







Investigation of garbage code deaths to improve the quality of cause-of-death in Brazil: results from a pilot study

Investigação de óbitos por códigos garbage para melhoria da qualidade de causas de morte no Brasil: resultados de um estudo piloto

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ABSTRACT: Introduction: Reliable cause-of-death statistics are an important source of information on trends and differentials in population health. In Brazil, the Mortality Information System is responsible for compiling cause of death (CoD) data. Despite the success in reducing R-codes ill-defined causes of death, other garbage codes (GC), classified as causes that cannot be the underlying CoD, according to the Global Burden of Disease study, remain a challenge. The Ministry of Health (MoH) aims to decrease the proportion of all GCs, and a pilot study tested a comprehensive strategy to investigate GC deaths that occurred in 2015. **Methods:** The research was conducted in seven Brazilian cities during five months in 2016: two rural cities, one metropolitan area, and four capitals. For all GCs selected, municipal healthcare workers collected information about the terminal disease from hospital records, autopsies, family health teams, and home investigation. The fieldwork was coordinated at Federal level in partnership with State and municipal teams. **Results:** Out of 1,242 deaths selected, physicians analyzed the information collected and certified the CoD in 1,055 deaths, resulting in 92.6% of cases having their underlying cause changed to a usable ICD-10 code. **Discussion:** It is noteworthy the capacity the health teams in the seven cities showed during the implementation of the pilot. **Conclusion:** After results analysis, the GC investigation protocol was modified, and the implementation scaled up to 60 cities in 2017.

Keywords: Cause of death. Death certificate. Mortality information systems. Vital statistics.

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RESUMO: *Introdução:* Estatísticas confiáveis em mortalidade são importante fonte de evidências de tendências e diferenciais na saúde da população. No Brasil, o Sistema de Informação sobre Mortalidade é responsável por compilar dados da causa de morte (CM). Embora tenha havido sucesso na redução de causas mal definidas de morte, ainda há um problema com outros códigos *garbage* (GC), classificados como causas de morte que não devem ser registradas como básicas, segundo o estudo de Carga Global de Doença. O Ministério da Saúde estabeleceu uma meta para diminuir a proporção de todos os GC e testou em estudo piloto uma estratégia abrangente para investigar as mortes. *Métodos:* A pesquisa foi realizada em 7 cidades do Brasil durante 4 meses: 2 em áreas rurais, 1 em área metropolitana e 4 em capitais. Os agentes municipais de saúde coletaram informações sobre a doença terminal obtida nos registros hospitalares, autópsias, equipes de saúde da família e investigação domiciliar. O trabalho de campo foi coordenado pelo nível federal, juntamente com as equipes estaduais e municipais. *Resultados:* Dos 1.242 óbitos selecionados, médicos analisaram as informações coletadas e certificaram a CM em 1.055 óbitos, resultando em 92,6% dos casos tendo sua causa subjacente alterada para código específico da CID-10. *Discussão:* Destaca-se a capacidade de articulação que as equipes de saúde apresentaram no cumprimento das etapas propostas para o trabalho. *Conclusão:* Após o estudo piloto, o protocolo de investigação foi modificado e sua implementação foi ampliada para 60 cidades em 2017.

Palavras-chave: Causa de morte. Atestado de óbito. Sistemas de informação. Estatísticas vitais.

BACKGROUND

Information on mortality is an important source of evidence of trends and differentials in population health. Vital statistics – produced by the legal registration of births and deaths by age, sex and causes – are an excellent source of demographic and epidemiological information on population diseases resulting in mortality. Health systems should rely on good quality information on causes of death for health policymaking to prevent premature mortality and promote population health¹.

In Brazil, the Mortality Information System (SIM) is responsible for compiling cause-of-death data for the whole country. This system has been maintained by the national Ministry of Health (MoH) since 1975, and it reports approximately 1.3 million deaths annually^{2,3}. The SIM is decentralized and reported over 95% of all deaths in the country in 2000-2010. However, the accuracy of cause-of-death data needs improvement. In 2000, 14.3% (n = 135,749) of all deaths were classified as ill-defined causes or R codes, that is, deaths codified as signs, symptoms and other abnormal clinical and laboratory findings, according to chapter 18 of the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10)⁴. These unknown or ill-defined causes of death (IDCD) are useless for public policy. In 2005, the Ministry of Health implemented a strategy to improve cause of death information that included investigation of IDCD, suspected maternal deaths in women of reproductive age, and deaths in infants under 1 year of age. In this strategy, regulations require a local surveillance team in the municipalities and hospitals to investigate ill-defined deaths and detect the true underlying causes of death. In 2010, of 97,314 deaths classified as IDCD,

30.3% were investigated and 65.5% were reclassified to a more informative cause⁵. Despite the national reduction in this indicator, regional discrepancies remain, being lower in the South and South-East regions and higher in Northern regions⁶.

Despite success in reducing IDCD, Brazil still has a problem with garbage codes (GC). The Global Burden of Disease (GBD) study pioneered this term to describe causes that cannot or should not serve as an underlying cause of death^{7,9}. These include R codes for ill-defined causes, conditions that cannot be classified as cause of death such as back pain, intermediate or immediate causes such as heart failure, or insufficiently specified causes such as pneumonia. Using the SIM database, the GBD Study 2015 showed that approximately 33% of deaths in Brazil were assigned a GC as the cause of death that year, compared with 30% for all reported causes of death globally^{8,10,11}.

In spite of a continuous decline in the percentage of IDCD, particularly in the North and Northeastern regions, the proportion of deaths assigned as other GCs remains the same every year, as the GBD study detected, with similar proportions in all regions^{2,12}. According to the MoH in 2015, whereas the majority (56.5%) of IDCD (chapter 18) occur in the decedent's home, over 65% of GC deaths occurred in hospitals. Regarding age and sex, no differences were found between two code groups with ill-defined causes of death. In both cases, it was more frequent in men, approximately 51%. In addition, most deaths occurred in the age group between 60 years or older (65%). Finally, although the proportion of ill-defined deaths or R codes is higher in the North and Northeast regions, geographically disaggregated data from the 2015 SIM database showed a high proportion of GC across the whole country².

Around 400,000 GC deaths occur in Brazil each year⁵, producing a significant challenge for the Ministry of Health, which has a history of developing innovative interventions to improve the quality of CoD data. However, until recently, this strategy was not extended to garbage codes from other chapters of the ICD-10¹³⁻¹⁵. Through this experience, the strategy used to reduce the proportion of R codes was adapted and extended to reduce the proportion of garbage codes.

The MoH developed a structured protocol to investigate deaths initially certified with GC and pilot tested it in seven cities distributed across the five regions of Brazil, each with a different demographic profile, in order to test the efficacy and feasibility of the implementation at national scale. To do so, the first goal was to investigate the possibility of reclassifying underlying CoD originally certified with GC to usable ICD-10 codes in seven cities during a five-month period in 2016. The second goal was to develop and verify a protocol with GC investigation forms to standardize the process in the whole country; this protocol was implemented by the municipal and state public health staff to advise the MoH prior to national rollout. The third objective was to strengthen physicians' capacity to correctly certify the underlying CoD, to improve the quality of mortality data in the long-term. Thus, the objectives of this pilot study were: (1) to investigate deaths certified with GC to establish more accurate underlying causes of deaths, (2) to examine the feasibility of this approach at national scale, and (3) to qualify physicians for accurate medical certification of cause of death. The final purpose of this pilot study was to develop a feasible strategy to improve the quality of mortality data for more informed health policies, resulting in better allocation of resources based on current and projected burden of disease in Brazil.

METHODS

The purpose of this pilot study was to conduct research in municipalities with documented cases of GC deaths that are representative of the diverse communities from each region of Brazil. Given the decentralized form of government, the project was first presented to representatives of the states and municipalities and to the municipal health surveillance teams, in order to obtain consent to participate in this pilot. Seven cities were selected for the pilot study – two rural cities, one city surrounding a metropolitan area, and four capitals. Thus, the study was implemented in all five regions of Brazil: South (Florianópolis), Southeast (Belo Horizonte), Northeast (Caicó and Parnamirim), Midwest (Goiânia and Ceres), and North (Palmas).

In June 2016, the selected municipalities consented to participate in the pilot study. To ensure consistency among the pilot sites, the MoH held inception meetings with each local team (municipality and state) to explain the project goals, define the methodology, and discuss the fieldwork strategy and local team composition. The local surveillance teams were comprised of an array of professionals including nurses, social workers, epidemiologists, statisticians, information technology specialists, lawyers, and physicians. The MoH and local governments, with advisory support from the Data for the Health Initiative (D4H) team in Brazil, conducted trainings for the local surveillance teams and physicians in the seven pilot cities before fieldwork implementation. Fieldwork commenced on June 1st, 2016 with the deadline for completion of all investigations set for November 20th, 2016; this timeline was established to allow the evaluation of the pilot study and presentation of results to a national stakeholder meeting in November 2016.

For data collection, selection criteria included deaths occurring between January 1st and December 31st, 2015 with an underlying cause of death meeting the garbage code criteria available at that time based on the 2010 GBD study, which classified over four thousand ICD-10 codes as garbage. The 2015 mortality records of residents from the seven pilot cities were analyzed to identify GC deaths.

To streamline data collection for the pilot, the MoH created an intranet website called SVS-Collect. Once cases meeting the criteria were identified, these records were extracted from SIM, uploaded to the SVS-Collect website, and access was provided to the municipal health surveillance teams. Teams were responsible for investigating deaths, uploading the data collected from each case to SVS-Collect and entering the revised underlying cause of death in SIM. The SVS-Collect website served as a tool for monitoring and evaluating the fieldwork progress in each municipality.

All investigations were performed using standardized investigation forms for health services and home interviews. The health service forms were provided by the MoH and were previously used in routine investigations of Chapter 18 R codes, infant deaths and suspected maternal deaths in women of reproductive age to collect information about the deceased's terminal illness. Fieldwork was coordinated by the National level in partnership with State managers and implemented by the local municipal teams. Surveillance teams collected information from various sources, including the routine autopsy services for natural deaths (SVO),

Institute of Forensic Medicine (IFM) records for external causes, police station records, Family Healthcare Program records, hospitals records (municipal, state, national and private hospitals), and cause or disease-specific databases, such as the Prevention of Deaths in Traffic Accidents Program, Cancer registries, and communicable diseases databases.

For deaths that occurred at home or when the information obtained from the health services was insufficient for ascertaining the underlying CoD, health professionals conducted structured interviews with surviving relatives or caretakers using a standardized verbal autopsy (VA) form for data collection. The VA interview collects information about the signs and symptoms presented by the decedent before death, and these were observed by family members who lived with the deceased during this period. The VA questionnaire used was based on the Portuguese version of the 2007 WHO instrument adapted by the MoH for the Brazilian context.

A team of sixty physicians from the seven cities in the investigation protocol reviewed the information collected for each case (Belo Horizonte 4; Caicó 6; Ceres 1; Florianópolis 4; Goiania 1; Palmas 6; Parnamirim 38). Based on available evidence, physicians determined and re-certified the underlying cause of death by filling in a new medical certificate of cause of death. All deaths selected for this study had their underlying cause of death reviewed, before and after investigation activities, by ten coders with significant experience in coding causes of death. Following medical re-certification, the team of coders coded the reclassified underlying CoD, which was uploaded to the SIM database and SVS-Collect website by the surveillance teams.

This study was approved by the Research Ethics Committee of the Federal University of Minas Gerais (CAEE 7555317.0.0000.5149) and developed in accordance with the ethical precepts established by the ordinance no. 466/2012 of the Health National Council.

RESULTS

Each city manager defined the number of deaths and the place of occurrence for each local team to investigate. Belo Horizonte opted to only investigate deaths of residents occurring in the municipality; the other six cities selected resident deaths regardless of the place of occurrence. The distribution of the cases selected for investigation by municipality is as follows: Belo Horizonte – 271 deaths; Caicó – 97 deaths; Ceres – 30 deaths; Florianópolis – 275 deaths; Goiania – 189 deaths; Palmas – 214 deaths; and Parnamirim – 166 deaths (Table 1).

In 2015, there were 6,090 deaths from the seven pilot cities registered in SIM with GC as the underlying cause of death. From this total, 1,242 (20.4%) cases were selected by the local teams, of which 1,145 (92.2%) investigations were successfully completed. Of the cases investigated, 53% were women and 13.1% were young people aged between 20 and 39 years, 21.1% were people aged 40 to 59 years, and 61.3% were people over 60 years. Following the investigations, physicians analyzed the information collected and re-certified the underlying causes of death in 1,055 deaths, which means 92.1% of cases had their underlying cause changed to a usable ICD-10 code. In 90 (7.9%) cases, the local teams were unable to find

adequate information to reclassify the cause of death. Additionally, in 78 (7.4%) cases, the causes of death were changed but remained as other garbage codes. For the deaths selected for the pilot study, the investigations resulted in the reclassification of the underlying cause of death in 85.3% of cases ($n = 977$), with 14.7% remaining as garbage codes (Figure 1).

Table 1. Distribution of deaths classified as garbage code to investigate the pilot study – Brazil, 2015.

Residence occurrence	Belo Horizonte	Caicó	Ceres	Florianópolis	Goiânia	Palmas	Parnamirim	Total
Number of deaths	271	97	30	275	189	214	166	1.242
Goiânia			2		189	1		192
Ceres			26					26
Anápolis			1					1
Rialma			1					1
Belo Horizonte	271							271
Piauí						1		1
Teresina						1		1
Caicó		88						88
Parnamirim							88	88
Natal		9					75	84
Macaíba							2	2
Canguaretama							1	1
Florianópolis				275				275
São Paulo						1		1
Barretos						1		1
Palmas						205		205
Dianópolis						2		2
Araguaína						1		1
Dois Irmãos Do Tocantins						1		1
Lajeado						1		1
Porto Nacional						1		1

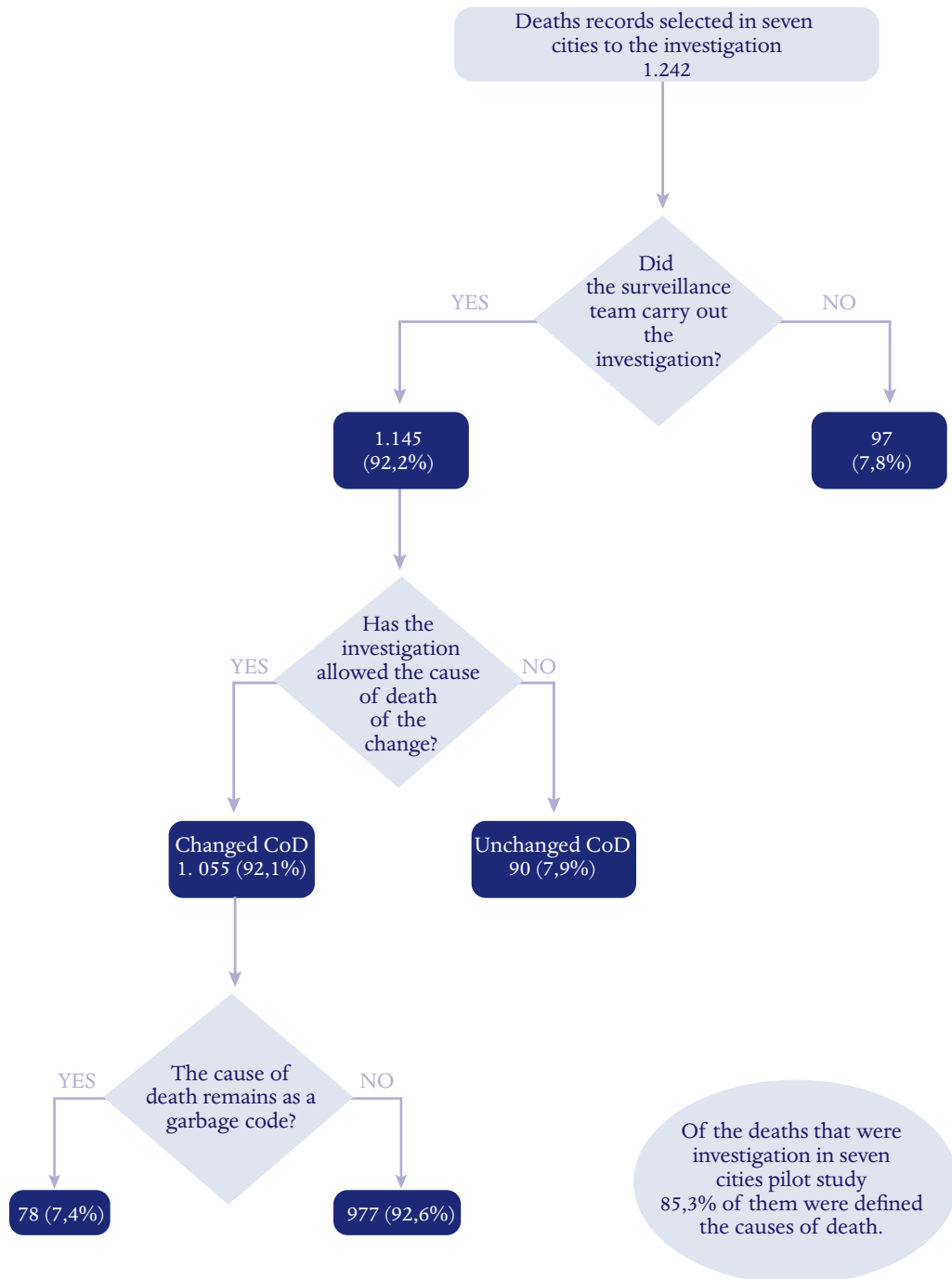


Figure 1. Flowchart of investigation protocol in the seven cities of the pilot study.

Source: Ministério da Saúde.

The investigations were carried out in multiple sources to re-create the comprehensive medical history of each case. The distribution was as follows: in 744 cases, information was collected from individual's medical records; in 328 cases, from laboratory or other clinical exam results; in 229 cases, from outpatient records; in 214 cases, from medical forensic records; in 169 cases, from VA interviews with surviving family members; and in 104 cases, from routine autopsy service (SVO) records. Police records and news websites were consulted for cases 1 and 2, respectively.

There was a significant redistribution of leading causes of deaths grouped by ICD-10 chapters following the investigation. The leading cause of deaths in the seven cities were in chapter 9 of ICD-10, Diseases of the circulatory system, with a total of 401 cases, of which 44.1% aggregated in the Cerebrovascular diseases group. External causes (chapter 20) were the second leading cause, comprising 28.7% of cases ($n = 202$), of which 14.3% were classified as motorcycle rider injured in a transport accident. Neoplasia deaths (chapter 2) were the third leading cause with 117 cases, of which 27.3% of cases were aggregated in the group of malignant neoplasms of the digestive organs. With a total of 98 cases, deaths from endocrine, nutritional and metabolic diseases (chapter 4) were the fourth leading cause, of which 78.6% were attributed to the diabetes mellitus. Finally, respiratory diseases (chapter 10) were the fifth leading cause (96), with nearly half (48.9%) of deaths attributed to influenza and pneumonia. It is noteworthy that one (01) case of maternal death was identified among the deaths investigated. Before investigation, ill-defined causes of deaths were the second leading cause based on identified cases, after investigation, this chapter shifted to the ninth leading cause. Table 2 shows the redistribution of the leading causes of death in the seven cities before and after investigation.

Table 2. Profile of the cause of death before and after investigation in the seven cities, 2015.

Chapter (ICD-10)	Before			After		
	Rank	n	%	Rank	n	%
Diseases of the circulatory system	1	420	36.7	1	401	35.0
Sympt. signs and abnormal clin. and laborat. findings, not classified elsewhere	2	200	17.5	9	26	2.3
External causes of morbidity and mortality	3	152	13.3	2	202	17.6
Neoplasms	4	85	7.4	3	117	10.2
Diseases of the genitourinary system	5	81	7.1	10	24	2.1
Infectious and parasitic diseases	6	59	5.2	8	29	2.5
Diseases of the respiratory system	7	54	4.7	5	96	8.4
Diseases of the digestive system	8	42	3.7	6	63	5.5
Diseases of the eye and adnexa	9	32	2.8			
Endocrine, nutritional and metabolic dis.	10	5	0.4	4	98	8.6
Dis. blood and blood-form. organs and cert. disorders inv. the immune mechanism	11	4	0.3	16	3	0.3

Continue...

Table 2. Continuation.

Chapter (ICD-10)	Before			After		
	Rank	n	%	Rank	n	%
Dis. of the musculoskeletal sys. con. tissue	12	3	0.3	13	4	0.4
Dis. skin and subcutaneous tissue	12	3	0.3	13	4	0.3
Mental and behavioral disorders	14	2	0.2	11	17	1.5
Certain cond. Origin. in the perinatal	14	2	0.2	13	4	0.3
Congenital malfor., deform. and chromosomal abnormalities	16	1	0.1	12	5	0.4
Diseases of the nervous system				7	49	3.8
Injury, poisoning and certain other consequences of external causes				17	1	0.1
Pregnancy, childbirth and the puerperium				17	1	0.1

For the 1,145 deaths investigated, it is noteworthy the capacity of the local health teams in the seven cities as shown by the rapid implementation and completion of the work and evaluation of results. The stages of implementation were as follows: (1) training of participating municipal health teams; (2) selection of death records; (3) collection of information from relevant sources; (4) review and re-certification of the underlying cause of death by the referring physician; (5) codification of the new underlying cause of death; (6) update of the underlying cause of death in SIM; and (7) upload of the investigation results in the monitoring panel (SVS-Collect). All steps were performed between June 1st and November 20th, 2016, with the presentation of results to the national meeting at end of November.

During the pilot, associated training workshops for physicians were also implemented by the MoH and local municipal governments, with advisory support from D4H and the Federal University of Minas Gerais (UFMG). A total of 449 physicians, including pathologists from death verification services (SVO), were trained in medical certification of cause of death and the importance of reliable CoD data for public health policy. The training workshops were held from July 1st to September 15th, 2016, with the following number of physicians trained per city: Belo Horizonte – 120; Caicó – 51; Ceres – 18; Florianópolis – 45; Goiania – 18; Parnamirim – 38; and Palmas – 159.

Results from the pilot study were presented at a national meeting in November 2016. The purpose of the meeting was to introduce the protocol and advocate for national adoption of the strategy by key stakeholders, illustrating the potential positive impact on reducing the proportion of deaths initially certified as garbage codes.

The results of the pilot study were used to identify initiatives to strengthen the death investigation process, as well as to improve the quality of CoD data, as described below (Box 1). These include a study protocol that describes the general components of the investigation, including a revised list of GCs for investigation. The GBD 2010 study list used in the pilot was updated to

the GBD 2015 list of garbage codes and reduced to only 12 groupings of GC. These priority GC account for over 80% of all GC in the country, and it includes the following: Ill-defined causes (R00-R99, except R95); Unspecified cerebrovascular accident and other sequelae of cerebrovascular (I67.4, I67.9, I69.4, I69.8, I64); Septicemia (A40-A41); Cardiac insufficiency and unspecified cardiopathies (I50, I51); Essential hypertension (I10); Unspecified neoplasia (C26, C55, C76, C78, C80); Pulmonary embolism (I26); Pneumonia (J15.9, J18); Respiratory insufficiency (J96) and other respiratory disorders (J98); Renal insufficiency (N17, N19); External causes with undetermined intent and unspecified accidents (Y10-Y34, X59); and Unspecified transport accidents and homicides (V89, Y09). Reducing the list of GCs to investigate these priority GCs made the protocol more feasible and effective to apply to 60 cities, after the completion of the pilot study.

Box 1. Positive initiatives proposed after the pilot study in seven cities in Brazil, 2015.

1. Analysis of the deaths investigated in the pilot study with the participation of local certifier physicians and municipal health workers.
2. Development of a modified protocol to investigate deaths classified as garbage codes in 60 cities, including:
 - 2.1. Defining a list of 12 groupings of priority GCs to be investigated in the 60 cities.
 - 2.2. Development of a new form to investigate deaths from natural causes classified as garbage codes for use in hospitals.
 - 2.3. Development of evidence criteria to change the cause of death.
3. Participation of physicians from the pilot study team in the testing of the first version of the medical training mobile phone application, "Certified."
4. Proposal to expand the new strategy for sixty cities in Brazil.

DISCUSSION

Despite previous considerable efforts to improve the quality of mortality data, the proportion of deaths initially certified as GC remains high, representing over 30% of all deaths in 2015. The MoH aims to decrease the proportion of deaths certified with GC by 10% in ten years. To achieve this goal, the MoH pilot tested a comprehensive strategy to investigate deaths and improve physicians' capacity to medically certify the cause of death through training.

The pilot study showed that there is a wealth of information pertaining to the underlying cause of death available in hospital medical records, primary care medical records, and in autopsy services for natural and external causes. As these cases are concentrated in a limited number of hospitals, this allows for targeted activities within the hospitals and requires fewer resources, bringing thus greater results in a shorter period. For deaths occurring at home or in cases where information from the medical records was insufficient, VA interviews with surviving family members served as complementary sources of information. Although the pilot study was developed in only seven cities, the deaths classified as GC from

those cities had the same distribution profile as other cities in Brazil, including sex, place of occurrence, and age group. Thus, the whole flow of operations in these seven cities was reproduced as close as possible to the proposal for the posterior major study.

Results of this pilot study set new procedures to improve the feasibility and efficiency of the study protocol. The previous GC list, which contained more than 4,000 ICD-10 codes for investigation was summarized into a more feasible list of 12 GC groupings that are responsible for over 80% of the total GC in Brazil. The pilot test also showed that the collection of data in hospitals was inadequate, so it was re-formatted to comprise more relevant information, including criteria of evidence, which was used by physicians to change and certify the cause-of-death after investigations.

The new strategy followed targeted efforts to improve CoD data in Brazil through IDCD investigation. The proportion of these causes from chapter 18 of ICD-10 declined from 14.3% in 2000 to 5.4% in 2017. Because ill-defined causes of death predominantly occur at home, the proven strategy for investigating these deaths primarily includes VA interviews with surviving family members and medical record review from hospitals and primary healthcare services. However, deaths occurring at home are dispersed throughout the city, which makes the investigation more difficult and resource-intensive. In contrast, hospitals are the place where deaths are initially certified with garbage codes, so a strategy involving the surveillance teams, hospital boards and the certifying physicians must be adopted in these services.

Consensus for adopting this strategy was reached during the national launch meeting held in November 2016. As such, the MoH and decentralized state and municipal health departments adopted the revised GC investigation protocol and extended the implementation to 53 cities in Brazil, totaling 60 cities, in 2017.

CONCLUSION

The MoH continues to review current policies and develop new strategies to improve the quality of mortality data in Brazil, including continued training for physicians in participating hospitals, development of new tools to guide physicians in filling in the medical certificate of cause of death, and capacity building for municipal health surveillance teams to conduct death investigations. Based on the positive outcomes of the pilot study, the Ministry extended activities from 7 cities to 60 cities. Ultimately, the MoH will extend these activities to the entire country.

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