

CHAPTER 3

CAUSE OF DEATH STATISTICS: PRODUCTION PROCESS, QUALITY AND INTERNATIONAL COMPARABILITY

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Background

The data analysed in this atlas are based on national causes of death (COD) statistics. COD statistics constitute a major source for comparing the health characteristics of European populations. The popularity of COD data as indicators for the status of health is readily explained by their availability. International cause of death data are published annually by international agencies such as the Statistical Office of the European Communities (EUROSTAT) or as the World Health Organization (WHO) using standardised lists of categories. COD data often provide the only information available for comparison of health status both between countries and within countries at a regional level. In each country, the production of these data involves two main stages: certification and coding of causes of death.

Results of comparisons presented in this atlas may be used as a starting point to investigate the sources of observed differences, (e.g. behavioural, cultural, ecological factors) or to assess the effectiveness of health prevention policies and the quality of health care. Because COD statistics include all deaths, the problems of bias and lack of representativeness due to sampling are avoided. Furthermore, some procedures for the collection of COD data are relatively homogeneous between European countries (WHO death certificate model, International Classification of Diseases, etc). In spite of these common features, important quality and comparability issues remain. Before

attempting to interpret inter-country or regional differences in mortality rates in terms of aetiological factors, it is important to be aware of the possible biases affecting the comparability of the data.

Sources

This chapter is based on information collected through various studies undertaken within the context of the European Commission (EC), whose statistical agency, EUROSTAT has created a specific Task Force dedicated to cause of death statistics. The main objective of this Task Force is to improve the quality and comparability of cause of death data within the EU. DG SANCO (that part of the EC dedicated to health) has supported this type of research through the Health Monitoring Program. A specific recent DG SANCO project has focused on the problem of comparability of COD statistics (Jougl et al., 2001). The objective was to complete investigations on certification practices among EU members and to make recommendations to Member States on improvement in data quality and comparability. This work was carried out by a network of experts from all the EU countries. The information considered consisted of (i) a survey on certification practices in each country (situation and opinion); and (ii) an international literature review of papers on quality and comparability of cause of death statistics. For codification, EUROSTAT funded a specific study to describe the existing coding systems (Pavillon et al., 1998); it made a number of recommendations and guidelines for the implementation and use of automated coding systems.

Certification of cause of death

The certification process begins with the death and ends when the death certificate is completed. In every European country, the medical certification of death is a statutory requirement.

The document used to certify a death is the medical death certificate (in addition to the administrative death certificate that permits the notification of the death in the civil register). The objective of the medical death certificate is to allow the certifier to enter clearly and thoroughly the causes of death. Most of the time, physicians are in charge of the certification. In the case of non-natural deaths, the certification could be made by forensic physicians or in some countries by legal professionals, such as

coroners in England. The international medical death certificate recommended by WHO (WHO, 1992; Figure 3.1) is divided into two parts, one designed for entering the sequence of diseases leading to death and the other for mentioning other contributing conditions. The certifier must also specify, for each cause of death entered, the time interval between onset and death.

Disparities between countries and possible biases

The overall implementation of the WHO international form of death certificate is on-going but the number of lines in part I, used to describe the morbid process leading to death, still varies across countries (from 2 to 4 lines).

Figure 3.1: International form of medical certificate of cause of death (WHO ICD-10)

Cause of death	Approximate interval between onset and death
I	
Disease or condition directly leading to death* (a).....
due to (as a consequence of)	
Antecedent causes (b).....
Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last (c).....
due to (as a consequence of)	
(d).....
<hr/>	
II	
Other significant conditions contributing to the death, but not related to the disease or condition causing it
.....
* <i>This does not mean the mode of dying, e.g. heart failure, respiratory failure. It means the disease, injury, or complication that caused death.</i>	

The type of additional information available on the death certificate differs between countries (autopsy, surgery, work accident, pregnancy, occupation, etc). Information on autopsy is often collected on the death certificate but the results of autopsy are not systematically included in final statistics (except in Finland where the results of the autopsy must be included in the death certificate). Moreover, the proportion of autopsies varies substantially between countries, from 8% in The Netherlands and Germany to 35% in Sweden and Finland. The indication of surgery is listed in very few countries. In some countries, mainly in Scandinavia, these types of additional information can be available through specific registers. Risk factors such as alcohol abuse or drug addiction are rarely systematically collected. Among the countries using a specific certificate for death in very young babies, the definition of the considered age-period differs (stillbirth, perinatal, neonatal, infant).

In most countries, the death certificate includes guidelines to help certifiers. Usually, they consist of a text explaining the certification rules and of examples. The certification training practices vary markedly (from examples to video) as well as the procedures of queries to the physician when death certificates are incomplete or ambiguous.

Another factor that may result in an important source of bias in inter-country comparisons is the variation of the frequency with which ill-defined or unknown causes of death are reported. This frequency ranges from 1% in England, Finland and Sweden to 6% in Denmark and France. For age groups younger than 25 years, the disparities are even more marked: from 3% in Italy and Spain to 20% in France (Pavillon, Jouglu & Maguin, 1994). In addition to these general differences in the percentage of imprecise conditions, there are also differences for unspecified causes within given chapters of the ICD classification of disease.

Specific studies on the certification process

The usual method of assessing inter-country variations in certification practices consists of asking a random sample of doctors to complete death certificates for the same case histories. This

method can help to determine whether physicians from different countries differ in certifying and selecting the underlying cause of death for the same cases. The information presented to the physician is the diagnostic information that would normally be available to hospital doctors or general practitioners when certifying a death. These studies are primarily oriented towards assessing certification practices but they also allow the study of coding practices, since the certificates are coded both by national offices and by WHO reference centres. Such investigations are still rare (Gittelsohn & Royston, 1982; Jouglu & Pavillon, 1997; Mackenbach, Van Duyn & Kelson, 1987). Before the 1980s, two studies had been performed, one in 1964 involving three countries (Reid & Rose, 1964) and the other by WHO in 1970 involving five countries (WHO, 1970).

More recently, the case history method has been used to investigate certification practices among EU countries for three types of cause of death: cancers (Kelson & Farebrother, 1987), respiratory diseases (Kelson & Heller, 1983) and diabetes (Balkau et al., 1993). For the study on cancers, a set of ten case histories was sent to samples of doctors in eight EU countries. After certification and coding by national coding offices, on average, 83% of all cases received a correct underlying cause code. There were important differences in certification between certain countries. The degree of inter-country variation was lower for cancers than for respiratory diseases. The study of cancer certification concluded that the differences observed may have serious implications for the international comparability of mortality data for cancers of the cervix and uterus (misclassifications between the two categories were attributable to doctors' entries). The main limitation of studies using case histories is the difficulty of ensuring external validity. Neither the case histories, in their content or complexity, nor the physician's responses are necessarily representative of the "real situation". Moreover, the analyses for cancer were restricted to fairly broad diagnostic categories and the case histories may not have been sufficiently sophisticated to enable the detection of subtle variations in diagnosis.

Studies have shown that the nature and amount of medical information entered on death certificates vary between countries, for example:

the way the diagnosis is established; the mean number of causes listed by the certifying physician in each certificate (Pavillon & Jouglu, 1997); and the degree of consistency of the certification process. For example, in the context of a specific study concerning certificates mentioning diabetes, the proportion of certificates “properly completed” (i.e. for which coding required simply the application of the ICD general rule) varied from more than 90% for The Netherlands to 60% for Germany (Jouglu et al., 1992). Other studies have noted marked differences between doctors’ certificates and autopsy findings.

If international studies directly aimed at investigating the biases due to national differences in certification practices are rare, a number of studies, undertaken on a national basis, have examined the validity of COD data. These studies compare the diagnosis entered on the death certificate with the one found from other medical sources (e.g. autopsy findings, medical records, retrospective inquiry to the certifying physician). Some of these studies observed large discrepancies in the certification of cardiovascular diseases but fewer differences have been found for cancers. A general review of these studies is available from the SANCO project (Jouglu et al., 2001). Pulmonary cancers, generally the most frequent type of cancer for males, are characterised by an acceptable concordance between mortality and morbidity information. In a longitudinal survey of an elderly population, 83% of the lung cancers identified by a registry or during hospitalisation were mentioned on the death certificate (Stang et al., 1999). These results have been confirmed by other longitudinal studies (Goldacre, 1993; Wells & Mannimo, 1996).

For breast cancer, the most frequent type of cancer for females, the studies based on a comparison of the underlying cause of death from the national statistical office with that produced by review of clinical care records concluded that the official statistics showed a slight underestimation of deaths (Garne, Aspegren & Balldin, 1996; Chamberlain et al., 1991; Brinkley, Haybittle & Alderson, 1984; Rutqvist, 1985; Nystrom et al., 1985).

For other cancer types, various biases may occur: imprecise diagnosis (pancreas, uterus

cervix-corporis, thyroid); misclassification between sites (stomach-oesophagus, large bowel-small intestine, urinary bladder-kidney, liver-hepatitis-cirrhosis); sites leading to metastasis (prostate-bone, lung-brain, breast-bone); and co-morbidity in elderly populations (prostate, pancreas). Apart from these potential sources of biases, low rates such as those for cancers of the skin, larynx, testis and thyroid, may show wider fluctuations than those for cancers with higher rates because of random variability in the small numbers of deaths.

Coding of cause of death

The purpose of the coding process is to select the underlying cause of death and to translate the literal text of the listed conditions into ICD codes (WHO 1977, 1992). The selection of the underlying cause is an essential stage since the available international data used for between-country comparisons are based on this single underlying cause. The ICD international coding rules are intended to help to select this underlying cause in difficult cases.

All countries use the ICD codes to code the cause of death but they can apply different revisions of the ICD. In the 1990s, there were two revisions that were used in Europe (ICD-9 and ICD-10) that, in spite of common principles, have important differences – such as the number of codes (around 6,000 in ICD-9 and 12,000 in ICD-10). In the mid-1990s, most countries still coded using ICD-9; and the dates of any implementation of ICD-10 have varied across countries. This simultaneous use of different revisions of the ICD may lead to problems of comparability.

Most countries are now routinely coding causes other than the underlying cause. This multiple coding is very useful because it facilitates the assessment of the consistency of the certification process and permits comparability studies based on multiple cause analysis. However, the total number of coded causes varies (and only a few countries code *all* the causes of death).

In most countries the selection of the underlying cause of death in the mid-1990s was still done manually by trained coders using the ICD rules,

but an increasing number of countries began to use, or planned to implement, an automated coding system. This development is very important for two reasons. It will lead to marked improvement in the inter-country homogeneity of coding; and it will facilitate the coding of all the conditions for each death.

The usual method of assessing the between-country comparability of cause of death coding involves the submission of identical sets of certificates to different countries and comparing of the results of the national coding with a reference centre coding. Such testing is still rather rare. A first study in 1965 involved six countries and 1000 certificates (WHO, 1967). A more recent investigation studied the coding of certificates concerning cancer. This study compared the national coding of the underlying cause of death of a random set of 1243 death certificates that mentioned cancer. Seven countries participated in the test coding of these certificates in an initial study based on ICD-8 (Percy & Dolman, 1978). Results showed that for nearly half the certificates, the assigned underlying cause differed (at the 3-digit level of the ICD). As a result, ICD-9 contained more specific rules concerning cancer coding. The study was repeated after ICD-9 implementation and as part of the preparation of ICD-10 (Percy & Muir, 1989). Nine countries coded the original 1243 death certificates. Differences at the 3 digit-level ranged from 10% for England to 16% for Germany and indicated a marked improvement since the first study. The Netherlands selected cancer as the underlying cause least often (90% of the certificates) and France selected cancer most often (96%). To evaluate the statistical effect of these differences in coding practices on published international mortality data, "corrected" mortality rates were computed using the proportion of deaths coded to cancer by the US as the standard. French mortality rates were most affected with a decrease of 9% in death rates for cancer after correction.

Conclusions

The literature review has shown that, despite many recommendations, very few investigations have examined the international variation in certifying and coding practices and their

consequences on published figures. These types of investigations may primarily focus on indicators specifically useful for health planners (e.g. premature deaths, avoidable deaths) or on causes of death with specific problems of comparability. These studies should be based on different types of methodologies such as certification of cases histories, confidential inquiries to the certifying physicians and recoding of samples of death certificates.

In this context, the SANCO project outlined important recommendations to improve the situation:

- the international form of death certificate with four lines recommended in ICD-10 should be adopted as widely as possible. The increased number of lines to describe the causes leading to death may allow for the death process to be more completely described, thus improving the quality of the certification and the validity of the coding process
- development of international guidelines for certifiers (medical examiners and coroners) will also improve homogeneity. Physicians need better initial and continuing training (medical school, occupational training, handbooks, etc) on how to complete the death certificate
- the querying of certifying physicians is recognised as an important method of improving data accuracy and training physicians about correct entry of causes of death
- information on autopsies should be systematically recorded on death certificates
- additional information should be collected to tackle the issue of unknown and ill-defined causes. It may include, in particular, specific national problems linked to legal investigations and confidentiality rules applied for certification
- the introduction of the 10th revision of the ICD should provide a good opportunity for

an international effort towards standardisation and improvement of mortality statistics. This revision is an important change compared to the 9th revision (the number of items doubled)

- the implementation of automated coding systems, similar to those used in the US to select the underlying cause of death,

will markedly improve the international comparability of mortality statistics and also the quality and consistency of national statistics over time. At the same time, ad hoc national coding rules need to be discussed and bridge coding between ICD-9 and ICD-10 and between manual and automated coding should be implemented.

References

- Balkau B, Jougl E, Papoz L and the Eurodiab study group (1993). European study of the certification and coding of causes of death of six clinical case histories of diabetic patients. *International Journal of Epidemiology* 22:116-126.
- Brinkley D, Haybittle JL & Alderson MR (1984). Death certification in cancer of the breast. *British Medical Journal* 289:465-467.
- Chamberlain J, Coleman D, Ellman R et al. (1991). Verification of the cause of death in the trial of early detection of breast cancer. *British Journal of Cancer* 64:1151-1156.
- Garne JP, Aspegren K & Balldin G (1996). Breast cancer as cause of death – a study over the validity of the officially registered cause of death in 2,631 breast cancer patients dying in Malmö, Sweden 1964-1992. *Acta Oncologica* 35:671-676.
- Gittelsohn AM & Royston PN. *Annotated bibliography of cause of death validation studies (1958-1980)*. Washington: US Government Printing Office, 1982 (Vital and Health Statistics, series 2, 89).
- Goldacre MJ (1993). Cause-specific mortality: understanding uncertain tips of the disease iceberg. *Journal of Epidemiology & Community Health* 47:491-496.
- Jougl E, Papoz L, Balkau B and the Eurodiab Subarea C study group (1992). Death certificate coding practices related to diabetes in European countries. *International Journal of Epidemiology* 21:343-351.
- Jougl E & Pavillon G. International comparability of causes of death data. In: Wunsh G & Hiancioglu A, eds. *Morbidity and Mortality data-problems of comparability*. Hacettepe, Hacettepe University-Institute of Population Studies, 1997:75-95.
- Jougl E, Rossollin F, Niyonsenga A et al. (2001). Comparability and quality improvement of European cause of death statistics. Luxembourg, European Commission, DG SANCO, agreement edc dgV/f3 soc 98 20108.
- Kelson MC & Farebrother M (1987). The effect of inaccuracies in death certification and coding practices in the EU/EEA on international cancer mortality statistics. *International Journal of Epidemiology* 16:411-414.
- Kelson MC & Heller RF (1983). The effect of death certification and coding practices on observed differences in respiratory diseases mortality in 8 EU/EEA countries. *Revue d'Epidémiologie et Santé Publique* 31:423-432.
- Mackenbach J.P, Van Duyn WM & Kelson MC (1987). Certification and coding of two underlying causes of death in the Netherlands and other countries of the European Community. *Journal of Epidemiology & Community Health* 41:156-160.
- Nyström L, Larsson LG, Rutqvist LE et al. (1985). Determination of cause of death among breast cancer cases in the Swedish randomized mammography screening trials – a comparison between official statistics and validation by an endpoint committee. *Acta Radiology & Oncology* 35:671-675.

- Pavillon G, Coleman M, Jouglu E & Kardaun J. Coding of causes of death in the European Community – Eurostat project on causes of death statistics, 96/s 99-57617/en. Luxembourg, Eurostat, 1988.
- Pavillon G & Jouglu E. Report on the International Collaborative Study on Multiple Causes Analysis ess/icd/c/97.18. Geneva, World Health Organization, 1997.
- Pavillon G, Jouglu E & Maguin P. Multiple causes of death analysis – proposition of routine data publication. Meeting on multiple causes of morbidity and mortality, WHO collaborating centres for the classification of diseases, London, 1994.
- Percy C & Dolman A (1978). Comparison of the coding of death certificates related to cancer in seven countries. *Public Health Reports* 93:335-350.
- Percy C & Muir C (1989). The international comparability of cancer mortality data. *American Journal of Epidemiology* 129:934-946.
- Reid DD & Rose GA (1964). Assessing the comparability of death statistics. *British Medical Journal* ii:1437-1439.
- Rutqvist LE (1985). Validity of certified causes of death in breast carcinoma patients. *Acta Radiology & Oncology* 24:385-390.
- Stang A, Glynn RJ, Gann PH et al. (1999). Cancer occurrence in the elderly – agreement between three major data sources. *Annals of Epidemiology* 9(1):60-67.
- Wells C & Mannimo DM (1996). Pulmonary fibrosis and lung cancer in the United States: analysis of the multiple cause of death mortality data, 1979 through 1991. *Southern Medical Journal* 89(5):505-510.
- World Health Organization. The accuracy and comparability of death statistics. *WHO Chronicle*, 1967, 21:11-17.
- World Health Organization. Study on the certification of causes of death. Geneva, WHO, 1970.
- World Health Organization. *International Classification of Diseases, Ninth Revision*. Geneva, WHO, 1977.
- World Health Organization. *International Classification of Diseases and Related Health Problems, Tenth Revision*. Geneva, WHO, 1992.