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**ORIGINAL ARTICLE/***ARTIGO ORIGINAL*

# Data for health: impact on improving the quality of cause-of-death information in Brazil

*Dados para a saúde: impacto na melhoria da qualidade da informação sobre causas de óbito no Brasil*

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**ABSTRACT:** ***Introduction*:** Knowing the number of deaths and their causes is relevant information for public health managers. However, the cause of death is often classified with codes that are not useful for mortality analysis, called garbage codes (GC). ***Objective*:** To describe and evaluate the impact of investigation of the underlying cause of poorly classified deaths on death certificates in 2017. ***Methods*:** Based on a standardized protocol, GC deaths from 60 municipalities were investigated, mainly in hospital records and autopsy services. Managers at the state level of the Mortality Information System also developed procedures to improve the classification of causes of death, with the consequent adherence of other municipalities (n = 4022). This made it possible to compare the results of GC research between these two groups of municipalities. ***Results*:** In the country, among the 108,826 GC investigated in 2017, 48% were reclassified to specific causes. In the 60 focus municipalities, 58% of the 35,366 investigated deaths from GC were reclassified. After the intervention, the proportion of deaths classified as GC decreased by 11% in the country and 17% in the municipalities. ***Discussion*:** The research in hospital records enabled almost half of the deaths from GC investigated to be reclassified. This is the first study to investigate GC in hospital records of more than 100,000 deaths. The 60 cities targeted by the intervention had better results than the other cities. ***Conclusion*:** The intervention proved to be an appropriate initiative to improve the quality of information on cause of death and should be encouraged.

***Keywords*:** Mortality. Mortality registries. Cause of death. Brazil.

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**RESUMO:** ***Introdução*:** Conhecer o número de óbitos e suas causas se constitui em informação de relevância para gestores de saúde pública. Entretanto, muitas vezes a causa do óbito é classificada com códigos pouco úteis para as análises de mortalidade, denominados códigos *garbage* (CG). ***Objetivo*:** Descrever e avaliar o impacto da investigação da causa básica de morte mal classificada no atestado de óbito em 2017. ***Métodos*:** Com base em protocolo padronizado, foram pesquisadas mortes com CG de 60 municípios que foram foco da intervenção, principalmente em prontuários hospitalares e serviços de autopsia. No nível estadual de gestão do Sistema de Informação de Mortalidade também foram desenvolvidas ações para melhoria da classificação da causa do óbito, com consequente adesão da maioria dos demais municípios (n = 4.022), o que permitiu comparações com os resultados da investigação de CG nas 60 cidades. ***Resultados*:** No país, de 108.826 CG investigadas em 2017, 48% foram reclassificadas para causas específicas. Já nos 60 municípios selecionados, 58% dos 35.366 óbitos por CG pesquisados foram reclassificados. A proporção de óbitos por CG declinou em 11% no país e 17% nos municípios em que houve intervenção. ***Discussão*:** Este é o primeiro estudo que investigou CG em registros médicos de mais de 100 mil mortes. A pesquisa possibilitou reclassificar para causas básicas específicas cerca de metade dos óbitos por CG investigados. As 60 cidades que foram alvo da intervenção tiveram melhor resultado que as demais cidades. ***Conclusão*:** A intervenção mostrou ser uma iniciativa adequada para a melhoria da qualidade da informação sobre causa de morte e deve ser estimulada.

***Palavras-chave*:** Mortalidade. Registros de mortalidade. Causas de morte. Brasil.

## INTRODUCTION

Health statistics are used for planning, monitoring and evaluation in health[1]. Significant human, physical and financial resources have been invested around the world in collecting data about population, health services, and health status, especially for levels of greater geographic disaggregation. Among these statistics, information on causes of death and demographic characteristics of deceased persons are important indicators of health and socioeconomic conditions. These statistics are also very sensitive metrics, enabling the identification of more vulnerable groups and evaluating results of social programs and policies. However, problems related to the quality of mortality information are still present, and many countries do not have reliable information on health[2].

Cause-of-death statistics in Brazil are the responsibility of the Ministry of Health (MH). The Mortality Information System (MIS) was created by the MH in 1975 to regularly obtain data on mortality and cause of death[3]. The quality of the MIS can be assessed by its reliability in terms of coverage of death records and the classification of cause of death, representing the actual mortality patterns of the Brazilian population. Thus, in mortality analysis, the degree of coverage and the quality of information on cause of death should be observed in order to reduce the risk of having mortality estimates with problems of underreporting and/or incorrect record of cause of death[4].

In recent decades, several interventions have been implemented to improve vital statistics information systems that had an impact on improving MIS coverage and cause-of-death notification quality[4,5]. These interventions were carried out jointly by

epidemiological surveillance teams at federal, state, and municipal levels. More recent analyses of the quality of the MIS indicate that the quality of mortality information in Brazil showed significant advances, capturing more deaths and improving the accuracy of information about the cause of death[6]. However, some notified causes of death require greater detail, such as unspecified cerebrovascular accident (if hemorrhagic or ischemic), pneumonia without specification of causal agent, and old problems not yet fully overcome, such as deaths without medical care, with unknown cause of death, or with ill-defined causes. These causes are called garbage causes or garbage codes (GC) for their potential impairment of analyses of the mortality profile of a population[6].

In 2016, the Brazilian Ministry of Health joined the Data for Health Initiative, invited by Bloomberg Philanthropies[7], which aimed to improve the lives of populations by improving the quality of information on mortality and the use of this information to formulate health policies. The MH's participation in the initiative expanded the scope of interventions that were being performed to improve the quality of information on causes of death. The problems of incomplete diagnosis of the underlying cause, which generate classification with unhelpful codes – the GC –, were prioritized and became the focus of specific interventions undertaken by the MH, by states and municipalities between late 2016 and March 2019.

The main objective of this study is to evaluate the impact of interventions of the Data for Health Initiative on improving the quality of cause-of-death notifications to the MIS in 2017, by analyzing the reduction of underlying causes of death with GC, through research in hospital records, reports of the Death Verification Services (SVO), and reports of the Forensic Medical Institute (IML).

## METHODS

This study evaluates the impact of implementing an intervention project to improve the quality of cause-of-death information recorded in the MIS. This is an initiative that involved all administrative levels of the Unified Health System (SUS) and had participation and support of states and municipalities. The project targeted cities that had a high number of GC notified to the MIS for causes of deaths that occurred in 2017. With methodological support from the Universidade Federal de Minas Gerais (UFMG), a project to evaluate ongoing interventions was initiated, aiming to assess whether there was a change in the quality of information on causes of death.

The project was implemented in 3 stages. The first was to sensitize managers about the importance of the project. The second stage was a pilot study of GC investigation in 7 cities. Finally, in the third stage, the research proposal was expanded to 60 cities in the country. The project also allowed other municipalities to implement the investigation.

In the project's initial development in 2016, meetings were held for sensitization of state and municipal MIS managers as to the quality problems of cause-of-death records

notified to the system, coordinated by the MH and the UFMG. In these meetings, there were intense discussions as to possible strategies to improve cause-of-death information through its recording by the physician that completes the death certificate (DC). One of the main results in this process was the decision to initiate the intervention in hospitals, which are responsible for recording the majority of deaths in the country. After a national meeting with the managers of 7 cities selected in the 5 regions of the country, a pilot project was immediately initiated for the reduction of GC deaths that occurred in hospitals[8].

The intervention in the pilot project was developed by surveying hospital records, using the cause-of-death investigation protocol already in use in the routine work of the municipal death surveillance, with training of hospital physicians for correct completion of the medical certificate with underlying cause of death and the sequence of causes that led to death. This pilot study's results were presented at a national meeting in late 2016, with participation of the cities involved, states and their capitals, municipalities, Brazilian universities, the University of Melbourne (Australia) and the Vital Strategies organization. Positive aspects were observed, indicating that the intervention was important to improve the quality of information on cause of death.

With the goal of continuing the intervention, the pilot study indicated the need to: review the routine form used in the investigation of hospital deaths with ill-defined causes (IOCMD); prioritize research in hospitals with higher percentage of GCs; introduce evidence criteria for definition of cause after investigation; standardize the information collection module; and include information and key fields for definition of cause of death[9]. Based on the pilot study's results, there was a proposal to expand the intervention to 60 cities, which concentrated 35% of deaths nationwide, representing all 5 geographic regions and with different population sizes.

For the expanded intervention, a new protocol was prepared, which included a revised form for data collection for investigation of hospital deaths with a cause of death classified as GC (IOCMD-H form). In the protocol, we defined a list of codes established as priorities, because they represent 80% of the deaths with GC[9] in the country. In the selection of cases, we extracted deaths with GC in the original underlying cause from the MIS, by hospital unit. The teams responsible for the MIS and for the death surveillance of the municipalities revised the coding of the DC, using the white copy of the DC archived in the Municipal Health Department[3], and supported the hospital units with collecting data in the medical records. Researchers from UFMG monitored the activities that were developed in the selected cities, clarifying doubts and answering questions in a continuous discussion process.

The form used in the standardized collection of information about the clinical case included results of exams and procedures to help elucidate the underlying cause of death, in addition to using levels of evidence to define the original cause. The investigation of deaths by GC was performed by health professionals of the death surveillance team of states and municipalities. The final evaluation of the investigated cause and the evidentiary

support for changing the cause of death were conducted by a physician trained[9] in assessing the result of investigation of deaths by GC, confirming the new cause of death with the collected information or maintaining the original cause due to insufficient information.

Other sources of information about terminal disease, such as SVO, were also investigated in some municipalities. Deaths due to nonspecific external causes were investigated in the IML. In the case of home deaths and even hospital deaths in which previous research in health services did not allow identifying the cause of death, data collection should use the verbal autopsy questionnaire[10]. This form has been used routinely since 2009 in household interviews to investigate cases of ill-defined causes of chapter XVIII of the International Statistical Classification of Diseases and Health-Related Problems (ICD-10).

For data analysis, we considered the classification of GC at levels proposed in the 2016 Global Burden of Disease Study (GBD), according to the redistribution of these causes to the hierarchical levels of the GBD list of causes[11,12]. In this classification, level 1 GCs – the ill-defined causes of chapter XVIII of ICD-10 and septicemia, for example – are those of worst quality, resulting in an underlying cause that could be inserted into any of the 3 broad cause groups of the GBD study: infectious diseases, chronic diseases, or accidents and violence. Level 2 GCs, such as essential hypertension, although less severe than those of level 1, are also codes of poor quality, as they affect knowledge about the main causes of death. Level 3 codes, such as malignant neoplasms without specification of site, and level 4 GCs, such as unspecified cerebrovascular accident (if hemorrhagic or ischemic), have a lower impact on the mortality profile, as they allow inferring that the underlying cause is related to a single group of causes or even to a single disease or injury, requiring only qualification.

This study was approved by the Research Ethics Committee of UFMG (CAEE 75555317.0.0000.5149) and developed according to the ethical precepts established in Ordinance No. 466/2012 of the National Health Council.

## RESULTS

In 2017, 348,155 deaths occurred in the 60 selected cities, ranging from 107 deaths per year in Augustinópolis (TO) to 76,000 in São Paulo (SP), and 35% of these deaths had a GC as the underlying cause of death. In the other cities of the country, 964,509 deaths occurred, and 37% of the causes of death were classified as GC. In the 60 focus cities, 35,366 deaths by GC (30%) were surveyed with an additional 73,460 (21%) investigated in the other cities in the country. Overall, 108,826 cases were surveyed in hospital records, corresponding to 23% of the GCs in the country. Of these, 70% were level 1 or level 2 GCs, providing poor quality of information. It was expected that at least 20% of the total GCs in the 60 cities would be investigated, according to result of the pilot study[8], which investigated 20% of the GCs in the participating 7 cities.

All 60 cities targeted by the intervention had positive results, with a change in the original proportion of GCs after the investigation (Chart 1). However, the level of effort in researching hospital records varied by city. Of the 60 municipalities, 40 investigated less than 1,000 deaths per city a year. The cities that researched more than 2,000 deaths were Rio de Janeiro, Belo Horizonte, and Salvador, in descending order, due to the higher number of deaths due to GC and the conditions of organization and structure of the teams, which favored the conduct of the investigations.

Several cities had a great impact on improving the quality of cause-of-death information, reducing GCs by more than 40%. In the 60 cities, 57% (n = 20,457) of the deaths by GC were reclassified to a well-defined cause of death, and in the other cities this percentage was 43% (n = 32,122). For the GCs considered the worst quality (level 1), 50% were reclassified to a well-defined cause in the 60 municipalities, while in the other cities this percentage was 44% (Table 1).

In general, of the total GCs in 2017, it was possible to reclassify 11% as a well-defined cause after the intervention (Table 2). If we consider level 1 and level 2 GCs, we have a 15% impact on the improvement of data. Whereas for the 60 cities, the impact was greater: 17% of the total GCs had the cause of death changed, and for level 1 and level 2 GCs the reduction was 21%. In the other cities, GCs were reduced by 9% in the definition of cause of death and 13% for level 1 and level 2 GCs (Table 2).

Figure 1 shows the proportion of deaths by GC before and after investigation in the municipalities. It is observed that the impact differed between the municipalities, but there was clear improvement in the quality of cause-of-death information in the 60 municipalities. This can be observed in Chart 2, which presents a reduction in GCs in most municipalities of the country. There were municipalities with more than 60% of causes of death by GC that presented a reduction in this index after the intervention. States such as Tocantins, Goiás, Minas Gerais, São Paulo, and Ceará should be noted, with significant improvement in data quality. Northern Minas Gerais still shows problems in quality, as well as part of the state of Bahia; but there were advances.

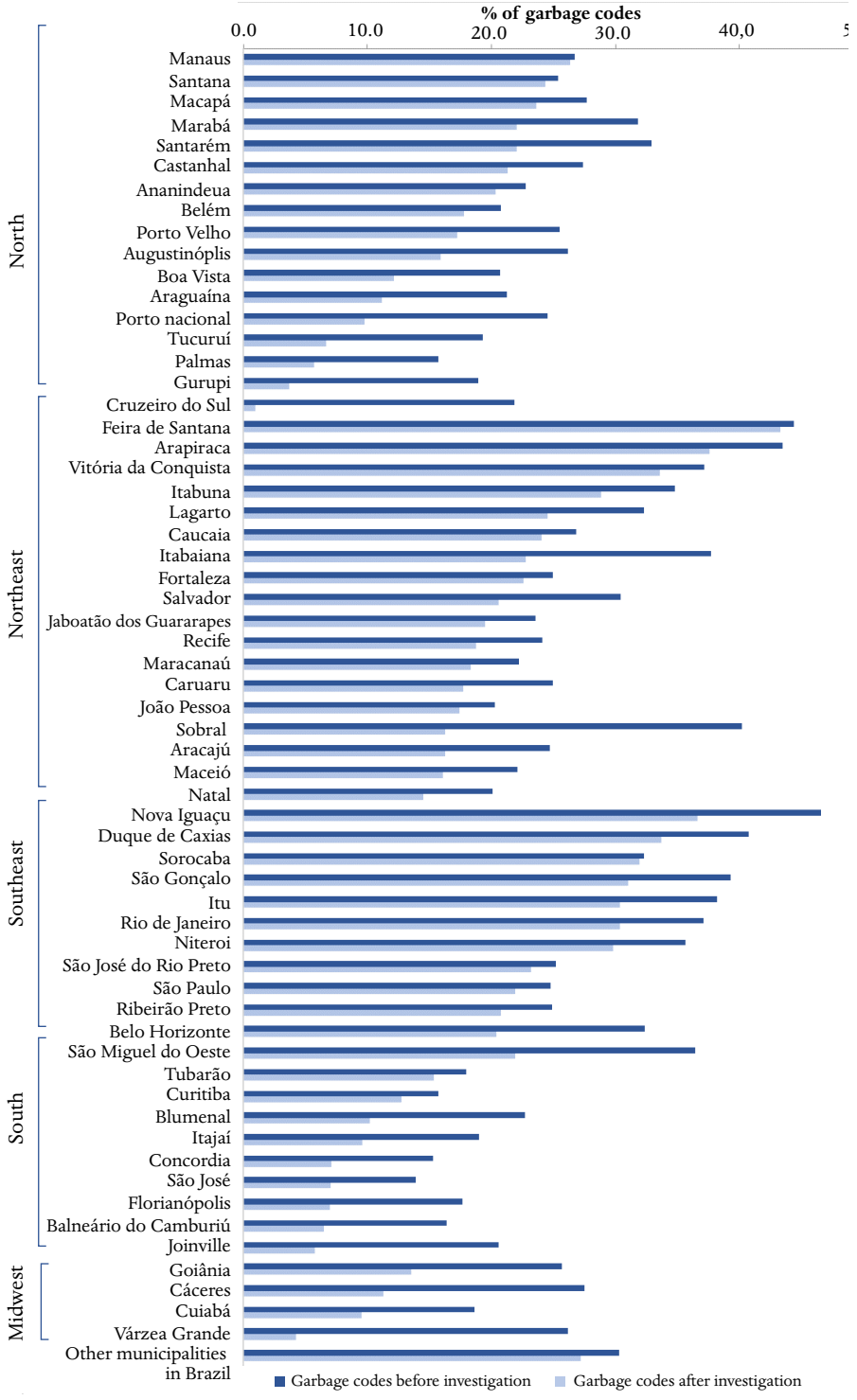


Chart 1. Proportion of priority garbage codes before and after the intervention, in each of the 60 cities targeted by geographic region and in the other cities, Brazil, 2017.

Table 1. Number of deaths from garbage codes (GC) investigated according to GC type and situation after investigation in 60 cities and other cities. Brazil, 2017.

| GC level (before investigation) | | Total GC | | Total GC researched | | Basic cause changed after investigation | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | BC defined | | GC level 1 | | GC level 2 | | GC level 3 | | GC level 4 | |
| | | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| 60 cities | 1 | 46,541 | 39.2 | 15,313 | 32.9 | 7,667 | 50.1 | 5,579 | 36.4 | 920 | 6.0 | 287 | 1.9 | 860 | 5.6 |
| | 2 | 21,457 | 18.1 | 9,211 | 42.9 | 6,407 | 69.6 | 201 | 2.2 | 1,815 | 19.7 | 35 | 0.4 | 753 | 8.2 |
| | 3 | 11,272 | 9.5 | 2,706 | 24.0 | 1,457 | 53.8 | 34 | 1.3 | 17 | 0.6 | 1,135 | 41.9 | 63 | 2.3 |
| | 4 | 39,410 | 33.2 | 8,136 | 20.6 | 4,815 | 59.2 | 160 | 2.0 | 60 | 0.7 | 52 | 0.6 | 3,049 | 37.5 |
| | Total | 118.680 | 100.0 | 35.366 | 29.8 | 20,346 | 57.5 | 5,974 | 16.9 | 2,812 | 8.0 | 1,509 | 4.3 | 4,725 | 13.4 |
| Other cities | 1 | 149,926 | 43.5 | 40,495 | 27.0 | 18,135 | 44.8 | 14,722 | 36.4 | 3,744 | 9.2 | 1,022 | 2.5 | 2,872 | 7.1 |
| | 2 | 49,400 | 14.3 | 13,343 | 27.0 | 6,948 | 52.1 | 309 | 2.3 | 5,318 | 39.9 | 90 | 0.7 | 678 | 5.1 |
| | 3 | 31,595 | 9.2 | 4,680 | 14.8 | 1,626 | 34.7 | 44 | 0.9 | 28 | 0.6 | 2,900 | 62.0 | 82 | 1.8 |
| | 4 | 114,098 | 33.1 | 14,942 | 13.1 | 5,418 | 36.3 | 240 | 1.6 | 99 | 0.7 | 63 | 0.4 | 9,122 | 61.0 |
| | Total | 345,019 | 100.0 | 73,460 | 21.3 | 32,127 | 43.7 | 15,316 | 20.8 | 9,189 | 12.5 | 4,075 | 5.5 | 12,755 | 17.4 |
| Brazil | | 463,699 | | 108,826 | 23.5 | 52,473 | 48.2 | 21,291 | 19.6 | 11,987 | 11.0 | 5,584 | 5.1 | 17,480 | 16.1 |

BC: basic cause of death; GC: garbage code.

Table 2. Number and percentage of deaths from GC, GC investigated, levels 1 and 2 and after investigation, 60 cities, other cities and Brazil, 2017.

| GC type | Total GC | GC investigated | | Defined cause of death | |
|---|---|---|---|---|---|
| | | n | % | n | % |
| 60 cities | | | | | |
| All GCs | 118,680 | 35,366 | 29.8% | 20,350 | 17.1% |
| Level 1 and level 2 GCs | 67,998 | 24,524 | 36.1% | 14,078 | 20.7% |
| Other cities | | | | | |
| All GCs | 345,019 | 73,460 | 21.3% | 32,135 | 9.3% |
| Level 1 and level 2 GCs | 199,326 | 53,838 | 27.0% | 25,091 | 12.6% |
| Brazil | | | | | |
| All GCs | 463,699 | 108,826 | 23.5% | 52,485 | 11.3% |
| Level 1 and level 2 GCs | 267,324 | 78,362 | 29.3% | 39,169 | 14.7% |

GC: garbage code.

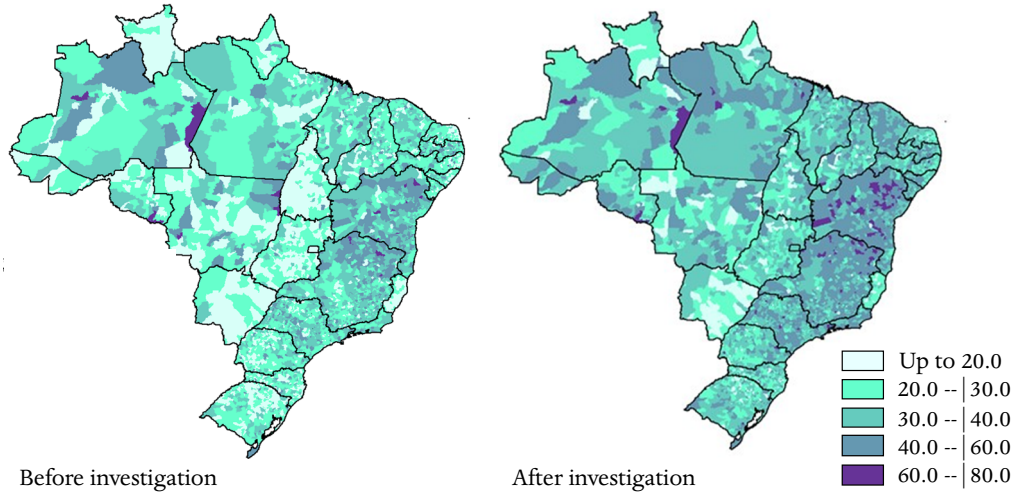


Figure 1. Proportions of deaths due to garbage codes before and after investigation in municipalities. Brazil, 2017.

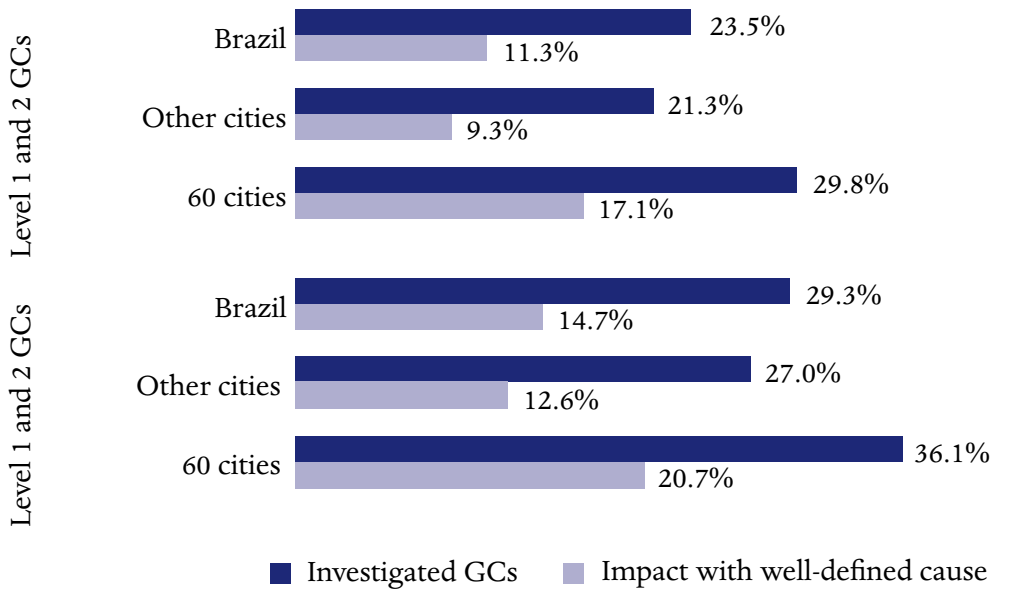


Chart 2. Proportions of deaths by total GCs and investigated level 1 and 2 GCs and proportion of those that changed to a well-defined cause, 60 cities, other cities, and Brazil, 2017.

GC: garbage code.

## DISCUSSION

The investigation of deaths by GC in 60 municipalities allowed reclassifying 58% of these deaths. This result is even more significant if only the results for levels 1 and 2 GCs are considered, which are of worst quality. The intervention proposal achieved the involvement of all states, which encouraged municipalities to participate, showing extra effort in the routine work they conducted. The role of surveilling deaths by GC was mostly assumed by the responsible managers and teams that routinely work in the investigation of maternal deaths, infant deaths, fetal deaths, and deaths with ill-defined causes, and in the proposition of prevention and control measures[13]. This feature contributed to advancing measures aimed at improving the MIS[10]. In addition, there was voluntary participation of other non-selected cities, particularly the other capitals that were not part of the sample defined by the project. Thus, municipalities that were not directly targeted by the intervention also achieved good results, indicating engagement with the proposal to improve the quality of cause-of-death information. It should be considered, therefore, that the initiative proved successful in its main purpose.

A fundamental stage for the project was the process of constructing and validating the investigation protocol, which resulted from discussions and consensus on problems in the information generated in the medical certificate of cause of death in the hospital setting. As for this aspect, the MH's proposal to adopt a standardized methodology to

clarify the cause of death was strategic to enable states and municipalities to carry out and monitor the investigation process.

This project was based on previous experience of investigation of deaths by ill-defined causes, which had positive results[8,10]. The research proposal was expanded to other causes considered garbage, which are ill-defined or unspecific codes that preclude the definition of priority strategies aimed at prevention. The term *garbage code* was created in 1996 by Murray and Lopez[14], as part of the GBD study, to designate these causes of death that are not useful for public health analysis. Subsequently expanded by Naghavi et al.[15], the list of GCs refers to the causes and corresponding ICD codes that cannot be the underlying cause of death, such as senility or low back pain, or intermediate causes, such as sepsis and heart failure, or causes which have no detailing in the coding, such as unspecified cancer or unspecified cardiovascular disease.

The existence of causes of death classified with GC in mortality systems is frequent[2,5,11,15]. When the proportion of GCs is high, corrections should be applied. For example, in the United States, a study of the trend of mortality by causes in the counties showed that between 1980 and 2014 the country had 25% of deaths by GC, which were corrected by the GBD methodology, adjusting the trend of some causes of death[16]. In South Korea, 25% of the causes of death were classified with a GC between 2010 and 2012. The redistribution of these codes resulted in a change in the main causes of death in the country, with a large increase in the tracing of ischemic heart disease, which became the leading cause of death. It is worth noting that, before the redistribution, lung cancer was considered the leading cause[17].

Several studies have sought to correct cause-of-death information by statistical methods, by using multiple causes or linkage between hospital data and mortality information systems[18-21], in order to obtain a mortality profile that better reflects the reality of the population. This research project is included in this effort, as it generated empirical data for the correction of GCs and can serve as a guideline for the corrections that have been applied on cause-of-death data in Brazil, considering the reality of hospitals and based on the level of information in hospital records. Therefore, this may be considered an unprecedented and innovative study, since more than 100,000 hospital records were researched, providing the reclassification of half of the GCs.

It was observed that physicians have little knowledge about how to correctly complete the sequence of causes of death in the death certificate and, moreover, in relation to the concept of underlying cause of death. Therefore, improving the quality of cause-of-death information in medical certificates of cause of death requires investing in efficient communication with physicians, with dissemination of knowledge, instructions and examples as to the completion of death certificates, in addition to other interactive forms[22]. It also requires better training of medical students and resident physicians for correct completion of death certificates. Considering this context, it is highlighted that the GC investigation process is subject to issues related to the structure of the service (human and material resources) and of processes (flows and adequacy as to technical

standards)[23]. The activities for investigation of deaths by GC should be a procedure to be fostered and effectively incorporated into health surveillance.

## CONCLUSIONS

The method used for investigating hospital records in the intervention to reduce the number of ill-classified causes of death in medical certificates resulted from a joint construction between the MH, states, municipalities, and universities, with the aim of improving the quality of cause-of-death information in all Brazilian regions, in order to optimize their use in the analysis of health status, in the monitoring and planning of health policies.

The initiative also presented the effect of improving the work processes of the MIS and its relationship with hospital care, because it encourages commitment to the quality of information in health professionals directly and indirectly involved with the systems and with care. Therefore, if the proposal is expanded and prioritized in the routine death surveillance its impact may be even more significant.

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