Accuracy in Using Pneumonia as an Underlying Cause in the Cause-of-Death Register

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Background. Pneumonia is often mistakenly registered as the underlying cause of death, thus blurring the analysis of causes and correlations. The present study validated pneumonia as the underlying cause of death in patients aged up to 75 years in the official register.

Methods. For a random sample of 1,376 cases, a new death certificate was completed ''blind'' on the basis of hospital records from the last episode of care. The degree of agreement with the original death certificate was measured with Cohen's kappa.

Results. Of 226 registered cases with pneumonia as the underlying cause of death, 53 (23%) were substantiated by the records. Conversely, of 1,079 cases registered as nonpneumonia, five were found to have pneumonia as the underlying cause of death. The degree of agreement was fair. For younger patients and for certificates from the Institutes of Forensic Medicine it was substantial. A clinical autopsy did not guarantee a high degree of agreement.

Conclusion. Other causes of death are concealed in cases registered as pneumonia deaths. The error is probably important when (small) clinical cohorts are followed up.

Key words: Mortality statistics; validity; international classification of diseases; pneumonia.

1. Introduction

Official cause-of-death (COD) registers are used for a multitude of purposes. In clinical research, mortality statistics can be used to evaluate the effects of treatment. In epidemiology, mortality statistics are often used when discussing aetiology, or as a measure of health in a population. Mortality and COD are criteria often used when determining the allocation of funds to the health service. The requirements of data quality vary according to purposes, but all users must be aware of the possibility of error in the register (Prior 1985).

The International Classification of Diseases is to be used by hospitals and meant for statistics. Diseases are classified by aetiology (e.g., infections), pathology (e.g., cancer), organs affected (e.g., lung diseases), age of patients (e.g., death in early life), and system (e.g., coronary heart diseases).

Some of the causes of death are subject of our concern. One of them is pneumonia, which is often used as a ''sink'' diagnosis. Cases where pneumonia is stated as the underlying COD deserve particular attention, as pneumonia often occurs concomitantly with other diseases, with trauma and with poisoning, which in reality are causes that triggered the chain of events leading to death. Such underlying causes of death are not always easy to identify. In the International Classification of Diseases (9th revision, ICD 9), it is pointed out that the words ''due to'' (or ''as a consequence of'') appearing on the medical certificate cover not only aetiological and pathological sequences, but also sequences where there is no such direct cause though an antecedent condition is believed to have prepared the way for the direct cause by damaging tissues or by impairing function even long afterwards (WHO 1997).

Another cause of death with which we are concerned is myocardial infarction, as the diagnostic criteria of this common disease are used inconsistently while the statistics are used as if the data were very hard. A third cause of death of greatest interest as to accuracy is breast cancer, because it has never been investigated as to false negative cases and the accuracy is important in the fierce discussion about preventive effects of breast cancer screenings. The two latter causes of death have influenced the design but otherwise been presently left aside.

We investigated the validity of pneumonia as the underlying COD and analysed certain determinants of the accuracy by comparing the official underlying COD with that based on the clinical and autopsy records.

2.   Materials and Methods

2.1.   Database

The study population consisted of 36,642 deceased persons aged 15–74 years who had died in Sweden during 1984. This population was stratified according to age (15–44, 45–64, 65–74 years) and diagnostic class as pneumonia or not, and simple random samples were extracted from each stratum. The class ''pneumonia'' was defined as numbers 480–486 in ICD 9. These categories denote viral pneumonia, pneumococcal pneumonia, other forms of bacterial pneumonia, pneumonia due to other specified organisms, acute interstitial pneumonia, unspecified bronchopneumonia, and unspecified pneumonia. The nonpneumonia stratum consisted of a self-weighted sample of all the nonpneumonia diagnoses.

2.2.   Study sample

A simple random stratified sample was drawn, comprising 236 cases where pneumonia was recorded as the underlying COD. All cases in the youngest age-class were extracted, as were 100 cases from each of the two older age-classes (sampling rates 0.44 and 0.17). Another 1,140 nonpneumonia cases comprised the self-weighted sample from three other diagnoses, namely breast cancer, ischaemic heart diseases and other diagnoses. For each case, the records of the stage when death occurred and the autopsy report were requesitioned from the institution where the death certificate was issued. The records included the text and reports of X-rays, bacteriology, and diagnoses. In 10 pneumonia and

61 nonpneumonia cases, no record could be obtained and these cases were therefore removed from the sample, leaving 226 pneumonia and 1,079 nonpneumonia cases (Table 1).

Most of the records emanated from hospitals, 83 came from health centres or nursing homes, and 272 from Institutes of Forensic Medicine. Autopsies of persons who died at home or otherwise outside institutions were often performed in the latter institutes.

2.3. Procedure

An expert panel who established the chain of events leading to death ''blinded'' to the death certificate, was constituted. A new certificate was then issued and coded at Statistics Sweden. The original issuing doctor's notes in the clinical record regarding the disease or injury initiating the chain of events leading directly to death was accepted by the panel and the data were used to issue a correct death certificate.

When the attending clinician had reported the course of symptoms and physical signs of pneumonia in a patient free from underlying serious pulmonary disease, or when the patient had not been suffering from generally impaired health, the panel noted ''pneumonia'' as the underlying COD. If the attending physician reported that the patient, prior to the onset of the symptoms of pneumonia, had a worsening disease impairing his or her resistance to the infection, or was bedridden, because of a condition other than pneumonia, then the progressing disease or the disease necessitating bed-care was discussed as the possible underlying COD.

Consensus within the panel was achieved in all cases. A small minority of cases proved difficult to assess, e.g., those with a generally progressing disease that had remained stable

Table 1.   *The numbers of deceased persons in 1984 in Sweden in our samples, pneumonia and nonpneumonia cases, and attrition*

Age at death	Pneumonia in register	Nonpneumonia in register[a]	All
Population			
15–44	36	3,438	3,474
45–64	226	12,412	12,638
65–74	581	19,949	20,530
15–74	**843**	**35,799**	**36,642**
Sample			
15–44	36	207	243
45–64	100	446	546
65–74	100	487	587
15–74	**236**	**1,140**	**1,376**
Attrition[b]			
15–44	1	14	15
45–64	6	25	31
65–74	3	22	25
15–74	**10**	**61**	**71**

[a]Originally four strata, presented here as a single stratum
[b]No clinical record retrieved, or no note about the death in the record.

for a long time. Obvious progression or exacerbation qualified a disease as constituting the underlying COD. If it had been stable for a long time, the disease was denoted as a contributory cause rather than the underlying cause. In instances of alcoholism, the autopsy often provided guidance, especially in cases of lobar pneumonia.

2.4. Coding

The new certificates thus obtained were then coded according to the ICD manual (WHO 1977). In most cases the condition identified by the panel as the starting point of the chain of events leading to death was also coded as the underlying COD. In some instances, however, the effect of the ICD coding rules or national instructions and guidelines derived from the ICD rules, was that this chain of events was interrupted, e.g.,

    I(a) Pneumonia
    I(b) Myocardial infarction
    I(c) Generalized atherosclerosis

where, according to the ICD instruction, myocardial infarction—and not atherosclerosis—is selected as the underlying COD. In other cases, coding rules and guidelines in ICD instruct the coder to select as the underlying COD the one that is contributory as stated by the panel

    I(a) Pneumonia
    II   Small cell carcinoma of the lung

Here the carcinoma will be selected as the underlying COD, irrespective of its clinical importance at the time of death. The effect of the ICD coding rules was demonstrated by using the panel's death certificate and comparing the underlying COD before and after the coding rules had been applied.

The age of the issuing doctor, the speciality in which he or she worked and the type of hospital were also coded.

2.5. Statistics

The agreement between the new death certificates and the official statistics was designated by Cohen's kappa (Fleiss 1981; Guggenmoos-Holzmann 1996; Lantz 1996). A kappa value less than 0.00 indicates poor agreement; 0.00–0.19 and 0.20–0.39 and the following quintiles indicates slight, fair, moderate, substantial, and almost perfect agreement (Landis and Koch 1977).

3.   Results

Pneumonia as underlying cause of death occurred in two percent of the total number of deaths and in six percent as contributing cause of death.

Of the 226 patients whose official underlying COD was pneumonia, only 53 actually had pneumonia as the underlying COD. On the other hand, of the 1,079 patients originally classified as nonpneumonia cases, 5 had pneumonia as the underlying COD. The corresponding weighted proportion originally recorded as pneumonia was 2.3% of deaths (true or false pneumonia) but according to the panel 1.9% (false pneumonia) of deaths

were falsely so reported. On the other hand, 0.2% (false nonpneumonia) of deaths were in fact caused by pneumonia even though they were recorded in the register as nonpneumonia cases. According to the panel, 0.7% (true pneumonia and false nonpneumonia) of deaths were due to pneumonia even though only 0.4% were included in the official statistics. This indicates a high degree of sensitivity, low specificity and a very low prediction value of pneumonia in the official register (Ahlbom and Norell 1990). Cohen's kappa was 0.29, indicating fair agreement (Table 2).

The underlying causes of death according to the panel among the 173 false pneumonia cases were often heart disease, malignant neoplasm, cerebrovascular disease, senile dementia, alcoholism, injuries and poisoning. In fact, the whole range of diseases and injuries were represented (Table 3).

A reliability study was performed three years after the first assessment by the panel. A simple random sample of 100 cases were selected for retest. Four of these 100 cases had to be excluded from the study as the records were not available; 96 cases therefore were analysed. The same procedure as in the first study was applied to reach consensus in the team for the individual cases, and on both occasions the coding was carried out according to the ICD rules. The agreement at the three-digit categories level of the code for underlying COD between the two studies was 77%.

3.3. Independent variables

Within the age range of the sample, 15–74 years, agreement decreased with age. The degree of agreement for those below age 45 was substantial (kappa 0.65), while for those 45–74 years old at death, agreement was 0.25–0.30, i.e. fair (Table 2).

To assess the importance of the experience of the individual doctor who had certified the cause of death, we checked the agreement between the two sets of certificates in relation to the age of the first certifier. Doctors aged 45–54 received the best grading. The Institutes of Forensic Medicine were better in setting pneumonia as an underlying COD than other hospital types (Table 4).

Table 2.   Point estimates of pneumonia as the official underlying cause of death in Sweden and as the true underlying cause of death in different age classes at death

Validated cause	Age at death, years			All ages
	15–44 ($n = 228$)	45–64 ($n = 515$)	65–74 ($n = 562$)	15–74 ($n = 1,305$)
True pneumonia, per 100 persons	0.5	0.4	0.5	0.4
False pneumonia, per 100 persons	0.5	1.4	2.4	1.9
True nonpneumonia, per 100 persons	99.0	97.9	97.0	97.5
False nonpneumonia, per 100 persons	0.0	0.3	0.3	0.2
Sensitivity, %	100	57	60	65
Predictive value, %	48	21	17	19
Cohen's kappa	0.65	0.30	0.25	0.29
SEM, kappa	0.05	0.04	0.03	0.03

Table 3.   Cases registering pneumonia as the underlying cause of death and classified otherwise by the expert panel

Cause of death according to the panel	ICD-8	*n*	Weighted proportion %
Malignant neoplasm	146–208	20	11.6
Diabetes	250	5	2.8
Senile dementia	290	13	9.3
Alcoholism	303	21	6.5
Multiple sclerosis etc	315–348	18	9.8
Ischemic heart disease	410–412	9	6.3
Symptomatic heart disease	427	7	5.1
Cerebrovascular disease	430–438	18	11.6
Cirrhosis of the liver	571	4	1.9
Accidents, poisonings	E820–989	14	9.3
Other causes	–	44	25.8
All causes		173	100.0

The importance of the certifier's professional environment was demonstrated by the influence of the clinical speciality of the ward from which the certificate was issued. The surgical specialities and thoracic medical wards were often found to inaccurately record pneumonia as being the underlying COD. There were also differences between districts, with the most rural districts having the lowest degree of agreement between the registered COD and the true one according to the panel.

Among the patients autopsied in hospitals, the degree of agreement was slight, while among patients autopsied at Institutes of Forensic Medicine agreement was substantial. For nonautopsied cases, agreement was fair. Certificates issued at departments of clinical pathology showed fair agreement with the panel's opinion that pneumonia was the underlying COD (kappa 0.23). Those issued by specialists in internal medicine showed a greater degree of agreement in cases where an autopsy was performed. Other specialities revealed a contrary tendency; autopsied cases showed poorer agreement between the official register and the expert panel.

4.   Discussion

The chain of events and diseases leading to death is not always easy to establish and sometimes for a single case, two or more quite different causes of death may be fully justified. At the beginning of the study, the discussions within the panel were sometimes lengthy, e.g., regarding chronic alcoholism. Alcoholism increases the risk of a wide range of other diseases and injuries (Sundby 1967). Hospitalization because of alcoholism, bronchial asthma, lung disease and heart disease is always followed by an increased risk of pneumonia (Koivulu 1994; Wright 1994; Smyth 1996). However, for a disease or condition to be designated the underlying COD it must have initiated the chain of events that led to death (WHO 1977) and not merely increased the susceptibility to other fatal conditions. Unless it is a distinct aggravation, the disease must be regarded as a contributing cause rather than the underlying cause (Sundman 1988; Mendonca 1994). When ageing and/or a slowly progressing disease impairing the host defences sometimes, according to the issuing doctor,

Table 4.   Degree of agreement as to pneumonia being the underlying cause of death, between the official register and the expert panel, related to hospital type and size (cases 15–74 years at death)

Validated cause	Institute of forensic medicine[a] (n = 272)	Hospital type			Nursing home[e] Health centre (n = 179)
		Large[b] (n = 218)	Intermediate[c] (n = 336)	Small[d] (n = 298)	
True pneumonia per 100 persons	1.5	0.6	0.3	0.3	0.3
False pneumonia per 100 persons	0.8	1.6	2.0	2.0	1.9
True nonpneumonia per 100 persons	96.8	97.7	97.7	97.7	97.1
False nonpneumonia per 100 persons	0.9	0.0	0.0	0.0	0.7
Cohen's kappa	0.63	0.44	0.20	0.22	0.15
SEM (kappa)	0.03	0.04	0.03	0.03	0.03

[a]Serving the police and issuing most certificates of unnatural and out-patient deaths.

[b]Serving a population of about one million and having all specialties.

[c]Serving a population of a few hundred thousands and having all main specialties but no subspecialties.

[d]Serving a population of up to one hundred thousand and having five to six clinical specialties.

[e]Serving a population of about ten thousand.

NOTE: $n = 1303$, two cases are not classified.

reached a threshold where pneumonia developed, our first rule was to accept such a statement in the records and to code the mentioned disease as underlying the pneumonia. We saw no cases where pneumonia on the certificate was totally irrelevant but they can have been overlooked as the underlying cause of death was our focus of interest.

Most often the latest record contained the most accurate information. When trauma was the COD, the external cause was sometimes recorded only on the original death certificate, to which the panel had no access. In 31 instances, the doctor gave a more specific description of the COD on the certificate than in the text of the clinical record. The certifiers in these cases obviously knew more details about the patient than were stated in the clinical record (Mattsson 1985). Therefore the panel's certificate cannot always be regarded as a ''gold standard'' and we have therefore refrained from treating it as such. The experts could however discuss the case amongst themselves, had in most instances more data, e.g., the autopsy record, and had more insight into the theoretical and practical problems of assessing the underlying COD, than had the average doctor. Nevertheless the panel accepted the attending doctor's description of the clinical course of the disease and merely interpreted it in the form of an accurate death certificate, without seeing the attending doctor's certificate. The chain described in a death certificate could look as follows. One of the patients suffered from diabetes mellitus and cardiosclerosis and had an infarction of the brain—all of these diseases contributed to death by decreasing his resistance. Then he got pneumonia as an underlying cause of death and later circulatory disturbances as intermediate cause of death and finally oedema of the lung as terminating cause of death.

A similarly constituted panel can easily reproduce the study, and the reliability of the panel's decision was good. The reliability study could have been affected by remembering but the size of the sample makes this less significant.

According to Landis and Koch (1977), the pneumonia registration was fair. According to Fleiss (1981) a kappa value below 0.4 indicates poor agreement, in which case the pneumonia registration is poor. We agree with this judgment as $\frac{3}{4}$ of the certified pneumonia deaths were in fact caused by other diseases. There were in all 280 registered cases with pneumonia registered as underlying, contributing or intermediate COD. Out of these we did not agree as to 143 cases. As mentioned above, out of 226 cases registered as having pneumonia as underlying COD the panel found that 173 were false while 53 actually had pneumonia as underlying COD. In 54 other cases registered as having had other diseases as registered COD but pneumonia as contributing or intermediate factor, the panel did not agree with the attending doctor in 3 cases but found pneumonia as underlying COD, and in 51 cases the panel agreed. In another 13 cases pneumonia was not mentioned anywhere on the certificate but should have been.

As regards the specification of alcoholism according to the ICD rules, we agree that the consequences of chronic alcoholism are most often more informative, but it is also important to follow the total impact of alcoholism in the official statistics.

Studies comparing the main diagnosis of in-patients with the underlying COD have revealed disturbing discrepancies, even though not as great as ours (see Alderson and Meade 1967; Gittelsohn and Senning 1979; Lee 1994; Selikoff 1992). This is probably due to the more meticulous method we applied when evaluating our cases, where all relevant clinical information was taken into account, the sequence of events reconstructed, and

a new certificate made out. We believe that there is a need to increase awareness of the fact that the words ''due to'' on the medical certificate form imply sequences which do not hold direct causation but in which an antecedent condition has led to the direct cause (WHO 1977).

It is not surprising that the original certificate was more accurate when the deceased was younger and when the doctor was more experienced or worked in a large hospital. But autopsy is traditionally seen as a guarantee of quality and surprisingly this was true only of medico-legal autopsies. The difference between clinical and medico-legal autopsies indicates that autopsy is of importance when the facts revealed are correctly used. By tradition pathologists emphasize morphological changes and refrain from describing the chain of events, while clinicians tend to describe the sequence and sometimes interpret the morphological changes incorrectly. In this investigation, many of the clinicians may have misinterpreted autopsy results. Another explanation could be that a case was more complicated when an autopsy was performed. In view of this, the death certificate for autopsied patients should perhaps be issued jointly by the pathologist and the clinician. According to Swedish recommendations (National Board of Health and Welfare 1991), it was primarily the attending doctor who was to issue the death certificate.

Mortality statistics regarding pneumonia were rather inaccurate and Sweden is probably not extreme in this respect. Pneumonia was registered in 2% of deaths as the underlying COD.

Although the official statistics of pneumonia are imperfect, as well as statistics following other uncommon diseases and small statistical samples, for analysing highly frequent diseases the error does not affect the overall quality of the mortality statistics.

Problems arise when scientists scrutinize clinical materials. If not unsurmountable the recommendation is that they should requisition the latest clinical record in order to trace the clinical chain of events and use experienced official coders to interpret the chain in order to establish a correct ICD underlying the cause of death.

5.   References

Ahlbom, A. and Norell, S. (1990). Introduction to Modern Epidemiology, 4th edition. Epidemiology Resources Inc., Newton Lower Falls: MA, U.S.A.

Alderson, M.R. and Meade, T.W. (1967) Accuracy of Diagnosis on Death Certificates Compared With That in Hospital Records. British Journal of Preventive and Social Medicine, 21, 22–29.

Fleiss, H.J. (1981). Statistical Methods for Rates and Proportions, 2nd edition. New York: John Wiley & Sons, 217–225.

Gittelsohn, A. and Senning, B.S. (1979). Studies on the Reliability of Vital and Health Records: I. Comparison of Cause of Death and Hospital Record Diagnoses. American Journal of Public Health, 69, 680–689.

Guggenmoos-Holzmann, I. (1996). The Meaning of Kappa: Probabilistic Concepts of Reliability and Validity Revisited. Journal of Clinical Epidemiology, 49, 7, 775–82.

Koivulu, J., Sten, M., and Mäkelä, P.H. (1994). Risk Factors for Pneumonia in the Elderly. American Journal of Medicine, 96, 313–320.

Landis, J.R. and Koch, G.G. (1977). The Measurement of Observer Agreement for Categorical Data. Biometrics, 33, 159–174.

Lanz, C.A. and Nebenzahl, E. (1996). Behaviour and Interpretation of the Kappa Statistic: Resolution of the Two Paradoxes. Journal of Clinical Epidemiology, 49, 4, 431–434.

Lee, P.N. (1994). Comparison of Autopsy, Clinical and Death Certificate Diagnosis With Particular Reference to Lung Cancer - A Review of the Published Data. Acta Pathologica, Microbiologica et Immunologica Scandinavica, 102, 1–42.

Mattsson, B. and Rutqvist, L.E. (1985). Some Aspects on Validity of Breast Cancer, Pancreatic Cancer and Lung Cancer Registration in Swedish Official Statistics. Radiotherapy and Oncology, 4, 1, 63–70.

Mendonca, E.F., Goulart, E.M., and Machado, J.A. (1994). Reliability of the Declaration of Underlying Cause of Infant Deaths in the Metropolitan Region of South-Eastern Brazil. (In Portuguese: Confiabilidade da declaracao de causa basica de mortes infantis em regiao metropolitana do sudeste do Brasil.) Revista Saude Publica, 28, 5, 385–91.

Prior, L. (1985). Making Sense of Mortality. Sociology of Health and Illness, 2, 167–190.

Selikoff, I.J. and Seidman, H. (1992). Use of Death Certificates in Epidemiologic Studies, Including Occupational Hazards - Variations in Discordance of Different Asbestos-Associated Diseases on Best Evidence Ascertainment. American Journal of Industrial Medicine, 4, 481–492.

Smyth, E.T., Wright, S.C., Evans, A.E., Sinnamon, D.G., and MacMahon, J. (1996). Death From Airways Obstruction: Accuracy of Certification in Northern Ireland. Thorax, 51, 3, 293–297.

Sundby, P. (1967). Alcoholism and Mortality. Oslo: Scandinavian University Press.

Sundman, L., Jakobsson, S., Nyström, L., and Rosen, M. (1988). A Validation of Cause of Death Certification for Ischaemic Heart Disease in Two Swedish Municipalities. Scandinavian Journal of Primary Health Care, 6, 4, 205–211.

The National Board of Health and Welfare. (1991). Regulations and Counsel Regarding the Death Certificate and Certificate on Cause of Death. (In Swedish: Socialstyrelsens föreskrifter och allmänna råd om dödsbevis och intyg om dödsorsaker m.m.). Socialstyrelsens författningssamling (SOSFS), 7, Stockholm.

World Health Organisation. (1977). Manual of the International Statistical Classification of Diseases, Injuries and Causes of Death, Vol. 1, 9th revision, Geneva: WHO.

Wright, S.C., Evans, A.E., Sinnamon, D.G., and MacMahon, J. (1994). Asthma Mortality and Death Certification in Northern Ireland. Thorax, 49, 2, 141–143.