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QUALITY EVALUATION OF THE SURVEILLANCE SYSTEM FOR DEATHS FROM CHAGAS DISEASE IN CEARÁ, 2013-2022

AVALIAÇÃO DA QUALIDADE DO SISTEMA DE VIGILÂNCIA DOS ÓBITOS POR DOENÇA DE CHAGAS NO CEARÁ, 2013-2022

EVALUACIÓN DE LA CALIDAD DEL SISTEMA DE VIGILANCIA DE LAS MUERTES POR ENFERMEDAD DE CHAGAS EN CEARÁ, 2013-2022

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ABSTRACT
Objective: To evaluate the mortality surveillance system for Chagas Disease (CD). CD is caused by *Trypanosoma cruzi* and transmitted by triatomines, affecting about 6 million people worldwide, the majority of whom are in Latin America. In Brazil, CD poses significant proportions with a high burden of morbidity and mortality. This was an evaluative study, using secondary data information collected from the Mortality Information System (SIM), available on DATASUS. **Method:** According to CDC guidelines, the quality of data (completeness and consistency) was analyzed, followed by representativeness. **Results:** The results showed a final completeness average ranging from 90.5% to 100.0%, which indicates excellent quality for gender, age group, and race, and good quality for education. Consistency was assessed as regular for the occupation field; very poor for deaths in public places and regular for deaths occurring at home. There was high representativeness in the variables of time, person, and place. **Final Considerations:** The data regarding the completeness of the SIM were deemed adequate and representative; however, there are gaps concerning the consistency of the system regarding deaths with the underlying cause of Chagas disease.
Keywords: *Chagas Disease; Death; Data Quality.*

RESUMO
Objetivo: Avaliar o sistema de vigilância da mortalidade por Doença de Chagas (DC). A DC é causada pelo *Trypanosoma cruzi* e transmitida por triatomíneos e afeta cerca de 6 milhões de pessoas em todo o mundo, sendo a maioria delas na América Latina. No Brasil, a DC assume proporções significativas com elevada carga de morbimortalidade. Esse foi um estudo avaliativo, utilizando informações de dados secundários, coletados do Sistema de Informação de Mortalidade (SIM), disponível no DATASUS. **Método:** Conforme as diretrizes do CDC, foram analisadas a qualidade dos dados (completude e consistência), seguido da representatividade. **Resultados:** Os resultados apresentaram uma média de completude final que variou de 90,5% a 100,0%, o que infere uma qualidade excelente para gênero, faixa etária e raça, e uma qualidade boa para escolaridade. A consistência foi avaliada como regular para o preenchimento do campo ocupação; muito ruim para os óbitos em via pública e regular para os óbitos com ocorrência em domicílio. Houve alta representatividade nas variáveis tempo, pessoa e lugar. **Considerações Finais:** Os dados referentes à completude do SIM foram considerados adequados e representativos, porém existem lacunas quanto à consistência do sistema, no que se refere aos óbitos com causa básica Doença de Chagas.
Descritores: *Doença de Chagas; Óbito; Qualidade dos Dados.*

RESUMEN
Objetivo: Evaluar el sistema de vigilancia de la mortalidad por Enfermedad de Chagas (EC). La EC es causada por el *Trypanosoma cruzi* y transmitida por triatomíneos y afecta a alrededor de 6 millones de personas en todo el mundo, siendo la mayoría de ellas en América Latina. En Brasil, la EC asume proporciones significativas con alta carga de morbilidad y mortalidad. Este fue un estudio evaluativo, utilizando información de datos secundarios, recolectados del Sistema de Información de Mortalidad (SIM), disponible en DATASUS. **Método:** De acuerdo con las directrices del CDC, se analizaron la calidad de los datos (completitud y consistencia), seguido de la representatividad. **Resultados:** Los resultados presentaron un promedio de completud final que varió del 90,5% al 100,0%, lo que infiere una calidad excelente para género, rango de edad y raza, y una calidad buena para la escolaridad. La

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consistencia se evaluó como regular para el llenado del campo ocupación; muy mala para los fallecimientos en vía pública y regular para los fallecimientos ocurridos en el hogar. Hubo alta representatividad en las variables tiempo, persona y lugar. **Consideraciones Finales:** Los datos referentes a la completud del SIM fueron considerados adecuados y representativos, sin embargo, existen lagunas respecto a la consistencia del sistema, en lo que se refiere a los fallecimientos con causa básica Enfermedad de Chagas.
Descriptores: *Enfermedad de Chagas; Muerte; Calidad de los datos.*

INTRODUCTION

Trypanosoma cruzi (T. cruzy) is a unicellular flagellated protozoan responsible for Chagas disease (CD), or American trypanosomiasis. It is transmitted through the feces of a triatomine insect (commonly referred to as the "kissing bug"), which contains the infective forms of *T. cruzi*. This anthropozoonosis is classified as a tropical disease with high prevalence and significant morbidity and mortality, characterized by a biphasic clinical course (acute and chronic)[1].

According to data from the World Health Organization (WHO) in 2023, approximately six million individuals were affected by the disease worldwide, with the majority residing in Latin America. However, due to increasing population mobility, the disease is increasingly being detected in non-endemic regions across different countries and continents. The WHO further estimates that around 21.8 million people are at risk in endemic areas[2].

In Brazil, Chagas disease represents a major public health concern due to its substantial burden of morbidity and mortality. It is currently estimated that at least one million individuals are infected with *Trypanosoma cruzi*, placing the disease among the four leading causes of death from infectious and parasitic diseases in the country. This epidemiological profile necessitates its inclusion in both global and national strategic agendas, as the disease's dynamics are influenced by migratory flows and adverse social determinants[3],[4].

The treatment of Chagas disease must be prescribed by a physician following laboratory confirmation. Benznidazole, the drug of choice, is provided free of charge by the Brazilian Ministry of Health upon request by the State Health Departments and should be administered in cases of acute disease when diagnosed early[5].

Regarding the notification of chronic Chagas disease, the process is conducted through the e-SUS Notifica system, in accordance with the case definition criteria and regulated by Ordinance GM/MS No. 5.201, dated August 15, 2024. This regulation also addresses the notification of acute Chagas disease (ACD), which is reported via the Notifiable Diseases Information System (SINAN NET). Mortality data related to CD are entered and analyzed through the Mortality Information System (SIM), which processes data based on the most prevalent causes of death[6]

Death Certificate (DC) is the standardized document used by the Mortality Information System (SIM) and is mandatory throughout the national territory. It is a standardized instrument, printed with a unique numerical sequence and consisting of three self-copying sheets in different colors (white, yellow, and pink), following a standardized layout defined by the Health Surveillance Secretariat of the Ministry of Health (SVS/MS). This format is essential to ensure the quality of the data entered into the SIM. Within this context, the SIM stands out as a vital information system that

supports health planning actions across the country. Therefore, the aim of this study is to evaluate the mortality surveillance system for Chagas disease (CD) by analyzing the qualitative attributes of the data—completeness, consistency, and representativeness—thus contributing to the overall assessment of the quality of epidemiological surveillance for CD.

METHODS

This is an evaluative, ecological descriptive, and cross-sectional study employing a quantitative approach based on the analysis of secondary data concerning deaths due Chagas disease as the underlying cause, recorded in the Mortality Information System (SIM), maintained by the Department of Informatics of the Unified Health System from Brazil (DATASUS).

The study population comprised death records attributed to Chagas disease that occurred in the state of Ceará between 2013 and 2022. The data analyzed were those reported to SIM/DATASUS, with cases of Chagas disease defined according to code B57 from the International Classification of Diseases (ICD-10).

To characterize the collected data, the study adopted the methodology proposed by the Centers for Disease Control and Prevention (CDC) in the *Updated Guidelines for Evaluating Public Health Surveillance Systems*. The analysis focused on the following attributes: consistency, completeness, and representativeness.

- **Consistency** refers to the degree to which related variables have coherent and non-contradictory values[7].
- **Completeness** is defined as the extent to which the fields in a health information system contain non-null values. Incompleteness is measured as the percentage of missing data-those either ignored (coded as "9" in the SIM manual) or left blank.
- **Representativeness** is the ability to accurately describe where, when, and in whom the health event of interest occurs. The analysis followed the selected variables from the Brazilian Official Death Certificate Form, which contains 59 variables distributed across nine blocks: identification, residence, occurrence, fetal or under one year of age, conditions and causes of death, physician, external causes, registry office, and locality without a physician. All variables require careful attention[8]

Table 1 - Evaluated Attributes Based on Evaluation Items, Classification, and Overall Assessment. Ceará, 2013 to 2022.

ATTRIBUTE	EVALUATION ITEMS	CLASSIFICATION	OVERALL ASSESSMENT
Data Quality	Incompleteness	Excellent (<5%), Good (5%–10%), Fair (10%–20%), Poor (20%–50%), and Very Poor (≥50%)	Good Quality: three or more fields rated as "good"; Poor Quality: fewer than three fields rated as "good"
	Inconsistency		

Representativeness	Time, person, and place	High Representativeness	>10 variables considered satisfactory (time, person, and place)
		Regular Representativeness	up to 5 variables considered unsatisfactory (time, person, and place)
		Low Representativeness	>5 variables considered unsatisfactory (time, person, and place)

Source: Adapted from Pacheco, 2021 (original author)[9].

As the study utilized secondary data in the public domain, it was exempt from review by a Research Ethics Committee (CEP). It is noteworthy that Resolution No. 510, dated April 7, 2016[10], of the National Health Council (CNS), stipulates that research exclusively based on publicly accessible databases with aggregated, non-identifiable information is exempt from ethical review, ensuring the anonymity of the study.

RESULTS

This study revealed a heterogeneous pattern in the number of deaths over the historical series analyzed, with the highest and the lowest numbers of deaths recorded in 2019 and 2013 respectively. The deaths distribution with Chagas disease (CD) as the underlying cause in the state of Ceará totaled 528 cases between 2013 and 2022. It was evinced that the number of cases had been gradually increasing, peaking in 2019 with 65 deaths. According to the World Health Organization, CD is included among the list of neglected tropical diseases. It was only in 2020, through Ordinance No. 1,061 of May 18, 2020, that chronic-phase CD became a notifiable condition. Therefore, the figures presented may underestimate the actual burden, as chronic cases of CD contribute to the underreporting and invisibility of the disease's true prevalence.

Table 2 - Quality assessment of the information system for deaths due to Chagas disease in Ceará, 2013 to 2022.

VARIABLE	AVERAGE FINAL COMPLETENESS (%)	FINAL INCOMPLETENESS (%)	QUALITY	OVERALL ASSESSMENT
Gender	100	0.0	Excellent	

Age Group	99.25	0.75	Excellent	**GOOD QUALITY**
Race/Color	98.5	1.5	Excellent	
Educational Attainment	90.55	9.45	Good	
Marital Status	97.9	2.1	Excellent	
Place of Occurrence	99.8	0.2	Excellent	
Occupation	89.6	10.4	Fair	
Autopsy	69.3	30.7	Poor	
Certified by Physician	68.2	31.8	Poor	

Source: The Author

According to Romero and Cunha (2006)[11], incompleteness is defined as the proportion of missing information, that is, fields left blank and codes assigned to unspecified information, as outlined in the guidelines for completing the Death Certificate (DC).

Regarding sociodemographic characteristics (gender, age group, race/ethnicity, educational attainment, and marital status), the final completeness averages ranged from 90.55% to 100.0%, classifying the data quality as excellen-except for educational attainment, which was rated as good. In this context, it is also noteworthy that the field for occupation was classified as having fair quality, according to the defined evaluation parameters. The variable “place of occurrence” showed excellent data quality. However, the fields concerning autopsy performance and type of certifying physician were both rated as poor.

Along with the completeness analysis, the Mortality Information System (SIM) demonstrated good data quality, as three or more of the nine variables analyzed were rated as “good.” In this scenario, it is also necessary to evaluate the consistency of the data, which refers to a dataset being free from contradictions or gross errors.

In the analyzed historical series, 144 individuals aged 20 to 59 years were recorded in the database with Chagas disease as the underlying cause of death. However, these data contradict the findings reported in the literature above. In this age group (20 to 59 years), 27.3% of deaths were attributed to Chagas disease, although this demographic is still within the life expectancy threshold of 60 years, as supported by Fuchs[12].

It is important to highlight that the profession “retired” was inconsistently reported in the occupation field (n=80/15.2%), indicating incorrect completion, which may compromise analyses of morbidity and mortality in relation to reported occupations. Additionally, six deaths were recorded as having occurred in public spaces,

with three cases lacking medical assistance. However, none of these deaths (0.0%) were certified by the Forensic Medicine Institute (IML) or the Death Verification Service (SVO).

According to the Joint Normative Instruction SESA/SSPDS, dated March 7, 2023, the state of Ceará has two SVO units: one located in Fortaleza and another in Barbalha. These units serve the designated municipalities and provide a portfolio of services in accordance with established agreements. Nonetheless, they are mandated to serve 100% of municipalities in Ceará for cases of epidemiological interest. The IML also ensures full (100%) municipal coverage across the state for all services offered by the SVO.

The data further showed that 186 deaths (35.22%) occurred at home, of which 83 had medical assistance, representing 44.62% of deaths due to Chagas disease. However, among home deaths without medical assistance, 28 cases (15.3%) were recorded, and only 5 of these (17.85%) were referred to the SVO. Consequently, 111 cases (59.6%) lacked information regarding medical assistance, rendering these data inconsistent for the purpose of analyzing deaths caused by Chagas disease.

Table 3 - Data inconsistencies based on data entry in the Mortality Information System (SIM) for deaths due to Chagas disease, Ceará, 2013 to 2022.

Variable	**PARAMETER**		**CAUSE**
	Inconsistency		**Inconsistency Evaluation**
Occupation	**n**	**%**	Incorrect completion in the occupation field
Retired	80/528	15,2	**FAIR**
Place of Death			
Public thoroughfare	**3/6**	**50,0**	06 Not issued by the SVO or IML; 03 with medical assistance **VERY POOR**
Home without medical assistance certified by the SVO	5/28	17,85	**FAIR**

Source: The Author. Romero and Cunha (2006)[11] proposed the following evaluation criteria: excellent (less than 5%), good (5% to 10%), fair (10% to 20%), poor (20% to 50%), and very poor (50% or more).

In the assessment of representativeness, which refers to the ability to accurately describe where and in whom the health event of interest is occurring, certain limitations were identified due to the inherent subjectivity involved in judging the representativeness of the information system under analysis. Within this scope, a review of relevant scholarly articles was conducted to identify studies addressing this subject, aiming to guide the evaluation of the representativeness of the demographic data from the Chagas disease mortality surveillance system, as the underlying cause of death, as detailed below:

Table 4 - Assessment of the Representativeness of Demographic Data from the Chagas Disease Mortality Surveillance System as Underlying Cause of Death, Ceará, 2013 to 2022

VARIABLE	Evaluation of the Mortality Surveillance System for Deaths Due to Chagas Disease as the Underlying Cause, Ceará, 2013 to 2022		Epidemiological Characterization of Deaths from Chagas Disease in Brazil, 2010 to 2019	
	Frequency	%	Frequency	%
Gender				
Male	340	64,4	24.694	54,38
Age				
60 +	384	72,7	34.051	74,99
Race				
White	113	21,4	17.956	39,54
Brown	383	72,9	19.113	42,09
Years of Education				
None	186	35,22	11.009	24,24
1 to 3 years	166	31,40		

Source: The Author

Below is Table 5, presenting the variables related to time, person, and place, along with the description of their completeness levels and corresponding classifications. Based on the evaluation criteria, the analyzed variables were defined as having high representativeness.

Table 5 - Final Classification of Representativeness in Mortality Due to Chagas Disease. Mortality Surveillance System as Underlying Cause of Death, Ceará, 2013 to 2022.

Variables	Degree of Completion	Classification	Representativeness Assessment
TIME			**High Representativeness**
Ano do óbito	100%	Satisfatory	
PERSON			
Sex	100%	Satisfatory	
Age	100%	Satisfatory	
Race	98,9%	Satisfatory	
PLACE			

Health Region	100%	Satisfatory
Location of the occurrence	100%	Satisfatory

Source: The Author

DISCUSSION

Chagas disease (CD) is among the neglected tropical diseases (NTDs) and represents a serious public health problem in impoverished areas with precarious socioeconomic conditions, particularly in Latin America. In Brazil, NTDs-especially Chagas disease-cause, on average, 10,000 deaths annually. In fact, Brazil is the Latin American country with the highest number of NTD cases. In a study by Melo conducted in 2015 in Ceará, focused on NTDs and using secondary mortality data from SIM over a 10-year periodsimilar to the present study-72,827 (72.0%) death certificates listed CD as the underlying cause of death, making it the most prevalent cause among NTDs[13].

The evaluation of the surveillance system for deaths due to CD prompted reflections on the importance of having a complete, consistent, and representative information system to analyze the health status concerning CD-related mortality in the state of Ceará—its causes and consequences. These findings align with Jorge *et al.*[14], who emphasize the relevance of death records and their investigation as fundamental elements for epidemiology and public health, as well as the necessity of obtaining accurate information and appropriate parameters in both quantity and quality. Although mortality data are components of numerous health indicators, few studies to date have addressed the quality assessment of mortality data related to CD.

One of the limitations encountered in this study from an epidemiological perspective is the comparison between notification databases for CD, using morbidity data such as those from SINAN, which include cases in both the acute and chronic phases. This renders the comparison between morbidity and mortality data in SIM unfeasible, given that the notification system for chronic-phase CD was only implemented in 2023.

These limitations are echoed in the findings of Jacó (2023)[15], who reports that, despite the significant impact of CD on health in endemic countries, 70.0% of individuals with chronic CD are unaware of their diagnosis. This is compounded by the absence of mandatory notification of the condition and insufficient investigation into the underlying cause of death, as a considerable proportion of deaths remain classified under ill-defined causes. These factors may point to underreporting of CD-related morbidity and mortality. It is thus agreed that state-level health planning must prioritize strategic actions, including funding, monitoring, and supervision of CD control efforts[15].

This study underscores the importance of analyzing data quality attributes and representativeness of SIM data for CD in Ceará. The completeness of the analyzed fields was rated as “good quality.” Nevertheless, while mandatory information may be complete, it is equally imperative that the data be consistent and reliable, reflecting the actual epidemiological scenario under investigation. It is worth noting that during the

study period, inconsistencies and incomplete fields were present in death certificates—particularly in the "occupation" field (15.2% incorrect entries), the "autopsy" field (30.7% incomplete), and the "certified by physician" field (31.8% incomplete) —which may compromise the effective planning of health interventions.

Regarding the place of occurrence, data quality was classified as excellent; however, the fields for autopsy performance and certifying physician type were rated as poor. It is essential to establish the underlying cause of death as CD, considering that autopsies contribute significantly to precise diagnosis. The data show that only 3.8% of deaths with CD as the underlying cause underwent autopsy, although 11.4% were certified by the Death Verification Service (SVO). These discrepancies suggest divergent outcomes, as completeness was rated excellent, yet the autopsy field showed 30.7% incompleteness, reflecting poor quality for this variable.

As for the inconsistencies in the "occupation" field (15.2% incorrect), it is important to note that the designation "retired" is inconsistent. According to the death certificate completion guidelines, if the deceased was retired, the field should be filled in with the individual's previous habitual occupation. Thus, 15.2% (80 cases) were incorrectly completed, potentially compromising the analysis of morbidity and mortality in relation to reported occupation. Another relevant point regarding the social determinants of health is the finding that 56.0% of occupations of those who died from CD were linked to rural areas, suggesting an association with outcomes, since rural environments are conducive to the presence of triatomine bugs, the vectors of *Trypanosoma cruzi*[17,18].

The issuance of death certificates for cases occurring in public places, without medical assistance or certification by SVO or IML, warrants investigation into the causes and implications for death surveillance. It was also observed that six deaths occurred in public spaces, without any reference to accidents—although such locations are often associated with traffic fatalities. Of these, three had no medical assistance, and 0% of the certificates were issued by the Forensic Medicine Institute (IML) or SVO. According to the Ministry of Health's death certificate manual, in cases of natural deaths without medical assistance occurring in areas with an SVO, the death certificate must be issued by the SVO physician (Art. 22 of Ordinance SVS/MS No. 116/2009). These records should be further investigated to verify the public nature of the occurrences and to understand the circumstances that led to 50.0% of the certificates not being issued by IML or SVO.

It is emphasized that this study demonstrated representativeness, particularly when analyzing variables related to time, person, and place. Therefore, the SIM was considered to have high representativeness. These findings confirm that the analysis of SIM data, in conjunction with similar literature and thematic studies[13,15,16,19], reveals good data quality in terms of completeness and that the system is representative for reporting deaths due to Chagas disease.

FINAL CONSIDERATIONS

Starting in 2015, several strategies were implemented in the state of Ceará aiming the promotion of active case-finding and individuals affected by CD diagnosis,

reinforcing the importance of health promotion, prevention, and disease control actions. These efforts were led by a working group (GT) focused on CD, involving the Public Health Laboratory of Clinical Analisis (LACEN), the Ceará Hematology and Hemotherapy Center (HEMOCE), and the Chagas Disease Research Laboratory at the Federal University of Ceará (LPDC–UFC).

It is essential to emphasize that defining CD as the underlying cause of death involves an integrated health care network, beginning with timely diagnosis and extending to vector control actions carried out by municipal endemic and zoonosis services in coordination with the public health laboratory. These actions must be integrated into the services provided by Primary Health Care (PHC).

Moreover, when the care continuum and vector control are weakened, this results in fewer cases being reported in SIM, as well as death certificates subject to inconsistencies in both quality and quantity. These issues arise from failures in the timely identification and coding of CD as the underlying cause, further contributing to the disease's neglection. Therefore, it is strongly recommended that health managers provide training for physicians on the proper completion of death certificates, following the standardized model and information flow outlined in the Ministry of Health's manual. Furthermore, systematic analysis of compulsory notification data for CD—correlated with morbidity and mortality data—should be encouraged. This includes the automatic linkage of SIM to SINAN and e-SUS Notifica. Developing and implementing a step-by-step tutorial in CD epidemiological surveillance services would also be beneficial, promoting active information retrieval from available databases.

Thus, conducting this study has contributed to expanding knowledge about the evaluation processes of the CD mortality surveillance system and highlighted the importance of accurate reporting and investigation of mortality data, as well as data quality, to support more informed and effective decision-making.

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