


# Investigation of schistosomiasis cases and deaths in the city of Recife, Pernambuco, Brazil, 2005-2013\*

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## Abstract

**Objective:** to describe schistosomiasis cases and deaths among residents of the city of Recife, Pernambuco, Brazil, from 2005 to 2013. **Methods:** this was a descriptive epidemiological study using data from the Mortality Information System (SIM) (2005-2013) and the Notifiable Diseases Information System (SINAN) (2007-2013); active tracing of the relatives of the dead was undertaken and probabilistic linkage of the databases (2007-2013) was performed using the Reclink program. **Results:** 297 schistosomiasis deaths were recorded on the SIM system; through active tracing, 130 relatives were contacted and 20.8% autochthony was identified; 388 cases resident in Recife were registered on the SINAN system; through probabilistic linkage, 23 matching records were identified on SIM and SINAN. **Conclusion:** investigation of deaths showed that some individuals had never traveled outside Recife and progressed to the chronic stage of the disease; 23.8% of the cases registered on SINAN had Recife as the municipality in which infection occurred.

**Keywords:** Schistosomiasis; Health Information Systems; Death; Epidemiology, Descriptive.

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## Introduction

Schistosomiasis, a parasitic disease caused by *Schistosoma mansoni*, can progress to the chronic form – such as hepatic-intestinal, hepatic, hepatosplenic forms – and to complicated forms – vasculopulmonary, glomerulopathy, neurological, pseudoneoplastic or lymphoproliferative disease –, and can cause death. In view of the magnitude of its prevalence and the severity of its clinical forms, schistosomiasis is characterized as an important Public Health problem in Brazil.<sup>1,2</sup>

In the Americas there are approximately 1.8 million individuals infected with *Schistosoma mansoni* and 25 million at risk of contracting the disease.<sup>3</sup> According to the National Survey of Schistosomiasis and Geohelminthiasis Prevalence, conducted between 2010 and 2014 with 197,564 school students aged 7 to 17 years old living in 521 Brazilian municipalities, Brazil's Southeastern and Northeastern regions had the highest positivity rates: 2.35 and 1.27 respectively. The states of Sergipe (10.7), Pernambuco (3.8), Alagoas (3.4), Minas Gerais (5.8) and Bahia (2.9) had the highest proportions of positive cases in areas with populations of up to 500,000 inhabitants.<sup>4</sup>

*Research on this disease has been conducted in the metropolitan region of Recife since the 1990s. The results indicate the systematic appearance of new hotspots of active schistosomiasis transmission in peri-urban and coastal areas.*

Pernambuco has a time series (1979-2010) of mortality rates around five times higher than the national frequency. Of the 185 municipalities in Pernambuco, 102 have endemic schistosomiasis and 46.1% of these are located in the *agreste* mesoregion of Pernambuco, 41.2% are located in the *zona da mata* mesoregion of the state and 12.7% in the metropolitan mesoregion of Recife.<sup>5</sup>

In Brazil, *Schistosoma mansoni* is traditionally considered to be endemic in rural areas. However, there has been an increase in the number of cases reported in coastal areas of the metropolitan region of Recife,<sup>6-9</sup> as well as in urban areas of the cities of Belo Horizonte, Salvador and Aracaju.<sup>10-13</sup>

The appearance of cases of the disease in urban areas is not evidence of local transmission of *S.*

*mansoni*, as it may be the result of infected migrants coming from endemic areas.<sup>6,11,13,14</sup>

Considering the existence of individuals infected with *S. mansoni* living in urban agglomerations with precarious basic sanitation systems, inadequate water supply and presence of the intermediate host, predictive conditions for the establishment of the cycle of this parasite can be identified. These factors have been reported in some urban and coastal locations of some Brazilian states.<sup>15,16</sup>

Research on this disease has been conducted in the metropolitan region of Recife since the 1990s.<sup>7,8,17,18</sup> The results indicate the systematic appearance of new hotspots of active schistosomiasis transmission in peri-urban and coastal areas, suggesting that the disease is out of control in the state of Pernambuco.<sup>19,20</sup>

A study conducted in the city of Recife between 2010 and 2012, identified 30 breeding grounds of vector molluscs in a variety of locations with snails. *S. mansoni* DNA was found in four of these 30 breeding grounds. A parasite survey carried out in the same period with 2718 school students from Recife, identified five autochthonous cases of infected children who had never gone outside the city and who reported exposure during the rainy season when the immediate area around their homes is flooded by water from neighbouring creeks.<sup>21</sup>

Despite this evidence and also despite the considerable number of schistosomiasis cases and deaths recorded on health information systems as being attributed to the city of Recife, it is not possible to assert that schistosomiasis transmission is taking place in Recife, since so far no vector molluscs eliminating *S. mansoni* larvae have been detected.<sup>16</sup>

Our study aimed to describe schistosomiasis cases and deaths among people living in the city of Recife between 2005 and 2013.

## Methods

This was a descriptive epidemiological study using secondary data comprised of: (1) deaths having schistosomiasis as their underlying cause (ICD-10: B65) recorded on the Mortality Information System (SIM) between 2005 and 2013; and (2) schistosomiasis cases reported on the Notifiable Diseases Information System (SINAN) between 2007 and 2013. Only cases and deaths of people resident in the city of Recife, capital of the state of Pernambuco, were included.

The SIM records (2005-2013) and the SINAN records (2007-2013) were made available by the Recife City Health Department. The data held on SIM and SINAN were recorded based on death certificates and case reporting/investigation forms. The two information systems were linked probabilistically to check whether cases recorded on SIM (2007-2013) had been reported on SINAN (2007-2013). As Recife is not a schistosomiasis endemic area, all cases should be recorded on SINAN in compliance with Health Ministry Ordinance GM/MS 104, dated January 25<sup>th</sup> 2011.<sup>22</sup> In this stage of the study, we considered deaths recorded on SIM with effect from 2007, since reporting on SINAN only started in 2007.

Probabilistic linkage between SIM (2007-2013) and SINAN (2007-2013) was performed using the OpenReLink III application. Automatic routines were used to process the files, together with manual review of uncertain matches with the aim of classifying them as true or false matches, using the following variables: name, sex, date of birth, mother's name, date of death, residence street address, residence number, additional residence identification, death certificate number and case reporting number. Blocking and pairing/matching techniques were also used. The soundex code for first and last name as well as the 'sex' variable were used for blocking. The soundex code is a phonetic code whereby slight differences in writing or pronunciation originate the same code.<sup>23</sup> The parameters were established based on 20% of the database sampling fraction: (i) by the approximate comparison algorithm for the name, with the following weighting factor, agreement equal to 96.0% and disagreement equal to 0.02%; and (ii) by the comparison algorithm, date of birth character, with the following weighting factor, agreement equal to 94.5% and disagreement equal to 1.2%.

For the purposes of record matching, the files were combined to create a new database based on the linkage file containing the records identified as true matches. The existence of underreporting on both of the above mentioned systems was assessed manually.

Active tracing of family members was done in order to investigate the autochthony of schistosomiasis deaths in the study population. We investigated the epidemiological history and the demographic and socio-economic profiles of patients whose underlying cause of death was schistosomiasis in the city of Recife between 2005 and 2013. Family members of people who had

died were interviewed using questionnaires in order to obtain the following sociodemographic variables: 'sex' (male; female); 'previous place of residence' (endemic municipality, non-endemic municipality, no information); age range (in years: 30-49, 50-69, 70 or over); schooling (illiterate, elementary school, high school, technical school, completed higher education) and length of time of residence in Recife before death ( $\leq 6$  months,  $>6$  months to 1 year,  $>1$  to 10 years,  $>10$  years, no information). Variables regarding the sanitary conditions of the household were also gathered: water supply (public supply network, well or spring, river, others) and disposal of faeces and urine (sewerage system, cesspit, open sewer, no information).

The 'municipality of infection' variable was used for cases reported on SINAN between 2007 and 2013, while the following variables were used to investigate case autochthony: origin, residence and possible place of contamination. Cases having any type of exposure to risk in places with or without endemic schistosomiasis other than the city of Recife, according to the key informant, were not considered to be autochthonous cases.

On the deaths flow chart (2005-2013), the starting points were the places of infection identified during investigations with family members of the dead; and the arrival points were the city of Recife, as this was the place of residence recorded on SIM. Searches on SIM as to possible place of schistosomiasis exposure and infection lead to 125 death records being analyzed, given that five records related to other Brazilian states.

On the flow chart of the SINAN cases (2007-2013), the starting points were the places of infection recorded on the system and the arrival point was the city of Recife.

The data were analyzed using Epi Info version 4.6.1, Tab for Windows 32, Wine version 3.6b and Microsoft Office Excel 2010 electronic spreadsheets. Central tendency and dispersion measures were applied, as well as frequency for the profiles shown in tables. Flow charts were later built to represent the starting and arrival points of individuals with schistosomiasis.

The research project was approved by the Oswaldo Cruz Foundation (Fiocruz) Aggeu Magalhães Research Center Research Ethics Committee – Certificate of Submission for Ethical Assessment (CAAE) No. 24924613.6.0000.5190, dated 27/02/2014 – as it complied with the ethical principles contained in National Health Council Resolution No. 466, dated December 12<sup>th</sup> 2012.

## Results

297 deaths recorded between 2005 and 2013 were identified on SIM as having schistosomiasis as their underlying cause, and 388 schistosomiasis cases were reported on SINAN between 2007 and 2013, in the city of Recife. Between 2005 and 2013, on average 33 (standard deviation = 5.3) schistosomiasis deaths in Recife were recorded annually on SIM (Table 1).

Active tracing of family members of the 297 people who died led to 134 (45.1%) informants being found, four (1.3%) of whom refused to take part in the study. As such, 130 individuals were interviewed. As to the relatives of the rest of the people who died, 126 (42.4%) had incomplete addresses on SIM, 15 had moved to a different address (5.0%) and 22 (7.4%) were not found at home after three attempts.

Of the 388 schistosomiasis cases recorded on SINAN between 2007 and 2013, 365 had not died as at 2013, hence why they were not identified on SIM. When analyzing the probabilistic linkage between schistosomiasis cases reported on SINAN and deaths recorded on SIM, for the period 2007-2013, only 23 – of the 238 deaths recorded – were matched (Figure 1).

According to the data obtained through interviews with family members, the majority of schistosomiasis deaths recorded on SIM between 2005 and 2013 were female (51.5%), adults aged over 50 (89.3%), illiterate or had not completed elementary education (86.9%),

were supplied with water via the public supply network (92.3%) and disposed of faeces in cesspits or open sewers (83.1%). Family members stated that 90.0% of individuals who died had previously lived in municipalities where schistosomiasis was not endemic, had moved to Recife for family reasons and job opportunities and had lived in Recife for more than ten years: average of 22 years (Table 2).

Of the 125 death records found on SIM having the state of Pernambuco as the place of exposure and infection, 26 (20.8%) were found to have the municipality of Recife as the place of infection. The municipalities of Goiana and Palmares were places of infection which both had seven cases. With regard to the division by mesoregion within the state of Pernambuco, 50.4% of cases were infected in the *zona da mata* region, 33.6% in the metropolitan region of Recife and 20.8% in the *agreste* region (Figure 2).

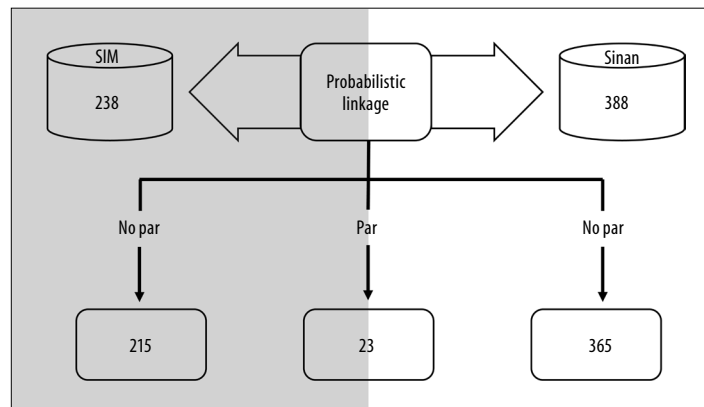
Figure 3 shows the flow chart for the 338 schistosomiasis cases recorded on SINAN. It was only possible to describe the flow of 276 cases, since 112 cases did not have the 'municipality of infection' field filled out on the information system. The flow charts recorded the internal flows, starting points and arrival points of 63 cases (23.8%) showing the municipality do Recife as the place of infection, followed by the flows of 15 cases (5.6%) from the municipality de Jaboatão dos Guararapes. In the state's mesoregions, 44.5% of flows related to the *Zona da Mata* region, 42.3% to the metropolitan region of Recife and 13.2% to the *Agreste* region (Figure 3).

**Table 1 – Number of schistosomiasis deaths and cases among residents of Recife, recorded on the mortality and notifiable diseases information systems, city of Recife, Pernambuco, 2005-2013**

Year	Information System			
	Deaths <sup>a</sup>		Cases <sup>b</sup>	
	n	%	n	%
2005	31	10.4	–	–
2006	28	9.4	–	–
2007	43	14.5	30	7.7
2008	35	11.8	41	10.6
2009	31	10.4	33	8.5
2010	39	13.1	49	12.6
2011	35	11.8	76	19.6
2012	29	9.8	72	18.6
2013	26	8.8	87	22.4
<b>Total</b>	<b>297</b>	<b>100.0</b>	<b>388</b>	<b>100.0</b>

a) Deaths recorded on the Mortality Information System (SIM).

b) Cases recorded on the Notifiable Diseases Information System (SINAN).



p-value = 0.036

\* p-value refers to the probability of a record being identified on both databases: Mortality Information System (SIM) and Notifiable Diseases Information System (SINAN). Therefore, a p-value of less than 0.05 is assumed to indicate that the number of matched records refers to the same person.

**Figure 1 – Probabilistic linkage of schistosomiasis case and death records reported on the Mortality Information System (SIM) and the Notifiable Diseases Information System (SINAN), city of Recife, Pernambuco, 2007-2013**

## Discussion

When analyzing the incidence of schistosomiasis cases recorded on SINAN in the period 2007-2013, a gradual increase in case identification was seen to occur following the implantation by the Recife City Health Department of compulsory reporting of schistosomiasis with effect from 2007. The majority of schistosomiasis deaths recorded for the city of Recife between 2007 and 2013 (238) were not reported on SINAN (215) at the time of diagnosis during the same period. This discrepancy between information systems is not in accordance with the provisions of Ministerial Ordinance SVS/MS No. 5, dated February 21<sup>st</sup> 2006, and Ministerial Ordinance GM/MS No. 104, dated January 25<sup>th</sup> 2011, which recommend that all schistosomiasis cases in non endemic areas be reported on SINAN.<sup>22,24</sup> This failure prevents the integration of information enabling investigation of deaths recorded on SIM and denotes weakness in linkage between the information systems, affecting both patient care and patient monitoring. Reporting and epidemiological investigation of schistosomiasis cases resident in the city of Recife are of fundamental importance, given that these procedures directly affect the planning of schistosomiasis control actions.

Less than a third of the individuals investigated had a health insurance plan, and even those who did have health insurance plans initially sought care in public

health services, before progressing to death. In our study we found that severe clinical forms of schistosomiasis only appear on information systems when patients die and are recorded on SIM. This indicates that in non-endemic locations health professionals have little awareness of the importance of diagnosing and reporting schistosomiasis, both in public and private health services. Studies demonstrate that correct recording of severe forms of schistosomiasis is related to the efficiency of health systems and services and also to the quality of care provided to service users.<sup>25</sup>

In this sense, SINAN is an information system the data of which should assist with analysis of the profile of disease morbidity, informing decision-making at municipal, state and federal level. Information is the tool that spurs health surveillance action, the main objective of which is to reduce deaths arising from severe forms of schistosomiasis.<sup>26</sup> In this way, timely identification and notification of schistosomiasis cases by the health network minimize the likelihood of people dying and enable surveillance activities in the municipality.

A case series study of the period 2008-2009 conducted by Silva and Domingues<sup>27</sup> in 2011 identified 159 hospitalized patients who had the severe clinical form of schistosomiasis. 60.3% of them were over 50 years old, there was higher incidence of people from Recife and its metropolitan region (20.1%), especially the municipality of Jaboatão dos Guararapes (11.9%), and 3.1% of cases

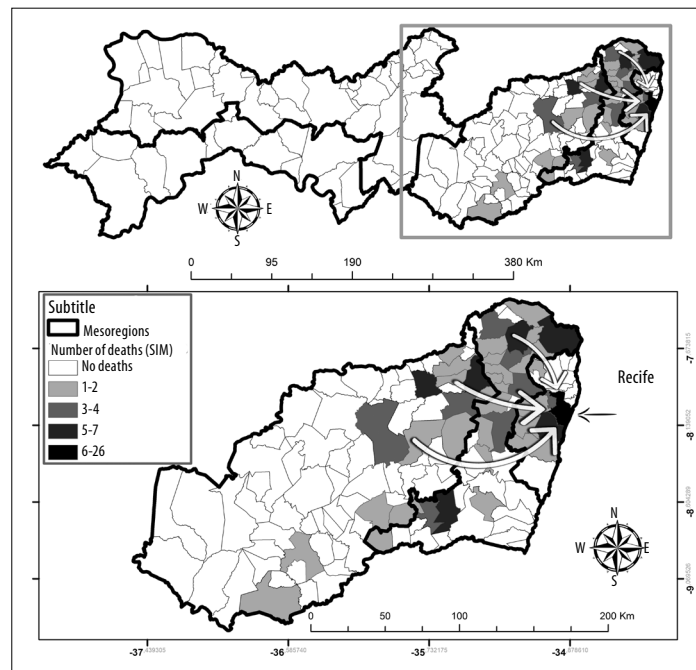
**Table 2 – Demographic and socio-economic characteristics related to schistosomiasis deaths (n=130) and sanitary conditions related to households, city of Recife, Pernambuco, 2005-2013**

Variable	N	%
<b>Sex</b>		
Female	67	51.5
Male	63	48.5
<b>Age range (in years)</b>		
<30	0	0.0
30-49	14	10.7
50-69	46	35.4
≥70	70	53.9
<b>Schooling</b>		
Illiterate	54	41.5
Elementary education	59	45.4
High school	9	6.9
Technical	5	3.8
Completed higher education	3	2.3
<b>Length of time of residence in Recife before death</b>		
≤6 months	3	2.3
>6 months to 1 year	1	0.8
>1 to 10 years	7	5.4
>10 years	117	90.0
No information	2	1.5
<b>Previous place of residence</b>		
Endemic municipality	12	9.2
Non-endemic municipality	117	90.0
No information	1	0.8
<b>Water supply</b>		
Public water supply	120	92.3
Well or spring	7	5.4
River	2	1.5
Others	1	0.8
<b>Disposal of faeces and urine</b>		
Sewerage system	21	16.1
Cesspit	75	57.7
Open sewer	33	25.4
No information	1	0.8

reported never having been exposed outside of the metropolitan region. Our study corroborates some of the findings of their study, such as incidence of severe forms of the disease in the over 50 age group, the presence of individuals with schistosomiasis in the metropolitan region and identification of possible

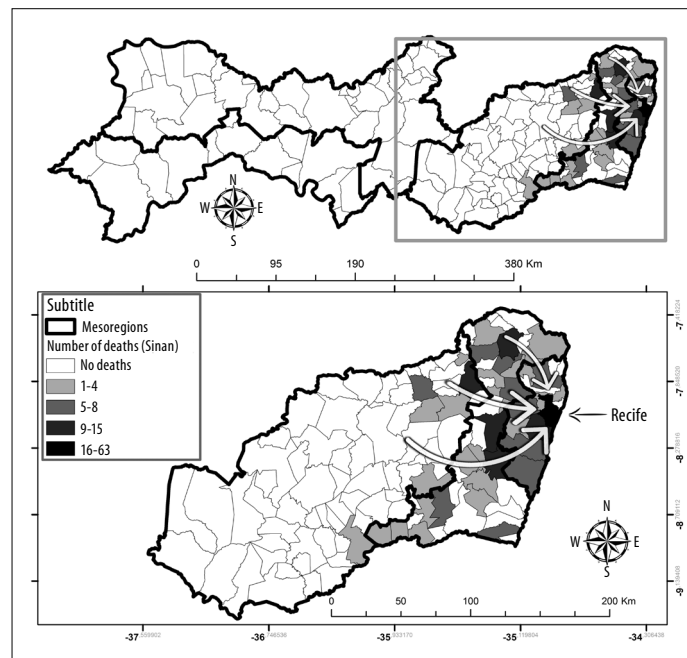
places of infection in Recife. Also with regard to age group, our results are similar to those of other studies of schistosomiasis conducted in Brazil which found people with schistosomiasis aged over 50 years old,<sup>28</sup> this being a stage of life when people are still considered to be economically active.





Source: Mortality Information System (SIM).

**Figure 2 – Flow chart for schistosomiasis deaths of people resident in the city of Recife, by frequency of Pernambuco state municipalities in which infection occurred, Pernambuco, 2005-2013**



Source: Notifiable Diseases Information System (SINAN).

**Figure 3 – Flow chart of schistosomiasis cases resident in the city of Recife, originating from endemic municipality in which infection occurred, recorded on the Notifiable Diseases Information System, Pernambuco, 2007-2013**

Noteworthy in our study are the reports by family members stating that 20.8% of the individuals who died from schistosomiasis had never travelled to endemic areas. This proportion almost coincides with the 23.8% of cases reported on SINAN whose municipality of infection was Recife. However, caution is needed when affirming case autochthony, given the possibility of informant memory bias; just one report of exposure in an endemic area would be sufficient for the case to be dismissed as an autochthonous case in our study. We investigated deaths occurring between 2005 and 2013 in 2015. There was therefore a time gap of at least two years, capable of leading to family members forgetting that the dead person had been in another municipality. Be that as it may, these findings are sentinels for health services which, in the event of a positive schistosomiasis case or death in Recife, should investigate and confirm the place of infection and develop health care and surveillance actions.

Regarding the sanitary conditions of households of people who died from schistosomiasis in Recife, 83.9% of them were found not to have a sewerage system. This data is more revealing than Instituto Trata Brasil statistics (2013), which concluded that 35.0% of the Recife area did not have sanitary sewer coverage.<sup>29</sup>

Moreover, the social and economic context of Pernambuco's rural areas induces internal migratory flows to Recife in search of jobs, bringing schistosomiasis cases with them. This is an epidemiological scenario of risk for schistosomiasis transmission in the city of Recife, considering that 12.7% of its metropolitan area has endemic schistosomiasis.<sup>30</sup>

Given that the number of matching records was low, the two information systems need to be used in an integrated manner in order to increase health system sensitivity to identification of people suffering from schistosomiasis, reduce underreporting on

SINAN and qualify causes of death on SIM. Reporting and epidemiological investigation of schistosomiasis cases living in the city of Recife are of fundamental importance, as procedures that directly affect the planning of actions to control the disease. Continuity is being provided to this study by means of environmental investigations in the areas surrounding the homes of those who died and cases identified by our study, in the quest for breeding grounds of vector molluscs and autochthonous cases of the disease in order to clarify schistosomiasis transmission in the city of Recife.

Schistosomiasis is a neglected and strongly socially determined disease. On the way to overcoming it, it is fitting to go beyond the biomedical paradigm and seek to undertake intersectoral population interventions, from a perspective of Health Promotion. Articulations capable of empowering the population to make the sociospatial environment healthier are fundamental to changing the status quo in which public health inequities are socially reproduced in Brazil.

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## Authors' contributions

Oliveira ECA, Pimentel TJE, Araujo JPM, Oliveira LCS, Fernando VCN, Loyo RM, Gomes ECS, Moreira RS and Barbosa CS took part in the study conception and design, data analysis and interpretation, writing and critically reviewing the manuscript, as well as approving the final version. All the authors state that they have no conflicts of interest in developing the study and declare their responsibility for all aspects of the work.

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