
RESEARCH COMMUNICATION

Reduction of Death Certificate Only (DCO) Registrations by Active Follow Back

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Summary

Death certificates are an important source of information for cancer registries that help to improve completeness of case finding. In many countries where routine mortality data are considered of poor quality, this source is often regarded as being of little value. We evaluated the contribution of death certificates to the total number of registrations in the years 1993-1997, in the Manila Cancer Registry (MCR). We compared the "standard" practice of retrieving clinical information if the death certificate was completed in a hospital, with active search of additional information from the deceased's relatives when the death was certified at home. The standard procedure allowed us to reduce the proportion of cases registered from a death certificate by 5%. The improvement varied significantly among the most common sites with a reduction of 10% for lymphomas to less than 1% for cancers of the cervix. The proportion of liver cancers registered from a death certificate only (DCO), originally 47%, was reduced to 29% by contacting relatives of the deceased patients. In countries with limited investment in information systems, death certificates, even when recognised as being of poor quality, are an important source of information for cancer registries.

Key Words: Cancer registration - Death Certificate Only

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Introduction

Death certificates mentioning cancer are one of the regular sources of information of population-based cancer registries, and the proportion of all recorded incident cases known only through the death certificate, provides a guide to the completeness of case ascertainment. In volume VII of Cancer Incidence in Five Continents (CI5) (Parkin et al, 1997) the maximum frequency of cases known to the registry only through the death certificate (DCO) was 24% but for only 20 of the 169 registries (12%) included in the volume did DCO cases exceed 10%.

The proportion of cases recorded as DCO is usually high in settings where hospital information systems are not computerised, so that case-finding must rely upon manual search and selection of information on new cancer cases. Additional, independent, sources of information may, in these circumstances, contribute significantly to completeness.

We evaluated the efficiency and cost of two procedures to trace back clinical information on cases first coming to the attention of the cancer registry via a death certificate (death certificate notifications; DCN) in order to reduce the proportion of DCO cases.

Methods

The Manila Cancer Registry (MCR) covers a population of about 4.5 million individuals living in the densely populated urban area of Metro Manila (Parkin et al, 1997). Cancer cases are diagnosed and treated in over 100 hospitals and clinics serving the area. In the Manila registry, case finding is performed by regular abstraction of cancer cases from lists of patients from hospital discharge books. For the period 1993-1997, after completion of data abstraction in all relevant hospitals and clinics, 29,456 cases were recorded. In the same period, 4,881 death certificates mentioning cancer were collected, and 678 were linked with existing

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registrations, leaving a total of 4,203 death certificate notifications (DCN) cases.

Normally we can follow back DCN cases, in order to obtain additional diagnostic information only, for cases that died in hospital. These cases may have been missed at time of case finding if the diagnosis is misreported in the discharge books, but they can be traced in the hospital archives by the name of the deceased person. For deaths certified as cancer, who did not die in hospital, the only potential source of additional information is the family of the deceased patient.

For deaths recorded as liver cancer, which is notoriously mis-classified on death certificates, we also contacted the relatives of the deceased. Home visits were made, and one registry staff member interviewed relatives to obtain information on the hospital where the case was diagnosed and treated, and the date and basis of cancer diagnosis. The information obtained was subsequently checked by tracing the patient's records in the hospital referred to by the relatives. This activity started July 15, 1999 and was completed by May 2000 (Figure 1).

Ninety-five percent confidence limits of the difference between proportions were calculated based on the normal approximation (Snedecor & Cochran, 1980).

Results

Figure 1 describes the two procedures and the outcome at every step of the process. A total of 4,881 death certificates

(DC) mentioning cancer were collected in the period. Of these, 678 (10%) were linked with recorded cases leaving 4,203 initial DCN cases, or 14% of recorded incidence. Nine hundred and ninety four of these death certificates (20%) had been completed in a hospital and clinical information was successfully obtained for 588 cases, (14% of the original number). The residual number of DCOs was therefore 3,615. Table 1 shows the proportion of DCO cases before and after the trace-back procedure, for all cancers and the 10 most common sites. By using follow-up of hospital deaths (the "standard procedure") we reduced the overall proportion of DCOs by 4.7%, from 16.4% to 11.7%. The largest improvements concerned leukaemia with a reduction of 9.8% (95%CL - 7.9-11.7%, lung and stomach with 6.2% (95% CI 5.0-7.4%) and 6.5% (95% CI 4.2-8.7%) respectively, followed by lymphomas with 4.5% (95% CI 2.9-6.1%).

For liver cancer Table 1 shows the overall reduction including the outcome of home visits described in the Methods. Of the 794 cases of cancer of the liver not already in the registry database, 164 (21%) were traced back by the standard procedure (tracing of hospital deaths) (Fig 1). Of the remaining 630, the residential address was not known for 104, leaving 526 (88%) eligible for home visits. Home visits led to the successful location of medical records for 155 of the cases. Relatives were either not present at the given address, or were not able to provide useful information, for 350 of the cases, and 21 deceased patients proved not to

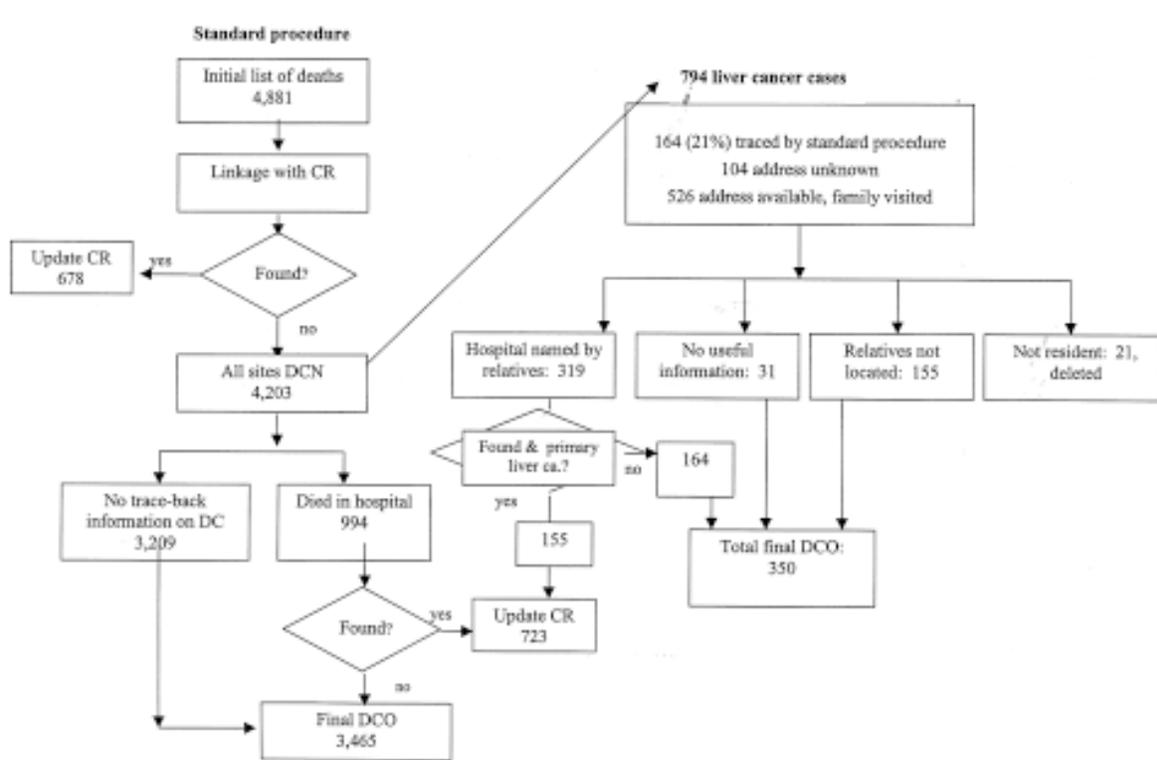


Figure 1. Graphical representation of standard procedure and ad hoc procedure to trace back DCN cases.

Abbreviations: DCO: death certificate only, CR: cancer registry data base

Table 1. Comparison of Proportions (%) of Cases Notified by Death Certificate (DCN) and Those Remaining After Follow Back (DCO) for All and the 10 Most Common Sites.

| | Dec 1999 (DCN) | May 2000 (DCO) | Difference (95% CI) | Total No of cases in Dec 1999 |
|-------------|-------------------|-------------------|------------------------|----------------------------------|
| All sites | 16.6 | 11.7 | 4.7 (4.3-5.1) | 29707 |
| lung | 23.5 | 16.9 | 6.2 (5.0-7.4) | 4070 |
| breast | 6.9 | 5.1 | 2.0 (1.3-2.7) | 4509 |
| cervix | 1.6 | 1.1 | 0.4 (0.1-0.9) | 1979 |
| leukaemias | 28.0 | 21.1 | 9.8 (7.9-11.7) | 1946 |
| colon | 11.5 | 6.7 | 3.9 (2.4-5.5) | 1286 |
| thyroid | 2.5 | 2.1 | 0.2 (0.6-0.9) | 1426 |
| stomach | 21.6 | 15.3 | 6.5 (4.2-8.7) | 1151 |
| nasopharynx | 6.3 | 4.2 | 2.3 (0.9-3.7) | 969 |
| lymphomas | 10.3 | 3.5 | 4.5 (2.9-6.1) | 782 |
| liver(*) | 46.8 | 28.6 | 18.2 (14.9-21.5) | 794 |

(*) reduction includes outcome of home visits.

be resident in the registry area, but had given a provisional address.

The proportion of DCNs among liver cancer cases varied significantly among the 4 cities covered by the registry ranging between 37% to 64% (Table 2). The differences persisted after follow-back – DCO between 25% and 45%.

Discussion

Death certificates are an important source of cases, and their availability helps to improve coverage (Parkin et al, 1994). In countries where death certification is known to be of poor quality because of incompleteness and inaccuracy of the certified cause of death, this source is often dismissed. We show that even in these circumstances death certificates can significantly improve data coverage. The quality of the information from this source is maximised by contacting the relatives of the deceased. This is a time-consuming activity, the cost of which varies considerably depending on local circumstances.

In many Asian countries the proportion of death certificates medically certified is well below 70% (WHOa). Mortality data of the Philippines were last included in the

WHO Mortality Data Bank (WHO_b) in 1996, data are estimated 75% complete, and less than 70% of the recorded causes of death are medically certified. Despite these limitations, death certificates remain a fundamental source of information, particularly in these countries where routine sources, i.e. hospital discharge books, pathology laboratories' files, also lack completeness and accuracy.

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Table 2. Comparison of Percent Proportions of DCN and DCO Cases of Liver Cancer According to Area.

| Area | DCN (Dec. 1999) | DCO (May 2000) |
|---------------|--------------------|-------------------|
| Manila | 44 | 27 |
| Quezon City | 37 | 25 |
| Caloocan City | 62 | 45 |
| Pasay City | 64 | 33 |
| All Areas | 46 | 29 |