EVALUATION OF THE MORTALITY SYSTEM DUE TO SCHISTOSOMIASIS IN PERNAMBUCO

AVALIAÇÃO DO SISTEMA DE ÓBITOS POR ESQUISTOSSOMOSE EM PERNAMBUCO

EVALUACIÓN DEL SISTEMA DE MORTALIDAD POR ESQUISTOSOMIASIS EN PERNAMBUCO

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ABSTRACT
Objective: to evaluate the surveillance of deaths due to schistosomiasis in Pernambuco from 2013 to 2022. **Methods:** evaluation study of the attributes 'data quality', 'representativeness', 'timeliness', and 'utility' of the system, based on the guidelines of the Centers for Disease Control and Prevention. Data from the Mortality Information System were used from 2013 to 2022. **Results:** the system showed good utility, completeness, excellent consistency, and was also representative and timely, with an improvement in data quality over the years. The variable 'medical assistance' (death conditions block) had lower completeness (76.9%), considered poor. Representativeness was adequate, except for sex, which was low. Regarding timeliness, 90.6% of death certificates were registered within 60 days, making it timely. Conclusion: the analyzed data indicate the need for improvements, especially in 'death conditions', to understand the circumstances and identify failures in diagnosis and patient assistance.
Keywords: *Schistosomiasis; Mortality Surveillance; Health Assessment.*

RESUMO
Objetivo: avaliar a vigilância de óbitos por esquistossomose em Pernambuco no período de 2013 a 2022. **Métodos:** estudo de avaliação dos atributos 'qualidade de dados', 'representatividade', 'oportunidade' e 'utilidade' do sistema, pautado nas diretrizes do Centers for Disease Control and Prevention. Utilizaram-se dados do Sistema de Informação de Mortalidade entre 2013 e 2022. **Resultados:** o sistema mostrou boa utilidade, completude, excelente consistência, além de ser representativo e oportuno, com melhora na qualidade dos dados ao longo dos anos. A variável "assistência médica" (bloco condições do óbito) teve menor completude (76,9%), considerada ruim. A representatividade foi adequada, exceto para o sexo, que foi baixa. Quanto à oportunidade, 90,6% das declarações de óbito foram registradas em até 60 dias, sendo oportuno. **Conclusão:** os dados analisados indicam necessidade de melhorias, especialmente nas "condições do óbito", para entender as circunstâncias e identificar falhas no diagnóstico e assistência ao paciente.
Descritores: *Esquistossomose; Vigilância de Óbitos; Avaliação em Saúde.*

RESUMEN
Objetivo: evaluar la vigilancia de las muertes por esquistosomiasis en Pernambuco entre 2013 y 2022. **Métodos:** estudio para evaluar los atributos 'calidad de los datos', 'representatividad', 'oportunidad' y 'utilidad' del sistema, con base en las directrices de los Centros para el Control y la Prevención de Enfermedades. Se utilizaron datos del Sistema de Información de Mortalidad entre 2013 y 2022. **Resultados:** el sistema mostró buena utilidad, completitud, excelente consistencia, además de ser representativo y oportuno, con mejora en la calidad de los datos a lo largo de los años. La variable "atención médica" (condiciones de muerte en bloque) tuvo menor completitud (76,9%), lo que se consideró pobre. La representatividad era adecuada, excepto para el género, que era bajo. En cuanto a la oportunidad, el 90,6% de los certificados de defunción se registraron dentro de los 60 días, lo cual es oportuno. **Conclusión:** los datos analizados indican la necesidad de mejoras, especialmente en las "condiciones de muerte", para comprender las circunstancias e identificar fallas en el diagnóstico y asistencia al paciente.
Descriptores: *Esquistosomiasis; Vigilancia de la Muerte; Evaluación de Salud.*

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INTRODUCTION

Schistosomiasis is a neglected tropical disease caused by trematode worms of the genus Schistosoma, affecting millions of people in 78 countries, with an estimated 230 million cases and up to 200,000 annual deaths.[1]In Brazil, Schistosomamansoni is the species responsible for the infection, which is endemic in 19 states and transmitted through contact with surface water contaminated with cercariae released by intermediate host snails of the genus Biomphalaria. The disease can be asymptomatic or progress to severe clinical forms, including hepatosplenic disease, which can lead to death. Approximately 1.5 million people are at risk of infection in the country.[2,3]

The state of Pernambuco is a significant endemic area, with cases concentrated in the Zona da Mata and Agreste regions, areas characterized by humidity, fertile soil, freshwater rivers, and frequent rainfall.[2]Between 2013 and 2022, 44,174 positive cases were registered in the state, reflecting an average positivity rate of 2.68% and 1,739 deaths – rates consistently above the national average.[4]

Despite significant advances in reducing schistosomiasis morbidity and mortality, the disease remains a critical public health challenge, with high mortality rates.[5,6]Among the main obstacles is the lack of a robust national standardization for monitoring and qualifying causes of death, which hinders consistent analysis and the prevention of new deaths.[7,8]In this context, it is essential to evaluate the performance of the schistosomiasis mortality surveillance system, with an emphasis on the use of the Mortality Information System (SIM)to support evidence-based decision-making.

Furthermore, studies specifically evaluating the performance of the schistosomiasis surveillance system are scarce, especially regarding the use of SIM, the official basis for national death registration, which is fed by the Death Certificate (DC). Given this gap, this study aimed to evaluate the schistosomiasis mortality surveillance system in the state of Pernambuco from 2013 to 2022, based on the Guidelines for Evaluating Public Health Surveillance Systems from the Centers for Disease Control and Prevention (CDC).[9]

METHODS

An evaluative study of the schistosomiasis mortality surveillance system using secondary data, based on data quality, representativeness, timeliness, and utility,was conducted according to the Updated Guidelines for Evaluating Public Health Surveillance Systems: recommendations from the guidelines working group – CDC[9],between January 2013 and December 2022.

Pernambuco consists of 184 municipalities and the Fernando de Noronha district. Furthermore, it has an estimated population of 9,058,931 inhabitants in 2024, occupying an area of 98,068.021 km², which represents a population density of 89.62 inhabitants/km².[10]The state health organization network is divided into 12 health regions, which, in turn, contain 11 reference hospital units for the care of severe forms.

The study analyzed all deaths of residents in the state due to schistosomiasis, registered under the codes: B65; B65.0; B65.1; B65.2; B65.3; B65.8; B65.9. Deaths occurring in the state but involving residents from other Federative Units (UF) were

excluded. The analyzed data covered the period from January 1, 2013, to December 31, 2022.

SIM was adopted as the data source. This system is responsible for the collection, transmission, and dissemination of data, being fed by the typing of the DC. These data were obtained by consulting the national database of the Department of Informatics of the Unified Health System (DataSUS) at the electronic address: https://datasus.saude.gov.br/transferencia-de-arquivos/. The information repository was accessed by the researchers in August 2024.

"Data quality" is understood as the validity and integrity of the data, which are analyzed based on the components: completeness and consistency. Completeness is understood as the degree of filling of the analyzed variable, while consistency refers to the level to which related variables present coherent and non-contradictory values.[9]For consistency, cases for which these fields were not filled were excluded to obtain the proportion of notifications with related variables filled with coherent values in the proposed pairings. For judging completeness, the following parameters were used: Excellent, $\geq$ 95%; Good, $\geq$90% to $\leq$94.9%; Fair, $\geq$80% to $\leq$89.9%; Poor, $\geq$50% to $\leq$79.9%; Very poor, <50%. For consistency: Excellent, $\geq$ 90%; Fair, $\geq$ 70% to $\leq$89.9%; Low, < 70%.

The attribute "Representativeness," in turn, accurately describes the occurrence of a health-related event, considering its distribution in the population by person, time, and place. This is achieved by: convergence with the two levels above = high representativeness; convergence with one of the levels = moderate representativeness; no convergence = low representativeness. For judgment, one or more criteria met = representative; no criteria met = not representative. Timeliness consists of the interval between different stages of the surveillance process to obtain information in a timely and efficient manner. [10]For judgment, it was considered: Timely $\geq$ 80%; Untimely $\leq$79.9%.

The variables considered in the study, selected from the blocks of 1) identification, 2) residence, 3) occurrence, and 4) conditions and causes of death, for the evaluation of the attributes, were:

a)   *Completeness*: Place of birth; Sex; Marital status; Education; Occupation; Municipality of residence; Place of death occurrence; Establishment; Municipality of occurrence; Medical assistance; Diagnosis confirmed by autopsy..

b)   *Consistency:*Age (<10 years) versus marital status (all, except 'ignored'); Type of death (non-fetal) versus age (except 'ignored' and 'blank'); Underlying cause versus death certified by a physician (except 'Forensic Medicine Institute -- IML'); Diagnosis confirmed by autopsy ('Yes') versus underlying cause (except B65.9).

c)   *Representativeness:*Age group; Sex; Race/skin color; Marital status; Education; Year of death; Classification of the transmission area; Place of occurrence.

d)   *Timeliness:* of Registration time between the date of death and the date of typing of the DC in the municipality of occurrence.

'Utility' reflects the system's ability to contribute to the prevention and control of an event, measure surveillance performance indicators, or even determine the importance of a public health event. The purpose is to evaluate the system's utility in

relation to its capacity to meet the characteristic objectives of a mortality surveillance system based on ten questions:

e) *Utility*:

1) Does it detect deaths from schistosomiasis?2) Does it quantify or establish the trend of deaths from schistosomiasis?3) Does it provide the necessary information about the behavior of schistosomiasis deaths?4) Does it identify risk factors associated with death from schistosomiasis?5) Does it stimulate epidemiological investigations for its control and prevention?6) Does it define a minimum standardization for conducts and procedures related to the notification, investigation, analysis, and monitoring of deaths? 7) Does it stimulate mechanisms to improve the quality of information about deaths, includingaccuracy in identifying the cause of death?8) Does it allow the identification of factors associated with the preventability of death?9) Does it enable guidance on the best clinical, behavioral, social, political, or environmental practices?10) Does it allow the evaluation of the effects of prevention and control programs?

For each "yes" answer, 1 point is assigned, while "no" answers receive 0 points. At the end, the total sum of the answers is interpreted as follows: 0 to 2 points: utility is considered low; 3 to 5 points: utility is acceptable; 6 to 7 points: utility is good; 8 to 10 points: utility is high.

Data were summarized in absolute and relative frequencies, measures of central tendency, as well as measures of centraltendency and dispersion. The database was processed, and for data analysis, the software Tabwin, Microsoft® Office Excel 365, and Epi-Info 7.2.4.0 were used.

Since it involves public secondary data, evaluation by an Ethics Committee was not required, in accordance with Resolution No. 466 of the National Health Council, dated December 12, 2012.

RESULTS

A total of 1,498 deaths from schistosomiasis were registered in the state of Pernambuco between 2013 and 2022.

In Table 1, the completeness analysis revealed that the average proportion of filled fields for the selected variables was good (92.2%). Among the four blocks analyzed for completeness, the lowest completeness was in "death conditions" (79.2%), classified as poor. The "identification" block (93.5%) showed good completeness, while the "residence" (100%) and "death occurrence" (96.2%) blocks were excellent. Furthermore, a 30.9% increase in data quality was observed over the years, with improvements recorded in all blocks and variables when comparing 2013 and 2022.

The lowest completeness among the variables was observed in "medical assistance" (76.9%), classified as poor. The variables "place of birth" (87.1%), "education" (87.3%), "establishment" (88.7%), and "autopsy" (81.5%) showed fair completeness. The variable "occupation" (91.9%) was considered good. For the other six variables, completeness was excellent. In the percentage variation analysis, the variables "place of birth", "medical assistance", and "autopsy" showed values above the average (11.4).The lowest completeness among the variables was observed in "medical assistance" (76.9%), classified as poor. The variables "place of birth" (87.1%), "education"

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Regarding consistency, all were classified as excellent, obtaining an overall average value of 98.9%, which was also classified as excellent. It was observed that the cross-tabulations of "Underlying cause versus certified by a physician (all, except 'IML'); Diagnosis confirmed by autopsy ('Yes') versus certified by a physician ('Death Verification Service – SVO'); and 'Diagnosis confirmed by autopsy ('Yes') versus underlying cause (except B65.9)" showed oscillations in consistency between the years.

The surveillance system was evaluated as representative. The age group with the most reported deaths was 75 and over, and the education level was 1 to 3 years, both with moderate representativeness. The predominant race/skin color was mixed-race (Parda), and the marital status was married, both with high representativeness. Regarding the person block, it shows that the most prevalent sex was female, with low representativeness.

The evaluation revealed that the system is timely, with 90.6% of records typed within 60 days of the municipality of occurrence. The overall median is 24 days over the years, with variations from 16 to 44 days.

Finally, regarding the 'level of system utility', it was found that the surveillance has good utility (score: 7 points), being capable of providing important indicators consistent with the recommended objectives and pointing out epidemiological trends in mortality.

DISCUSSION

Based on the criteria evaluated in this study, from the records of schistosomiasis deaths in SIM in the state of Pernambuco between 2013 and 2022, the evaluation indicated that, overall, the system demonstrated good utility, good completeness, excellent consistency, and is representative and timely.

The system is an essential tool for death registration in the country, covering all municipalities, generating over 1 million annual records.[11] Studies point to advances in the surveillance system, such as greater capture of deaths and improvements in the accuracy of cause-of-death information, receiving a high evaluation from the quality classification system of information systems by the Global Burden of Diseases.[12] This study observed the mentioned progress, identifying an improvement in the percentage of filled fields, which indicates advances in data quality and completeness.

Despite the advances, challenges coexist, such as deaths without medical assistance and ill-defined causes, with a greater impact in the North and Northeast regions, where schistosomiasis mortality records reflect the worst conditions in these aspects.[13,14] Although completeness is satisfactory, the variables associated with "death conditions" expose limitations that compromise notification, analysis, investigation, and qualification, which are essential to support effective control and prevention actions. Such gaps can impact activities, hindering the identification of factors associated with

the preventability of death from schistosomiasis, an essential step for more effective control and prevention actions.[15]

Furthermore, considering that schistosomiasis is a preventable cause of death, the analyzed indicators can reveal not only the performance of the health service but also its effectiveness. This panorama highlights the need for strategic interventions, including strengthening surveillance, training health professionals, and expanding prevention actions, especially in the most vulnerable regions.[15]

The variable with the worst performance was "medical assistance," which refer to relevant information concerning the health care provided throughout the course of the illness that led to the patient's death, and not just at the time of death. Additionally, the absence or inadequate recording of the "autopsy" field also compromises the precise knowledge of the cause of death, as well as behindering the evaluation of natural causes, lack of medical assistance, or the absence of a diagnosis of the disease while still alive[16]These findings corroborate previous studies, underlining the need to stimulate improvements in data filling, especially regarding schistosomiasis.[17,18]

The evaluation of consistency, in turn, revealed the coherence of the information from the notified deaths, allowing for the gathering of information through the association between selected variables. However, the scarcity of studies addressing this component highlights the importance of additional investigations in this area, paving the way for future research.

Another factor contributing tothe incomplete filling of forms may be the perception of the activity as merely bureaucratic by health professionals, attributing secondary importance to it[19–22]. Furthermore, a national absence of standardization of conduct and procedures related to the notification, investigation, analysis, and monitoring of death due to schistosomiasis is observed.

Significant advances in data quality in Brazil have been driven by death surveillance initiatives, in addition to the active search for deaths in civil registry offices, hospitals, health establishments, cemeteries, and unofficial sources, such as community health workers, traditional midwives, and community leaders.[12] These actions have resulted in improved event capture, and, given the new epidemiological patterns of schistosomiasis and the difficulties of diagnosis in low-endemicity areas, they represent an opportunity to establish more accurate statistics, identify vulnerable groups, and evaluate program outcomes.[23,24]

Regarding the system's representativeness, notifications were registered in all endemic municipalities for schistosomiasis in Pernambuco. Furthermore, the distribution of sociodemographic characteristics, predominantly moderate to high, classifies it as representative. In general, it was observed that most deaths affected elderly people with low education levels and who were predominantly of mixed race (Parda). These characteristics corroborate other findings and possibly reflect delayed access to diagnosis and treatment, in addition to highlighting the strong social determinants associated with the disease.[24]

Sex was the only variable classified as low, since the female sex was the most prevalent in the records. Although this prevalence contradicts the expected trend, considering that men are more exposed to infection due to occupational activities (e.g.,

fishing or agriculture) or leisure activities[25–27], other studies conducted in Brazil and Pernambuco identified a higher prevalence in women in Recife.[6,18]

The 2021 population projections indicate that the female sex is more prevalent in the state of Pernambuco, representing 52% of the population.[28] This demographic difference may, in part, justify the predominance of deaths among women while reinforcing the need for more detailed analyses to understand the phenomenon.

The identification of a higher prevalence in females raises important questions about classical theories of exposure and epidemiological monitoring. Future studies could investigate, for example, the role of women in informal activities that expose them to the parasite, in addition to factors related to access to health care and early diagnosis. This critical focus is essential to base more effective interventions targeted at the specificities of the Pernambuco population.

Table 1 - Percentage of completed fields in death certificates by variable and year of death, Pernambuco state, 2013-2022

Block / Variables	Year of death										Percentage variation	Mean percentage (SD)	Evaluation
	2013 (N= 141)	2014 (N= 140)	2015 (N=140)	2016 (N= 186)	2017 (N= 174)	2018 (N=167)	2019 (N=158)	2020 (N=150)	2021 (N=142)	2022 (N=100)			
	%	%	%	%	%	%	%	%	%	%			
Identification	**78,6**	**95,2**	**94,4**	**93,4**	**95,4**	**94,7**	**94,4**	**96,1**	**96,5**	**96,5**	**22,8**	**93,5 (±5,3)**	**Good**
Place of birth	0	96,4	96,4	93,5	96,5	94,6	96,8	98,6	99,3	99,0	99,0	87,1 (±30,7)	Fair
Sex	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	0,0	100,0 (±0,0)	Excellent
Race/color	97,8	99,2	97,1	98,9	99,4	98,2	98,1	99,3	97,8	99,0	1,2	98,4 (±0,8)	Excellent
Marital status	95,0	98,5	95,7	95,7	96,5	95,8	96,2	94,0	99,3	95,0	0,0	96,1 (±1,6)	Excellent
Education level	85,1	85,0	84,2	85,4	87,9	88,6	84,8	88,0	92,2	92,0	8,1	87,3 (±2,9)	Fair
Occupation	93,6	92,1	92,8	87,1	91,9	91,2	90,5	96,6	90,1	94,0	0,4	91,9 (±2,6)	Good
Residence	**100,0**	**100,0**	**100,0**	**100,0**	**100,0**	**100,0**	**100,0**	**100,0**	**100,0**	**100,0**	**0,0**	**100,0 (±0,0)**	**Excellent**
Municipality of residence	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	0,0	100 (±0,0)	Excellent
Occurrence	**95,5**	**100,0**	**95,5**	**95,4**	**96,3**	**96,0**	**96,2**	**94,4**	**96,9**	**96,3**	**0,9**	**96,2(±1,5)**	**Excelente**
Place of death	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	0,0	100 ± (0,0)	Excellent
Healthcare facility	86,5	100,0	86,4	86,2	89,0	88,0	88,6	83,3	90,8	89,0	2,9	88,7 (±4,5)	Fair
Municipality of occurrence	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	0,0	100 (±,0,0)	Excellent
Death Conditions	**64,2**	**62,1**	**75,3**	**82,2**	**85,3**	**87,1**	**83,8**	**87,6**	**80,6**	**84,0**	**30,9**	**79,2 (±9,2)**	**Poor**
Medical assistance	58,8	60,7	72,1	80,6	85,0	85,6	80,3	86,6	78,8	81,0	37,8	76,9 (±10,0)	Poor
Autopsy performed	69,5	63,5	78,5	83,8	86,2	88,6	87,3	88,6	82,3	87,0	25,2	81,5 (±8,6)	Fair
									93,5	94,2	11,4	92,2 (±3,9)	Good

Source: Mortality Information System (SIM)/DataSUS, Brazilian Ministry of Health

Additionally, it was observed that the place of death has mostly been the hospital, which reflects the worsening of the patients' clinical condition and possibly indicates a failure to access timely diagnosis. Another aspect that draws attention and requires deeper analysis is the deaths occurring at home, which may indicate difficulties in accessing medical care, especially follow-up by Primary Health Care.

The typing of the DC in the municipality of occurrence was timely; however, its execution, often treated as a mere bureaucratic activity, can yield unsatisfactory results. This points to the need for continuous monitoring of activities related to the process.[8]

Among the study's limitations, the use of secondary data from the registration system stands out. Secondary data can produce biases by underestimating the number of deaths from schistosomiasis, which influences the indicators. It is not possible to quantify underreporting, although a reduction in this risk is presumed since the official mortality information system was used. Additionally, in the database available on DataSUS, the registration date was used as an approximation of the batch receipt date, as this information is not available in the exported database. Furthermore, another limitation is the scarcity of studies evaluating information systems on this specific theme, which makes it difficult to compare results with those from other research.

CONCLUSION

This study allowed for the evaluation of the schistosomiasis mortality surveillance system in Pernambuco, which was found to have good data quality, be representative, timely, and useful. The findings are valuable for public health, contributing to efforts to eliminate the disease as a public health problem. The results indicate an improvement in the quality of SIM over the years; however, they also highlight the need for greater attention to the completion of death conditions. These variables are fundamental for identifying possible failures in diagnosis and patient care actions, and it is crucial to invest in activities that ensure the accuracy of data on the occurrence of the disease.

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