Perceptions and Experiences of a Population at Risk of Schistosomiasis in Four Villages in Burkina Faso

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Abstract

BACKGROUND

Schistosomiasis remains a public health problem in Burkina Faso, despite decades of efforts to combat the disease. Knowing and considering the opinions of at-risk populations can help to improve the control of this disease. This study, therefore, aimed to explore the perceptions and experiences of an at-risk population in the schistosomiasis control region in four villages from Burkina Faso.

METHODOLOGY

A qualitative study was carried out in March and April 2022 in Bourzem, Pana, Vy, and Zam. In each village, four individual interviews were conducted with community leaders and four focus groups with school-age children, men, women, and patients. The data was analyzed thematically.

RESULTS

The representation of haematuria, the main symptom of the disease, has gone from being a sign of virility and fertility a few decades ago, to a cause of infertility that needs to be combated. The experiences reported have been painful, with difficulties in finding an effective treatment. Although considerable efforts have been made to control the disease, vaccination has been proposed by the population as an additional weapon.

CONCLUSION

The population is apprehensive about schistosomiasis and is open to measures that can improve their quality of life without affecting their need to use the village water point. By requesting an increase in the frequency of mass drug distribution campaigns and greater awareness-raising, this population is showing itself to be receptive to a more inclusive schistosomiasis control policy.

Keywords: *Schistosomiasis, Perceptions, Experiences, Burkina Faso*

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Introduction

Schistosomiasis is a parasitosis caused by trematodes of the genus *Schistosoma*. In some countries, such as Egypt, the morbidity of schistosomiasis has been controlled mainly by the combined efforts of the government, the international community, and local populations. In other tropical countries, such as Burkina Faso, despite efforts to control the disease, schistosomiasis persists and is a public health problem[1]. Burkina Faso is implementing a control policy which has been strengthened over the last two decades by the organisation of mass treatment campaigns with Praziquantel. These efforts have helped to lower the prevalence of the disease, but have not been enough to eradicate it[2]. Humans have been identified as the main culprits in maintaining and spreading the disease in their functional environment. The proliferation of hydro-agricultural dams and the

development of areas for vegetable growing provide conditions for the expansion of intermediate hosts and promote human-parasite contact[3]. The existing literature highlights the epidemiological, environmental, socio-demographic and economic considerations that may lead to the persistence of the disease. These studies present important results that show the extent of the problem in a region at a given time. However, a significant gap remains in the thorough exploration of anthropological aspects, which could constitute the roots of all the factors that could be associated with the persistence of the disease in a community. People's perceptions of schistosomiasis and the means of control, as well as their experience with the disease in the socio-cultural context in which they live, can considerably influence their participation in the disease eradication process. The cognitive sociological approach to the problem of the persistence of the disease shows the variations not only at the level of individuals from the same culture but also within a more heterogeneous group[4], highlighting the particularities that need to be taken into account when implementing policies to control the disease. An in-depth analysis of these aspects would help to adapt control strategies for greater community involvement. Cultural or traditional beliefs can impact perceptions of the disease[5]. The integration of health education programmes and the promotion of behavioural change, in conjunction with a preventive chemotherapy strategy, are emerging as key pillars for future schistosomiasis eradication initiatives[6,7]. It's therefore important to deepen our understanding of perceptions within the community[8], for developing effective interventions. This study aimed to explore the perceptions and experiences of an at-risk population in the control of schistosomiasis in Burkina Faso. Specifically, it was to identify the representations of schistosomiasis within the study population, document their experiences with the disease, analyse their opinion on the persistence of the disease in their community, and collect their ideas for improving the schistosomiasis control.

Methodology

Study design and population

This was a qualitative study combining focus groups and semi-structured interview techniques. Four villages in Burkina Faso were selected on a purposive basis: Bourzem, Pana, Vy, and Zam. These villages had a prevalence of schistosomiasis of more than 5%[9].

Participant recruitment

Participants screening for semi-structured interviews. Resource people within the populations of the study area were targeted. In each village, the head of the health centre, a community health worker, a school headmaster, and a religious leader were interviewed.

Participants screening for focus group. In each village, interviews were scheduled with four sub-groups of the study population: men (heads of household or their representatives), women, school-age children, and patients (past and present). For each group, ten individuals were recruited from households randomly selected. Men were selected from the first ten even-numbered households. The same process was applied to the women in the odd-numbered households. When no candidate was recruited from a household, the next household was visited, respecting parity.

For the group of patients, around ten people with or who had previously had symptoms of schistosomiasis were recruited using the snowball method.

As for the school-age children, 5 boys were selected from households with even numbers and 5 girls from those with odd numbers.

Data collection

The speeches were recorded by Dictaphones. Data was gathered using: (1) a semi-directive interview guide gathering resources on people's knowledge of the disease and their opinions on individual behaviour towards schistosomiasis and (2) a focus group discussion guide to gather information on the disease as perceived within the community, and

their practices in terms of preventive and curative measures against the disease.

Data analysis

The speeches recorded in local languages were translated and transcribed manually into Word. The different texts were coded following a thematic analysis. These codifications were compared to highlight regularities. The themes identified represented the different social constructions of the disease, the therapeutic itineraries, and the causes of the persistence of the disease in their community. Inductive and deductive analysis was used to enrich our understanding of the data collected.

Ethical considerations

Ethics approval N°2021-02-035 dated February 03, 2021, was obtained from the Burkina Faso Health Research Ethics Committee for this study. Written informed consent was obtained from adults before interviews. Children aged 12 and over also signed an informed assent form in the presence of their parent or legal guardian. In addition, anonymity was rigorously respected during data processing. All participants were free to leave the study at any time without justification.

Results

Seventeen individual interviews with school headmasters (5), community health workers (4), head nurses (4), village chiefs (2), and church leaders (2) were conducted. Sixteen focus groups were conducted, with one focus group per specific group (Men, Women, School-age children, and patients) per village.

The main themes identified were "poor interpretation of haematuria", "inappropriate recourse to care", "dissatisfaction with disease control measures" and "suggestions for more effective control".

Representation of schistosomiasis

The disease was well known in the four villages and was designated locally by the expressions "N'titibié" in Vy, "Dor ziin baalo" in Pana, “Roûd-kioussi” in Zam, and “Son so term” in Bourzem.

The appearance of blood in the urine was once seen as a sign of virility and male fertility., bringing a feeling of pride and joy. With the spread of time and awareness campaigns to control the disease, this sense of pride has gradually been transformed into anguish over the space of a few decades.

“When we were little, the end of the pee had to be red, it was so beautiful (laughter and collective murmurs). It made us real boys (...) When a little boy didn't have red pee, it was a disgrace. Today, we know it's bad”- (Focus Group men, Vy)

"In our traditions, it was even said to be a sign of virility. It means that the person will be virile and fertile. So every child had to show blood in the urine at a given time, according to the traditional view. But now with the progress we've realized that it's not related, it's just a misinterpretation" - (School leader, Zam).

The understanding of the disease was similar in the villages, but its description through its symptoms varied slightly between men and women. Men were more likely to talk about the pain when urinating, while women were more likely to talk about pelvic pain. In addition, those who had suffered from the disease also described the excessive frequency of low-volume urination. This symptom was exacerbated in hot weather.

"I don't know about women, but for us men, it really hurts when we want to pee" (Focus Group men, Zam)

For all the participants, schistosomiasis was a disease whose seriousness was linked both to the presence of blood outside the body and to the fact that the genitals were affected. The fear of infertility as a consequence was shared by several participants regardless of age.

“This is a serious illness because the person sees his own blood being drained out of his body”. (Focus Group men, Pana)

“Yes, it's a serious disease because it can make you sterile.” - (Focus Group school-age children, Bourzem)

The main cause of the disease mentioned by the participants was contact with contaminated water during bathing, farming, or household activities. However, the mechanism by which soiled water contaminates people is not known.

"The problem is that we don't even know what exactly causes this disease. We've only been told that it's something in the water. It's not a living thing like fish that you can catch, so it's difficult"- (Focus Group women, Pana)

Some representations of the disease disconnected it from its infectious cause and attributed various origins to it, such as urinating several times in the same place, sharing the same mat with a patient, prolonged exposure to the sun, sexual contact with an infected person, flies contaminating food, and inappropriate use of toilets. The participants were aware that they were in a high-risk area but thought that they were powerless to apply preventive measures and asked for a vaccine or preventive drugs.

"What we do as a job exposes us to the disease, but we have no choice other than to do it so that we can eat." (Focus Group Men, Bourzem)

While there was unanimity on the existence of an effective treatment, it was the nature of this treatment that varied. Although several participants said they trusted modern medicine for treatment, most thought that effective treatment was more likely to be found in traditional medicine.

"There are old people who can cure this disease, but we don't know the secret. But I think it's decoctions that they give you to drink. Otherwise it's treated in the traditional way."- (School leader, Zam).

" In the past, we used to have potions made from tree roots, which were available from traditional healers. But now, if you go to the health centre, doctors can find a suitable modern treatment for you."- (Community leader, Bourzem).

Experience with the disease

The participants were unanimous about the presence of the disease in their village. Several participants had already had the disease in the past. Their quest for a cure had led them to try both traditional and modern treatments. The difficulty people had in overcoming the disease led them to resort to both types of treatment, a behaviour that continues to this day.

"Yes, schistosomiasis is present in this village, but people are ashamed to talk about it. People who work in the rice fields and also school-age children, when they urinate there's blood in the urine."- (Healthcare worker, Bourzem).

"…if I get this disease, I would go for traditional medicines first before going to the dispensary if the potions didn't cure me"- (Focus Group Women, Vy).

None of those who had symptoms could identify the circumstances in which the disease was contracted. However, they mainly suspected contact with contaminated water during their daily activities. The symptoms presented by these people were similar in all four villages: haematuria, oliguria, urinary pain, and abdominal pain. For all of them, the heat was identified as a factor that intensified the symptoms.

School headmasters worked to raise awareness among their students about ways of avoiding the disease, in the hope that they would pass on the message to their parents. Religious leaders were responsible for conveying the information provided by the Community Health Worker. The mass treatment campaigns were well-known and positively appreciated by participants. However, several concerns and complaints emerged from their discussions, in particular the fact that part of the population was being cut off, as well as the side effects of Praziquantel.

"…these campaigns are good, but they don't cover everyone (...) we're asking the government to organize frequent mass treatment campaigns that will cover the whole village of Zam as well as neighbouring villages."- (Village chief, Zam)

"I once took this medicine and it shook me up so much that I didn't bathe that day before going to bed. (Laughs…)" - (Focus Group men, Pana)

Opinion on the persistence of the disease

Several participants thought that it was impossible to completely cure the disease. In their opinion, after treatment, the symptoms disappeared but returned for some time. They also felt that a lack of hygiene among people

and the type of activity they engaged in kept the chain of transmission going. The lack of latrines led people to relieve themselves in the bush, resulting in contamination of water points used daily in their activities. In addition, poverty, low levels of schooling, and the lack of sanitation infrastructure were also raised.

"You fall ill you get better after taking the medicine at the health centre. But you go back to the fields and the water, and there you pick up the illness where you left off"- (Focus Group Women, Vy*).*

"People live in precarious conditions, there's no hygiene, many didn't go to school. When people have been to school, they're easier to raise awareness than when they haven't. They also work the land to get food, so they're in contact with the environment, they come into contact with dirty water." - (Healthcare worker, Bourzem)

Other factors were mentioned as leading to the persistence of the disease at both individual and community levels: concealing the disease and refusing to take Praziquantel during campaigns. The latter was justified by the side effects associated with taking the drug.

"*The problem is that patients don't declare themselves. Someone may have it, but because he's ashamed, he won't talk about it with those around him so that he can be treated, and he ends up infecting those around him*" - (Focus Group Men, Bourzem).

Suggestions for improving schistosomiasis control

While the school-age children suggested hygiene and dietary measures, the adults insisted on raising awareness and reinforcing sanitation and vaccination.

"...to avoid it, you have to keep your hands clean at all times, you mustn't enter or bathe in dirty water; you have to use latrines to relieve yourself and avoid drinking dirty water too" - (Focus Group school-age children, Vy)

"For the control to be effective, we need boreholes in our village, we need awareness, we need a vaccine against this disease. Some people don't like medicines, so the vaccine might be better accepted here." - (Health care worker, Pana).

Screening campaigns and mass distribution of Praziquantel were also in demand, with the entire population being targeted more frequently. Some participants, while acknowledging the usefulness of treatment campaigns, also recognized their limitations in terms of eliminating the disease. Vaccination was also requested in all the villages. It was presented as a solution that would be better accepted than chemoprevention.

"*We need to extend the treatment campaign to the whole village. I think we need to come and vaccinate people, otherwise, we can't do anything; we work under the sun and we don't have enough money to drink mineral water every day*." (Focus Group Men, Zam)

Discussion

Schistosomiasis is a parasitic disease that can develop acutely or chronically10. Urinary and intestinal forms are present in Burkina Faso [11,12] and the diagnosis is made by detecting parasite eggs in urine or stool, or by looking for egg antigens using rapid tests13. The urinary form is well-known to the population. However, people's perceptions of the disease have changed over time, ranging from a lack of knowledge of the disease to an awareness of its seriousness. The disease was described in terms of its symptoms, and the main symptom was haematuria.

Schistosomiasis control in Burkina Faso took a decisive step forward at the WHO General Health Assembly in 2001[14] during which the control strategy based on screening and Praziquantel-based treatment was adopted. This strategy has helped to significantly reduce the morbidity of this disease[15.] The mass treatment campaigns are positively appreciated by the population. However, they deplore that some groups are not being considered, as they are equally affected by the disease. The population targeted by this strategy was mainly school-age children leaving out a section of the population who were also affected by the disease.[16] WHO has revised its guidelines including some population groups that were not considered in campaigns before[1,17].

Several participants had already had the disease. Their quest for a cure had taken them to both traditional healers and health centres. The presence of symptoms of the disease leads patients to seek care. According to Kroeger, there are three types of factors that motivate people to seek care: predisposing factors, the perception of the disease through its symptoms and perceived seriousness, and finally the accessibility and acceptability of care and communication between the carer and the patient, the quality of care and the cost of medicines.[18]

While modern medicine concludes that a disease exists following a positive diagnosis, in this study area, the disease was identified simply through the presence of blood in the urine. This observation was also made in Côte d'Ivoire[19]. Haematuria is a major symptom directly linked to urinary bilharziasis, in contrast to the symptoms of intestinal bilharziasis, which appear to be more discreet and may be confused with other illnesses such as dysentery. However, it should be pointed out that not all haematuria is necessarily linked to bilharzia.

In the past, the presence of blood in urine was perceived as a sign of virility and fertility for males, perhaps by analogy with menstruation in the opposite sex. This misperception of haematuria was reported in northern Cameroon over fifty years ago20. The authors also mentioned that haematuria in young girls was mistaken for their first menstrual period wrongly leading them to change their social status.

The participants mentioned almost nothing about the complications of the disease. This does not necessarily mean that they were unaware of its manifestations, but rather that they did not attribute it to bilharziasis. This lack of awareness of complications was also noted by Brou among school-age children in Côte d'Ivoire19.

Three main causes emerged: individual behaviour encouraging the spread of the disease, socio-economic activities of the population, and the lack of hygiene and sanitation infrastructures.

At the individual level, this resulted in the recurrence of symptoms after treatment, and at the community level, it maintained the transmission chain of the disease. Regarding the recurrence of symptoms, Praziquantel isn't effective on larval forms[24], so there was a possibility of reinfection following treatment. Fear of stigmatization due to the nature of the symptoms could lead some patients not to seek treatment promptly, thus maintaining the chain of transmission.

As the study population was mainly rural, the main activities were farming and fishing. Participants were all aware of the role of water in the onset of their illness but admitted that they were powerless to do anything about it because they couldn't live without using the village's pond. Lack of hygiene and sanitation was identified as an important factor in the persistence of the disease. In the villages, people were accustomed to relieving themselves in nature and/or at the village watering hole. Children also bathed almost daily in these potentially contaminated water sources. Since getting people to change their activities is difficult, they are constantly exposed to the disease.

Mass treatment campaigns have long focused on school-age children, neglecting other groups16. Pre-school-age children, adults, and the elderly actively contribute to maintaining the chain of transmission of the disease within their community. Although the new WHO measures include preschool-age children and women, it would be judicious to include the entire population with a formulation of galenic forms that increase patient compliance.[16,21] It would be also appropriate not only to seek ways of limiting people's contact with contaminated water but also to sanitize water points. Eliminating larvae from water points would be effective in interrupting the transmission chain. As suggested by Viadis, these strategies would include awareness campaigns, the installation of boreholes, the treatment of patients, and vaccination [22.]

Limits and strengths of this study

The data was collected from a small sample of villages and people. Although the results highlight specific areas for improvement in disease control, they do not allow conclusions to be drawn for the general population. Also, interviewing community leaders, although providing important information about their community, could lead them to want to show a positive side because of their social standing (Hawthorne effect) 23.

The speeches were for the most part collected in local languages and transcribed into French; the loss or deviation/reduction of the meaning of expressions may have affected the interpretation somewhat. To limit this bias, the interviewers and transcribers were nationals of the said villages and had some knowledge of the disease studied. The openness of the questions allowed participants to express their feelings with a minimum of subjective guidance from the interviewers.

Conclusion

This study aimed to understand how at-risk populations perceive schistosomiasis and document their experience of the disease. The disease was well known to the study population and the social construct around it had evolved. Several participants had personal experience of the disease and had used both modern and traditional treatments. According to the participants, strengthening the resources already deployed, such as screening and mass treatment with Praziquantel, sanitation, molluscs control, and awareness-raising, is the winning combination in schistosomiasis control in Burkina Faso. Considering the opinions of at-risk populations in the design and implementation of strategies could increase the chances of eliminating this disease as a public health problem.

Recommendations

The findings of this study highlighted the need to raise awareness of the disease and the control methods available. The communities don't have a good understanding of the disease. For this reason, information and awareness campaigns must be undertaken frequently for at-risk populations, using the appropriate communication channels for each community. In the study area, traditional medicine plays an important role in the process of seeking care for symptoms attributed to bilharzia. The development of ethno-medical evidence and the raising of awareness among traditional practitioners will provide a suitable framework for the practice of this medicine. The gap created by the systematic failure to include non-school-going populations in treatment campaigns should also be reviewed and corrected to reduce the reservoirs of the parasite within the population. As the WHO has revised its policy to make it more inclusive, it is imperative that the new guidelines are properly implemented in the field. In addition, it will be wise to increase the frequency of mass treatment campaigns to reach as many people at risk as possible. Moreover, Praziquantel is not always accessible to the population, and the continuous availability of this medicine in the Essential Generic Medicines (EGM) depots of health centres would facilitate the treatment of cases received there.

The active involvement of community leaders is important in the control of the disease. They can be trained and use their authority and influence to spread awareness messages within their community. Also, good management of the health infrastructure in their community helps to ensure a healthier lifestyle for the population.

The people of Vy, Pana, Bourzem, Zam, and all other localities in Burkina Faso must be made aware that schistosomiasis is a chronic disease that can lead to serious complications. In case of any suspicious symptoms, they must be sensitized to reach out to the health centres for treatment. Most notably is that his disease can be prevented by simply applying basic rules of hygiene. With a little organization and determination, latrines can be built and used thus avoiding soiling the water points that are essential for daily activities.

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