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Abstract

Objective: We present an approach to obtain accurate and complete data on the last known vital status, and the date of last known vital status of all Kuwaiti cancer patients. These data are essential for robust estimation of population-based cancer survival.

Methods: Government-issued Civil ID numbers (IDs) of patients registered during 2000–2013 were obtained from the Kuwait Cancer Registry. Missing IDs were traced using the Ministry of Health’s Information System or the patient’s medical records. IDs were manually entered in the Public Authority of Civil Information (PACI) database to ascertain vital status for patients whose vital status was not known in the registry. To obtain the date of death for deceased patients, IDs were then manually entered and searched in the electronic archive of “Death Announcements” at the Ministry of Health’s Central Records Department of Births and Deaths. Patients not found in the “Death Announcements” archive were considered alive as on 31 December 2015.

Results: The traditional method to obtain data on cancer patients’ vital status, restricted to patients whose death was certified as due to cancer, had captured only 62% of all patients’ deaths. This new approach resolved the vital status for 98.3% of patients for whom it was previously unknown. The impact was substantial: the proportion of patients known to be dead rose from 27.9% to 45.0%, while the proportion presumed alive dropped from 72.1% to 53.7%. Only 1.3% of the patients remained lost to follow-up.

Conclusion: This approach substantially improved the quality and completeness of follow-up data for all Kuwaiti cancer patients. We recommend that this approach should be performed routinely in Kuwait to enable accurate estimation and monitoring of population-based survival trends.

Keywords: population-based cancer registry, net survival, vital status, date of last known vital status

Introduction

Cancer is the second most common cause of death in Kuwait, following diseases of the circulatory system. Reducing cancer-related deaths can be achieved primarily in two ways: by reducing cancer risk, or by improving the health-care system in terms of management and treatment of cancer patients. Population-based cancer survival is a key measure of the effectiveness of a health system in managing cancer. Monitoring survival over time, between sub-populations and between countries, is also crucial for assessing inequalities and driving policies for cancer control.

The aim of population-based survival analysis is to estimate net survival, which represents the cumulative probability for cancer patients to survive their cancer up to a given time (say, 5 years) since diagnosis, after controlling for competing risks of death (background mortality). Net survival can be measured in two contexts: a cause-specific setting, when the exact cause of death is known and accurately reported, or a relative survival setting, when the exact cause of death is unknown, unreliable or inaccessible.

Original Article

A Novel Approach to Obtain Follow-up Data on the Vital Status of Registered Cancer Patients: The Kuwait Cancer Registry Experience

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Cause-specific survival estimation requires information on the underlying cause of death, and uses as an end–point those deaths that were attributed to cancer. Patients who die from other causes are censored, in order to estimate the cancer-specific hazard of death (excess hazard). This approach relies on the assumption that the death certification and the coding of the underlying cause of death are accurate. However, due to the variability in determining the cause of death accurately between physicians, hospitals, and countries, cause-specific survival estimates are not considered suitable for comparisons between countries or over time.7–9

The procedure for coding the underlying cause of death also differs between countries. For example, the procedures are different in Kuwait and the United Kingdom (Figure 1). In Kuwait, the "Death Announcement" is similar to the Medical Certificate of Cause of Death (MCCD) used in the UK,10 which includes a section on the cause of death. Both are completed by physicians or hospital authorities, in accordance with the World Health Organisation (WHO) recommendations in the International Statistical Classification of Diseases and Related Health Problems (ICD).11 However, the categories used to report cancer as the underlying cause of death differ in the two countries (Figure 1). The Kuwait Cancer Registry (KCR) reports the cause of death as “due to cancer” if either the first line (a) of the Death Announcement (the so-called “immediate cause” of death) or the third and last line (c) of the Death Announcement (the so-called “original or underlying cause” of death) is a cancer-related condition. The second line (b) of the Death Announcement is not coded, and will not be considered as the underlying cause of death even if the last line is not completed. In the UK, all three lines (Ia, Ib, Ic) of the sequence of events leading to death on the MCCD are taken into account to determine the underlying cause of death. This difference in coding the underlying cause of death may lead to under-estimation of cancer mortality rates in Kuwait, compared to the UK. Even minor misclassifications of the underlying cause of death have been shown to result in large changes in net survival estimates.12 In addition, cause-specific estimates tend to be higher than relative survival estimates,12, 13 therefore overemphasising the effectiveness of the health system in dealing with cancer.

Estimating cancer survival within a relative survival framework eliminates any differences or inaccuracies in certifying or coding the underlying cause of death, because the cause of death is not required for analysis. Relative survival is estimated as the ratio of the cancer patients’ all—cause survival, where the endpoint is death from all causes, to the survival that the patients would have experienced if they had had the same background mortality as the general population (expected survival).14, 15 Expected survival is estimated from population life tables that adequately represent the all—cause mortality experience of the population under study.16–18 The relative survival framework is more appropriate for the estimation and comparison of net survival.12, 19–21

To produce reliable and accurate population—based survival estimates, it is necessary to have complete, reliable and long—term data for all patients diagnosed with cancer in a defined geographical area. It is thus imperative to have accurate and complete data on the date of diagnosis, the last known vital status and the date of last known vital status. When the patient has died, it is essential to know the date of death, regardless of the cause.

Many countries are able to maintain long—standing, high—quality population—based cancer registries and provide accurate incidence data. However, it is becoming increasingly difficult to obtain follow-up data and ascertain complete vital status for all patients. Many countries, including high—income countries such as Canada and Saudi Arabia, have reported difficulties in accessing this information for all cancer patients, due
to technical, legal or administrative barriers. A recent international meeting on strengthening the health system and breast cancer care in the Middle Eastern countries, organised by the Harvard Medical School Center for Global Health Delivery in Dubai, highlighted the fact that even in high-income Middle Eastern countries, efficient civil registration and availability of unique identification codes, both crucial to obtain the follow-up data, are still problematic. Such difficulties hinder robust survival estimation and, in many cases, prevent survival estimates from being produced at all.

An example of a national population-based registry that maintains high-quality cancer incidence data for the whole country is the Kuwait Cancer Registry (KCR), a department of the Kuwait Cancer Control Centre (KCCC). However, complete data on vital status for all registered cancer patients are not available, since the registry has only been able to capture information on deaths due to cancer.

This study presents a novel approach to obtain accurate and complete follow-up data on the last known vital status and the date of last known vital status, as on 31 December 2015, of all Kuwaiti cancer patients registered between 2000 and 2013; thus enabling robust estimation of population-based survival in Kuwait.

Materials and Methods

Data on 12,469 patients diagnosed during 2000–2013 were obtained from the KCR database, including the patient’s hospital file number, the Civil ID number where available, and the date of diagnosis (Figure 2, step 1). The Civil ID number was missing for 2,026 patients, and it was necessary to obtain these numbers, either electronically from the Health Information System or manually through the medical records (Figure 2, step 2), so that the records for all patients could then be manually linked with the Public Authority of Civil Information (PACI) database. The PACI database is considered to be the most reliable and up-to-date source to obtain the last known vital status, and the date of last known vital status, of any person resident in Kuwait, provided that their Civil ID number is known.

Only Kuwaiti patients were included in this study since vital status information for non-Kuwaitis is relatively inaccurate. Non-Kuwaitis are mostly expatriate labourers employed with short contracts (e.g. two–year contracts) who generally choose to return home upon completion of their contracts or when they become terminally ill. Although the vital status (alive or dead) of non-Kuwaitis in Kuwait is also recorded in the PACI database, it cannot be used to track the vital status of persons who have left the country. Therefore, the vital status data for non-Kuwaitis are incomplete.

Tracing of Civil ID numbers

To obtain the Civil ID number for Kuwaiti patients for whom it was not available, an “electronic search” using the patient’s hospital file number was queried from the Health Ministry’s Health Information System (HIS) database. If the Civil ID number was not available in the HIS system, a “manual search” was performed: the patient’s hospital file number was used to locate and check the physical medical file in the Medical Records Department at the KCCC, in order to identify the Civil ID number of each patient. This step was performed twice (once at the beginning of this tracing process and once after 6 months), to increase the prospect of locating patients’ files that might previously have been misplaced.

If the Civil ID number could not be traced, but a date of last known vital status earlier than 31 December 2015 was available in the medical records, this date was extracted to update the database. These patients were considered lost to follow-up and will contribute to survival analysis until that date.

Vital status and date of last known vital status update

To obtain follow-up data on last known vital status and date of last known vital status, a list of Civil ID numbers, sorted by year of diagnosis, was printed. Direct linkage with the PACI database was not permitted, therefore indirect access was granted through the Central Records Department of Births and Deaths at the Ministry of Health. Employees from this Department who have access to the PACI database manually entered the Civil ID numbers to determine each patient’s vital status. If the patient was alive, the employee recorded the status as “alive” on the printed sheet. If the patient was dead, the employee used the patient’s Civil ID number to access the Central Records Department’s computerised database in order to obtain the exact date of death from the electronic archive of “Death Announcements”, which is updated on a continuous basis. Each cancer patient’s updated vital status was then entered manually into our existing cancer dataset, matched to the patient’s record with the corresponding Civil ID and file numbers. The vital status was recorded as alive at 31 December 2015 for patients who were alive, or dead, with the date of death, for deceased patients.

Quality control

To ensure the correct transfer of vital status data from hard copy to the electronic database, data entry was verified by checking every 10th record on the hard copy with the vital status data that had been entered. This
Follow-up data on cancer patients’ vital status, Eiman Alawadhi, et. al.

Process was performed on all the records that had been linked with the PACI database, and errors were corrected. All dates of death entered manually were also double-checked, to ensure correct transfer from the hard copy to the electronic database.

Results

During 2000–2013, Civil ID numbers were available in the registry for 10,443 (83.7%) of 12,469 Kuwaiti cancer patients registered (Table 1; Figure 2, step 1). Among these patients, 2,781 were known to be “dead”, with the
cause of death attributed to cancer, while the vital status was unknown for the remaining 7,662 patients (61.4%).

The Civil ID number was not available for 2,026 patients (16.3%). Of these, 694 were known to be dead due to cancer, while the vital status of the remaining 1,332 (10.7%) patients was not known and needed to be traced and updated.

Most of the patients with unknown vital status and without Civil IDs had been diagnosed during 2000–2004; the proportion dropped from 35.4% to 0.5% for those diagnosed during 2010–2013 (Table 2; Figure 2, step 2). This combination of manual and electronic search enabled tracing of 1,175 out of 1,332 Civil ID numbers; 157 Civil ID numbers remained unavailable. However, for these patients, a date of last known vital status earlier than 31 December 2015 was available from the medical records. Therefore, these patients were considered lost to follow-up at that date. The overall proportion of patients without a Civil ID who would be considered lost to follow-up decreased from 10.7% to 1.3%.

Tracing the Civil ID numbers enabled the vital status to be reliably ascertained through the PACI database, and updated for 8,837 (98.3%) of 8,994 of patients for whom it was initially unknown (Table 3; Figure 2, step 3). As a result, the number known to be dead rose by 2,131.

The proportion of total deaths increased from 27.9% (3,475 patients, of which 2,781 had Civil ID numbers and 694 did not) to 45.0% (5,606 patients, including 3,475 known to be dead due to cancer and 2,131 known to be dead due to other causes). About 54% (6,706) out of the 12,469 patients were shown to be alive, leaving only 157 classified as lost to follow-up.

<p>| Table 1: Number of Kuwaiti cancer patients, with and without Civil ID numbers, by period of diagnosis |</p>
<table>
<thead>
<tr>
<th>Calendar period of diagnosis</th>
<th>2000–04</th>
<th>2005–09</th>
<th>2010–13</th>
<th>All periods</th>
</tr>
</thead>
<tbody>
<tr>
<td>All patients</td>
<td>3,489</td>
<td>4,545</td>
<td>4,435</td>
<td>12,469</td>
</tr>
<tr>
<td>Civil ID number available</td>
<td>1,656</td>
<td>47.5</td>
<td>4,402</td>
<td>96.9</td>
</tr>
<tr>
<td>Dead (due to cancer)</td>
<td>496</td>
<td>14.2</td>
<td>1,400</td>
<td>30.8</td>
</tr>
<tr>
<td>Unknown vital status</td>
<td>1,160</td>
<td>33.3</td>
<td>3,002</td>
<td>66.1</td>
</tr>
<tr>
<td>Civil ID number not available</td>
<td>1,833</td>
<td>52.5</td>
<td>1,43</td>
<td>3.1</td>
</tr>
<tr>
<td>Dead (due to cancer)</td>
<td>597</td>
<td>17.1</td>
<td>69</td>
<td>1.5</td>
</tr>
<tr>
<td>Unknown vital status</td>
<td>1,236</td>
<td>35.4</td>
<td>74</td>
<td>1.6</td>
</tr>
</tbody>
</table>

Discussion

We present a novel approach to obtain complete follow-up data on the vital status of all Kuwaiti cancer patients. This approach enabled us to update the vital status for most (98.3%) Kuwaiti cancer patients registered during the period 2000 to 2013.

Of the deaths occurring by 31 December 2015 among cancer patients registered during 2000–2013, only 62.0% (3,475 of 5,606) had initially been recorded in the KCR database through the traditional follow-up method, relying solely on deaths that had been certified as due to cancer.

The process of tracing Civil ID numbers enabled ascertainment of the vital status for almost all registered cancer patients, including all deaths, regardless of the cause. This had a substantial impact on the proportion of cancer patients who were known to be dead, which rose from 27.9% to 45.0%, while the proportion considered to be alive at the end of follow-up dropped from 72.1% to 53.7%.
The most evident changes resulting from tracing the Civil ID numbers occurred during 2000–2004, where the proportion of patients without Civil IDs and with unknown vital status was much greater (52.5%) than in 2005–2009 (3.1%) and in 2010–2014 (1.1%). This difference was probably due to several improvements in KCR registration practices, implemented over the years: the routine practice of obtaining the patients’ Civil ID during registration was progressively enforced, resulting in lower numbers of patients without ID numbers. The availability of Civil IDs is crucial to the implementation of our approach: a higher proportion of IDs made linkage between the cancer registry data and the patients’ vital status records more effective. Complete and accurate data on follow-up for vital status are essential to enable robust estimation of population-based cancer survival.

Observed survival (also called all-cause survival) can be useful in predictive tools and cost-effectiveness analyses, but it cannot be used to provide information on the probability of surviving a specific cancer, or to examine cancer survival trends within a given country, because its estimation also includes deaths from causes other than cancer (competing risks of death), which are likely to be decreasing over time due to continuous medical advancement. Similarly, observed survival estimates cannot be used for international comparisons of cancer survival, since background mortality also varies very widely between countries. Estimates of observed survival can also substantially overestimate the true observed survival if based only on deaths that were certified or coded as due to cancer, because deaths from causes other than cancer are not included in the computation.

The accuracy of death certification and of the coding of the underlying cause of death can vary between countries and over time within a country. These can arise from inaccuracies in the certification of death when compared with autopsy findings and clinical data, differences among physicians in completing the death certificates, and variations in coding the underlying cause of death. Inaccuracies in certifying the cause of death have been found in Kuwait when original death certificates were compared with the patients’ medical records, indicating poor agreement in the certification of death between the original and revised certificates.

Other differences in death registration practices can arise from changes to the death certificate forms used in a country, when coding rules are updated or revisions of the ICD are introduced, from changes in diagnostic terminology and measurement, or when there is a lack of training in certifying the cause of death.

For all these reasons, international comparisons of population-based cancer survival require statistical methods that do not rely on the cause of death (net survival). By eliminating the effect of background mortality, differences and trends in net survival reflect differences in cancer outcome, rather than differences in competing causes of death. Net survival estimates are thus better suited for international comparisons and to evaluate the impact of changes in health policy over time.

Our approach to obtain follow-up data through individual record linkage between the KCR database and the PACI database provides the most complete and up-to-date information on the vital status for almost all Kuwaiti cancer patients. However, to conduct this update manually is labour-intensive and time-consuming, and requires extensive quality checks on the manual entry and extraction of data. If performed efficiently, electronic linkage between the cancer registry database and the vital status data stored in the PACI database would be more accurate and timelier, but it is more complex and requires ministerial agreement and collaboration.

The use of this novel approach will provide the Kuwait Cancer Registry with more accurate and complete information on Kuwaiti cancer patients’ vital status, on a routine basis. It will allow clear distinction between patients who are alive and patients who are dead from any cause (i.e. not just those who have died from cancer). These data, together with the use of appropriate life tables of background mortality, would enable Kuwait to monitor routinely net survival trends and to compare cancer survival in Kuwait with survival in other countries.

Conclusion

Robust estimates of population-based cancer survival are crucial to assess the effectiveness of the health system in managing cancer. Complete and reliable follow-up data on the vital status of all cancer patients, regardless of the cause of death, are essential to produce robust cancer survival estimates that can be monitored over time and compared internationally.

Prior to this study, there was no system to update the vital status for all Kuwaiti cancer patients. With support from the Kuwait Ministry of Health and the Ministry of Interior/PACI this approach could be performed routinely by the KCR to ensure (a) that virtually all deaths of Kuwaiti cancer patients, regardless of the cause, are systematically recorded; and (b) that the follow-up on the vital status of all cancer patients is accurately updated through record linkage between the KCR database and the PACI database.

The ultimate goal would be to establish routine electronic linkages with the PACI system, making the process more efficient and timely.
Several countries in the Gulf Cooperation Council (e.g., Qatar, Bahrain and United Arab Emirates) have an administrative system similar to the one in Kuwait. This study may assist cancer registries in these countries to integrate the conceptual framework in their administrative system, to improve their follow-up procedures and to enhance the quality of cancer patients’ vital statistics.

**Ethical Approval**

Ethical approval [2015/276] was granted by the Standing Committee for Coordination of Health and Medical Research at Kuwait’s Ministry of Health.

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**References**


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