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In evaluating cause of death on death certificates, methods and criteria are often insufficiently described

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Abstract

Objective - Statistics on causes of death are important for epidemiological research. Studies that evaluate the source data often give conflicting results, which raise questions about comparability and validity of methods.

Study design and setting - For 44 recent evaluation studies we examined the methods employed and assessed the reproducibility.

Results - Thirty studies stated who reviewed the source data. Six studies reported reliability tests. Twelve studies included all causes of death, but none specified criteria for identifying the underlying cause when several, etiologically independent conditions were present. We assessed these as not reproducible. Of thirty-two studies that focussed on a specific condition, 21 provided diagnostic criteria such that the verification of the focal diagnosis is reproducible. Of sixteen that discussed the difference between dying "with" and "from" a condition, eight described how competing causes had been handled. For these eight, the selection of a principal cause is reproducible, but in three the selection strategy conflicts with the international instructions issued by the WHO.

Conclusion - Methods and criteria are often insufficiently described. When described, they sometimes disagree with the international standard. Explicit descriptions of methods and criteria would contribute to methodological improvement and would allow readers to assess the generalizability of the conclusions.

1. Introduction

Whereas cause-of-death information on death certificates is collected using highly structured and standardized forms, it has been amply demonstrated that many death certificates are not properly completed. Many studies have shown discrepancies between cause of death reported on death certificates and cause of death reported on other sources such as medical records and autopsies. However, these studies do not show consistent results and sometimes are in conflict. Whereas it is understandable that the quality of reporting may vary with cause of death, it is surprising that even studies of the same condition sometimes arrive at different conclusions. The purpose of the present paper, therefore, is to review the methods used in recent studies on the reliability and accuracy of causes of death reported to the agency in charge of the official mortality statistics. We have concentrated on the criteria by which the reviewers judged the reported diagnostic information to be accurate or not.

2. Material and methods

We performed repeated MedLine searches for papers evaluating cause of death reported on death certificates. To capture the current status of methodology, we limited the searches to papers published from 1998 onwards. For each title we examined the MedLine abstract. We excluded papers that clearly did not involve a panel of experts reviewing causes of death reported to the official statistical agency and then reviewed the full text of the remaining papers. Again, those that did not involve an expert panel or causes of death reported to the official statistical agency were excluded. For the now remaining papers we searched the reference lists. All in all, we finally included 45 papers describing 44 studies.

Following a structured protocol, we examined the studies regarding data collection, review procedures, and how the authors arrived at the principal cause of death. We also assessed the reproducibility of the study.

3. Results

Data collection (Table 1)

The number of cases investigated was stated in all papers. The volume varied considerably, from 21 cases in a study on injury deaths in children to 10,098 cases in a study on colorectal cancer. Thirty-two of the 44 studies focussed on a selected condition or a group of conditions, like asthma or cardiac death.

The source material to which the cause of death reported on the certificates was compared was also always stated.

Review procedures (Table 2)

The number of people reviewing the information was stated in 30 of the 44 studies and varied from one person to, at most, a panel of eight. Six papers reported that a reliability test had been performed. The remaining 38 papers mentioned no quality assurance of the evaluation procedure. However, 33 papers discussed figures or conclusions from previous, similar studies.

Identifying a principal cause of death (Table 3)

Of 12 studies that included all causes of death, nine made a distinction between principal and contributing cause of death. Of these nine, six compared the principal cause of death arrived at through the review process to the underlying cause reported by the physician on the lowest used line in Part I of the death certificate. Seven compared the panel's principal cause to the cause of death on the original death certificate as classified by the panel, arrived at either by the classification rules of the ICD or by rules devised by the panel. Only one study compared the panel's principal cause to the official underlying cause in the mortality register.

Of 32 studies focussing on a particular condition, 21 specified diagnostic criteria for that condition. One study compared the panel's principal cause to the underlying cause reported on the death certificate, while 15 studies compared the panel's principal cause to the cause of death on the original death certificate as classified by the panel. In eight studies, the panel's principal cause was compared to the official cause of death in the mortality register. Eight studies described how the panel had identified the principle cause of death in complex cases. In three, the strategy applied is in conflict with the ICD coding instructions for selecting the underlying

cause of death that will appear in the mortality statistics.

Reproducibility

Of the 12 studies on all causes of death, none described how competing causes of death were handled. This means that none of these studies is repeatable.

Of the 32 studies on selected conditions, 16 state diagnostic criteria and are reproducible as concerns the presence of the focus condition at death. Of the likewise 16 studies that also evaluate the certifier's underlying cause of death, eight specify both panel composition, diagnostic criteria, and assessment of competing causes. These eight studies are reproducible.

4. Discussion

It might be assumed that authors evaluating official causes of death would assess whether the cause of death had been correctly reported on the death certificates. Instead, a substantial number of studies assess how well the data suit a particular purpose. Thus, some try to assess how well reported causes of death mirror the prevalence of a particular condition at death, whether or not it caused the death. Other studies always assign the death to a specific condition if present regardless of the other conditions from which the decedent may have suffered. Still other studies try to establish a sequence of events leading to death, but emphasize one of the complications rather than the originating cause. Consequently, a number of studies judge cases as "misclassified", even though both the death certificate and the classification of the underlying cause of death by the statistical office were correct, that is, completely in accordance with the specifications of the ICD.

As far as can be judged from the method descriptions, most studies confined themselves to comparing the cause of death arrived at by the review panel to the causes of death reported on the original death certificate. Only nine also considered the official cause of death as registered by the statistical agency in charge of the mortality statistics. This is unfortunate, since the classification performed by the statistical agency sometimes leads to a more useful underlying cause of death, especially where the certificates are not completed correctly. Many statistical agencies also routinely ask certifiers for additional information when the original death certificate seems incomplete. Therefore, the mortality register may contain information other than the death certificates. Consequently, evaluating only the death certificates does not necessarily give a correct estimate of the quality of the official mortality statistics.

Reproducibility and transparency of methods are generally considered hallmarks of scientific work. It would seem obvious that procedures used to assess the quality of reported causes of death should themselves be subject to, or at least allow, quality assurance. However, in more than two-thirds of the studies that evaluate the certifier's choice of underlying cause, either the composition of the review panel or the criteria for identifying the cause of death were not specified. We believe this is tantamount to lack of reproducibility.

Tables

[No percentages given if the base is less than 20]

Table 1. Data collection methods used in the studies

Sample size

	Studies	
-	*number*	*- %*
0-99	7	16
100-499	20	45
500-1499	11	25
1500-4999	4	9

5000 -	2	4

Scope

	Studies	
	- number	*- %*
All conditions	12	27
Selected condition(s)	32	73

Reported cause of death compared to

	Studies	
	- number	*- %* [1)]
Medical records	39	89
- Autopsy reports only	3	7
Police/Coroner/ME	8	18
Interviews		
- physician	6	14
- relatives	14	32
Other	1	2

[1)] The sum exceeds 100%, since some studies use several data sources

Table 2. Review procedures used in the studies

Members of review panel

	Studies	
	- number -	*%*
1	7	16
2 - 3	12	27
4 - 5	7	16
6 -	4	9
Not stated	14	32

Reliability or repeatability test?

	Studies	
	- number	*- %*
Yes	6	14
Not stated	38	86

Results from similar studies discussed?

	Studies	
	- number	*- %*
Yes	33	75
No	11	25

Table 3. Identification of a principal cause of death in the studies

Studies on all causes of death:

- Distinction made between principal and contributing cause of death?

-	*Studies number*
Yes	9
No	3

- If distinction made, panel's principal cause of death compared to

-	*Studies number*
Underlying cause from original death certificate:	
- as reported	6
- as classified by panel	7
Underlying cause from mortality register 1	

- Competing causes of death: criteria stated?

-	*Studies number*
Yes	0
No	12

Studies on selected conditions:

- Explicit diagnostic criteria?

	Studies	
	- number -	*%*
Yes	21	66
No	11	34

- Distinction between principal and contributing cause of death?

	Studies	
	- number	*- %*
Yes	16	50
No	16	50

- If distinction between principal and contributing cause, criteria stated for competing causes of death?

	Studies
	- number
Yes	8
No	8

- If criteria stated for competing causes: criteria compatible with ICD definition of underlying cause?

	Studies - number
Yes	5
No	3

- If distinction made between principal and contributing cause, panel's principal cause of death compared to

	Studies - number
Underlying cause from original death certificate:	
- as reported	1
- as classified by panel	15
Underlying cause from mortality register	8