Data quality in the Causes of Death Registry

The Causes of Death Registry is a key basis for health monitoring and preparedness, production of statistics and research. It is therefore crucial that death certificates are of adequate quality. The introduction of an electronic death certificate may hopefully improve the updating frequency as well as the data quality of the registry.

Anne Gro Pedersen
Christian Lycke Ellingsen
christian.lycke.ellingsen@fhi.no

The purpose of the Causes of Death Registry is to monitor causes of death and elucidate changes in these causes over time, and provide a basis for preparation of statistics, research, planning and quality assurance (1). It is thus essential that the quality of the registry is optimal.

Public registration of deaths started in Norway in 1685, when local vicars were charged with registering births, marriages and deaths in the parish register. Systematic statistics on causes of death have been prepared since 1853, on the basis of reports from public medical officers, but not until the 1920s did these reports encompass 90 % of all deaths (2). Responsibility for statistics on causes of death was transferred to Statistics Norway in 1925, and since 1928 these statistics have been prepared on the basis of death certificates. The Norwegian Institute of Public Health has been responsible for processing data for the Causes of Death Registry since 2001. In 2014, the institute also took over the operation of the registry, which contains digitised information on causes of death dating back to 1951. The Norwegian Institute of Public Health has used these data to publish overviews of mortality and causes of death in Norway over a period of 60 years (1951–2011) (3).

What is a cause of death?

For all deaths, a doctor must complete a declaration of death (death certificate, paper form IS-1025 B). The structure of the death certificate conforms to principles established by the World Health Organization, and the Causes of Death Registry has used the ICD (International Classification of Diseases and Related Health Problems) (4) coding system since 1951.

The key concept in statistics on causes of death is *the underlying cause of death*. This refers to «the disease or injury which initiated the train of morbid events leading directly to death» (5). It is the underlying cause of death that is shown in the statistics and is interesting in a public-health perspective, since it can help us identify risk factors and initiate preventive measures. When doctors complete the death certificate they occasionally focus more on the *immediate cause of death*, the terminal event or complication, for example pneumonia, since this was present at the moment of death, and not the underlying cause, for example lung cancer. In case of death from external causes, the underlying cause of death will be the specific circumstances of the event, for example «pedestrian hit by a tram». The term *contributing cause of death* refers to «other significant conditions contributing to the death, but not related to the disease or condition causing it». The completed death certificate must show a logical sequence from the underlying to the immediate cause of death. A great number of death certificates, however, have an illogical structure. In a study undertaken at Akershus University Hospital this applied to 32 % of these (6).

The long journey of the death certificate

The doctor who examines the dead body completes the death certificate and sends it to the local county court/police, which issue new documents for administrative purposes. The death certificate is then forwarded to the Chief Municipal Medical Officer, who sends it to the Causes of Death Registry at the Norwegian Institute of Public Health. Here the paper form is scanned for further processing. The Causes of Death Registry also receives notifications of autopsy findings (approximately 3000 each year). In case of deaths among children under one year old, information is retrieved from the Medical Birth Registry. For certain deaths caused by cancer, the diagnoses are compared to information in the Cancer Registry. In some cases (currently approximately 2 % of all deaths) supplementary information is retrieved from the doctor who signed the death certificate. The reporting sequence is extremely complex and almost totally paper-based (Figure 1). All these processes require a considerable manual effort, and ten months elapse before the final statistics for a cohort can be published, so that up to 22 months may pass from the time a death occurs until it appears in published statistics.

Data quality

Several attempts have been made to identify objective quality indicators for causes of death registries (7–9). Criteria used include degree of coverage and completeness, the use of an updated and sufficiently detailed coding system (ICD-9 or ICD-10), and that few deaths are registered with unspecific diagnostic codes for their underlying cause.

Degree of coverage refers to the proportion of the population encompassed by a registry. Completeness indicates whether information is actually collected from the persons who are included in the registry. In Norway, both of these are high; on the whole, we assume that we have medical information on more than 98 % of all deaths. The Causes of Death Registry encompasses all residents, irrespective of whether they die in Norway or abroad, and since 2012 non-residents (tourists, labour migrants etc.) who die in Norway are also included. Cross-checks against the National Registry are made, and reminders are sent to the Chief Municipal Medical Officers to collect missing certificates. Each year, death certificates are missing for 500–700 deaths, even after multiple reminders have been sent. Approximately half of these pertain to residents who have died while abroad. For non-residents who die in Norway the degree of coverage cannot be established, since the National Registry cannot be used for verification.

For coding we use the computer program IRIS with the ACME module (10) to allocate an ICD code to the diagnoses on the death certificate and identify the underlying cause of death. In approximately half of all deaths, the underlying cause is selected with the aid of IRIS/ACME. For the remaining deaths, an assessment by a professional coder is required. As noted above,

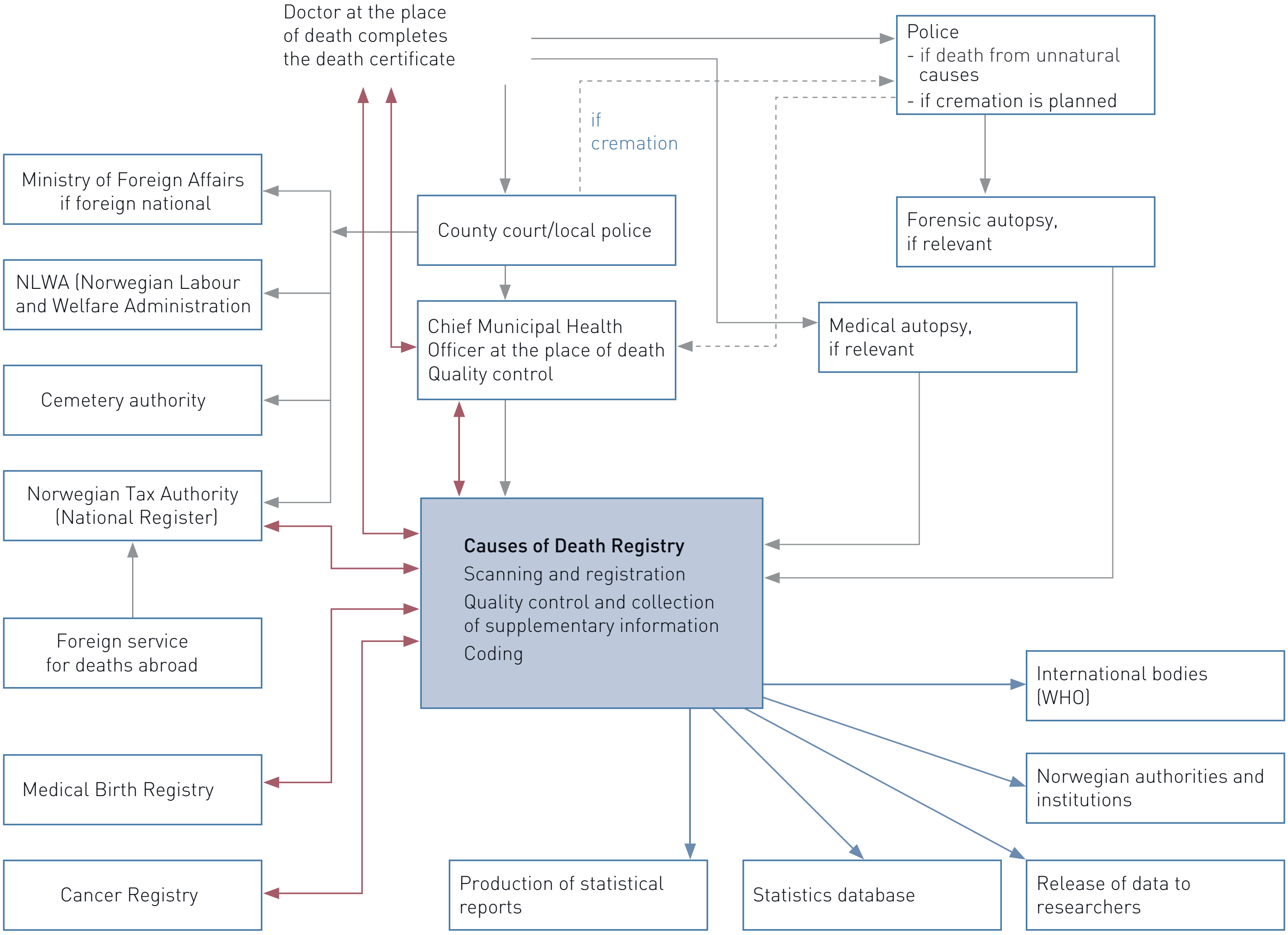

Figure 1 *The complex reporting process for death certificates. In the great majority of cases they are paper-based. The grey arrows indicate the information flow in the case of a death, the red arrows represent feedback and quality control, while the light blue arrows show delivery of data from the Causes of Death Registry*

a considerable proportion of the death certificates have an illogical structure, but the underlying cause of death may nevertheless be identified by the ICD-10 coding rules.

An important objection against the data quality of the Causes of Death Registry is the frequent occurrence of unspecified or non-meaningful diagnoses, so-called «garbage codes» (11), as the underlying cause of death. These are often diagnoses that reflect a terminal stage or complication (immediate cause of death), but fail to provide any information on the underlying cause. A typical example is «heart failure», which is reported as the underlying cause of death in approximately 4 % of all death certificates (12). Without any additional information it is impossible to know whether this heart failure is a result of ischaemic heart disease, cardiomyopathy or chronic pulmonary disease, to mention only a few possibilities. Another example is death caused by injuries, without any information on the event that caused the injury.

In two of the quality assessments referred to above (7, 8), the Norwegian Causes of Death Registry was assessed in the second-best group, with a «medium» and «medium-high» quality respectively. In the third (9) we were ranked in the best group, with a total point score of 87.6 out of 100, but below the other Nordic countries. In all these three studies, the extensive use of unspecific codes served to lower our score.

Additional to these criteria is the question of whether the diagnosis on the death certificate actually reflects the real underlying cause of death. The cause of death cannot always be determined, and it cannot always be taken for granted that the idea of a single underlying cause of death conforms to reality. Autopsy is often seen as the gold standard, but autopsies are infrequently undertaken and the selection for an autopsy is not random. Therefore, the results from autopsy studies may not be directly transferable. A Norwegian study showed that autopsy findings changed the underlying cause of death in 61 % of all cases, in 32 % even to another ICD chapter (13). The proportion of deaths in which a medical autopsy was undertaken was low, however, at 4.3 %.

Another approach consists in reviewing the patient records and completing a «renewed death certificate» on the basis of available information. Using this method, the study from Akershus University Hospital (6) found erroneous content in 27 % of the death certificates. Continuous quality assurance at the hospital provided an important corrective at the individual level and reduced the number of unspecific diagnostic codes, but because of the balancing effect of exchanges between different ICD chapters, this generated only minor changes at the group level (14) and thereby also in the statistics on causes of death.

A Swedish study rediscovered the main diagnosis from the last hospitalisation period on the death certificate for 83 % of those who had died in hospital (15). In a French study there was an «acceptable» consistency between the main diagnosis from the last hospitalisation period and the reported cause of death in 88.8 % of deaths that had occurred in hospital and 72.9 % of deaths outside hospital (16). In such studies, however, it must be kept in mind that there is not necessarily any concurrence between the condition for which the patient was treated in hospital and the underlying cause of death.

Data for research

The use of data from the Causes of Death Registry is regulated by the Health Research Act (17), the Health Registry Act (18) and the Regulations for the Causes of Death Registry (1). Data can be released as finished statistics, as anonymous data sets or as personally identifiable data sets. It will often be relevant to collate data from the Causes of Death Registry with other health registries or sources of data. Normally, no special permission is required for release of statistics or anonymous data sets. Release of personally identifiable data sets requires prior approval with exemption from the duty of confidentiality by a regional committee for medical and health research ethics, as well as a licence from the Norwegian Data Protection Authority if relevant. Further information can be found on the website of the Norwegian Institute of Public Health (19).

New death certificate

The death certificate which is currently in use has remained unchanged since 1982. Two working groups that were appointed in 1996 and 2006 have assessed the need for amendments to the form, but these efforts were not continued/completed, in the final account because of a desire to develop a new electronic death certificate, rather than a new paper-based form.

In 2007, the Office of the Auditor General pointed out some weaknesses in terms of the updating frequency and quality of the Causes of Death Registry (20). Comments stated that the processing time is so long that registry data on causes of death cannot be used to capture fluctuations in mortality as part of preparedness plans, for example in case of an epidemic. The National Health Registry Project is the government's programme to ensure «better utilisation, better quality and safer management of the national health registries» (21). One priority is to achieve faster updating of the Causes of Death Registry, and one of the instruments in this respect is an electronic death certificate. In collaboration with other agencies, the Norwegian Institute of Public Health has therefore started the preparation of an electronic death certificate.

In 2007, Denmark was the first country in the world to introduce fully electronic reporting of death, and we will assess the Danish experience (22). Sweden, France and Portugal have also developed electronic solutions. A fundamental question pertains to the amount of guidance, decision-making support and real-time quality control that should be incorporated into the reporting system. The reporting flow will also present a challenge, since a number of different public and private agencies are involved in the management of deaths.

Conclusion

The Causes of Death Registry constitutes an important basis for health monitoring/preparedness, production of statistics and research. The registry's degree of coverage is near-complete, but the use of unspecific codes for the underlying cause of death remains high. Few validation studies have been conducted. Ten to twenty-two months may pass from the time a death has occurred until the statistics can be published. The introduction of an electronic death certificate incorporating guidance and decision-making support may hopefully improve the updating frequency as well as the data quality of the registry.

Anne Gro Pedersen (born 1960)
cand.mag. of political science and Senior Adviser at the Causes of Death Registry, Department of Health Registries, Norwegian Institute of Public Health, Bergen.
The author has completed the ICMJE form and declares no conflicts of interest.

Christian Lycke Ellingsen (born 1967)
specialist in pathology and Senior Consultant at the Causes of Death Registry, Department of Health Registries, Norwegian Institute of Public Health, Bergen.
The author has completed the ICMJE form and declares no conflicts of interest.

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