Improving the reliability of cause of death diagnoses in cooperation with public health authorities and the Hungarian Central Statistical Office

Thesis of Doctoral (PhD) dissertation

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Introduction

Cause-specific mortality (and premature cause-specific mortality, years of life lost (YLL) due to a specific illness as well as decreased life expectancy) is a core health indicator which plays a crucial role in health indicator systems for international comparative analyses established and maintained by EUROSTAT, OECD and WHO. The WHO recommendation on death certificates (Medical Certificate of Cause of Death, here in after referred to as death certificate), which are used as a basis for ascertaining the cause of death (COD), i.e. for cause of death data collection, has been widely adopted, however it is not applied uniformly in the world, and verifying the quality of data is a global concern.

In the developed countries it is the national statistical office that is responsible for collecting mortality data as laid down by the law and all the data derive from cause of death diagnoses (indicating the direct cause of death, preliminary cause of death, underlying cause of death, i.e. disease or injury leading indirectly to death, comorbidities etc.) compiled by WHO in compulsory reports free of charge. In the case of death by natural cause, it is the physician or the coroner who completes the death certificate and reports COD data to the competent authority while this role is transferred to the forensic physician when circumstances of violence lead to morbid events. Illness(es) leading to death is identified by processing medical data in the death certificate following WHO ICD-10 coding system, its selection rules and in many cases software-based automated coding. Mortality data gained after processing are disseminated and published in the official statistics of the respective county.

The amount of data can be best controlled by comparing routinely collected data, as well as the number of registered death cases and registered death certificates. A common method for controlling the accuracy i.e. quality of COD data is to examine the prevalence of death cases registered under ICD-10 category R (“Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified”). Failing to fill in the “cause and manner” field on the death certificate (natural, accident, suicide, homicide, undetermined) can be improved primarily by applying the ICD-10 coding rules to encode the registered diagnoses. The number of missing certificates or incomplete certificates not appropriate for being processed is approximately 1%.

In the developing countries the mortality reporting system is incomplete or has not been established at all. Neither data from civil organisations, nor basic statistical data are adequate and accurate for the purpose of calculating crude death indicator even. According to the data released by WHO in 2014, 81 out of 194 countries report cause-specific mortality data of good or average quality that are suitable for further processing.

Thanks to the legal framework in Hungary, a cooperation was built up between the Hungarian Central Statistical Office (HCSO) and national public health authorities in 1999 under which the medical officer can effectively contribute to the improvement of mortality data accuracy, not only with their medical expertise but their broad networks of COD data providers.

Objectives

(1) to assess the quality and accuracy of cause of death diagnoses (by determining the prevalence of wrong CODs, including wrong diagnostic codes associated with infectious diseases, and identifying physicians reporting inaccurate data),

(2) to test the effectiveness of data completion as well as of the modification of the registered COD coordinated by the competent public health authority of the respective county (which is based on data reconciliations with the reporting person or authority and on counselling as well as organising appropriate trainings),

(3) to draw up a proposal for establishing a quality assurance procedure within healthcare administration and an indicator set thereof, based on the experience gained in Tolna county.

Methods

Our investigations were based on processing death certificates of deceased residents in Tolna County, who died in 2003, 2004, 2011 and 2015 in Tolna County.

A database was built up for these years in cooperation with the IT specialist at Tolna county institute of the National Public Health and Medical Officer Service (NPHMOS) to register all the medical data contained in death certificates, including originally reported data and cause of death codes (CDC) modified according to the suggestions of the medical officer. After closing an investigated calendar year, the Hungarian Central Statistical Office provided our research group with the final database on the underlying causes of death, which then were restricted to deceased residents of Tolna County died in Tolna County, as in these cases we could review the death certificates completed by public healthcare service providers. (Perinatal death certificates of infants died at the age of 0 have not been processed, as an autopsy or judicial autopsy has to be carried out in all such cases which of course means reporting accurate data.)

In 2005 the HCSO introduced computerised coding to determine the underlying cause of death and since then death certificates that the social statistician found, on the basis of available data, inaccurate or misleading and inadequate for declaring the immediate COD have undergone medical review. The revision of certificates and the consultations necessary due to death certificates assumed to be inaccurate were carried out by a group of professionals working at the National Public Health and Medical Officer Service (NPHMOS) and HCSO Tolna county institute. Assessments were based on analysing the differences which have been found upon comparing originally reported codes with those corrected as a result of HCSO social statistical reviews and with the data gained after NPHMOS medical reviews.

Results

The distortions of information provided by the certifying physician in defining the cause of death will lead to mistakes that can not be corrected later on and hence decrease the reliability of COD statistics. Therefore, we tried to identify physicians who may code incorrectly and our aim was to reveal wrong COD diagnoses as well (**Table 1**), on the basis of which we could highlight the defects in medical training.

As for COD coding, the following results could be observed in each investigated year: based on COD data reported by healthcare providers, the occurrence of “Neoplasms”

(main category C) was underrepresented, similarly to “Diseases of the circulatory system” (main category I), except for the year of 2015. In contrast, “Endocrine, nutritional and metabolic disease” (main category E) was overrepresented.

“Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism” (major category D), “Diseases of the nervous system” (major category G), “Diseases of the respiratory system” (major category J) and “Diseases of the digestive system” (major category K) are typically overrepresented when manual coding is applied. Less significant differences were observed when data were processed by automated coding. Upon comparing COD data reported by public healthcare service providers with those published by the HCSO, the results showed moderate difference in terms of coding (at the level of ICD main categories).

If we compare the data suggested by the NPHMOS with those published by the HCSO, the results reveal only two instances, both of them in 2004, when significant difference could be seen in the underlying causes of death reported: “Mental and behavioural disorders” (main category F) was overreported, as opposed to “Diseases of the digestive system” (main category K) which was underreported.

The assessment of “Certain infectious and parasitic diseases” (major category A and B) and violent death (major categories S, T, V and Y) would require a separate study. This is explained by the fact that the surveillance of infectious diseases has roots going back to 1927 when the National Institution for Public Health started its operation. Moreover, data reconciliation between public health authorities and HCSO is a routine procedure. As far as violent death CODs are concerned, significant differences can be marked between the final diagnoses set up by healthcare providers and those defined by NPHMOS and HCSO. Physicians (clinicians and medical officers) identified the anatomical localization of the injury as the underlying cause of death. Considering HCSO’s publications, it is the condition of the injury indicated as COD in accordance with the national practice. To sum it up, cooperation has proved to be effective in general, since as a result of surveillance there was in many cases need for data clarification, completion or supplement regarding the circumstances of violence or external cause (accident, suicide, homicide, time, cause and location of the injury) which all contributed to fulfilling HCSO’s reporting obligations.

In 2003, 116 physicians completed at least 1 death certificate that had to be corrected. For the remaining years in concern, these figures were as follows: 188 physicians in 2004, 120 physicians in 2011 and 67 physicians in 2015.

Table 1 The number of death certificates in Tolna countyin 2003, 2004, 2011 and 2015 filled in by healthcare service providers (Hc.s.p.), reviewed by NPHMOS and published by the HCSO according to ICD-10 major categories

ICD-10 major category	2003			2004			2011			2015		
	Hc.s.p. 25.I.d	NPHMOS 25.I.d	HCSO	Hc.s.p. 25.I.d.	NPHMOS 25.I.d	HCSO	Hc.s.p. 25.I.d	NPHMOS 25.I.d	HCSO	Hc.s.p. 25.I.d	NPHMOS 25.I.d	HCSO
-	24			95			3			18		
A	2			3			2			3	7	7
B		1		1		1				1	1	
C	12	35	40	13	74	75	57	67	68	58	79	79
D	7	2	1	12	2	2	2	1	1	1	1	1
E	8	3	3	13	10	10	33	19	19	42	31	31
F	7	6		15	22	5	7	9	10	9	30	31
G	10	2	2	14	9	11	8	2	4	10	11	11
H										1		
I	39	108	102	67	169	165	89	102	96	176	159	160
J	46	18	18	33	26	27	24	28	27	34	21	19
K	15	10	13	28	9	20	12	16	18	35	38	38
L		1	1	3						3		
M	2			3	2	1	2	3	3	3	3	4
N	2	2	3	11	4	5	7	3	3	2	1	1
P												1
Q				2	2	1	1					
R	11			17			2			3		
S	3	3		7	9		22	23		17	31	
T				2	3		2	3		1	1	
W	1	1	9	1	3	19	4	4	29	5	4	34
X		1	1			2	3		2	6	7	10
Y	1										3	1
Z	3			4								
Total	193	193	193	344	344	344	280	280	280	428	428	428

(-) “Underlying cause of death” not declared

Table 2 Number of deaths in Tolna county in 2003, 2004, 2011 and 2015 based on death certificates completed by healthcare service providers, as well as on medical reviews carried out by NPHMOS and on reviews by HCSO social statisticians, indicating the most significant COD categories, the proportion of CODs to be modified and the effect of modifications on county-specific COD statistics

Year	ICD-10 major category	Total number of death in Tolna county (a)	Number of certificates to be modified upon NPHMOS's proposal (b)	Proportion of certificates to be modified upon NPHMOS' proposal (c = [b/a] x 100)	Case numbers indicating CODs re-coded upon NPHMOS' proposal (d)	Modifications carried out upon NPHMOS' proposal (e = [d-b]/a x 100)	Case numbers as a result of CODs re-coded by HCSO (f)	Modifications carried out upon KSH's proposal (g = [f-b]/a x 100)
2003	AB	15	2	13.3%	1	-6.7%	0	-13.3%
	C	822	12	1.5%	35	2.8%	40	3.4%
	I	1809	39	2.2%	108	3.8%	102	3.5%
	J	130	46	35.4%	18	-21.5%	18	-21.5%
	K	207	15	7.2%	10	-2.4%	13	-1.0%
	STVWXYZ	241	8	3.3%	5	-1.2%	10	0.8%
	all death causes	3396	193	5.7%	---	---	---	---
2004	AB	5	4	80.0%	0	-80.0%	1	-60.0%
	C	847	13	1.5%	74	7.2%	75	7.3%
	I	1761	67	3.8%	169	5.8%	165	5.6%
	J	148	33	22.3%	26	-4.7%	27	-4.1%
	K	192	28	14.6%	9	-9.9%	20	-4.2%
	STVWXYZ	248	14	5.6%	15	0.4%	21	2.8%
	all death causes	3377	344	10.2%	---	---	---	---
2011	AB	10	2	20.0%	0	-20.0%	0	-20.0%
	C	834	57	6.8%	67	1.2%	68	1.3%
	I	1562	89	5.7%	102	0.8%	96	0.4%
	J	141	24	17.0%	28	2.8%	27	2.1%
	K	155	12	7.7%	16	2.6%	18	3.9%
	STVWXYZ	162	31	19.1%	30	-0.6%	31	0.0%
	all death causes	3119	280	9.0%	---	---	---	---
2015	AB	13	7	53.8%	7	53.8%	0	-53.8%
	C	729	79	10.8%	25	7.4%	0	-10.8%
	I	1488	160	10.8%	45	7.7%	1	-10.7%
	J	123	19	15.4%	6	10.6%	0	-15.4%
	K	161	38	23.6%	13	15.5%	0	-23.6%
	STVWXYZ	121	45	37.2%	18	22.3%	33	-9.9%
	all death causes	3009	428	14.2%	---	---	---	---

6-14% of CODs on death certificates required some corrections. Furthermore, there were no instances for failing to fill in the "underlying cause of death row" (25.I.d) and unjustified overreporting under main category R has decreased. The proposals for modification has changed county-specific cause of death statistics by more than 5% and it was the category of infectious diseases in which said change was the most significant in both years. The proposed changes affected more than 5% of death cases registered under diseases of the respiratory system" code in 2003, as well as under "neoplasms" code, "diseases of the circulatory and the digestive system" code in 2004. In 2011, when automated coding was used, the proposed changes had little effect (with the exception of infectious diseases), but in 2015 the effect of modifications was over 5% in all the categories.

In 2015 we saw some examples for COD qualified by the social statistician as appropriate for being processed. The social statistician found 275 certificates (i.e. 9.1% of total death certificates in Tolna county) when the registered diagnoses were detailed and accurate, and on the basis of ICD-10 they could identify the diagnosis leading directly to death. However, thanks to the clinical knowledge of the reviewer, additional questions were raised. This affected primarily the death cases registered under I, E, C main categories.

Discussion

During the investigations, we have developed a validation process, which was tested in practice. Then we could identify the wrongly coded diagnosis reported as the underlying cause of death as well as certifying physicians reporting misleading or inaccurate data. We described the impact of COD review on county-specific COD statistics. After reviewing death certificates and consulting with death data providers, the underlying cause of death had to be corrected in 6-14% of death certificates. There was no difference between manual and automated coding in this respect.

The number of COD diagnoses which required some corrections was proportional with the importance of the COD in each investigated year. Correction was necessary mainly by CODs coded as respiratory disease or violent death. "Diseases of the digestive system"

code and violent death code were in the second place as a lot of originally reported COD diagnoses under these categories had to be re-coded.

Corrections had to be carried out in a relatively balanced way: approximately the same number of cases had to be re-coded in each main category. Therefore, modifications had a moderate effect on county-specific COD statistics. There was a greater change in county-specific ICD code statistics derived from manual coding when compared to statistical data got in the first reviewed year of automatic coding. In 2015 however, a more significant change could be seen for all main codes, especially in the case of digestive diseases and violence CODs.

Infectious disease CODs showed the largest change after review in each year, which can be explained by low case numbers as well as with well-established official data reconciliation process.

Half of the certificates to be corrected was completed by the respective institution (hospital/nursing home) where the descendant has died and half of them was completed outside these institutions. A quarter of death certificates was filled in by a physician, who completed only 1 death certificate a year. In the case of death certificates which were completed outside the institutions and required some modifications, every second certificate was completed by a physician who had only 1 death certificate per year.

Overall, the results show that

(1) it is necessary to incorporate medical review into the validation of cause of death statistics, since as a result of this review, a modification or correction is required in 6-14% of CODs which is also accepted by HCSO as well;

(2) medical reviews carried out on almost all death certificates processed in the county by manual coding as well as medical review of death certificates preselected by social statisticians after automated coding were equally efficient but automatic coding is clearly more effective than manual coding in terms of main category level COD statistics. The so-called garbage codes which are inappropriate for statistical coding of underlying CODs (e.g. cardiac insufficiency, respiratory insufficiency, senility, marasmus, “Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified” under code R00–R99) could be eliminated by the introduction of automated coding. In 2003 and 2004, 11

(3.6‰) and 17 (5.5‰) CODs were reported under category R while this number was only 2 (0.7‰) in 2011, as opposed to 11 (3.6‰) in 2015 when an increase could be observed.

(3) Ad hoc consultations as part of medical reviews were well received by physicians. They cooperated with reviewers and by revising descendants' documents helped to gather more accurate data and then to correct COD diagnoses if necessary.

In order to overcome the deficiencies in medical training, a guide entitled "Physicians' handbook on medical certification of death" written and published by HCSO in 2006 was made available to certifying physicians, but self-learning has not delivered the expected results. There was also little interest in voluntary postgraduate training. However, this separate training module on death certificates could not be integrated into the compulsory training for residents and medical professionals.

Cooperation between HCSO and NPHMOS contributed to the development of the legal framework which resulted in improved death certificate data as well as the amendment of Government Decree No. 145/1999 and No. 351/2013. Furthermore, a new interface for registering COD data has also been introduced. A new death certificate form and a general notification form called "Notice Regarding Modification of Death Certificate" (Hungarian title for reference: "Értesítő a halottvizsgálati bizonyítvány módosításáról" were also developed and tested within the framework of cooperation.

However, compulsory autopsy in the event or suspicion of infectious diseases could not be enshrined into law and remained an unresolved problem. Autopsy is often not carried out at the request/pressure of relatives, especially when opening up the skull would be necessary. If there is an in vivo potential of an infectious disease as COD, setting up the diagnosis simply by imaging is sufficient on its own, without further microbiological examinations (e.g. bacteriological sampling, serological tests, polymerase chain reaction test etc.), for the introduction of an empiric therapy, but will not be thorough enough for epidemiological measures. If the patient died outside (home or nursing) institution, autopsy is not carried out, and hospitals will not be informed about the death.

There is no specific guideline or methodological letter foreseen what the chief medical officer can or should do if CODs are inaccurate or death certificates are incomplete. Nothing has indicated that death certificates had undergone any review.

The role of NPHMOS is not specified when it fails to accept a request for cremation without autopsy. What the NPHMOS can do is to reject the requested cremation in accordance with Act CXL of 2004 on the General Rules of Administrative Proceedings and Services i.e. it rejects the request for cremation without autopsy, but the descendant can have a coffin burial.

Furthermore, the person authorised for completing death certificates is not legally specified. Row 22 states that the certificates have to be filled in by the competent NPHMOS institution at the place of death. Thanks to the lack of human resources in public administration, there is a vacant medical officer job in many county districts. District medical officers are only appointed in county districts with a relatively large population. Therefore, it is the county district officer, who usually has a diploma in law, or they entrust graduates (health visitor nurse, public health and epidemic inspector, public health inspector, engineer etc.) working at the public health department of the county district. Death certificates filled in manually are in many cases almost illegible and COD can only be identified by relying on medical knowledge. An administrator prepares the documentation for signing which means that they thoroughly examine personal data in order to determine whether the person requesting the cremation or their authorised representative is entitled to the administration based on the documents (including the death certificate). It is also important to note that cremation is carried out if the death certificate satisfies the formal requirements (e.g. it is signed and sealed). This can lead to problems when a counterparty years later would like to validate their claim(s).

It is very difficult to get into contact with the reporting physician when a review is to be carried out. Should that be the case, healthcare workers are asked to answer questions from the descendant's documentation. These are mainly simple routine and clear questions (Type I or Type II diabetes; where did the primary tumour grow; the place and time, manner and circumstances of the injury etc.) but there may be complicated cases too when the diagnosis turns out to be quite different after analysing the data on the death certificate. This raises ethical questions too.

A constant improvement can be observed in COD statistical systems as well as in the history of death certificates. Due to the recent improvements in IT infrastructure as well as the legal institutional framework in Hungary, the primary obstacle in the effectiveness of statistical systems built up on CODs is data quality. Technical improvement should be

followed by the development of a quality assurance system as well as the improvement of medical training. These could make the system more appropriate for planning and monitoring the effectiveness of specific (public) health interventions at different levels. By improving data quality, COD analysis could be centredon the population of smaller regions as well as more accurately coded COD diagnoses. Thus, the processing of COD certificates for statistical purposes could serve as a more efficient tool for monitoring the quality of public healthcare services (taking into account hospital-acquired infections (HAI) or the consequences of anticoagulant therapy) and would then contribute effectively thereto. It is true however that the increasing expectations from authorities responsible for planning interventions and implementing specified programs in terms of COD data monitoring could mean the largest motivation to implement possible improvements.

New results

1. The protocol of medical revision of death certificate has been elaborated and tested, which is simple, can be applied in real-life circumstances in a cost efficient manner, and which can be accepted by both public health authorities and by the Hungarian Central Statistical Office (HCSO):
    a. the social statistician employed in the HCSO check each death certificate, and select the documents required medical review; the I. copy of selected certificates is copied and completed with the notion on the cause of selection,
    b. copies of selected certificates are pooled, and sent to the public health authority providing the county where the death happened, in 4-6 weeks taking into consideration the required actions to carry out the medical review,
    c. the public health officer checks the content of death certificate originally declared by the physician who completed the certificate, according to the question declared by the social statistician, and correct the sequential diagnosis for cause of death if the information provided by the certificate make it possible,
    d. if the declared information makes it not possible (certificate has missing or incongruent data), the medical officer consult (by phone or by personal discussion) with the physician who completed the certificate or with the physician who cared the patient; the correction of the cause of death sequence and the registration of corrected underling cause of death is carried out after the consultation,
    e. both the original and the corrected CODs are registered on the death certificate,
    f. expenses related to consultations (telephoning, mailing, personal meeting) are incomparably small compared to the gain in COD database quality (6-15% of COD needs correction).
2. Tasks for the public health authorities with the death certificates were identified, which are not defined at present

a. who is eligible to sign the death certificate (row 22: representative of local health authority is nor defined),
b. what ids the institutional protocol in local health authority to correct the originally registered COD in death certificate if missing or incorrect data are identified,
c. beyond the collection of VI. copies of death certificate, what kind of indicators or reports have to be prepared in local public health authorities.

3. A set of indicators has been elaborated which can be used to monitor the quality COD statistics, and which supports the use of county level quality indicators in comparative time trend or geographical evaluations.
4. It was demonstrated that it is necessary to implement sentinel sampling from death certificates not selected for correction by social statistician of HCSO, to organize consultation between social statistician and public health officer on the in order to evaluate the appropriateness of the cause of death sequence registered by the social statisticians of the HCSO.

1.5. It was shown that the omission of autopsy is not justified in vase of diagnosis or suspicion of infectious diseases as COD. Clinicians initiates frequently a treatment without microbiological diagnosis on the basis of the results from modern imaging technologies. The autopsy is the last opportunity to make up the omitted microbiological investigation. If the diagnosis of an infectious disease AB cod is the result of an autopsy, the pathologist is obliged to notify the infectious disease to the public health authority.

3. Ten indicators have been set up to monitor our correction procedure which we recommend for the purpose of comparing county-specific reviews.

1. The number of death certificates completed in the respective county for descendants who were residents of the county, and its proportion as per total death rate.
2. The number of suggested COD corrections and its proportion as per death certificates of all the county residents who died in the respective county.
3. The number of death causes wrongly coded by the healthcare service providers and its proportion as per COD main categories.
4. The number of death causes to be corrected as a result of medical review and its proportion as per COD main categories.

5. Change in the percentage rate of county cause-specific mortality, according to code corrections carried out after medical review.
6. The number of corrections approved by the HCSO and it proportions as per COD main categories.
7. Change in the percentage rate of county cause-specific mortality, according to code corrections suggested as a result of medical review and carried out by HCSO.
8. The number of death certificates completed by a hospital/nursing home which have to be corrected, and its proportion as per total number of death certificates completed by the respective institution which have to be corrected.
9. The number of death certificates completed by a hospital/nursing home which have to be corrected, and its proportion as per total number of death certificates completed outside institution framework.
10. The number of death certificates corrected as per death data providers (i.e. physician/hospital etc.).

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Cumulative impact factor of publications dissertation basedon: 2.321

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