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Capturing deaths not informed to the Ministry of Health: proactive search of deaths in Brazilian municipalities

Captação de óbitos não informados ao Ministério da Saúde: pesquisa de busca ativa de óbitos em municípios brasileiros

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ABSTRACT: *Introduction:* The proactive search of deaths is a strategy for capturing events that were not informed to the Mortality Information System of Ministry of Health. Its importance to reduce underreporting of deaths and to evaluate the operation of the information system is widely known. *Objective:* To describe the methodology and main findings of the Proactive Search of Deaths, 2013, establishing the contribution of different information sources. *Methods:* The research was carried out in 79 Brazilian municipalities. We investigated several official and unofficial sources of information about deaths of municipality residents. Every information source investigated and all cases found in each source were typed in an on-line panel. The second stage of the research was the confirmation of cases to verify information of year and residence and to complete missing information. For all confirmed cases, we estimated the completeness of death registration and correction factors according to the adequacy level of mortality information. *Results:* We found 2,265 deaths that were not informed to the Mortality Information System. From those, 49.3% were found in unofficial sources, cemeteries and funeral homes. In some rural municipalities, precarious burial conditions were found in cemeteries in the middle of the forest and no registration of the deceased. Correction factors were inversely associated to the adequacy level of mortality information. *Conclusion:* The findings confirm the association between level of information adequacy and completeness of death registration, and indicate that the application of the proactive search is an effective method to capture deaths not informed to the Ministry of Health.

Keywords: Vital statistics. Information Systems. Mortality registries. Death certificates. Underreporting. Brazil.

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RESUMO: *Introdução:* A busca ativa de óbitos é uma estratégia de captação de eventos que não foram informados ao Sistema de Informações sobre Mortalidade (SIM) do Ministério da Saúde (MS). Sua importância na redução do sub-registro de óbitos e na avaliação da operacionalização do sistema de informações é amplamente conhecida. *Objetivo:* Descrever a metodologia e os principais achados da pesquisa de busca ativa de óbitos realizada em 2013, estabelecendo a contribuição das diferentes fontes de informação. *Métodos:* A pesquisa foi realizada em 79 municípios brasileiros. Foram investigadas diversas fontes oficiais e não oficiais de informações sobre óbitos de residentes nesses municípios. Todas as fontes de informações investigadas e os casos encontrados foram digitados em um painel *on-line*. A segunda etapa da pesquisa foi de confirmação dos casos para verificar as informações sobre o ano do óbito e o município de residência, assim como para completar informações faltantes. *Resultados:* Foram encontrados 2.265 óbitos que não foram informados ao SIM. Desses, 49,3% foram encontrados em fontes não oficiais, cemitérios e funerárias. Em alguns municípios rurais, condições precárias de sepultamento foram encontradas em cemitérios no meio da mata, sem registro do falecido. Os fatores de correção foram inversamente associados ao nível de adequação das informações de mortalidade. *Conclusão:* Os achados confirmam a associação entre o nível de adequação das informações e a cobertura do registro de óbitos, e indicam que a aplicação de pesquisas de busca ativa é um método efetivo para capturar óbitos não informados ao MS.

Palavras-chave: Estatísticas vitais. Sistemas de Informação. Registros de Mortalidade. Declaração de óbito. Sub-registro. Brasil.

INTRODUCTION

The unavailability of complete and reliable vital data makes the population's mortality profile difficult to trace and compromises the identification of problems and the evaluation of health actions[1,2]. Despite their importance, a significant number of countries do not have vital information systems for continuous registration, and among those that do, data coverage is not always complete, making their direct use for the construction of mortality indicators unfeasible[3].

In Brazil, the Mortality Information System (SIM) was implemented in 1976, based on the death certificate. From 1996, the information became available online by municipality, making it possible to detect local irregularities. Methods for the evaluation of vital information by municipality were proposed, using indicators constructed with data from the systems themselves to evaluate the coverage and the regularity of the information[4-6].

Since the implementation of SIM, the Ministry of Health (MoH) has undertaken efforts, with the support of States and municipalities, to reach full coverage with accurate data. The establishment of targets related to increased coverage of mortality information; the development of information monitoring panels; and the implementation, at a national level, mortality committees of maternal, infant, fetal mortality and for ill-defined causes of death are activities undertaken by municipal, state and federal health authorities[7,8], which contributed to the significant improvement in the death registry[9].

Proactive search surveys used since the 1980s to investigate the problems of capturing vital events were also encouraged. A joint initiative by the Department of Health Surveillance

of the Ministry of Health and Oswaldo Cruz Foundation conducted two active search surveys for vital events throughout the decade of 2000. The first search surveyed infant deaths occurring in 2000 and not reported to the SIM in a non-probabilistic sample of municipalities in the States of Amazonas, Pará, Maranhão, Piauí and Bahia, chosen for the precariousness of mortality information. The objective of this search was to estimate infant mortality in Brazil, as well as to identify operational flaws in vital information systems[4,6,10].

The second active search survey had its scope expanded, seeking deaths and births in 2008 in a probabilistic sample of 133 municipalities located in the Northeast and in the Legal Amazon, stratified by population size and level of adequacy of the vital information. In this second edition, one of the objectives of the research was to estimate the coverage of the SIM and the Information System on Live Births (Sinasc) per Federation Unit (UF)[11-13].

The results of this second search enabled the estimation of correction factors by level of adequacy of the vital information of the municipality, allowing to generalize the method for the years after 2000 and to estimate mortality indicators per UF based on SIM and Sinasc data[9,12,13]. The method was adopted by the MoH and the Interagency Health Information Network (RIPSA) for the construction and dissemination of mortality indicators, leading to relevant changes in the method for estimating infant mortality in the country[12].

With a focus on the municipality and with the need to estimate death coverage in small towns, the third active search for deaths was conducted in relation to the events occurred in 2012. The purpose of this article was to describe the findings of this search, to establish the contribution of the different information sources in the municipalities visited, as well as identifying unusual situations associated to the lack of information in the official records.

METHODS

In this edition of the proactive search survey, information on deaths occurring from January 1st to December 31st 2012 were collected. In addition to the States of the North and Northeast, the states of Mato Grosso, Goiás and Minas Gerais were included.

A probabilistic sample was selected from 79 municipalities located in these States, taking into account the region — North, Northeast, the Legal Amazon, Minas Gerais and Goiás —, population size — municipalities with a maximum of 150,000 inhabitants — and the adequacy of the mortality information, based on the Age-Standardized Mortality Rate (ASMR), calculated for municipalities, in the triennium 2009-2011, using the population of Brazil in the year 2010 as standard[12]. ASMR has been used as an indicator of the adequacy of vital data. Values below 4 indicate the underreporting of deaths[4,5].

The second criterion used to characterize the adequacy of the mortality information of the municipality was based on the underreporting of infant deaths. The municipality was classified as inadequate in relation to infant deaths when the number reported was lower than the minimum expected number, estimated by the product between half of the Infant Mortality Rate (IMR) of the UF and the estimated number of live births in the municipality[14].

In the municipalities of the sample, a proactive search process was performed for deaths that were not included in the MoH list, in order to identify both death certificates (DC) issued and not reported to the SIM, and deaths that did not generate the respective DC. The search was performed in the municipality itself and in neighboring municipalities considered a reference for health care.

Among the municipalities that had the worst levels of adequacy of mortality information and a large underreporting of infant deaths, three were selected from the State of Amazonas — Santo Antônio do Içá, Tonantins and São Paulo de Olivença — and one from Acre — Marechal Thaumaturgo — for a more detailed study, aiming to investigate the difficulties of access, the use of health services and problems in the recording of vital information. The municipalities of Amazonas are located in the Upper Solimões River, near the triple border — Brazil-Peru-Colombia —, where the difficulties of access are aggravated due to the river being the main mean of transportation, which depends on the level of the tides. Marechal Thaumaturgo has border with Peru, and can be accessed through the river and air.

The following sources of information were investigated: state and municipal health departments; registry offices; official and unofficial cemeteries; funeral homes; primary health care units; hospitals and other health facilities (clinics, emergency units) of the municipality-case and neighboring municipalities; institutes of forensic medicine and death investigation services; Unified Registry of the Federal Government Social Programs; And police stations. Community health agents and family health team professionals, as well as key informants such as traditional midwives and community leaders, were sought. All the visited sources were registered in an online panel, in which the information from the sources and the cases found in the fieldwork were stored.

In each source, the names of the deceased or the name of the mothers of children under one year of age — in the case of infant deaths — that appeared on the municipality's nominal list were verified. After the verification, a standardized active search instrument was completed, with the names not listed in the nominal list. The data was entered into an online panel built for monitoring the fieldwork. The project was approved by the Research Ethics Committee of the Joaquim Venâncio Polytechnic School of Health of Oswaldo Cruz Foundation. All the professionals involved in the research signed a confidentiality agreement and committed to maintaining the confidentiality of the data referring to the nominal lists of vital events.

Data from the deaths obtained by proactive search were paired with the 2012 national SIM death list by key variables, such as the name of the deceased, date of birth, date of death, age, mother's name, municipality of residence and number do the DC. Through this procedure, we identified the deaths found in the proactive search that were not informed to the SIM and those that were already in the system. This method was also used to establish the relationship between the proactive search database and the Computerized System for Death Control of the Social Security Information and Technology Company (SISOBI/DATAPREV), which is a system for collecting information on deaths registered in the registry offices[15].

In the second stage of the project, confirmation of the cases found in the survey was carried out, to confirm the residence and the year of death of the deceased and to complete

missing information. Confirmation was not requested only in cases of events found at registry offices or primary health care units and those with full information of residence, date of death, sex and date of birth or age. For the other information sources and/or incomplete data, the confirmation was made at the primary health care units or at home, when possible. This confirmation was also requested for all infant or fetal deaths found in the search.

The list of cases requiring confirmation was made available on the online panel of the Department of Health Surveillance (SVS) of the Ministry of Health. For all the cases in which confirmation was possible, specific instruments were filled in and the information was entered in the proactive search's monitoring panel, in which the justifications of non-compliance in unconfirmed cases were also recorded.

After the search of the events, the identification of the cases that were already in the information system and the confirmation of the cases that needed to be confirmed, the descriptive analysis of the data and the identification of the main sources of death information were carried out. In addition, it was possible to calculate the coverage of death information from the SIM from the cases found in the search that had not been reported to the system.

For the calculation of the correction factors of the mortality information of the municipalities in the sample, the deaths were found in the proactive search and confirmed, in addition to those not located. We did not consider deaths that were already in the SIM, those proven to reside in another municipality or death in a year other than 2012. For each municipality in the sample, the correction factor for reported deaths (FCob) was estimated by Equation 1:

$$FC_{ob} = \frac{Ob_{SIM} + Ob_{BA}}{Ob_{SIM}}$$
(1)

Where:
Ob_{SIM} is the deaths reported to the SIM in the year 2012; and
Ob_{BA}, the deaths found in the proactive search that were confirmed as absent in the system.

RESULTS

The proactive search process was carried out in 79 selected municipalities. Of these, approximately 14% had a ASMR of less than 3.5 per thousand inhabitants in the 2011-2013 triennium, indicating a high precariousness of information on deaths, while 40.5% had a satisfactory situation in relation to SIM coverage, with ASMR higher than 5.5 per thousand inhabitants (Figure 1). Regarding the adequacy of information on infant deaths, 16 (20.3%) were inadequate.

There were 3,188 deaths in the proactive search. After pairing the information of these deaths with the SIM data, we verified that 873 cases were already in the system. Thus, 2,656 deaths found in the study had not been reported to the SIM.

The distribution of the cases found in the proactive search according to the source of the information is presented in Table 1. Due to the multiplicity of sources, they were hierarchized as follows: hospitals and other health facilities (clinics, emergency units); registry offices;
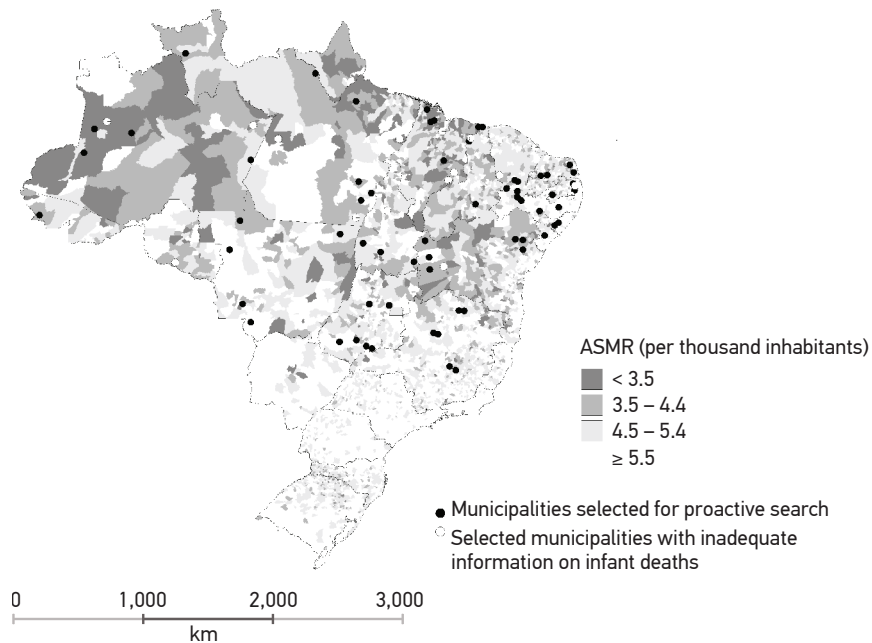
Source: Mortality Information System of the Ministry of Health.
ASMR: Age-Standardized Mortality Rate.

Figure 1. Age-Standardized Mortality Rate (per thousand inhabitants) and municipalities selected for the proactive search. Brazil, 2012.

Table 1. Distribution of the deaths found in the proactive search according to the information source. Municipalities selected in the sample, 2012.

Information Source	Proactive search		Proactive search and SISOBI	
	n	%	n	%
Hospitals/other health facilities	287	12.7	97	33.8
Registry Offices	309	13.6	212	68.6
Primary health care units	267	11.8	19	7.1
Institutes of forensic medicine/ Death investigation services	45	2.0	3	6.7
Cemeteries	683	30.2	39	5.7
Funeral homes	432	19.1	9	2.1
Unified Registry of the Federal Government Social Programs	27	1.2	6	22.2
State and municipal health departments	41	1.8	10	24.4
Others	174	7.6	12	6.9
Total	2,265	100.0	407	18.0

SISOBI: Computerized System for Death Control.

primary health care units ; Institutes of forensic medicine / Death investigation services; official and unofficial cemeteries; funeral homes; social programs; State and municipal health departments; and other sources. It was observed that 28.3% of deaths were found within the health system, including state and municipal health departments (1.8%), hospitals and other health facilities (12.7%), primary health care units (11.8% %) and Institutes of forensic medicine / Death investigation services (2.0%). In the registry offices, 13.6% of the deaths were found. It is worth noting that almost half of the deaths (49.3%) were found in cemeteries and funeral homes, and which were not registered in hospitals or in registry offices.

The relationship with SISOBI also showed relevant results (Table 1). Of the 2,265 deaths identified in the survey and not reported to the SIM, 407 (18.0%) were in SISOBI, a system in which 212 (68.6%) of the 309 deaths found in registries were also found in the proactive search. However, of the 1,115 deaths captured in unofficial sources — cemeteries and funeral homes —, only 48 (4.3%) were reported to SISOBI.

In the more detailed study carried out in the selected municipalities of Amazonas and Acre, the existence of several unofficial cemeteries, which do not have log books, was evidenced. In these places, graves are generally unidentified, poorly maintained, and have no physical barriers. Many small pits were found, most likely for infant deaths. In the emblematic photo taken during the fieldwork, there is a baby bottle and a powdered milk can next to the cross, indicating the burial of a child (Figure 2).
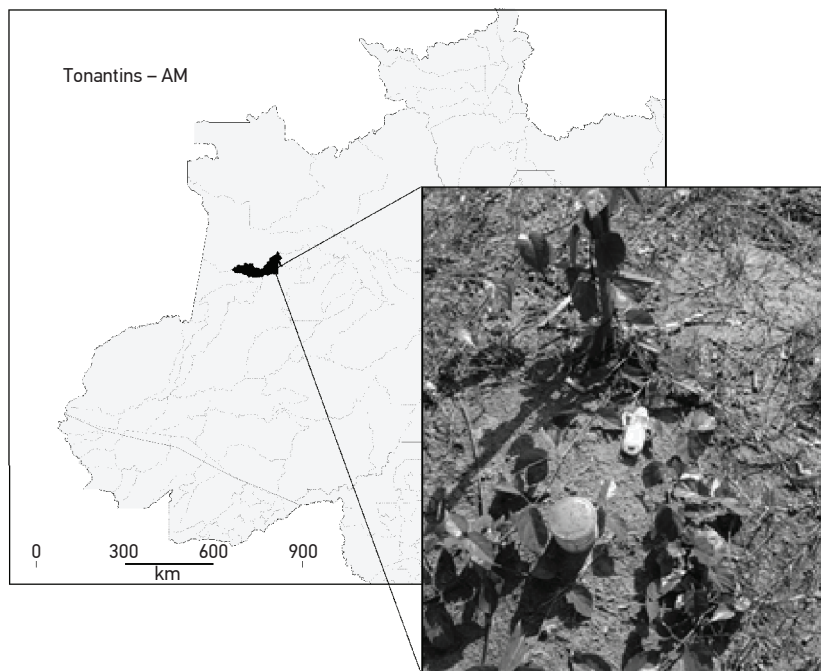

Photo: Marcelle Lemos

Figure 2. Cemetery of the indigenous community Marí-Marí, Tonantins – AM.

Of the 2,265 deaths found in the proactive search, 797 (35.2%) required confirmation. At the end of this stage, 157 cases (6.9%) could not be located, while 60 (2.7%) could not be confirmed due to difficulties in accessing the municipality. We also observed that 320 deaths (14.1%) were not confirmed to reside in the municipality of the search or did not have 2012 as the confirmed year of death (Table 2).

Among the municipalities in the sample, it was possible to calculate the coverage of the SIM information, as well as the correction factors according to the level of adequacy of the information, established by the ASMR (Table 3). A total of 1,945 deaths were considered, excluding the 320 who had an unconfirmed residence or year of death. The results show the inverse relationship between the adequacy of the information and the coverage of the SIM, with correction factors increasing as the ASMR decreases.

DISCUSSION

Although the improvement in SIM coverage and in the quality of mortality data is widely recognized[9,13,16], the findings of the third edition of the proactive search showed the persistence of underreporting of deaths in some municipalities in Brazil, especially among small population, located in the North and Northeast, and located in areas with many difficulties in the access to health care.

Table 2. Proactive search results after the confirmation step. Municipalities selected in the sample, 2012.

Proactive Search Result	n	%
Found in the search and confirmed	1,728	76.3
Found in the search and not confirmed because they were not found	157	6.9
Found in the search and not confirmed for other reasons	60	2.7
Residence or year of death unconfirmed	320	14.1
Total	2,265	100.0

Table 3. Coverage of the Mortality Information System and correction factors by category of the Age-Standardized Mortality Rate (per thousand inhabitants). Municipalities selected in the sample, 2012.

ASMR category	Number of deaths found in the proactive search	SIM	SIM coverage	Correction factor
< 3.5	176	494	73.7	1.36
≥ 3.5 e < 4.5	323	979	75.2	1.33
≥ 4.5 e < 5.5	504	3,435	87.2	1.15
≥ 5.5	942	9,427	90.9	1.10

ASMR: Age-Standardized Mortality Rate; SIM: Mortality Information System.

Previous results using several estimation methodologies show incomplete coverage of mortality information, mainly in the North and Northeast regions of the country[5,6,17,18]. In this sense, the investigation of the local reality and the evaluation of vital statistics are important strategies for the expansion of the records and of the quality of information, as well as for the monitoring of the implemented policies[19], which certainly contribute to identify the irregularities at the municipality level, or even in communities, and to subsidize interventions to improve the health situation[20].

Proactive search surveys aim to investigate information sources in which cases can be found that are not informed to the SIM. The results of the present study evidenced the potential of some sources, corroborating the findings of other studies that used the proactive search strategy[6,21].

The comparison of the results of the present study for the year 2012 with the findings of the second edition of the proactive search, regarding deaths occurred in 2008, showed differences in the distribution of deaths found according to the information source. In 2008, more than 35% of the deaths were found in hospitals and other health facilities, and 31% in registry offices, totaling 66%[11]. In 2012, the share of official sources was much lower (42%), evidencing the improvement in the flow of mortality information. The difficulties of access to health services highlight the importance of searching for deaths in alternative sources, which, in the present case, showed a considerable participation in the collection of deaths, such as unofficial cemeteries and funeral homes.

In the municipalities where a more detailed study was carried out, the search for deaths in official sources did not add an expressive number to the deaths reported originally to the SIM. Only from the investigation of the unofficial cemeteries, hidden in the forests of the region, the great number of burials without registration was verified. In these municipalities, the majority of the population live on the banks of rivers, many peoples are indigenous, the river being their main means of transportation. In view of the great difficulty of movement, lack of adequate infrastructure, extreme climatic conditions — constant heat and rainfall — and geographic isolation in the region, access to healthcare is very problematic[22,23].

In addition to unregistered burials, a focused proactive search enabled the identification of cultural aspects of indigenous communities, which influence the information on vital events and the monitoring of the health situation. In some villages, it is customary to protect the child in the first days of life, making it difficult for the Indigenous Health Agents (AIS) to visit the newborns and control the infant deaths. The illustrative picture presented in this work shows the adoption of paradoxical habits, feeding with artificial milk, but unregistered burial, in pits without physical barriers and in inadequate conservation conditions.

For countries like Brazil, obtaining and maintaining complete vital information systems is a challenge[24]. In addition to the difficulties inherent in information systems, mainly related to underreporting and lack of information quality, there are aspects related to the territorial dimension, such as remote places, difficult to reach, often inhabited by social groups with their own cultural values.

The innovations introduced in the third edition of the proactive search were productive. The relationship with SISOBI showed that the system could be an interesting

alternative source for routine use and capture of deaths recorded in registry offices and not reported to the SIM. SISOBI is the responsibility of the National Institute of Social Security (INSS) and aims to subsidize the process of cancellation of benefits due to the death of those insured under Social Security[19]. Finally, the development of an online panel by the SVS allowed to monitor the fieldwork and to solve, in a timely manner, the problems encountered.

At the confirmatory stage, an expressive percentage (14%) of the deaths found in the research was not confirmed in the municipality of the search or year of death, confirmed as 2012, thus evidencing the importance of this procedure in the research. The investigation at home provided more detailed information about the deaths and was the most used to confirm cases found in the research and to fill important information related to the year of death and age of the deceased, with special attention to infant and fetal deaths.

Another benefit of the confirmation at home was the opportunity given to the research team to interview a member of the deceased's family and to know the reason for the unmarked burial. Among the deaths that were not recorded, the main reason was that "the family did not find it necessary", corroborating the results of previous studies[25,26].

However, the source in which the case was found influenced the confirmation process. About 7% of deaths were not localized due to the lack of information about the deceased. Most were found in funeral homes and cemeteries, which, due to being unofficial sources, sometimes do not have a log book and do not have the identification of the deceased.

The lack of information about the deceased is the main limitation of the proactive search survey, not only because there is no way to confirm the residence of the deceased, but also because it ignores sex and age, which are important variables for tracing the mortality profile. Aiming at the expansion of the reporting and investigation of the deaths, SVS has been promoting the registration of unofficial cemeteries and the establishment of means to carry out burial records at these places. Cemeteries found in rural areas of the state of Amazonas were unknown to the system, and were additional contributions to the search.

The application of the proactive search process in several sources of information has shown that the search, not only in the official but also in the unofficial sources, contributes strongly to the increase of the coverage of deaths in SIM, especially when it comes to infant mortality[6,21,27].

The calculation of correction factors for the death information in the municipalities selected in the active search sample was based on the cases found in the search and the deaths already found in the SIM. The results confirm the relationship between the adequacy of the information and the level of coverage of the mortality information system, as already verified in previous proactive search surveys for deaths[6,9,12]. The advances in this edition of the search refer mainly to the validation of the criteria for the underreporting of infant deaths. In the municipalities of the Amazon region and Acre, selected in the sample and classified as inadequate in relation to infant deaths, unofficial cemeteries were found hidden in the forest of rural areas, in which the buried children are completely unknown in official records and outside the control of the health system.

CONCLUSION

The precariousness of information and the fluctuation of vital data in municipalities with small populations significantly influence subnational estimates of infant mortality. Thus, more attention has been given to disaggregated information. MoH seeks, together with municipal and state managers, strategies to increase the quality of vital data and the expansion of SIM coverage. In this sense, the procedures for active search for deaths have contributed to identify the factors that limit the comprehensiveness of mortality data at the national level, establishing priorities for intervention. The results of the present study showed that the system coexists with improved mortality information in much of the country, but still lives with the partial absence of data due to problems that multiply in geographically disadvantaged socioeconomic areas with difficulty of access to health care and which are diversified by the cultural aspects of local communities.

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