

## **ILLNESS AND DEATH BY SCHISTOSOMIASIS: PATHS AND WAYS**

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**Abstract:** The objective was to understand the care trajectories of individuals with a record of death from schistosomiasis in Recife in 2012. Analytical, retrospective study with a qualitative design. Seventeen key informants participated in the interviews. After data collection, we opted for content analysis in the thematic modality: the demand for health services from interurrences; pilgrimage in search of treatment; causes in different ways. It is noticed that the needs of the population are not respected. The lack of knowledge about the disease and the underlying cause of death is evident. Patients did not perceive the initial signs and symptoms. Diagnosis and treatment were started late, at the hospital level, after the patient's general condition worsened. The indispensability of (1) strengthening primary care for the initial diagnosis and effective treatment of schistosomiasis is evident; (2) education for health among the population and (3) guaranteeing specialized care at referral centers for disease.

**Keywords:** Public Health Policies, Health care, Schistosomiasis, Death.

## INTRODUCTION

Schistosomiasis has been on the world stage for a long time as a serious public health problem. In addition to the high rates of morbidity and mortality, it has been expanding territorially with new outbreaks of transmission and endemicity, especially in the northeast region (FARIAS et al., 2007; CARMO; BARRETO; SILVA-JÚNIOR, 2003). Despite being preventable, even though it is proven that deaths from schistosomiasis must not occur and that the subject is of great importance, the disease has been neglected in Brazil (WORLD HEALTH ORGANIZATION, 2009).

When studying the magnitude of deaths from this disease in the country, the state of Pernambuco concentrates the highest

rates (NASCIMENTO, 2013). Linked to this fact is the difficulty in ensuring access to diagnosis and treatment in a timely manner, as evidenced in studies that revealed the low level of implementation of the Schistosomiasis Control Program (PCE) in Pernambuco municipalities, as well as insufficient knowledge regarding the program, the precarious planning of control actions and the low priority given to the disease (QUININO; BARBOSA; SAMICO, 2010).

Among the mortality data from the disease in the state, despite not being considered endemic, the municipality of Recife maintains the supremacy of records and, in 2012, was responsible for an estimated percentage of 17.09% (BRASIL, 2014). This suggests the need to use methods capable of understanding the processes and contexts that make up this percentage. As well as the factors that may be involved.

Certainly, the specific treatment for the disease constitutes the main factor in the prevention of chronic complications, minimizing the aggravation to a negative prognosis (SOUZA, 2012). However, the fact that the disease is linked to poverty and less favored socioeconomic conditions affects a population with risk factors that are more associated with unfavorable outcomes.

In addition, the assistance given to individuals with schistosomiasis in health services during the illness and treatment process is a topic that has not been explored much. Based on empirical knowledge, it is clear that many cases are diagnosed when they are in a chronic or terminal phase, having often received inadequate treatment for the disease. Thus, we assume that this fact occurs because the health system is not prepared to receive people affected by schistosomiasis, leading to an unnecessary pilgrimage in the health system, causing suffering and avoidable death in the search for health care. This path

was defined in this article as care trajectory (LOPES; VIEIRA-DA-SILVA; HARTZ, 2004). From this perspective, the study aimed to: understand the care trajectories of individuals with death records from schistosomiasis in Recife in 2012.

## METHODOLOGY

The qualitative research design was adopted. By favoring the identification of interpretations closer to the contexts of individuals, when it highlights situations that would go unnoticed in statistical combinations (GROULX, 2008).

Data collection took place in two stages: 1) Selection of key informants from the death records and adequacy of the interview script: The starting point was the selection of the 27 records of deaths due to the underlying cause of schistosomiasis in residents of Recife in 2012, in the database of the Municipality's Mortality Information System. After analyzing the deaths, 16 records were identified and selected, which took place in 17 key informants according to the selection criteria, as follows: a) being in physical and mental health conditions that allow participation in the research, since it was talk about a loss, a death in the family; b) have a blood and/or affective bond with the individual who died; c) having followed the care trajectory of the individual who died, at least, in the last six months prior to death and d) agreeing to participate in the research. Such criteria were constructed after a pilot interview with a family member. One of the records had two key informants because the children shared the mother's care trajectory.

2) In-depth interview with key informants: The interview script had as an initial question: "Tell me, from the beginning, when (name of deceased individual) became ill and sought which health services". After this question, the informants talked about the care trajectory

and the interviewer only interrupted if he needed to clarify some information about the beginning of the illness, services used, needs to use the service of the private network. The interview began with the presentation of the proposal and answers about the profile of the informant.

The interviews lasted about 2 to 3 hours and were carried out in the informants' homes - keys after prior appointment by phone or visit. In addition to the use of the recorder, a field diary was used to describe the environments and the reaction during the collection of the interviews: gestures, body signs, changes in the tone of voice, that is, elements that could support the understanding of the trajectory.

Thus, 17 key informants were interviewed who had the following characteristics: 02 male and 15 female, with an average age of 49 years, all literate with an education level between incomplete elementary school and higher, income around 2 minimum wages . Only one informant did not have a blood relationship, but with strong affection and monitoring of the last two years of care trajectory, which preceded death. The others were daughters, sons, sisters and granddaughter.

Data analysis: content analysis was chosen, which makes use of the body of the text (understood as a means of expression) in a hybrid way, with a quantitative and qualitative treatment, capable of producing results for its social context in a objectified. So that the source and the context are inferential materials (BAUER, 2008). In the content analysis organization stage, the following are considered important: the floating reading and after, the in-depth reading that goes beyond the manifest meanings of the source (MINAYO, 2010; FRANCO; MERHY, 1999). This deepening is achieved when relating semantic aspects, sociological structures and the socioeconomic, cultural and psychological context (FRANCO; MERHY, 1999). Then, the

thematic analysis modality was applied, it is about identifying in the body of the text units of meaning, whose frequency or absence, have meaning and conformity with the research problems (FRANCO; MERHY, 1999). In this treatment, the following themes were identified: the demand for health services from interurrences; the pilgrimage in search of treatment and the causes of the different paths. These themes were constructed a posteriori. All key informants were presented with codenames to preserve the confidentiality and privacy of informants: Severinas (Severina 1, ...Severina 15) and Joãos (João1 and João 2), in reference to the work: “Morte e Vida Severina” by João Cabral de Melo Neto.

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## RESULTS AND DISCUSSIONS

### THE DEMAND FOR HEALTH SERVICES FROM COMPLICATIONS

*“She had a history of bleeding. Then there was one time she took a few gulps of blood, that’s when we helped her. (Daughter of Severina 1)”.*

*“We noticed that mainha was not doing very well. That was about two years before she was admitted. Then you see, started vomiting,*

*diarrhea, a lot of stomach pain. The swollen belly. Her legs felt like a bomb! [apprehensive] Now, like this, her getting thin and her belly growing. And the belly was growing. There was one day, when I arrived here, she went to the hospital with my stepfather, she was out of time, she just looked at the ceiling and didn’t answer anything. She went to the hospital (daughter of Severina 05)”.*

These speeches generally contemplate what was observed among the other interviews, when they reported as a form of initial contact with the health services, urgent and emergency care, in a situation of some interurrence. Information converged with research from the 90s, which identified the need to improve the efficiency of the recently implemented Family Health Program, when a large part of the users made the levels with greater technological density the way to solve their problems (FRANCO; MERHY, 1999). This barrier in the current decade remains a challenge, according to a recent systematic review article that analyzes the first contact from the perspective of PHC users (PAULA et al., 2016).

Despite the advances achieved with the ESF in recent decades, such as a decrease in infant mortality, a decrease in hospitalizations due to sensitive conditions and an improvement in care with the Mais Médicos Program, the strategy remains with different challenges requiring investments in professional practice, in the use of information among others (FACHINI; TOMASI; DILÉLIO, 2018). Regarding schistosomiasis, another study points out that FHS professionals do not know the disease control program, the PCE, and carry out their activities in a critical or unsatisfactory way (QUITES et al., 2016).

These data point to the need to invest in continuing education for FHS professionals both in endemic and non-endemic areas for schistosomiasis, such as in the city of Recife. In addition to being a permanent issue for the

FHS, emergency services need to be aware of this possibility, as the entry point for the user is often an intercurrent. It is known that this control involves, among other actions, the permanent detection of cases and the cure of the disease, preventing the evolution to the severe forms (BRASIL, 2008).

These actions must occur in partnership with epidemiological surveillance, with the objective of optimizing resources and preventing a solution to the continuity or spacing of work cycles, allowing greater impact at endemic levels (BRASIL, 2008). However, the focus of actions in the city of Recife and as seen elsewhere (QUITES et al., 2016), has been focusing on emergency and focal measures (BARBOSA et al., 2013), rather than the requalification of primary care and the health network in relation to the disease. In addition to investing in health education for the population so that they can understand the disease that, because it is asymptomatic, can be neglected (BARBOSA et al., 2013; MASSARA et al., 2016).

*“Then he underwent surgery [removal of the spleen] ... during this whole time he became an adult, got married and felt nothing. Then one day he started to feel some things, now after getting old, he felt his belly swell... his feet... and he felt sick, in his belly, liver and everything else... oh, yeah... he didn't care, he thought it wasn't a worm anymore, right?! There were other things, but, yeah, he took some baths in the river afterwards (Daughter of João 03)”.*

As can be seen in the above statement, this profile of use of services is possibly also associated with the chronic and long-term nature of the disease, with the acute phase going unnoticed, its signs and symptoms undervalued (MASSARA et al., 2016). This lack of knowledge occurred by the individuals themselves in their self-care and by the professionals who provided assistance, because as an example there is the report of João 02's

daughter who, despite receiving follow-up for Chagas disease, did not guarantee the diagnosis in time for schistosomiasis.

Thus, care trajectories go through a dynamic process of construction and reconstruction that vary according to the subjects' needs and how they experience experiences in solving their health problems. In such a way that, in practice, individuals are not always able to obtain assistance with primary care as a gateway.

In addition, those who live in endemic areas usually do not show the manifestations of the acute phase, and their presentation is related to ecological tourism and poor sanitation conditions (BRASIL, 2021). It is worth emphasizing that many of them, when reporting that they previously lived in other municipalities, in addition to Recife, they included endemic areas, or also reported previous contact with these areas, routinely, for leisure and work reasons, during their residence in Recife. That is, individuals in contact with the outbreaks and constant contamination are characterized, keeping the active cycle of the disease and the less noticeable acute phase.

#### The pilgrimage in search of treatment

The term “pilgrimage” has been used by maternal and child health researchers when investigating assistance to women during antepartum. They consider a “pilgrim” to be a woman who is faced with frustration and failure in seeking care (ALBUQUERQUE et al., 2011). In the present study, given the paths and misdirections of care trajectories taken by deceased individuals, we started to use it to characterize the search for health care, as shown in the following statement:

*“She [referring to the doctor] said that it was no longer her problem and that she would go to another hospital, went back to hospital W, left hospital K, she was like this, in this shuttle ... she returned to hospital W, when she arrives at his emergency, in that horrible,*

*terrible emergency... Then she wanted to throw her to hospital Z. She went to hospital Z and there, she asked; - what was? what? always there, from being in the red phase, in the yellow phase... those things in the rooms, right? And us on top. And the doctor: - Look, you're not well, you have a heart problem now. I'm going to transfer her to hospital Q. About fifteen days she passed and nothing got better (...) she stayed ten days, ten to fifteen days in the ward of hospital Q and ten more days in the ICU, she died swollen, too swollen (Severina's sister 03)".*

It can be seen in the pilgrimage reports that basic needs such as humanized care are not respected. Regulation in the health network and the use of services are not planned, as well as a line of care that allows meeting the population's demand and offering some diagnostic support services. Without the guarantee of diagnosis in primary care, individuals end up arriving at health services with different complications, some in serious condition and, as a consequence, they suffer to get adequate care for their problems and the underlying disease.

*"Then the doctor took it and sent the referral to hospital T [referring to the outpatient referral service for liver treatment] he went... I went with him and then he didn't want to go anymore, then I forced him to go again and he it was, (...) he was supposed to come back for tests, he didn't come back, he didn't want to come back. He spent two or three months, then he made an appointment, there was no vacancy, there were those strikes, all these things, then it became difficult, he became annoyed. Then he said he wouldn't go any further. It was about eight consultations and then she gave up (Daughter of João 02)".*

In turn, specialized care must exist to support family health teams in guaranteeing comprehensive care and expanding access (SANTOS et al., 2010). However, the contact with the referral outpatient service, according to the speech of João 02's daughter, occurs with difficulties. Such failures were identified from

the first appointment to the subsequent ones, with long waiting periods and scheduling between one appointment and another, impairing proper monitoring and attendance. As seen, the pilgrimage in chronic illness was present, as was observed in the care provided to people affected by acute events, such as pregnant women.

In the midst of obstacles, many users give up looking for these services. This repressed demand reveals the insufficiency of the secondary care level in offering adequate treatment to symptomatic patients, as well as hospital and surgical interventions for severe cases in a timely manner, activities recommended by the Ministry of Health (BRASIL, 2008). Characteristics also found in a study that analyzed the health regulation of Recife, with description of problems in the offer of consultations and exams for specialties such as urologist and cardiologist (ALBUQUERQUE et al., 2014). Considering the fact that Recife is a capital and the second largest medical center in Brazil, these results generate reflections on the need to invest in the regulation and management of the system, as well as the role of the private service provider that prioritizes the offer to S.U.S. (Unified Health System) only the most profitable procedures and services.

Thus, health planning is necessary that aims to overcome the place of neglected diseases, seeking to integrate new meanings into vulnerable territories (OLIVEIRA, 2018). Therefore, this planning involves measures that need to be included in a health network, where primary, secondary and tertiary care activities exist in an integrated way. Thus, care must involve the organization of services related to diagnosis, treatment, rehabilitation and health promotion, working as a means of improving access, quality, user satisfaction and efficiency within a general framework. improvement of equity and a networked

system (MENDES, 2010).

*“Nothing, no diagnosis, nothing closed. He never received anything [refers to the diagnosis of schistosomiasis], never, ever. She had several problems in the uterus and everything and we thought it was cancer of the uterus, because she was bleeding. But I knew her liver was kind of bad. (...) hospital in hospital, each one says something, but it wasn't and didn't know about any diagnosis... I know that the diagnosis, my niece has everything in a report [referring to the death certificate]( Severina's granddaughter 04)”*

This speech exemplifies and adds the fact that the diagnosis maintains a hybrid cause/consequence relationship in the pilgrimage of these cases. In many of them, the diagnosis was given only at the time of death, or, unexpectedly, with contact during the interviews in this study, which reinforced the importance of the same and the care taken in the approach of the interviewer during data collection. In others, diagnostic conflicts were responsible for unnecessary deviations and displacements.

Late or incomplete diagnosis could be avoided through clinical practice, with the use of anamnesis as a fundamental tool that leads to early diagnosis, especially in non-endemic areas. Making it possible to associate signs, symptoms and physical examination findings with information about some risk behavior for the disease (FAUCI et al., 2008).

## **THE CAUSES OF THE DIFFERENT PATHS**

The different paths observed in the care trajectory suggest the absence of a line of care for the disease. In summary, it represents the details, the design of the paths taken in the network, with the definition of where and how those affected will be treated (BRASIL, 2010). However, the literature establishes two portraits of health care networks: “fragmentation and pointlessness or integration under a systemic

view” (LAMAS et al., 2013). For the reality studied, the first option is configured, without guidelines and defaults.

This lack of organization and demand planning leads to a random flow of users, without receiving the proper guidance and answers, using the services in different ways. They make use of some strategies to guarantee health care, such as: private services, the influence of friends, services from another state and social control, which will be demonstrated below.

*“He was hospitalized there, in hospital X [private hospital]. And then they saw that he had other problems [besides the hematological problem] so they asked him to do an endoscopy. Then, in the endoscopy, they saw that he had bleeding in that vein, he had to undergo an exam, he had to undergo a treatment that the plan did not cover. Then my brother kept sending emails to Brasília and the doctors there sent them here and he stayed for six months to do the treatment, so we could do the first session. He said; -You have two more sessions to do. [referring to the doctor at hospital X]. Then nobody had time anymore” (Wife of João 01).*

The speech of João 01's wife arises as a consequence of the commodification of health, the valorization of the private to the detriment of the public. Motivated by this view and the attempt to circumvent the bureaucratization of health services in the S.U.S. (Unified Health System), a portion of individuals with better socioeconomic conditions use direct disbursement or the private network through health plans, mainly in carrying out support exams. diagnosis and care with a specialist doctor. However, private assistance is often unable to offer this guarantee of speed and quality, as observed in her speech.

This difficulty could be alleviated, if it were not for the culture that only high technological density is decisive in health care and with its use, a health model is established that works at high costs, due to the

predominance of requests for exams and focus on medicalization rather than prevention. Such aspects must be discussed on other bases for the case of neglected diseases with new ways of understanding health and the use of resources (OLIVEIRA, 2018).

*“She went to hospital Z, she went to consult. That’s because there was a doctor there that the mulé here also managed to find a place for her to be consulted. But also, it wasn’t even worth it, because she got here she said something to my mother, but I wasn’t there. Then it was a struggle, because she took it and said: - No, I’m not going to help anymore.” (Daughter of Severina 02).*

On the other hand, as observed with the daughter of Severina 02, in the face of situations of failure and frustration, new possibilities of paths appear due to the use of help from third parties. A support network is built with friends/colleagues from different professional categories (among them: security guards, stretcher workers and hospital nurses), in order to obtain care in the health services. A fragile way of guaranteeing care, since it depends on solidarity and changes with the type of relationship and ties established, generating greater or lesser possibilities.

*“She went to São Paulo to be treated there, I have a sister who lives there. My sister was the one who managed it, her husband is from the countryside and managed to talk to this doctor, (...) But it was very fast, she managed to come back from São Paulo to get this transplant. In an instant she was called” (daughter of Severina 01).*

With the principle of universality that places the possibility of service throughout the national territory without the support of territorialization and regulation strategies, through family members and third-party indications, Severina 01’s daughter was able to make use of health services and actions at the hospital level of the state of São Paulo, placing the city as the path of the care trajectory.

Fact linked to the old and persistent belief that the Southeast region has sovereignty in health care, associated with strong industrial and economic development. This “invasion” of other states and municipalities in other regions, in addition to the demand from the population itself, is significant and was negatively reported on the referencing process in studies carried out in the capital of São Paulo (VENANCIO et al., 2011).

*“She was transferred to hospital Q, when she got there, she stayed in the emergency 24 hours, to get a room, to get a chair, she stayed on the stretcher, only in the middle, like, of everyone, wanting to relieve themselves, everything, with everyone was looking, I was desperate... Then I put my mouth out, look, you can’t, my niece too, then when she went, a high-ranking girl came out, I talked to the girl, then she was a very nice girl, I’ll see if I fix it, then it did, she stayed in that room. In the room she started to get worse (...) only being in a little box, then we started to fight, fight, fight... I want to put her in a room. Then, after a lot of fighting, with the doctor, nurse, with everything, we managed to put her in the ICU, because she was feeling sick, waiting for her to die in bed” (Granddaughter of Severina 04).*

The speech of Severina 04’s granddaughter reveals that, sometimes because of the overload in hospitals, sometimes because of the negligence on the part of professionals, the scenarios of abandonment and omissions provoke feelings of suffering and revolt in individuals, who leave the inertia of silence and try to adopt other avenues of treatment. Empowered by the right to information and humanized care, they use strategies to overcome these difficulties, such as the possibility of transferring to other hospitals.

Finally, despite all this pilgrimage, a positive aspect for the individual differences in the care trajectories of the interviewees, the fact that despite all suffering, the user behaves as an active subject in front of his health process -illness.



## FINAL CONSIDERATIONS

The challenge facing the stories about the care trajectory of people who died having schistosomiasis as the underlying cause is the construction of a line of care for it. Such a line perspective refers to the need to reposition the disease in the health network, understanding the possibility of care throughout its different phases, creating a possibility of care from acute to chronic events. Guided by

comprehensive health models, based on the plurality of the population's needs. Not least, the strengthening of primary care in its role of organizing care, reinforcing the health responsibility of professionals in the Family Health Strategy. It is important to recognize that this construction requires, a priori, political will and that it gains relevance if we consider the context of schistosomiasis as a neglected disease that needs to be overcome.

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