survey. Despite its small sample size, this survey showed an increasing proportion of patients with adenocarcinoma histology, female sex, and lung cancer with no history of smoking compared to prior surveys by the KATRD² and KALC in 2007 (Figure 1)³.

Lung cancer screening with low-dose computed tomography for high-risk populations is planned to be incorporated into the national cancer screening program. As never smokers are not regarded as a high-risk group for lung cancer, these patients are not screened by the national cancer screening program. However, never-smoker lung cancer patients are more likely to be female, have adenocarcinoma, and manifest with stage I or IV disease compared to lung cancer patients with a smoking history^{6,9}. Thus, active research is needed to identify the predictors in high-risk individuals within the population without a smoking history.

Following the successful pilot survey for lung cancer from patients diagnosed in 2013, the KALC and KCCR are conducting a larger-scale nationwide survey of lung cancer patients. About 10% of lung cancer cases diagnosed every year are sampled and a detailed survey using KALC-R is going to be performed yearly. In 2014, there were 24,253 newly diagnosed lung cancer cases, and a total of 2,659 sampled cases were surveyed from 52 hospitals.

Conclusion

As the whole case registration is impractical, we are using unbiased systemic sampling strategy and pursue the completeness of data for these selected cases. The KALC-R has detailed information about symptoms, lung function, staging information, specific treatment, and survival data, in addition to basic demographic information. Thus, more useful statistic results are expected to be generated in future surveys.

Authors' Contributions

Conceptualization: Kim YC. Methodology: Kim YC, Won YJ. Formal analysis: Kim YC. Approval of final manuscript: all authors.

Conflicts of Interest

No potential conflict of interest relevant to this article was reported.

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