https://doi.org/10.1590/1980-549720220003.supl.1

ORIGINAL ARTICLE / *ARTIGO ORIGINAL*

Trend of incompleteness of cancer death records in the Mortality Information System database, state of Mato Grosso, Brazil, 2000 to 2016

Tendência da incompletude dos registros de óbitos por câncer do Sistema de Informação sobre Mortalidade em Mato Grosso, Brasil, 2000 a 2016

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ABSTRACT: ***Objective***: To describe the trend of incompleteness of cancer death records in the Mortality Information System (SIM, in Portuguese) database, state of Mato Grosso, Brazil, 2000 to 2016. ***Methods***: This is a descriptive, ecological, time series study of records of death from cancer of people living in the state of Mato Grosso (codes C00 to C97 of the 10th revision of the International Statistical Classification of Diseases and Related Health Problems – ICD-10), collected from SIM. To asses incompleteness in the filling of the variables of race/skin color, education, marital status, occupation and underlying cause of death, the relative frequency was calculated in the percentage of null values. The time trend analyzes of the incomplete percentage of categories and variables of interest was performed using linear regression ($p<0.05$). ***Results***: From 2000 to 2016, there were 31,097 deaths from cancer among residents of the state of Mato Grosso. Race/skin color, marital status and occupation presented a stable trend of incompleteness; education and underlying cause of death were decreasing. An increasing trend was observed in the categories *ignored* (marital status) and *retired* (occupation); a decreasing trend was observed for *blank* (education), *unidentified* and *housewife* (occupation), and C76-other and ill-defined sites and C80-without specification of site (underlying cause of death). Incompleteness of occupation was classified as very poor, with emphasis on *housewife* and *retired*. For the remaining variables and categories, the classification was excellent or good. Conclusions: Although most of the indicators showed satisfactory trend and classification, the marital status and occupation variables stood out for indicating poorer quality in the records.

Keywords: Mortality. Cancer. Health information systems. Temporal distribution.

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Conflict of interests: nothing to declare – **Financial support:** Mato Grosso State Health Department and Public Labor Ministry of the 23rd Region.
Associated editors: Elisete Duarte, Gulnar Azevedo e Silva
Scientific editor: Cassia Maria Buchalla
This document has an erratum: https://doi.org/10.1590/1980-549720220003.supl.1erratum

RESUMO: ***Objetivo***: Descrever a tendência da incompletude dos registros de óbitos por neoplasias do Sistema de Informação sobre Mortalidade (SIM) no estado de Mato Grosso, Brasil, no período de 2000 a 2016. ***Métodos***: Trata-se de um estudo descritivo, ecológico, do tipo série temporal, com dados referentes aos óbitos de residentes em Mato Grosso por neoplasias (códigos C00 a C97 da 10ª revisão da Classificação Estatística Internacional de Doenças e Problemas Relacionados à Saúde — CID-10), provenientes do SIM. Para a avaliação da incompletude no preenchimento das variáveis raça/cor, escolaridade, estado civil, ocupação e causa básica do óbito, foi calculada a frequência relativa em percentual de valores nulos. Análises de tendência temporal do percentual de incompletude das variáveis de interesse e categorias foram realizadas por meio de regressão linear ($p<0,05$). ***Resultados***: De 2000 a 2016, ocorreram 31.097 óbitos por neoplasias em residentes no estado de Mato Grosso. Raça/cor, estado civil e ocupação apresentaram tendência estável da incompletude; escolaridade e causa básica do óbito foram decrescentes. Nas categorias, tendência crescente foi observada para *ignorado* (estado civil) e *aposentado* (ocupação); tendência decrescente foi verificada para *em branco* (escolaridade), *não identificado* e *dona de casa* (ocupação) e C76-outra localização e mal definidas e C80-sem especificação de localização (causa básica do óbito). Incompletude da ocupação foi classificada como muito ruim, com destaque para *dona de casa* e *aposentado*. Para as demais variáveis e categorias, a classificação foi excelente ou bom. ***Conclusões***: Embora a maior parte dos indicadores tenha apresentado tendência e classificação satisfatórias, as variáveis estado civil e ocupação destacaram-se por indicarem piora na qualidade dos registros.

Palavras-chave: Mortalidade. Câncer. Sistemas de informação em saúde. Distribuição temporal.

INTRODUCTION

Cancer is one of the leading causes of death recorded worldwide. For the year 2020, about 19.3 million new cases and 9.9 million deaths from cancer are estimated worldwide[1]. In Brazil, neoplasms are the second leading cause of death in the population, which represented, in 2015, 16.6% of all deaths in the country. It was calculated that, in each year of the 2020-2022 triennium, there would be 625,000 new cases of cancer[2], of which 8,120 new cases were estimated for the state of Mato Grosso[3].

Knowing the occurrence of cancer and its consequences can contribute to the formulation and strengthening of national and regional programs to control this disease. Incidence and mortality indicators allow to analyze the occurrence, distribution and evolution of cancer, besides being guiding elements for surveillance actions. In regard to information on mortality, the main source of data on deaths in Brazil is the Mortality Information System (SIM), that has the death certificate as the standard form of data registration, which was implemented in the country in 1976[4].

Among the information available on death certificates, the sociodemographic and type of cause related to mortality from neoplasms are privileged information sources for the study of health inequalities, however there are variations in the degree of incompleteness in filling of the data, characterized by the presence of null values in the fields present in the collection instruments[5]. Despite the increase in SIM coverage in recent decades and

the improvement in the quality of data on mortality, especially the reduction of ill-defined causes, efforts are still needed for significant advances to be achieved[6,7].

Therefore, monitoring and evaluating the quality of data recorded in the health information systems (HIS), especially in regard to the proper completion of the collection instruments and/or database, contribute to identifying the weaknesses and potential of the data produced. Although there has been an increase in the number of studies that assess the quality of HIS information in the Brazilian context, there are still gaps, given the large volume and diversity of data produced by these systems[8].

Thus, the objective of the present study was to describe the trend of incompleteness of cancer death records in SIM in the state of Mato Grosso, Brazil, from 2000 to 2016.

METHODS

This is a descriptive, ecological, time series study, in which the trend of incompleteness in the registration of deaths from neoplasms in the state of Mato Grosso, from 2000 to 2016, was analyzed. The state of Mato Grosso is located in the west of the Central-West region of Brazil, with most of its territory occupied by the Legal Amazon. It has an area of 903,207.019 km^2 and its capital is Cuiabá. With 141 cities, its estimated population for 2019 was 3,567,234 inhabitants[9].

Data referring to the deaths from neoplasms of residents in Mato Grosso, codes C00 to C97, according to Chapter II of the 10th edition of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) [10], came from SIM, as part of the Extension Project "VIGICAN: cancer surveillance and associated factors: updating of population-based and hospital records", carried out in partnership with the Mato Grosso State Health Department (SES-MT) and its funding[11] and whose validity took place from April 2016 to March 2021. To carry out the analyzes and publish the results, SES-MT authorized the use of the data and of the research project entitled "Cancer and associated factors: analysis of population-based and hospital records".

To assess the incompleteness in filling in the variables of deaths from neoplasms, the relative frequency in percentage of null values was calculated, considering:

1. Blank fields;
2. Filling with skipped code;
3. Answer options not provided in the answer fields;
4. Deaths from neoplasm of ill-defined, secondary or unspecified site.

The variables evaluated for incompleteness were: education, race/skin color, marital status, occupation and underlying cause of death. For the variables of education and marital status, the options *blank* and *ignored* were considered; and for race/skin color, the *blank* option was considered. To facilitate the understanding and capture of information on indicators

of incompleteness, deaths of children under 5 years of age, for the education variable, and those under 16, for the marital status variable, were excluded from the analysis.

The occupation variable was categorized, according to the Brazilian Classification of Occupation (BCO), into ten large groups[12]. According to the Instruction Manual for Completing the Death Certificate[4], the occupation field consists of "the type of work that the deceased developed for most of his/her productive life". Therefore, it should not be completed for deaths of children under 5 years of age, and in case the deceased is retired, the field must be filled in with the previous usual occupation. However, answer options *unemployed*, *retired/pensioner*, *housewife* and *student* were observed, which, despite being allowed to be registered in the SIM, are not occupations classified in the BCO, and should, therefore, be avoided. In addition, vague response options, which made it impossible to identify the corresponding occupation in the BCO, were included in the *unidentified occupation* category.

Regarding the underlying cause of death, the ICD-10 codes C76 to C80 – malignant neoplasm of ill-defined, secondary and unspecified sites – were considered incomplete diagnoses, categorized as:

- C76. Malignant neoplasm of other and ill-defined sites;
- C77. Secondary and unspecified malignant neoplasm of lymph nodes;
- C78. Secondary malignant neoplasm of respiratory and digestive organs;
- C79. Secondary malignant neoplasm of unspecified site;
- C80. Malignant neoplasm without specification of site[10].

The total incompleteness was analyzed for each of the variables, characterized by the sum of all the categories that represent the null value, already mentioned, as well as the incompleteness of each category separately. In addition, a score was assigned for the incompleteness of the variables and of each category, as proposed by Romero and Cunha[5]: excellent (less than 5%), good (5 to 10%), fair (10 to 20%), bad (20 to 50%) and very bad (50% or more).

Time trend analyzes of the percentage of incompleteness of the categories and the variables of interest were performed using linear regression. In the simple linear regression analysis, the percentage of incompleteness was considered as the response variable (y), and the years of the period were considered as the explanatory variable (x), according to Equation 1:

$$Y=\alpha+\beta x \quad (1)$$

In which:
Y = response variable (or dependent);
α = the constant;
x = the exposure variable (independent);
β = the simple linear regression coefficient[13].

The regression coefficients and the respective p-values of the statistical significance tests were calculated. In order to estimate the increase or decrease in the percentage of

incompleteness in the period, the annual percentage variation was calculated through the ratio of the regression coefficient in relation to the percentage of incompleteness at the beginning of the analyzed period[14]. Variations in the percentage of incompleteness that presented a significance level of 5% in the linear regression were considered significant.

In the period from 2000 to 2016, the percentages of incompleteness of the variables sex, age and city of residence, available in the database, were 0.01% (n=1), 0.01% (n=2) and 0.03% (n=11), respectively. Therefore, the variables were not included in the trend analyses.

Trend graphs of the percentage of incompleteness of the variables of interest were created for the period from 2000 to 2016. Data analysis was performed in Windows Excel and Stata version 12.0.

This study was approved by the Research Ethics Committee of the Hospital Universitário Júlio Müller (CEP-HUJM), under opinion number 3,048,183, of November 20, 2018, and by the Research Ethics Committee of SES-MET, under opinion number 3,263,744, of April 12, 2019.

RESULTS

From 2000 to 2016, there were 31,097 deaths from neoplasms in residents of the state of Mato Grosso.

Race/skin color variable had an important reduction in the percentage of incompleteness (*blank*) from 2001 to 2003 (5.92 to 0.71%). From 2003 to 2016, the percentages ranged from 0.36 (2006) to 2.57% (2014). For the education variable, there was a decrease in incompleteness (*blank* category) between 2000 (15.57%) and 2003 (2.28%), remaining around 2% until 2011, when it reached 1.07%, and staying below 1% until the end of the period. In the *ignored* category, incompleteness had a maximum value of 7.84% in 2001 and later remained between 4 and 7% (Figure 1).

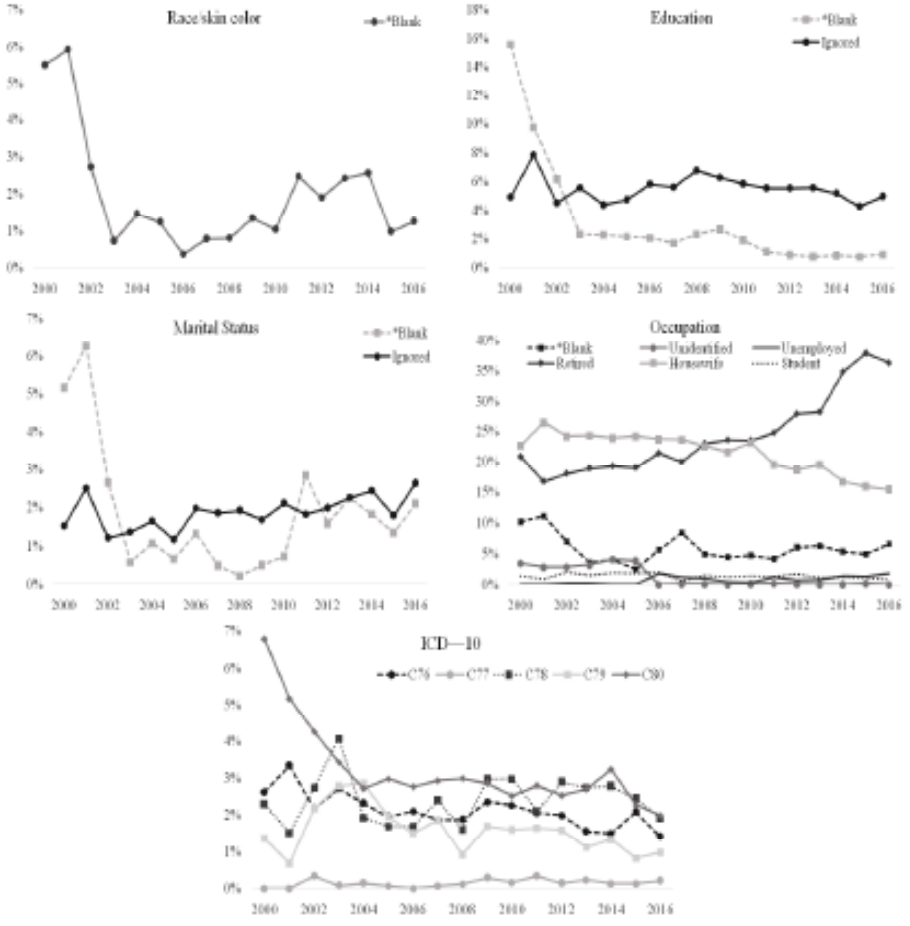
For the marital status variable, the *blank* category reached the maximum value of incompleteness (6%) in 2001, decreasing to values below 1% which remained until 2010, when there was a new increase, remaining above 1% until the end of the period. The incompleteness of the *ignored* category remained between 1 and 3% in all the years (Figure 1).

In the analysis of the incompleteness of the occupation variable, the highest percentages were observed in the *retired* and *housewife* categories in all the years of the study, ranging from 16.60 (2001) to 37.61% (2012) and from 26.27 (2001) to 15.36% (2005), respectively. Still in regard to the occupation variable, the *unemployed* and *student* categories had the lowest percentages of incompleteness – between 0 and 1%. However, for the *blank* category, higher percentages were observed in the years 2001 (10%) and 2007 (8%) and values around 5% in the other years, until the end of the period. As for the *unidentified occupation* category, percentages around 5% were verified until 2005, when it showed a reduction, and minimum values were maintained until 2016, reaching 0% of incompleteness in 2009, 2012, 2013 and 2014 (Figure 1).

For the underlying cause of death, category C76 (other and ill-defined sites) had the highest percentage of incompleteness in 2001 (3.34%) and the lowest in 2016 (1.40%). On the

other hand, category C77 (secondary and unspecified of lymph nodes) had the lowest values, ranging between 0.32 (2002) and 0% (2000, 2001 and 2006). Category C78 (secondary of respiratory and digestive organs) reached 4.07% in 2003, but remained between 1 and 3% in all the other years. Category C79 (secondary of unspecified site) had an increase from 0.67% to 2.85% in the percentage of incompleteness from 2001 to 2004, decreasing to 1% in 2008, and later assuming a behavior of slight decrease, with values from 1 to 2% until the end of the period. Category C80 (without specification of site) had its maximum value in 2000 (6.77%) and minimum in 2016 (1.98%) (Figure 1).

When considered in its entirety, the variables race/skin color (*blank*), marital status and occupation showed a stable trend of incompleteness in the period, while education and the underlying cause of death were decreasing. By evaluating the categories separately, it was possible to verify that, in relation to education, while the *blank* answers showed a decreasing



ICD-10: International Statistical Classification of Diseases and Related Health Problems; SIM: Mortality Information System.

Figure 1. Incompleteness (%) of the mortality data from neoplasms recorded in the SIM according to race/skin color, education, marital status, occupation and cause of death. Mato Grosso, Brazil, 2000 to 2016.

trend, the *ignored* one remained stable. For marital status, there was a stable trend in the *blank* option, but increasing in the *ignored* option. With regard to occupation, the *blank*, *unemployed* and *student* options showed a stable trend, and *retired* showed an increasing trend. A decreasing trend was found for the categories *unidentified* and *housewife*. With regard to the underlying cause of death, a stable trend was observed for categories C77 (secondary and unspecified of lymph nodes), C78 (secondary of respiratory and digestive organs) and C79 (secondary of unspecified site). On the other hand, categories C76 (other and ill-defined sites) and C80 (without specification of site) showed a decreasing trend (Table 1).

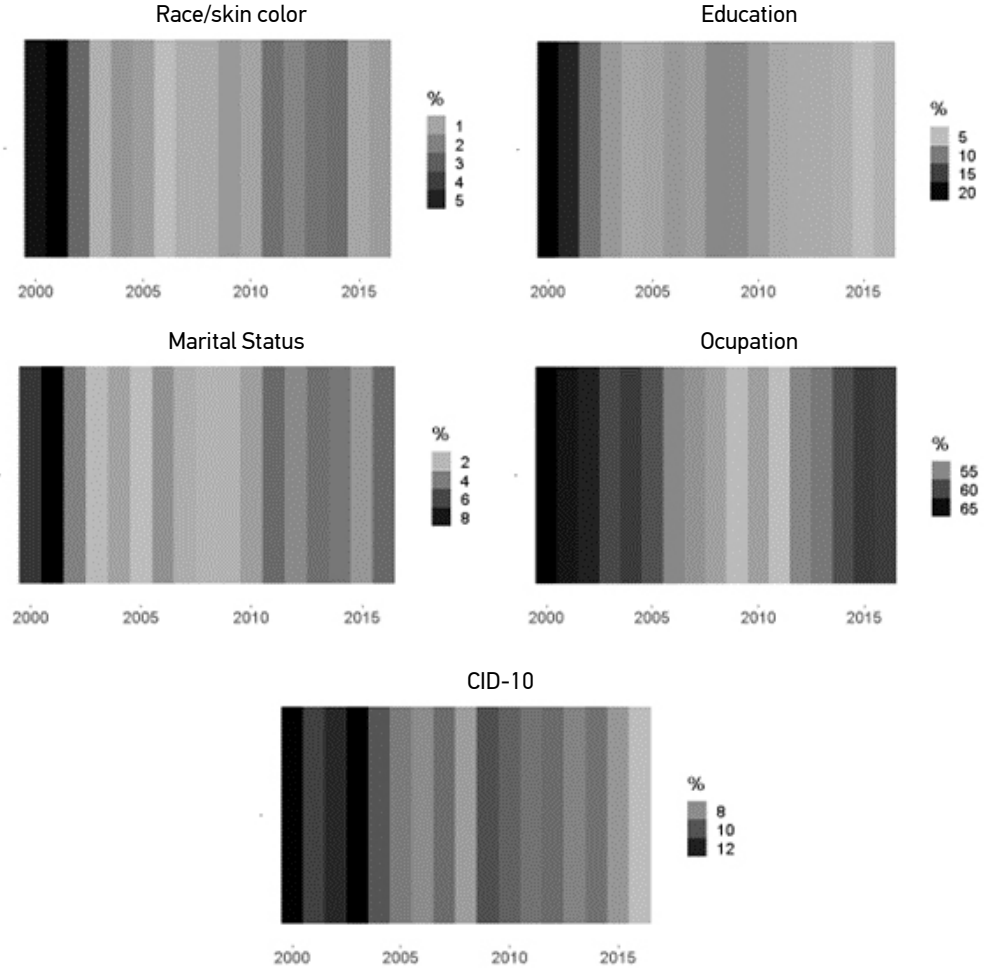
Table 1. Trend in the percentage of incompleteness of the variables for race/skin color, education, marital status, occupation and underlying cause of death. Mato Grosso, Brazil, 2000 to 2016.

Variables/Categories	Beta	p-value	Annual percentage change	95%CI	Trend
Race/Skin color					
Blank	-0.13	0.093	-2.36	-5.24–0.45	Stable
Education	-0.59	0.001	-2.88	-4.44–-1.33	Decreasing
Blank	-0.56	0.001	-3.60	-5.51–-1.69	Decreasing
Ignored	-0.03	0.480	-0.61	-2.60–1.35	Stable
Marital Status	-0.07	0.451	-1.05	-3.97–1.86	Stable
Blank	-0.12	0.159	-2.33	-5.56–1.00	Stable
Ignored	0.05	0.021	3.29	0.53–5.67	Increasing
Occupation	-0.38	0.091	-0.58	-1.27–0.10	Stable
Blank	-0.15	0.196	-1.32	-3.76–0.40	Stable
Not identified	-0.84	<0.001	-8.34	-11.74–-5.05	Decreasing
Unemployed	0.06	0.070	-	-	Stable
Retired	1.17	<0.001	5.69	4.23–7.16	Increasing
Housewife	-0.59	<0.001	-2.63	-3.27–-1.83	Decreasing
Student	-0.03	0.133	-2.22	-5.38–0.87	Stable
Underlying cause of death	-0.27	<0.001	-2.10	-3.11–-1.10	Decreasing
C76	-0.07	0.001	-2.67	-4.00–-1.37	Decreasing
C77	0.01	0.568	-	-	Stable
C78	0.01	0.695	0.44	-2.58–3.77	Stable
C79	-0.05	0.087	-3.70	-8.45–0.64	Stable
C80	-0.17	0.001	-2.51	-3.82–-1.27	Decreasing

95%CI: 95% confidence interval.

The variation of incompleteness percentages over the period for each analyzed variable is shown in Figure 2. The darker areas presented at the beginning of the period indicate that incompleteness percentages were higher for all the variables in the first years. Although lighter areas are observed in the middle of the period, represented by lower percentages of incompleteness, the variables race/skin color, marital status, occupation and underlying cause of death have darker areas at the end of the period. The occupation variable stands out, presenting in the last three years (2014 to 2016) percentages as high as those at the beginning of the period.

Regarding the classification of the incompleteness, it was found that, for the education variable, which showed a decreasing trend, the degree of incompleteness was classified as good, while for the *ignored* and *blank* categories the result was good and excellent,



ICD-10: International Statistical Classification of Diseases and Related Health Problems

Figure 2. Incompleteness intensity map (%) of the variables for race/skin color, education, marital status, occupation and cause of death. Mato Grosso, Brazil, 2000 to 2016.

respectively. All the categories of the underlying cause of death variable, which also showed a decreasing trend, were classified as excellent, however the average value of the sum of the categories showed a value of almost 10%, with the incompleteness of the variable being classified as good (Table 2).

Of the variables that showed a stable trend, incompleteness for race/skin color and marital status were classified as excellent, both for the variable and for the categories. The incompleteness of the occupation variable, which also showed a stable trend, remained classified as very bad in all the years, and the categories were classified as good (*blank*), excellent (*unidentified*, *student* and *unemployed*) and bad (*housewife* and *retired*) (Table 2).

Table 2. Average percentage and incompleteness classification* of the variables for race/skin color, education, marital status, occupation and underlying cause of death. Mato Grosso, Brazil, 2000 to 2016.

Variables	Categories	Mean (%)	Classification
Race/skin color	Blank	1.97	Excellent
Education		8.66	Good
	Blank	3.17	Excellent
	Ignored	5.49	Good
Marital Status		3.73	Excellent
	Blank	1.85	Excellent
	Ignored	1.88	Excellent
Occupation		57.95	Very Bad
	Blank	6.54	Good
	Not identified	3.80	Excellent
	Unemployed	0.69	Excellent
	Retired	24.18	Bad
	Housewife	21.40	Bad
	Student	1.33	Excellent
Underlying cause of death		9.45	Good
	C76	2.12	Excellent
	C77	0.14	Excellent
	C78	2.39	Excellent
	C79	1.57	Excellent
	C80	3.23	Excellent

*The classification created by Romero e Cunha[5] was considered.

DISCUSSION

The study revealed the trend of incompleteness of demographic, socioeconomic and cause of death variables, relevant to the knowledge of mortality from neoplasms in Mato Grosso. Although most of the indicators showed a stable trend and excellent or good classification, the variables marital status and occupation stood out for indicating a growing trend of incompleteness in their categories, pointing to a worsening in the quality of the records.

The decreasing trend for the five categories studied referring to the variables education (*blank*), occupation (*unidentified, housewife*), and cause of death (C76-malignant neoplasm of other and ill-defined sites and C80-malignant neoplasm without specification of site) indicates improvement in the completion of death certificates, however, it should be noted that for the categories *housewife* and *retired*, incompleteness was bad, and, in the case of this last variable, the tendency was increasing, along with the *ignored* category, of the variable marital status. Despite being registered in the SIM, these categories should be avoided, as they are not considered occupations according to the 2002 BCO, contributing to the loss of comparability with other sources[4].The variations found suggest a lack of understanding of the instructions to complete the death certificate.

Other studies point to the poor quality of the occupation variable in the hospital cancer records in Brazil[15,16]. It should be noted that the quality of this variable implies results from causality investigations, given that 8 to 16% of tumors result from occupational exposure. According to the National Cancer Institute (INCA), work environments can contribute to the exposure of workers to various carcinogenic agents, whose effects can be potentiated if added to other cancer risk factors[17,18]. In this regard, it's important to highlight the large-scale use of pesticides, potentially toxic to humans, in the state of Mato Grosso, in order to protect crops and increase productivity, which is associated with other health events[19].

Education is recognized as a variable that indirectly assesses the individual's socioeconomic status and, therefore, may be related to illness and death[17]. According to data from the 2008 National Household Sample Survey (PNAD), a low level of education, used to analyze inequalities in the living conditions of the adult population, was associated with a higher prevalence of chronic diseases. It may thus indicate difficulties in accessing health services and information, contributing to the fact that individuals may not receive adequate care or even be unaware of their health situation in relation to these diseases[20]. Therefore, it is important to seek to maintain the quality of the record of this variable.

The filling in of the underlying cause of death proved to be of excellent quality. Factors such as increased coverage of medical care and technological availability for medical diagnosis may have influenced the results[21]. On the other hand, a study that sought to assess the impact of the redistribution of deaths from the main cancers of the elderly in the northeast showed improvements in the quality of the data, with considerable increase

in the number of deaths recorded for the main types of cancer, as well as a repositioning of the causes of death. According to the authors, this change may be attributed to inconsistency errors in the basic records of the original deaths[22]. This fact implicates the knowledge of the true levels of mortality from cancer, and consequently, the direction of prevention and intervention initiatives.

Although there has been an improvement in the rates of completeness in the SIM over the years studied, there is still a high number of information ignored or not filled in, or filled in incorrectly. The decreasing trend of incompleteness and the improvement of the quality of the cancer mortality data, may be related to the institution of the death surveillance in 2009 through the creation of teams at a local level, committees and epidemiology centers[6]. The Ministry of Health, with the support of partner institutions, has also been developing initiatives to reduce the proportion of SIM deaths with basic causes registered with garbage codes, considered not very useful or insufficiently specified. The investigation of these deaths and the reclassification of the underlying cause of death indicated an improvement in the coverage of the system between 2000 and 2016, the same period evaluated here. While there was an increase in notification coverage, the proportion of deaths with the garbage code in the country reduced from 42.7% in 2000 to 34.3% in 2016[7]. In this sense, it is essential to strengthen strategies for the supervision, monitoring and quality control of the information, seeking to maintain the completeness of SIM data and reduce the incompleteness of those that remain inadequate.

Although it represents the main source of data on mortality in Brazil, the SIM faces obstacles to improve the quality of its data, mainly due to the inadequate completion of the death certicate[23]. The problem scenario presented about the incorrect completion in this study demonstrates how the quality of the declared information still needs improvement. Despite the scarcity of studies for comparison and the likely difference in the definition of the incomplete field, the present study provides an evaluation of state data from the Central-West region, contributing to overcoming this gap[8].

Even after so many years of SIM implementation, it is observed that some important variables still remain with reasonable quality, which may compromise the knowledge of the magnitude of cancer deaths, impairing the planning of actions aimed at its monitoring and prevention. In this sense, some measures related to improving the completeness of data in the death certificates should be implemented, such as valuing medical curricula and professional qualification, especially for those who work in state and municipal Health Departments, regarding the complete, correct and reliable completion of the death certificates, with relevant action by the Ministry of Health. Other strategies should be considered, such as the implementation and performance of death surveillance and mortality committees for the investigation and systematic discussions of deaths, thus contributing to the search for information of better quality.

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Received on: 08/30/2021
Reviewed on: 02/16/2022
Accepted on: 02/22/2022
Preprint: 04/25/2022
https://preprints.scielo.org/index.php/scielo/preprint/view/4008
Corrected on: 09/13/2024

Author's contributions Souza, B.S.N.: formal analysis, writing – original draft, writing – review & editing, methodology. Lima, D.V.: formal analysis, writing – original draft, writing – review & editing, methodology. Caló, R.S.: writing – original draft, writing – review & editing, methodology. Oliveira, J.C.S.: writing – original draft, writing – review & editing, methodology. Andrade, A.C.S.: formal analysis, writing – original draft, writing – review & editing, methodology. Oliveira, L.R.: writing – original draft, writing – review & editing, methodology. Galvão, N.D.: project administration, writing – original draft, writing – review & editing, methodology, funding acquisition.