The impact of National Death Index linkages on population-based cancer survival rates in the United States

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Abstract

Background

In order to ensure accurate survival estimates, population-based cancer registries must ascertain all, or nearly all, patients diagnosed with cancer in their catchment area, and obtain complete follow-up information on all deaths that occurred among registered cancer patients. In the US, linkage with state death records may not be sufficient to ascertain all deaths. Since 1979, all state vital statistics offices have reported their death certificate information to the National Death Index (NDI).

Objective

This study was designed to measure the impact of linkage with the NDI on population-based relative and cancer cause-specific survival rates in the US.

Methods

Central cancer registry records for patients diagnosed 1993–1995 from California, Colorado, and Idaho were linked with death certificate information (deaths 1993–2004) from their individual state vital statistics offices and with the NDI. Two databases were created: one contained incident records with deceased patients linked only to state death records and the second database contained incident records with deceased patients linked to both state death records and the NDI. Survival estimates and 95% confidence intervals from each database were compared by state and primary site category.
Results
At 60 months follow-up, 42.1–48.1% of incident records linked with state death records and an additional 0.7–3.4% of records linked with the NDI. Survival point estimates from the analysis without NDI were not contained within the corresponding 95% CIs from the NDI augmented analysis for all sites combined and colorectal, pancreas, lung and bronchus, breast, prostate, non-Hodgkin lymphoma, and Kaposi sarcoma cases in all 3 states using relative survival methods. Additional combinations of state and primary site had significant survival estimate differences, which differed by method (relative versus cause-specific survival).

Conclusion
To ensure accurate population-based cancer survival rates, linkage with the National Death Index to ascertain out of state and late registered deaths is a necessary process for US central cancer registries.

Keywords: Death certificate accuracy, National Death Index, Cancer survival

1. Introduction
Cancer registries play a critical role in monitoring effective cancer control activities by providing population-based incidence and survival data. In addition, information on cancer survival can be used to evaluate the overall effectiveness of healthcare delivery to cancer patients [1,2].

Net survival estimates the probability of surviving cancer in the absence of other causes of death and provides a means for tracking survival over time and across populations with different life expectancies. The two methods for estimating net survival are relative survival (i.e., the ratio of the observed survival in the cancer patient cohort to the expected survival from a comparable group in the general population) and cause-specific survival (i.e., probability of death from a specific cause where deaths from all others causes are treated as censored observations).

In order to ensure valid relative and cause-specific survival estimates, population-based cancer registries must first ascertain all, or nearly all, patients diagnosed with cancer in their catchment area [3], and second, obtain complete follow-up information on all deaths that occurred among registered cancer patients [4-5].

Ascertaining deaths can be particularly challenging to cancer registry staff as the resources required to conduct follow-up increases as the number of registered patients increases. Over time, these numbers will continue to increase due to the maturity of the cancer registry, a growing and aging population, and improved survival [6].

To assist in the ascertainment of cancer patients who may have been missed at the time of their diagnosis, or who may have been diagnosed with cancer only at the time of their death, cancer registries routinely link their incidence data with death certificate data from their jurisdictional vital records offices [7]. During this linkage process, known as death clearance, the cancer registry database can be updated with cause and date of death information among deceased incident cases.

Over the past several decades, advances in early detection and treatment have resulted in increased survival time for cancer patients [8]. Patients may move from one jurisdiction to another within the same country between the time of their diagnosis and their death and, depending on practices regarding the recording of deaths in the country, the cancer registry reporting the incident case may not learn of the patient’s death. In the United States (US), deaths are recorded in the state where the decedent expired and shared, if different, with the state of residence at the time of death. This may or may not be the state in which a person resided when they were diagnosed with cancer. Another limitation may result from the exchange of information between state vital statistics offices (VSO). For example, a cancer patient may seek treatment out of state and subsequently die. The VSO where the death occurred may be slow to report the death to the VSO in the state where the patient resided, or the VSO may place restrictions on the use of death certificate data in a way that precludes or impedes the use of the death records in linkages with cancer registry records [9]. Therefore, linkage with state death records may not be sufficient to ascertain all deaths that occurred among cancer patients registered in statewide or metropolitan-area based cancer registries.
The US Centers for Disease Control and Prevention (CDC)’s National Center for Health Statistics (NCHS) maintains the National Death Index (NDI). Since 1979, VSOs in all 50 states, Puerto Rico, and the Virgin Islands have reported their death certificate information to the NDI [10,11]. Cancer registries are encouraged to link their incidence records with both state death records and the NDI for the purpose of ascertaining deaths and updating date and cause of death information [9]. Record linkage with the NDI has been used with both adult and pediatric cohort studies [12–17].

The present study uses secondary data from the Accuracy of Cancer Mortality Statistics Based on Death Certificates (ACM) study [18]. The main objective of the ACM study was to characterize the concordance between cancer cause of death information from death certificates and primary cancer site at diagnosis recorded in US cancer registries [19]. Cases included in the ACM study had follow-up for at least 9 years, and data collected for the ACM study provided a unique opportunity to investigate the impact of NDI linkages on survival estimates by comparing survival rates based on deaths ascertained solely by state death record linkages with rates based on linkage to state death records and the NDI.

2. Materials and methods

The ACM study has been described in detail elsewhere [18]. Briefly, population-based central cancer registries in California, Colorado, and Idaho were selected because they met study eligibility criteria including but not limited to the following: the registry was statewide and population-based; cancer incidence data were complete and high quality (e.g., met publication criteria [20]); and the registry performed routine death clearance with state death records. In addition, these registries agreed to send their incidence data to the NDI to ascertain deaths that were not recorded in their state vital records offices. If a death was ascertained via the state process, the record was not sent for NDI linkage.

In the current study, we investigated the impact of NDI linkage on 5-year cancer survival rates based on incident cases diagnosed between January 1, 1993 through December 31, 1995 and deaths that occurred up to 5 years after diagnosis.

2.1. Analysis

Data from the three statewide cancer registries were combined into one dataset using SAS (Version 9.2, Cary, NC), and two datasets were subsequently created and processed using SEER*Prep (Version 2.4.5, Information Management Services, Inc., Silver Spring, MD). A field demarcating the source of follow-up information at the state cancer registry was used to identify deaths ascertained through NDI linkages. To maintain consistency between the datasets, all patients with vital status alive were censored at the end of the study period, December 31, 2004. The first dataset included deaths ascertained through state processes and NDI linkages (NDI augmented file). In order to keep sample sizes consistent in both datasets, the second dataset (NDI censored file) was created with all NDI deaths censored at the end of the study period (vital status alive as of December 31, 2004) as if the NDI linkage had not been performed. A small proportion of deaths was ascertained via follow-up by hospitals and other sources and lacked cause of death information (1.6% in California, 1.0% in Colorado, and 0.7% in Idaho). These are included in the totals for state source of death ascertainment in Table 1 and included in the survival analyses as is the general practice in the states.

| Table 1 |
| Incident cases and number of deaths ascertained at 60 months follow-up via state follow-up and death clearance processes and via linkages with the National Death Index (NDI), by state of diagnosis and primary site category. |

Analysis was performed using the survival functions in SEER*Stat (Version 7.0.5, Information Management Services, Inc., Silver Spring, MD). Cancer site-specific 5-year survival rates were generated according to SEER primary site recodes that group cases by major site/histology categories and are commonly used in the reporting of
cancer statistics [21]. Ninety-five percent confidence intervals (CIs) for the survival functions were based on the log–log transformation. Parallel survival analyses were conducted on the two datasets in order to compare site-specific survival rates with NDI (augmented) and without NDI (censored) linkage results. Thus, the comparison is between death ascertainment solely by state processes versus state processes supplemented by the NDI. Differences between survival rates were calculated by subtracting the value from the NDI augmented analysis from the NDI censored analysis, such that the differences were all in the positive direction. As there is no formal statistical test to compare survival estimates on (nearly) the same population using different analysis methods with grouped data, we considered as significant those rate differences where point estimates from the NDI censored analysis were not contained within the corresponding 95% CIs from the NDI augmented analysis, which we considered to be the gold standard.

Calculations were performed using the actuarial method on monthly follow-up intervals, and the cumulative summary survival rate at 60 months (5 years) is shown. For the relative survival analysis, the expected survival table available in SEER*Stat titled “U.S. 1970–2006 by individual year (White, Black, Other (AI/API) All races for Other Unspec 1991+ and Unknown)” was used (AI/API refers to American Indian or Alaskan Native/Asian or Pacific Islander) [22]. Ederer II was selected as the cumulative expected method for relative survival; for expected survival, values from the expected survival table were matched to each patient by age, sex, race, and year and considered to be at risk until the corresponding cancer patient died or was censored [23]. For the cause-specific survival analyses, two definitions were used: the first (narrow) definition required a match between the primary site at diagnosis and the cancer-specific death whereas the second (broad) definition required a match with any cancer cause of death [18].

The analyses were limited to data on first (or only) primary invasive cases among persons diagnosed with cancer. Cases reported solely by death certificate or autopsy were excluded from all analyses, as were cases missing age, sex, or with an invalid race code. In order to maintain consistency of sample sizes across analyses (relative versus cause-specific), deceased cases with missing or unknown cause of death were censored at the date of death in the cause-specific analyses. Such deaths would be considered events in relative survival where fact but not cause of death is necessary for the analysis.

2.1.1. Human subjects protections The study protocol was formally reviewed for protection of human subjects in research, and was exempted by CDC and ICF Macro (Bethesda, MD), yet approved by the institutional review boards governing the individual state cancer registries. To ensure the protection of patient confidentiality and the stability of the survival estimates, analysis cells with a frequency of five or fewer cases were suppressed in tables.

3. Results

Table 1 shows the numbers of eligible cases diagnosed between 1993 and 1995 and the numbers of deaths that were ascertained via state processes and via NDI linkages at 60 months of follow-up, by state of residence at diagnosis and primary site category. Among 306,422 incident cases in California, 147,278 (48.1%) deaths were ascertained via state processes and 2224 (0.7%) cases linked with the NDI. Among 35,261 incident cases in Colorado, 14,845 (42.1%) deaths were ascertained via state processes and 768 (2.2%) linked with the NDI. Among 11,282 incident cases in Idaho, 4869 (43.2%) deaths were ascertained via state processes and 387 (3.4%) linked with the NDI. Linkage with the NDI identified additional deaths among cancer patients in all 3 states and in all primary site categories examined. The proportion of deaths identified through NDI linkages at 60 months of follow-up varied by state (1.5% in California, 4.9% in Colorado, and 7.4% in Idaho). Extending the follow-up period to the end of the study (December 31, 2004) resulted in a higher proportion of deaths identified through NDI linkages (2.2% in California, 6.4% in Colorado, and 9.0% in Idaho).

The impact of NDI linkage on survival rates was evaluated by examining the differences between rates based on state processes and linkages with the NDI (NDI augmented) and rates based solely on state death ascertainment (NDI censored).
Table 2 shows 5-year relative survival rates, 95% CIs and rate differences comparing NDI censored with NDI augmented rates. For California, Colorado and Idaho, significant rate increases were seen for all sites combined (0.9%, 2.6%, and 4.2% respectively), colorectal cases (1.0%, 3.1%, and 5.1% respectively), pancreas cases (1.0%, 3.8%, and 4.2% respectively), lung and bronchus cases (1.4%, 4.3%, and 7.5% respectively), breast cases (0.5%, 1.2%, and 2.2% respectively), prostate cases (0.6%, 1.6%, and 3.5% respectively), non-Hodgkin lymphoma cases (1.0%, 3.5%, and 6.9% respectively), and Kaposi sarcoma cases (2.7%, 10.1%, and 36.7% respectively). For both Colorado and Idaho, rates differed significantly for leukemia cases (3.9% and 5.9% respectively). For Colorado, rates differed significantly for stomach, liver and bile duct, and brain cases (4.0%, 5.4%, and 4.8% respectively). Within each state, the largest rate difference occurred for Kaposi sarcoma.

Table 2
5-Year relative survival (RS) statistics\(^a\) with and without NDI augmentation of state vital records linkages, by state of diagnosis and primary site category.

Table 3 shows 5-year cause-specific (narrow definition) survival rates, 95% CIs and rate differences comparing NDI censored with NDI augmented rates. Fewer differences were noted and they were smaller. For California, Colorado and Idaho, significant rate differences were seen for all sites combined (0.5%, 1.5%, and 2.2% respectively) and for cancers of the lung and bronchus (1.3%, 3.9%, and 6.7% respectively). For California and Colorado, rates also differed significantly for colon and rectum cases (0.6% and 1.9% respectively) and pancreas cases (1.0% and 4.0% respectively). Rates differed significantly for breast cases (0.8%) and brain cases (4.4%) in Colorado and non-Hodgkin lymphoma cases in Idaho (5.2%). Kaposi sarcoma cases are not included in Tables 3 and 4 because for these cases the underlying cause of death is coded to HIV/AIDS.

Table 3
5-Year primary site category cause-specific (CS) survival statistics\(^a\) with and without NDI augmentation of state vital records linkages, by state of diagnosis and primary site category.

Table 4 shows 5-year cancer cause (broad definition) survival rates, 95% CIs and rate differences comparing NDI augmented with NDI censored rates. For California, Colorado and Idaho, significant rate differences were seen for all sites combined (0.6%, 1.7%, and 2.6% respectively), pancreas cases (1.0%, 3.5%, and 3.7% respectively), and lung and bronchus cases (1.3%, 3.9%, and 6.4% respectively). For California and Colorado, rates also differed significantly for colon and rectum cases (0.7% and 2.0% respectively). Rates differed significantly for breast cases in California (0.4%), brain cases in Colorado (4.8%) and non-Hodgkin lymphoma cases in Idaho (5.4%).

Table 4
5-Year any cancer cause-specific (CS) survival statistics\(^a\) with and without NDI augmentation of state vital records linkages, by state of diagnosis and primary site category.

4. Discussion
Population-based survival is an important measure of the cancer burden because it measures the actually achieved survival for all patients in the general population regardless of age, health status, stage of disease and access to care\(^{[24]}\). This information can be used by cancer control planners to identify groups who may not experience optimal outcomes following a diagnosis of cancer, and can help target early diagnosis and treatment activities in areas most in need.
Identifying all, or nearly all, deaths is critical to obtaining valid survival estimates. Missing only a small proportion of deaths can result in spuriously high survival proportions particularly among highly lethal cancers [3–5] and as length of follow-up increases [4].

During routine death clearance, central cancer registries can update vital status and date and cause of death information from intra-jurisdictional death records. In this study of three US states, routine death clearance identified the vast majority of deaths. However, the NDI linkage did ascertain additional deaths in all primary site categories investigated and in all three states, and was critical for obtaining valid survival estimates, particularly for cancer sites with large numbers of deaths (all sites combined, colorectal, lung and bronchus, breast, and prostate) and the more lethal cancers (lung and bronchus, liver and bile duct, and pancreas).

Variation in percentages of out-of-state deaths in this study may be partly explained by interstate migration patterns and the location of population centers near adjacent states. In California, large cities are mostly coastal, and neighboring states generally do not have large population centers near the population centers in California. There is extensive interstate migration in the US. In 2010, 2.2% of the US populations resided in a different state 1 year earlier [25]. In 20 of 51 jurisdictions (states/District of Columbia), including Colorado and Idaho, annual interstate migration was 3.0% or greater. In California, annual interstate migration was tied for lowest in the US at 1.2%. This partly explains the differences among states in this study in the impact of NDI linkages on cancer survival rates. The results from Colorado and Idaho are likely more representative of many other US states than are the California results.

This study did not investigate the impact of NDI linkage on survival estimates with longer than 5 years of follow up. However, a study using data from the Finland Cancer Registry demonstrated that completeness of death ascertainment was increasingly important with longer length of follow up [4]. For this reason, linkage with NDI is also likely to be important with the reporting of longer term survival estimates.

In order to report valid survival estimates at the regional and national level, it will be important for all US registries to conduct NDI linkages and report their results to their respective federal cancer surveillance programs: the CDC’s National Program of Cancer Registries and the NCI’s Surveillance, Epidemiology and End Results (SEER) Program. The precision or statistical power of survival estimates for any and all sites will be improved as data are pooled from multiple cancer registries.

Theoretically, the NDI should identify all deaths among US residents and in combination with state death records appears adequate to identify greater than 99% of all deaths (personal communications with C McLaughlin, New York State Department of Health and ML Almon, Georgia Comprehensive Cancer Registry). The development of matching algorithms has helped facilitate the processing of results from the NDI with its large volume of output, potential for multiple NDI matches per registry record submitted, and cryptic output [11]. However, in practice, NDI misses some deaths as evidenced through sensitivity analyses when information on known decedents failed to successfully link with the NDI [26]. Other sources of death information include hospital-based cancer registries and the Social Security Death Index (SSDI); however, while these two sources are adequate for updating vital status and date of death, SSDI does not have, and hospital-based cancer registries in the US often do not have, coded cause of death information which is necessary for cause-specific cancer survival analysis.

Passive follow-up methods, such as state death certificate and NDI linkages in the US, may fail to ensure complete follow-up of cancer cases due to international migration or poor data quality that prevents linkage. Using passive follow-up methods alone, these cases are censored alive at the study cutoff, and such missed deaths may bias survival statistics [4,5]. However, conducting (active) follow-up on alive patients in the presence of near complete death ascertainment has been shown to be of lesser importance [5]. For these reasons, registry staff should pay particular attention to identifying and following “immortal patients” – patients reported as alive despite being diagnosed with a lethal cancer or with advanced disease, or patients who are reported as alive well past their normal life expectancy.
While not a main objective of this study, it is worth noting the influence of cause and source of death data on survival estimates depending on the analytic method. Relative survival requires fact but not cause of death information. Hence, it is the preferred method of estimating population-based survival where information on cause of death – routinely reported by death certificates – may not be available or may not accurately reflect the mortality experience of the cancer patient [22]. Cause of death information comes from death certificates, and the accuracy of the information may depend on the certifier [27]. For example, the site of cancer recurrence or metastasis may be listed as the cause of death instead of the primary site of the cancer.

Relative survival requires life tables that are matched to the cancer population by age, sex, race and/or ethnicity, geographic area and, ideally, other risk factors for the cancer under study (e.g., socio-economic status, smoking status). However, relative survival can be biased and under- or over-estimate survival if there is a mismatch between the life table and the cancer patient cohort under study [28]. Because life tables appropriate for the purpose of the study (e.g., by state or socio-economic status) may be unavailable, cause-specific survival is sometimes used as an alternative to relative survival. The US National Cancer Institute has developed and published a classification variable for cause of death associated with site-specific cancer diagnoses that takes into account likely misclassification of cause of death while not overly expanding the causes of death that are associated with each cancer diagnosis [29]. This broader definition of cause-specific survival gave estimates that more closely approximate those of relative survival.

5. Limitations

Survival estimates from this study were calculated for the purpose of comparing jurisdictional death clearance with national death linkages, and were not intended to represent the survival experience of cancer patients in the three states. The field demarcating the source of follow-up information used to identify NDI linkages may have been incomplete in earlier years of death in some states (personal communications with R Rycroft, Colorado Central Cancer Registry), meaning the differences in survival rates between NDI censored and NDI augmented datasets may be understated. Furthermore, as life expectancy varied between states in the US [28], comparisons among the three registries are not valid because relative survival estimates were not age-standardized nor were state specific life tables used to adjust for background mortality.

6. Conclusion

In the US, linkage with the NDI to ascertain out of state and late registered deaths is a necessary process for central cancer registries to calculate accurate population-based cancer survival rates. Linkage with state death records alone appears inadequate for reporting valid population-based cancer survival rates using either relative or cause-specific analytic methods. These results may be germane to other disease registries in jurisdictions that rely on record linkage with death notifications in the registration area for mortality follow-up.

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Abbreviations

ACM Accuracy of Cancer Mortality Statistics Based on Death Certificates
CDC Centers for Disease Control and Prevention
ICD International Classification of Diseases
Appendix A. Accuracy of Cancer Mortality Study Group

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Footnotes

Conflict of interest statement

There are no financial or personal conflicts of interest reported from any of the authors.

Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the U.S. Centers for Disease Control and Prevention.

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