Can we rely on cancer mortality data? Checking the validity of cervical cancer mortality data for Slovenia

Maja Primic Žakelj¹, Vera Pompe Kirn², Fani Škrlec², Jožica Šelb³

¹Epidemiology Unit, ²Cancer Registry of Slovenia, Institute of Oncology, Ljubljana, Slovenia, ³Institute of Public Health. Ljubljana, Slovenia

Background. Valid inference on cervical cancer mortality is very difficult since – on the basis of death certificates – it is not always possible to distinguish between cervix, corpus and unspecified uterine cancer deaths. Our aim was to estimate the extent to which cervical cancer as the official cause of death reflects the true mortality from cervical cancer in Slovenia.

Material and methods. The data on 2245 deaths from cervix, corpus uteri, and uterus-unspecified cancers for the period 1985-1999 were linked to the Cancer Registry of Slovenia database from the mortality database of Slovenia.

Results. Officially, in the period 1985-1999, there were 878 cervical cancer deaths. The comparison of these causes of death with the cancer sites registered in the Cancer Registry revealed that they include only 87.7 % patients with a previous diagnosis of cervical cancer. Of 650 corpus uteri cancer deaths, 17.1 % of patients were registered to have cervical cancer, and of 717 unspecified uterine cancer deaths, 31.4 % were registered. Taking into account the correctly identified cervical cancer cases among cervical cancer deaths and misclassified cervical cancer deaths as corpus uteri and unspecified uterine, the corrected number of deaths would be 1106.

Conclusions. When evaluating the impact of cervical cancer mortality from national mortality rates, the stated underestimation should be taken into account. However, this does not hold for some other cancers.

Key words: cervix neoplasms - mortality; death certificates; registries; Slovenia

Received 5 November 2001 Accepted 25 November 2001

Correspondence to: Maja Primic Žakelj, M.D. Ph.D., Epidemiology Unit, Institute of Oncology, Zaloška 2, SI-1000 Ljubljana, Slovenia. Phone: +386 1 43 22 316; Fax: +386 1 43 10 271; E-mail: mzakelj@onko-i.si

Introduction

In our everyday practice, we often meet clinicians seeking the information on the official cause of death of their patients believing that this source is the most reliable. To prove that this is not always true we present our analysis of the data on cervical cancer mortality in Slovenia. Their validity is of special importance because mortality is the final measure of the effectiveness of cervical cancer screening programs in a country.¹

It has already been pointed out that a valid inference on cervical cancer mortality is very difficult since – on the basis of death certificates – it is not always possible to distinguish between cervix, corpus and unspecified uterine cancer deaths.² To estimate the extent to which cervical cancer as the official cause of death reflects the true mortality from cervical cancer in Slovenia, all causes of death from uterine cancers (ICD 8 codes 180 and 182) were matched with the diagnosis registered in the Cancer Registry of Slovenia (CRS). The CRS has been operating since 1950 and is a unique basis for such epidemiological analyses.³

The official crude mortality rate from cervical cancer increased from 12.5/100,000 in

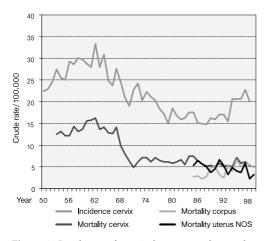


Figure 1. Incidence of cervical cancer and mortality from cervical, corpus and unspecified uterine cancer; 1950-99.

1953 to 16.3/100,000 in 1962. Since then, it was slowly decreasing (Figure 1). In 1968, it was the first time below 10/100,000. In 1997, it was 6.2/100,000 and in 1999, $5.1/100,000.^{4,5}$

Material and methods

Data on 2245 deaths from cervix, corpus uteri, and uterus-unspecified cancers in the period 1985-1999 were linked to the Registry database from the mortality database of Slovenia.⁵ During the calendar period under study, the eighth revision of the International Classification of Diseases (ICD) was used in the CRS, while the ninth and tenth in coding cancer deaths. 6,7,8 The classification of cancer deaths was thus re-coded according to the eighth revision. The linkage was based on PIN. The cause of death was compared to the diagnosis registered in the Registry. In case more than one cancer had been registered, the gynaecological cancer (ICD 8 codes 180-184) was considered as the cancer of interest irrespective of the status of cervical cancer at death of the patient.

Results

Officially, in the period 1985-1999, there were 878 cervical cancer deaths. The comparison of these causes of death with the cancer sites registered in the Cancer Registry revealed that they include only 770 (87.7%) patients with a previous diagnosis of cervical cancer. But of 650 corpus uteri cancer deaths, there were 111 (17.1%) patients registered to have cervical cancer and of 717 in whom unspecified uterine cancer was recorded as the cause of death, 225 (31.4%) were registered to have cervical cancer. Taking into account the correctly identified cervical cancer cases among cervical cancer deaths and misclassified cervical cancer deaths as corpus uteri and un-

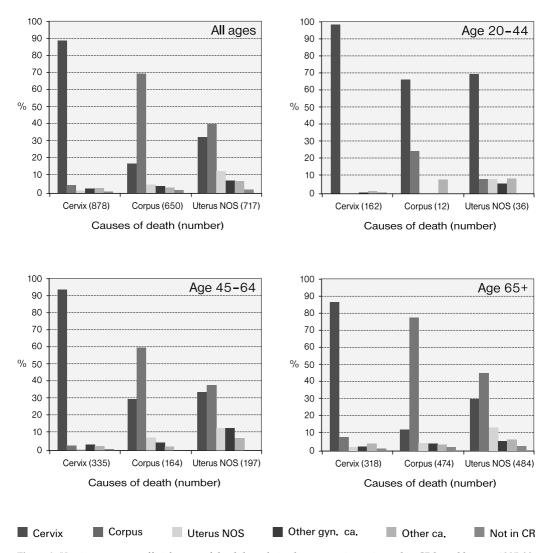


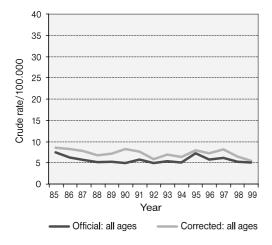
Figure 2. Uterine cancer as official cause of death by subsite, by cancer site registered in CRS, and by age; 1985-99.

specified uterine, the corrected number of deaths would be 1106.

Hence, the official cervical cancer mortality would be underestimated by 26%. This underestimation differs by age groups. In women, aged 20-44 years, nearly all deaths from cervical cancer (158 of 162) were confirmed at the Registry. However, the death of 33 young patients who had been registered as cervical cancer cases was attributed to the corpus uteri (8) and uterus unspecified cancer

(25). The official data on cervical cancer mortality would thus be underestimated by 17% in this age group, while in the age group 45-64 years and in the oldest one for 23 and 33%, respectively (Figure 2).

The trend of official and corrected cervical cancer mortality in the period 1985-1999 is presented in Figure 3. The shape of the time trend was not appreciably affected by the underestimation of mortality.



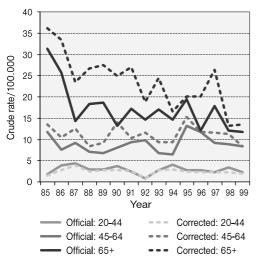


Figure 3. Trends in official and corrected cervical cancer mortality; 1985-99.

Discussion

Though mortality data are available for more countries than incidence data, they have several disadvantages. Death certification is less precise in terms of cause of death than the incidence data recorded by cancer registries. 9,10 In cervical cancer we face also the problem of erroneous cause of death statements and of a varying proportion (20-65%) of cervix cancer deaths that are coded to "uterus not otherwise specified". 2,11

Our study revealed that among "uterus not otherwise specified" cancers about a third are attributable to cervical cancer. Also, among cervical cancer deaths not all cancers have been diagnosed as this cancer. After combining the erroneous cause of death statements and inexact coding, the official mortality statistics underestimates cervical cancer deaths for about a quarter.

In mortality statistics the underlying cause of death is coded according to the rules of the International Classification of Diseases currently in use. In most patients who have ever been diagnosed with cancer, this disease is recorded on death certificate as the underlying cause of death. But it depends on the doctor, completing the death certificate, whether cancer site is determined properly and, consequently, properly coded in mortality statistics.

It has been shown that the degree of misclassification varies with cancer site, being greater for those that are more difficult to diagnose. ¹⁰ It is well known that the reliability of diagnoses recorded on death certificates depends on the place of death, being more accurate for those who died in hospitals and where the autopsy had been performed.

It was assumed that, in women below the age of 45 years, most deaths from uterine cancers are due to cervical neoplasm; so, many international comparisons take into account all uterine cancer deaths. 2,12,13 Our study provides a numerical estimate for this hypothesis: officially, there were 210 uterine cancer deaths in this age group in the period under study, of which only 192 were identified as cervical cancer cases in the CRS. Older women less often dye in hospitals than younger ones. This could also explain a greater proportion of misclassified cervical cancer deaths in older age group. Namely, in case of the patients who did not dye in the hospital, the physician, certifying death, was not always the family doctor or the doctor who treated the patient, but the one who was

on duty and did not know the medical history of the deceased in details; so, the cause of death may be less precise.

Our study suggests that the extent of misclassifications and improper or less precise coding of death causes have not changed appreciably in the time period observed, and the curve shape of the time trend in cervical cancer mortality was not considerably affected. But it may happen that by improving death certification reliability, changes in mortality from cervical cancer may lead to an apparent increase, as already experienced in some countries.¹¹

Conclusion

When evaluating the impact of cervical cancer mortality drawn from national mortality rates, the underestimation as stated above should be taken into account. However, this is not true for some other cancers. In lung cancer, in the CRS during the data cleaning proces, we observe, each year, an overestimation of death officially attributed to lung cancer.

Due to misclassifications described in cancer mortality data and similar deficiencies in the data on suicide and other injuries and poisonings, infant mortality data and maternal mortality, the Institute of Public Health plans to delay the publishing of the official edition on mortality for at least one year. It is hoped that this time will be enough to link mortality data with other databases to render mortality data more reliable. But in monitoring long term trends in mortality this change will have to be taken into account.

Acknowledgement

We appreciate the financial support from the European Commission, contract grant number SI2.305757 (2000 CVG2-029).

References

- 1. Prorok PC, Kramer BS, Gohagan JK. Screening theory and study design: the basics. In: Kramer BS, Gohagan JK, Prorok PC, editors. *Cancer screening. Theory and practice*. New York: Marcel Dekker Inc., 1999. p. 29-53.
- Levi F, Lucchini F, Negri E, Franceschi S, la Vecchia C. Cervical cancer mortality in young women in Europe: patterns and trends. *Eur J Cancer* 2000; 36: 2266-71.
- Pompe-Kirn V et al. Cancer incidence in Slovenia 1998. Ljubljana: Institute of Oncology, 2001. p. 5-6.
- 4. Pompe-Kirn et al. *Cancer incidence in Slovenia 1993*. Ljubljana: Institute of Oncology, 1996. p. 14.
- 5. *Mortality data-base*. Ljubljana: Institute of Public Health of the Republic of Slovenia, 2001.
- World Health Organisation. *International classifica*tion of diseases: 8th revision. Geneva: World Health Organisation, 1967.
- World Health Organisation. *International classification of diseases*: 9th revision. Geneva: World Health Organisation, 1977.
- World Health Organisation. *International classification of diseases*: 10th revision. Geneva: World Health Organisation, 1992.
- Parkin DM, Whelan SL, Ferlay J, Raymond L, Young J. Cancer incidence in Five Continents. *IARC* Sci Publ 1997; 143: 45-53.
- 10. Dos Santos Silva I. Cancer epidemiology: principles and methods. Lyon: IARC, 1999. p. 31-2.
- 11. Smith J, Parkin DM. Evaluation and monitoring of screening for cervix cancer: time trends. In: Sankila R, Demaret E, Hakama M, Lynge E, Schouten LJ, Parkin DM, editors. Evaluation and monitoring of screening programmes. European Commission, Europe against cancer programme. Luxembourg: Office for Official Publications of the European Communities, 2001. p. 59-76.
- 12. Cuzick J, Boyle P. Trends in cervix cancer mortality. *Cancer Surv* 1988; 7: 417-39.
- 13. Levi F, Lucchini F, Negri E, Boyle P, La Vecchia C. Cancer mortality in Europe, 1990-1994, and an overview of trends from 1955 to 1994. *Eur J Cancer* 1999; **35:** 1477-516.