Validity of the stage of lung cancer in records of the Maastricht cancer registry, The Netherlands

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Abstract

Information collected in a clinical study on a random sample of 99 patients with inoperable lung cancer, treated with radiotherapy, was compared to the staging information in the Maastricht cancer registry. Validity of sex (0% disagreements), date of birth (0%), histology (1% major disagreements) and treatment (1%) was high, but the validity of stage was lower: 12% major and 23% minor disagreements. The misclassification of stage did not result in a shift in the survival estimates. If cancer registries intend to use stage in comparisons of survival, more validation studies are necessary. © 1997 Elsevier Science Ireland Ltd.

Keywords: Cancer registry; Lung cancer; Staging; Validity
1. Introduction

Cancer registry information is being used increasingly to compute and compare cancer survival rates. Survival estimates of cancer registries have the advantage of being population-based. In clinical trials, inclusion and exclusion criteria often result in biased estimates of survival.

A recent publication by the Eurocare-project had to refrain from using staging information to estimate survival because information on stage distribution is not always available in cancer registries, the coding of stage is not standardized and only a few re-abstraction studies have been executed [1].

The Netherlands Cancer Registry collects staging information using the TNM classification according to the UICC [2]. The validity of several aspects of data have been investigated [3]. The relative frequency of major disagreements was 0% for date of birth, 5% for date of incidence, 6% for tumour site and 2% for histological type. In general, the data of the registry seemed to be very accurate [3]. However, the validity of staging information has not been studied.

We estimated the validity of lung cancer staging in a Dutch regional cancer registry by comparing the information collected in a clinical study on lung cancer to the staging information in the cancer registry. We also investigated whether the misclassification influenced survival estimates by stage.

2. Methods

2.1. Cancer registry

The Maastricht cancer registry was established in 1984. The cancer registry receives lists of newly diagnosed cases on a regular basis from the pathology departments, the medical records departments at the hospitals and the radiotherapy institute. Following this notification, the medical records of newly diagnosed patients (and tumours) are collected and the relevant information for the cancer registry is abstracted at the hospital from the medical records by trained registration personnel from the Maastricht cancer registry [4]. The majority of the cases are recorded 6–12 months after diagnosis. Topography and morphology are coded according to ICD-Oncology [5]. Stage is coded according to the fourth edition of the TNM system [2]. Stage is grouped into five categories: I, II, III, IV and unknown [2]. To collect information on tumour stage, special forms and a computer program have been developed to avoid inconsistencies and errors and to calculate the staging codes.

2.2. Patients

In this validity study, data from the Maastricht cancer registry were compared to data obtained in an independent clinical study. The clinical study evaluated the prognosis of lung cancer patients treated with radiotherapy. All the patients were
staged with a CT scan of the thorax and bronchoscopy; a bone scan, echography
and/or CT scan of liver were performed where indicated. In this study, data were
collected on 1000 patients by an investigator (J.L.) from the radiotherapy institute.
The staging information was carefully reviewed by the investigator (J.L.).

A random sample of 100 patients with inoperable lung cancer, treated with
radiotherapy alone, was drawn. Owing to the fact that the cancer registry has been
using the fourth edition of the TNM staging since 1988 [2], only patients whose
lung cancer was diagnosed after 31 December 1987 were selected. Information on
99 out of the 100 patients could be found in the cancer registry files. The missing
patient was not eligible for cancer registration, because he was living outside the
registration area of the cancer registry.

2.3. Assessment of validity

After record linkage, the following information was compared between the two
files: date of birth, sex, morphology, TNM staging and treatment. In Table 1, the
rules used for small and large disagreements are summarized. If large disagreements
existed for stage, morphology and the date of incidence, the clinical file at the
radiotherapy institute was inspected to find the most reliable information and a
possible explanation for the disagreement. In a few cases the information obtained
in the clinical study was not correct according to the coding rules of the cancer
registry. The two principal investigators (L.S. and J.L.) then decided what the
correct classification should be. The correct information was considered to be the
'golden standard'.

2.4. Statistics

Survival was calculated using the Kaplan-Meier method. Differences in the
duration of survival were tested with the logrank test.

<table>
<thead>
<tr>
<th>Table 1</th>
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<table>
<thead>
<tr>
<th>Definition of minor and major disagreements</th>
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</table>

<table>
<thead>
<tr>
<th>Item</th>
<th>Codes</th>
<th>Minor disagreement</th>
<th>Major disagreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of birth</td>
<td></td>
<td>Unknown versus known or differences in subgroups</td>
<td>Any difference</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td>Other differences</td>
<td>Any difference</td>
</tr>
<tr>
<td>Histological type</td>
<td>ICD-O</td>
<td>Unknown versus known or differences in subgroups</td>
<td>Differences in four groups*</td>
</tr>
<tr>
<td>Staging</td>
<td>TNM</td>
<td>Unknown versus known or differences in subgroups</td>
<td>Difference in stage main groups (I versus II vs III vs IV)</td>
</tr>
</tbody>
</table>

* Main groups: squamous cell carcinoma, adenocarcinoma, small cell carcinoma and other malignancies.
Table 2
Distribution of the validity of cancer registry information compared to the golden standard (N = 99)

<table>
<thead>
<tr>
<th>Item</th>
<th>Disagreement (N, %)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Date of birth</td>
<td>99 (100)</td>
</tr>
<tr>
<td>Sex</td>
<td>99 (100)</td>
</tr>
<tr>
<td>Histological type</td>
<td>92 (93)</td>
</tr>
<tr>
<td>Treatment</td>
<td>98 (99)</td>
</tr>
<tr>
<td>Stage</td>
<td>68 (69)</td>
</tr>
</tbody>
</table>

3. Results

In 49 out of the 99 patients, the clinical files at the radiotherapy institute had to be inspected to assess disagreements in stage, morphology or date of incidence. The differences between the initial cancer registry information and the 'golden standard' are shown in Table 2.

No differences were observed for date of birth and sex. For the item morphology one major and six minor disagreements were observed. The major disagreement comprised a case in which the pathologist had changed a diagnosis of squamous cell carcinoma into adenocarcinoma after the initial diagnosis. This revision was apparently unknown to the cancer registry.

The recorded information with respect to treatment was very accurate. There was disagreement with the golden standard in only one out of the 99 patients.

Disagreements with respect to stage were more frequent. Twelve major and 23 minor disagreements were observed. The minor disagreements concerned eight cases in which the cancer registry had not been able to code an adequate stage (information was coded as unknown) and 15 cases in which the subdivision of the stage (IIIA versus IIIB) was in error.

Table 3
Stage according to the cancer registry compared to the stage according to the golden standard (N = 99)

<table>
<thead>
<tr>
<th>Stage according to cancer registry</th>
<th>Stage according to the golden standard (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I</td>
</tr>
<tr>
<td>I</td>
<td>14</td>
</tr>
<tr>
<td>II</td>
<td>—</td>
</tr>
<tr>
<td>III</td>
<td>—</td>
</tr>
<tr>
<td>IV</td>
<td>—</td>
</tr>
<tr>
<td>N/A*</td>
<td>—</td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>15</td>
</tr>
</tbody>
</table>

*NA, not applicable (e.g. no histological confirmation).
Table 4
Stage according to the cancer registry compared to the stage according to the golden standard for patients with stage III (N = 57)

<table>
<thead>
<tr>
<th>Stage according to cancer registry</th>
<th>Stage according to the golden standard (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>IIIA</td>
</tr>
<tr>
<td>IIIA</td>
<td>19</td>
</tr>
<tr>
<td>IIIB</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>27</td>
</tr>
</tbody>
</table>

In Table 3 the stage as coded by the cancer registry is shown compared to the stage according to the golden standard. Of the eight cases coded by the cancer registry as stage IV (distant metastasis) no case was in accordance with the golden standard. In two cases an error had been made by registration personnel: brain metastasis discovered after the start of treatment should have been coded as progression during follow-up, but were coded as stage IV malignancies. In the other six cases the existence of metastasis was uncertain: on three bone scans bone metastases were suspected, on two chest X-rays other lesions in the lung were suspected and one patient had some symptoms that could be explained by brain metastasis. In one of these cases there was disagreement between the treating clinicians with respect to the existence of distant metastasis.

The four other major disagreements comprised errors made by the registration clerks. Essential information had been overlooked or typing errors had been made at data-entry into the cancer registry database.

In Table 4 the validity of the stage subgroups IIIA and IIIB is tested. Fifty-seven lung cancers were classified as stage III by both the cancer registry and the golden standard and there was agreement in 42 cases (= 74%) regarding this subdivision.

The disagreements with respect to stage did not influence the survival estimates to any great extent (Figs. 1 and 2). Median survival of the stage III patients was estimated to be 7.4 months by both the golden standard (N = 74) and the cancer registry (N = 57).

Median survival was estimated to be 10.7 months for the 36 patients with stage IIIA according to the golden standard and 11.1 months for the 26 patients with stage IIIA according to the cancer registry (see Fig. 2). In patients with stage IIIB, median survival was estimated to be 5.2 months, irrespective of the reference group.

4. Discussion

We studied the validity of the registration of lung cancer data by the Maastricht cancer registry. Items such as date of birth, sex, histology and treatment were recorded with great accuracy, but the validity of stage was much lower: 12% major disagreements and 23% minor disagreements (8% concerned missing information). Six of the 20 disagreements concerned errors made by the registration personnel.
The remaining 14 disagreements were caused by missing information in the clinical files, by inconclusive information in the clinical file or by the results of additional radiological investigations at the radiotherapy institute.

The results of this study are unlikely to be representative for the total cancer registry, because validity was checked only for patients without surgery, so the pathological post-surgery information was not taken into consideration. The validity of staging information when pathology results are available will probably be higher.

In American recoding studies, standards have been formulated for the allowable proportion of major disagreements [6]. These proportions amount to 4% for morphology, 12% for stage and 2% for treatment. The results of this study meet these requirements. It should be noted, however, that the CCPDS codes stage by the extent of disease, which is a simpler classification system with less stages than the TNM classification used by the Netherlands cancer registry.

Disagreements according to subgroup (IIIA and IIIB) were considered to be minor disagreements. However, this distinction may be of clinical importance, because at some oncology departments the subgroup determines the treatment modality and/or intention of treatment. When we also considered these disagreements, the agreement between the cancer registry and the golden standard was fairly low.

Fig. 1. Survival of lung cancer patients according to stage as recorded by the cancer registry (N = 86) and according to the golden standard (N = 93). Patients with unknown stage are excluded.
Survival

1 Golden standard
IIIA (N = 38)

0.8

IIIb (N = 36)

p = 0.004 (df = 1)

Cancer registry
IIIA (N = 26)

0.6

p = 0.03 (df = 1)

IIIb (N = 31)

0.4

1

0.2

0 10 20 30 40 50 60 70

Months

Fig. 2. Survival of stage III lung cancer patients according to stage as recorded by the cancer registry (N = 57) and according to the golden standard (N = 74).

Surprisingly, the misclassification of stage did not result in a shift in the survival estimates. Cases with stage I–II according to the cancer registry had a longer median survival, while cases with stage IV according to the cancer registry had a shorter median survival, even though they should have been coded as stage III according to the golden standard.

5. Conclusion

Recording the stage of disease in lung cancer is difficult and can give rise to many different interpretations. If cancer registries intend to use stage in international comparisons of survival, more validation studies are necessary.

References

