

Counting the dead and what they died of

Editor – The paper published by Mathers et al. in the *Bulletin* addresses the important matter of the quality of mortality data.¹ The quality of data supplied by countries to WHO is evaluated as high, medium, or low. This evaluation is based on two main criteria: completeness of reporting and proportion of deaths assigned to ICD codes that the authors consider ill-defined. We have major concerns about the methods used by Mathers et al.

1. Construction of the quality measure:

- Data quality is considered to be high for countries with >90% completeness of reporting and <10% ill-defined causes. This is an unstable measure. For example, data quality for a country with 91% completeness and 9% ill-defined causes is rated as “high”, while one with 100% completeness and 11% ill-defined causes has “medium” quality. In the first case, however, the data loss is 18% (9% lack of completeness and 9% ill-defined causes of death), but in the second case only 11% (ill-defined causes).
- The “medium” quality class is very wide. A country with 100% completeness, 100% coverage and 11% ill-defined causes gets a “medium” rating, as does a country with 90% completeness, 50% coverage and 17% of ill-defined causes.

2. Quality of certification vs quality of coding:

- The proportion of deaths assigned to ill-defined causes is used as a measure

of the quality of coding. However, this proportion is more likely to be the result of the quality of certification than that of the coding.

3. Selection of causes counted as ill-defined:

- Some codes that ICD-10 does not consider to be ill-defined are classified as such; for example, sudden infant death syndrome (R95) and malignant neoplasms of independent multiple sites (C97).
- They do not consider typically terminal conditions to be ill-defined, such as septicæmia, pulmonary embolism, venous thrombosis, pneumonia, pulmonary oedema, and urinary tract infection. In a significant number of cases these are not underlying causes but complications of other conditions.
- Generalized and unspecified atherosclerosis (ICD-10 code I70.9) is considered to be ill-defined. This may be fully justified for younger people but hardly for those dying at an advanced age.
- Events of undetermined intent (ICD-10 codes Y10–Y34) are also considered to be ill-defined. However, in countries with a well-functioning medico-forensic system, deaths from such causes are better investigated and certified than most.

4. Comparisons between countries without age adjustment:

- Mathers et al. note that “the selection of a single underlying cause of death is frequently problematic in elderly people, who often have had several chronic diseases that concurrently led to death”. Surprisingly, however,

they do not adjust for differences in the age–sex distribution of the population when calculating the proportion of deaths attributed to ill-defined causes. In Sweden, 10.3% of deaths are due to ill-defined causes as defined by Mathers et al. However, a significant number of these deaths involve those aged >85 years, and the average of the five-year age-group rates is 8.1%.

Strengthening the quality of vital registration systems and of mortality statistics is an urgent need. We believe, however, that the methods employed in this paper do not yield sufficiently reliable estimates of differences in data quality. Also, the definition of ill-defined causes could, encourage coding procedures that are at variance with ICD rules and guidelines. ■

Competing interests: none declared.

Lars Age Johansson,^a
Gérard Pavillon,^b Robert Anderson,^c
Donna Glenn,^d Clare Griffiths,^e
Donna Hoyert,^f Graham Jackson,^g
F. Sam Notzon,^h Cleo Rooney,ⁱ
Harry M Rosenberg,^j Sue Walker,^k
& Stefanie Weber^l

Capturing health information — a coding perspective

Editor – In discussing the current status of global reporting of mortality data, Mathers et al.¹ examine several indicators of quality and completeness of the coded data; however, they do not deal with the influence that the capacity, knowledge and skills of individual

^a Senior Statistician, Board of Health and Welfare, Stockholm, Sweden.

^b Research Engineer, Centre d'épidémiologie sur les causes médicales de décès, 44 chemin de Ronde, Le Vésinet, France, Correspondence to this author (email: pavillon@vesinet.inserm.fr).

^c Chief, Mortality Statistics Branch, National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC), Atlanta, GA, USA.

^d Chief, Mortality Medical Classification Branch, NCHS, CDC, Atlanta, GA, USA.

^e Branch Head, Mortality Statistics, Office for National Statistics, England and Wales

^f Health Scientist, NCHS, CDC, Atlanta, GA, USA.

^g Head of Vital Events and National Health Statistics, General Register Office for Scotland.

^h Director, International Statistics Program, NCHS, CDC, Atlanta, GA, USA.

ⁱ Medical Epidemiologist, Office for National Statistics, England and Wales.

^j Formerly: Chief, Mortality Statistics Branch, NCHS, CDC, Atlanta, GA, USA.

^k Associate Director, National Centre for Classification in Health (Brisbane), Brisbane, Australia.

^l Deutsches Institut für Medizinische Dokumentation und Information, Medizinische Klassifikationen, Cologne, Germany.

“coders” of health data can have on the quality of the resultant information.

Coders are responsible for translating the documented causes of death into the codes listed in the ICD-10² or its previous iterations. This is to enable reporting of standardized health information for use at local health service level and also at national, regional and international levels. Use of ICD facilitates the storage, retrieval and analysis of data and their comparability.

In general, cause of death information is recorded by a medical officer on the cause of death certificate recommended by WHO. However, in some countries, a different certificate may be used, or recording causes of death may rely on lay reporting or the results of verbal autopsies. In all of these situations, coders transform the documented information into standardized ICD codes.

Mortality coding is a highly specialized task that requires a thorough understanding of the coding rules in order to assign a code for an underlying cause of death. Thus the knowledge of the coder is vital to the accuracy of the resultant statistical data.

There are major differences among WHO Member States in terms of the training they provide to coders to ensure that they understand and can accurately apply the conventions and guidelines implicit in ICD. In the most developed countries, coders of mortality are generally highly qualified professionals who work in a statistical office or the Ministry of Health. Coders in such countries may learn their craft at university or community college and are employed specifically to code. They learn to abstract relevant data, use the coding rules and guidelines to determine an underlying cause of death, and produce an ICD code that accurately reflects this cause. They need a knowledge of medical terminology and medical science to ensure that the underlying cause selected for coding is in line with the requirements documented in vol. 2 of ICD-10.

In contrast, in small and developing countries, coders may not have been given any coding education at all or only have followed a short training programme. Also they may be low-paid

clerical workers who not receive appropriate recognition and support for their specialized role. In some countries, even a basic level of training is not available.

WHO has a series of collaborating centre networks which function cooperatively to support work on WHO's priority health programmes. The WHO Collaborating Centres for the Family of International Classifications (WHO-FIC) operates through various national and regional centres that have expertise in health classification, coding, and terminology development and application. The WHO-FIC Education Committee (http://www.cdc.gov/nchs/about/otheract/icd9/nacc_ed_committee.htm) assists and provides advice to WHO in improving the quality and use of the WHO classifications in Member States by developing training and certification strategies, identifying best training practices, and providing a network for sharing expertise. The Committee's work is based on the premise that good health outcomes depend crucially on the availability and use of good health information.

The Committee has joined forces with the International Federation of Health Records Organizations (www.ifhro.org) to work on addressing the issue of coder development. The resulting Joint Committee's work is currently focused on specifying a standard curriculum for use by educators in training courses on coding. Educators who have relevant modules have been invited to submit them for possible approval in order to be considered as meeting the Joint Committee's "gold standard" for training. Further submissions of materials are welcomed. (More information is available from the Co-Chairs of the Joint Committee (Sue Walker) or Margaret Skurka (Indiana University Northwest (email: mskurk@iun.edu)). Coders who complete the full curriculum, taught by approved educators, will be eligible to apply for a certificate that acknowledges their competence, which should assist them in gaining recognition for their work. A certificated education level for coders provides a uniform base for building universal coding consistency and therefore information comparability. Ultimately, it is hoped to improve

the quality, consistency and timeliness of the coded mortality data on which so many decisions are based. Finally, certified education of coders can enhance understanding of the vital role that they play in the process of creating health information and hopefully bring about improvements in their working conditions and appreciation of their needs for support and encouragement. ■

Competing interests: none declared.

Sue Walker^a

Authors' response

Editor – We welcome the interest and debate that our paper¹ has stimulated. Our two major aims were to promote interest in assessing and addressing quality issues in cause-of-death attribution and to facilitate better interpretation of such data. We comment here on the specific points raised by Johansson et al.

Construction of the quality measure

We used three quality categories only in the print version of the paper. The details provided in Table 2 of the paper (available from: <http://www.who.int/bulletin>) enable readers to decide whether or not data for some countries are close to the boundaries of these categories. Our analyses of data from the WHO mortality database show that patterns of causes of death from countries with >90% completeness are stable and allow good inferences to be drawn on the cause of death pattern in the total population. Thus level of incompleteness and per cent coded to ill-defined categories should not be simply added as a measure of “data loss” as suggested by Johansson et al.

Quality of certification versus quality of coding

We have only analysed the data available to WHO, which consist of ICD-coded deaths by age and sex. It is not possible to infer from these data whether certification or coding is responsible for excessive proportions of ill-defined causes. Good-quality coding practice should include procedures to query and correct

^a National Centre for Classification in Health, Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland 4059, Australia (email: s.walker@qut.edu.au).

as far as possible certificates that yield an ill-defined code for the underlying cause. We assume that countries with high proportions of ill-defined categories do not implement such verification procedures at the coding stage. We used the term “quality of coding” to cover both certification and coding, but agree that it would be more accurate to refer to “quality of certification and coding”.

Selection of causes counted as ill-defined

In selecting broad groups of ill-defined causes, we were constrained by the fact that a number of countries still report data in much aggregated form. For example, sudden infant death syndrome (SIDS) is not reported separately if the country uses the ICD-10 condensed list 1. We thus examined the proportion of deaths assigned to the entire chapter for “symptoms, signs and ill-defined conditions”. Similarly, some of the causes proposed by Johansson et al. as ill-defined could not be examined across all countries. This type of analysis is certainly feasible for countries reporting data using detailed ICD codes.

Although a more refined analysis would exclude SIDS, it represents <0.5% of ill-defined deaths in those countries where the proportion of ill-defined deaths is high. Exclusion of SIDS would make no real difference to the results we reported. Similarly, while ICD-10 code C97 may not represent an ill-defined code for some deaths, it represents a highly variable proportion of total ill-defined cancer deaths, ranging from ca 1% in Finland or Denmark, to 20–30% in France, Germany, and Switzerland. This suggests that it may be overused in some countries. In any case, its exclusion from the analysis would make little difference to our results.

For many of the additional causes mentioned by Johansson et al. it is not easy to decide statistically what proportion should be treated as ill-defined codes rather than appropriate underlying causes of death. Such quality issues are probably better addressed through specific recoding studies at country level.

We did not retain atherosclerosis (I70.9) as an underlying cause of death

as it is more important from a public health perspective to know the nature of the resulting disease. ICD-10 Modification Rule C (Linkage) specifically moves assignment away from atherosclerosis and hypertension to the disease manifestations, principally cardiac, renal or cerebrovascular. The overuse of atherosclerosis as an underlying diagnosis does indicate a departure from ICD coding rules, and it is thus appropriate to include generalized atherosclerosis among the ill-defined cardiovascular codes. It would probably also be appropriate to treat I10 (Unspecified (primary) hypertension) in the same way.

Events of ill-determined intent (Y10-34) represent ca 0.1% or less of deaths in countries with well functioning medico-forensic systems (e.g., 0.05% of deaths in Australia). This probably represents a lower limit of deaths where intent is not possible to determine. As this category has a median value of 0.5% and ranges up to 5% in some countries, high values are likely to indicate inadequate medico-forensic investigation. While it would be possible to estimate an irreducible minimum for this category and subtract it for all countries, this would make little difference to the analysis we presented, and we opted for a simple and readily understood indicator.

Comparisons between countries without age adjustment

Differences in the age distribution of deaths do not explain the variations in use of ill-defined categories that we reported. For example, around 6.7% of deaths in Sweden are coded to ill-defined cardiovascular codes. In Finland and Australia, where the age distributions of deaths are comparable, the corresponding proportion is 1.3% and 2.8%, respectively. Also ca five times as many deaths are coded to the “ill-defined causes” chapter of ICD in Sweden than in Finland or Australia.

As far as we know, our paper is only the second to assess the quality and availability of data on causes of death globally.³ We chose a set of simple indicators, and summarized them using three broad categories to highlight the large variations in completeness and quality of cause-of-death information

across both middle- and high-income countries as well as the huge lack of mortality data for low-income countries.

We look forward to the publication of more detailed analyses of the quality of death registration data. A cursory examination of cross-country variations in the use of many cause-of-death codes suggests that problems of consistent and comparable measurement are far greater for many causes of death than our analysis has identified. For example, among the countries of continental Latin America, there is a more than 100-fold variation in death rates for Alzheimer disease and other dementias.

Finally, it should be noted that, by highlighting the overuse and inappropriate use of some ICD codes, we did not mean that all use of such codes should be avoided, only their overuse. The huge differences across countries in use of these codes points to the existence of poor certification and coding practices that need to be debated and addressed. WHO and its Collaborating Centres can play an important role in supporting countries to improve the quality and relevance of death certification and coding practices if data on population levels of disease and injury are to be truly useful for the purposes for which they are intended. ■

Competing interests: none declared.

Colin D Mathers,^a Doris Ma Fat,^a
Mie Inoue,^a Chalapati Rao,^b
& Alan D Lopez^b

1. Mathers CD, Ma Fat D, Inoue M, Rao C, Lopez A.D. Counting the dead and what they died from: an assessment of the global status of cause of death data. *Bull World Health Organ* 2005;83:171-7.
2. *International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10)*. Geneva: World Health Organization; 1994.
3. Ruzicka LT, Lopez AD. The use of cause of death statistics for health situation assessment: national and international experiences. *World Health Stat Q* 1990; 43:249-58.

^a Evidence and Information for Policy, World Health Organization, 1211 Geneva 27, Switzerland. Correspondence to Dr Mathers (email: mathersc@who.int).

^b School of Population Health, University of Queensland, Brisbane, Australia.