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**Beth Maina Ahlberg, Rose Mwangi, Gabriel Poggensee, Hermann Feldmeier, and Ingela Krantz**

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## Abstract

*This paper is about how a community in Northern Tanzania experiences and reasons around urinary schistosomiasis and more specifically female genital schistosomiasis or schistosomiasis of the reproductive tract. As a disease, female genital schistosomiasis presents itself with a variety of symptoms which neither the affected woman nor the medical professionals usually recognise as schistosomiasis. The study therefore focused on symptom recognition, the question being whether women living in an endemic area can distinguish symptoms of urinary and genital schistosomiasis from those of other diseases presenting in similar ways. Data were generated using a combination of qualitative methods including observation, individual interviews and focus group discussions with diverse categories of people. All the research participants were aware of the link between water and infection. Because the disease is associated with farming, the main livelihood, there was a strong feeling among the research participants that treatment, whether in hospital or by traditional medicine could not effect permanent cure. Re-infection was considered inevitable and as schistosomiasis was said to be less poisonous than malaria, it was felt there was little choice between being infected and having food. Making sense of the symptoms was considered moreover difficult although women and men said they could tell whether blood in urine was due to urinary schistosomiasis or other conditions such as sexually transmitted diseases which present similar symptoms. The similarity of symptoms was said to be problematic also because of the sensitivity and stigma in sexually transmitted diseases. Urinary schistosomiasis is therefore a complex health problem and for any effective control there is clearly a need to grasp this complexity.*

## Introduction and conceptual background

This study, a part of an interdisciplinary research project assessing prevalence, morbidity and disease manifestation of female genital schistosomiasis (FGS), focused on illness perceptions, knowledge and beliefs about the disease, its perceived cause and the health care options available and used. It also focused on symptom recognition and specifically whether women living in an endemic area can distinguish symptoms of schistosomiasis from those of other diseases presenting in similar ways.

Female genital schistosomiasis can present itself with a variety of symptoms including painful and heavy menses, inter-menstrual and post-coital bleeding, discharge, lower abdominal pain and pain during sexual intercourse. However, none of these symptoms are specific for genital schistosimiasis and neither the affected woman nor the medical professionals usually recognise them as schistosomiasis. Furthermore, the consequences of FGS may be infertility, ectopic pregnancy and miscarriage (Feldmeier et al 1995). Thus, besides the troublesome symptoms and sequelae, the physical and mental well-being of the diseased woman may be seriously affected by stigmatisation due to infertility or FGS mistaken as sexually transmitted disease (STD). Women may for these reasons be reluctant to seek medical care or participate in control programmes, which request urine or stool specimens to be examined.

Female genital schistosomiasis or disease in general and the associated symptoms are thus socially defined and this paper is informed by the conceptual framework that sees disease as a social construction and context bound. According to this conceptualisation, illness may be located in the body. However, it involves all the patterns of social life – the interlocking social roles, power and conflict, social statuses, networks of family and friends, bureaucracies and organisations, aspects of work and occupations, social control, ideas of moral worth, social norms, definitions of reality and the production of knowledge (Brown 1995). Moreover, as McEllroy and Jezewski (2000) argue, how people define and perceive symptoms, how they experience illness is inextricably intertwined with the self and others across time. This is to say that illness is not only a self-experience. It is a social and community experience with contextual factors such as gender, environmental, economic and political constraints impinging on health and illness as well as availability and provision of health services (Frohlich et al 2001, Hahn 1995, Lane and Cibula 2000, Lorber 1998). Illness may be experienced and presented differently by women and men, not to mention that they may be exposed to the risk of infection differently because of their gender roles, position and expectations (Cameron and Bernardes 1998, Lorber 1997). This is the human context of disease or the world of the 'infected' (Agar 1996, van der Geest 1995, Lorber 1997, Flick 1998). Given this, interventions - whether diagnosis and treatment, or prevention at individual or societal level - cannot depend just on the laboratory tests or knowledge of the single disease agent. Rather, it should depend also on interpreting meanings and subjective worlds of the affected people, of the local practices in which are embedded both risks and preventive measures, and indeed of variables or notions of what counts as a disease (Agar 1996). Similarly, this has consequences for knowledge creation. This is to say for example, that interdisciplinary collaboration is not a matter of choice. Rather, as van der Geest (1995) argues, the approaches of social science and bio-medicine, divergent as they may be, are required. Moreover the potential for collaboration lies in their divergence.

As a disease, FGS has a number of critical elements. Firstly, although schistosomiasis is endemic, FGS was only recently professionally acknowledged. Secondly, its manifestation and symptoms may, as already pointed out, be confused with the morally charged STDs, making interventions, whether diagnosis or treatment, challenging. Thirdly, it is intertwined with the basic form of livelihood - farming - in an area where there are few other alternatives and where therefore the traditional health education based on professional knowledge alone make little sense. This study was about understanding the social context of FGS, the assumption being that only when these social contexts are taken into account can interventions including policy make sense to those for whom it is meant (Hahn 1999).

## The research process and methods

This study combined focus group discussions, individual interviews, and observation as data collection methods in part to capture general opinions and ideas about the various aspects of the disease, the individual experiences of the disease, and the contexts within which the disease occurs (Barbour and Kitzinger 1999, Kvale 1996). Data were collected from women, men, teachers and healers. We thus used method and research participant triangulation, not really to converge on one point. Rather it was to deepen our understanding by uncovering the layers of meaning, the different perspectives of the problem, and the ways different stakeholders reason about the disease (Seal 1999, Oakley 2000).

The study was carried out in two villages, situated in the Masai Plains at the slopes of the Northern Pare Mountains in Mwanga District, Kilimanjaro Region. Since 1995, or prior to the current study, studies on prevalence, morbidity, sanitation status and knowledge about schistosomiasis had been carried out (Poggensee et al 1999, 2000).[1] In addition, interventions in the form of screening and treatment of school children and women, water and sanitation improvement and health education were undertaken. A village committee for water and sanitation improvement had also been formed.[2]

Acceptance or refusal to be tested and examined gynaecologically during the previous studies were used as criteria for recruiting women into this study. The men were also recruited using the same criteria i.e. whether their wives had accepted or refused to be tested and examined gynaecologically. Traditional healers and traditional birth attendants (TBAs), initially selected with the help of a staff member at the village health centre, were also interviewed and were then asked to identify other healers known to them, a form of snowball selection (Hornby and Symon 1994, Marshall and Rossman 1999).

Individual interviews were conducted with ten women who had been treated for urinary schistosomiasis, five traditional healers and four TBAs. Five focus group discussions with participants numbering from 4-12 were conducted. These included teachers in one of the two schools [3] in the area (4), health centre staff (8), men whose wives were examined and treated for FGS (11), men whose wives had not been examined (12) and women who had refused to be examined or treated (4). A total of 58 individuals were interviewed individually or in groups in 20 sessions. Individual interviews with TBAs, traditional healers and women were conducted at home while focus group discussions took place at the health centre. It was easy to reach the participants since people in the area live closely together in villages. Moreover, the field guide, a staff member of the village health centre turned out to be a real 'village encyclopaedia'. When people were not at home she could guide us to their farms as she knew where each household had their fields.[4] During home and farm visits, observations were made regarding the latrine availability,[5] the state and use of the water pumps provided through the project and the situation in the rice fields.

Data analysis has been a continuous process and was, according to principles of qualitative research, started already during the fieldwork (Denzin and Lincoln 2000). At the end of each field day, the three field assistants, the first author (BMA) and the field guide had a discussion to reflect on the issues observed and those being generated unexpectedly. Where found necessary, such issues were included in subsequent interviews and observations.

Two such issues warrant some attention because they help clarify ideas about cosmology and the local belief systems, the socio-cultural and economic contexts relevant for FGS as well as the way women and men communicate, particularly when a disease condition is considered sensitive or shameful. The first is the term *kibishi,* referring generally to STDs. The interest in investigating *kibishi* arose because whenever the term was mentioned, it caused laughter or giggling, especially among the men. We thus included it in subsequent interviews to find out its meaning. Secondly, women had refused to be examined gynaecologically for fear not only of being tested for STDs including AIDS, or having their reproductive capacities terminated, but also because their husbands had prohibited them from being screened. The role of men in FGS screening and treatment within the project was therefore discussed in men's groups.

The audio-taped interviews and FGDs were transcribed by a person well versed in Swahili and translated from Swahili to English by the second author (RM). The transcripts were read and re-read by BMA, at the same time listening to the original tapes. Text segments containing relevant meaning units were then identified in the transcripts. The segments and units identified were manually marked, coded and then sorted by comparing and collapsing them to form the four themes presented here.

## The empirical data on perceptions and reasoning around urinary schistosomiasis

This section presents the views of women and men concerning urinary and female genital schistosomiasis, how they make sense of the symptoms, their beliefs about the disease, their health seeking behaviours, and their reasoning about infection in women and girls.

### *Views about infection in women*

All the participants in individual interviews and focus group discussions indicated that women and men suffer but that women had different patterns of contact with infected water. As the plots under rice cultivation per family are small, men tend to perform other activities away from the water for the survival of the family. More importantly, however, were descriptions of the time in the day when women and men performed farming activities likely to bring them into contact with infected water. Women's household chores including preparing breakfast for the husband and the rest of the family, sending the children to school and doing other necessary tasks in the home, which were said to delay women in getting to the farm. They arrive late morning when according to the research participants, the risk of infection is highest. A male focus group participant said:

> Because women perform many other household chores, they arrive at the farms from around ten o'clock, the time when according to the professionals the cercariae (infective larvae) start moving.

Another participant in the same group implied that women did not plan or use their time properly. As a result they get to the farm when it is most dangerous:

> …I must be in the shamba (farm) at nine o'clock. My wife goes round and round. She gets to the shamba at 12 o'clock, the time when all the germs are awake.

### *Knowledge of causation and prevention challenges*

The cause of schistosomiasis was common knowledge among those interviewed. The link with water was mentioned, and after probing, the cycle of infection, the snail, the urine, the latrines and water contact were all mentioned. In some cases however a proper connection was not made. A participant in a focus group discussion, for example, said:

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There was the feeling that since schistosomiasis was so much intertwined with farming, the main source of livelihood in the area, there was little people could do to avoid infection and re-infection unless the water was treated:

> ….it is true we have been treated, but given the way of life in this village where we live, we are farmers you know and we depend and work in water. Our survival depends on water. Now you can give me medicines and I take them as instructed. It is true I start feeling well. But then, because my livelihood comes from that water, I have to use that same water. At home I use boiled water just as the doctors have said 'boil the water, filter the water, drink that water'. But even so, slowly, slowly, I start having the symptoms of schistosomiasis. I pray to you professionals to help us because even if we are given medicine, I don't know what we shall do to avoid schistosomiasis.

Men in the same group described a neighbouring village where pieces of land under rice cultivation were larger. But, unlike the study villages where rice, maize and beans are produced twice a year, production in the neighbouring village was said to be once a year. Although the farms are larger, the people in that village were said to suffer from famines. In the opinion of the men in the focus group discussion, the production twice per year increases their exposure to the infected water. In spite of this, they stressed it is better to be infected than suffer starvation. One participant said amid agreement from other group participants:

> …*wacha niugue lakini nishibe* (let me be infected but have enough to eat).

In spite of the knowledge about infection cycle, those interviewed considered preventive measures that would interfere with food production not feasible. Neither was construction of latrines in the fields seen as a feasible solution because of the soggy nature of the soil:

> …the piece of land is soaked with water. So you ask yourself, 'how can I dig a hole? How can I build a latrine when it is water all over?' What do you think? Can't you (professionals) find other ways for this problem than digging latrines…?

Similar sentiments had been echoed earlier during health education sessions in the previous studies. During one session a participant made the following comment concerning the difficulties in building and using latrines:

> Of course people should be ashamed and everybody should use a latrine at home, but in the farm there is water everywhere. Shall we dig latrine in the water? If we have to go to Mulaki (about 5 kilometers away) every time we feel like helping ourselves, then we won't have any work done. Mulaki is the only place fit to dig a hole.

### ***Health seeking behaviour***

All those interviewed had a great deal of knowledge about the disease, indicating furthermore that the disease had been there long before the project. One traditional healer said:

> … the disease is very common in our village. It seems this is the place it originated. Doctors come and give us services to help us but the disease is never eradicated… because of water.

Schistosomiasis was compared to malaria in terms of occurrence. It was however stressed that the two diseases differ in the way they present themselves, malaria being very poisonous, attacking suddenly and killing fast. One healer said:

> Malaria and schistosomiasis are the same. But malaria comes suddenly and strongly and you can die. If not well treated, it goes to the brain, spinal chord and finally you die…for schistosomiasis, you may be treated two, five, six times and you get better. But malaria is very poisonous.

There were mixed responses regarding treatment. However, it became apparent that schistosomiasis is not one of those diseases for which the traditional healer is the first line of care. This is not to say that traditional medicine is not used. In the discussions about treatment options, herbs were said to exist, but that they are not widely used. Women in a group discussion said:

> We can say that herbs exist even today because when you go to the market or town, you find those healers of schistosomiasis…but because you do not even trust them, you never know whether it’s true because it’s just business.

Another female group participant added:

> My father was a traditional healer and he showed me a herb which he said was treatment for schistosomiasis, but I have never used it….So even before modern treatment came, there was cure for schistosomiasis….Yes there was medicine even in those days.

Although such medicines were said to exist, schistosomiasis was viewed as a disease that would always be around as long as the farming and the dam water remained untreated. A traditional healer said in an interview:

> We use traditional medicine, but this is not as effective as treating a dam. If the schistosomiasis worms are killed then it could be much better. Even if we are treated with local medicine or with western medicine, but still the source of water is not treated… schistosomiasis will never be eradicated.

Traditional medicine was described as useful in relieving pain rather than effecting a cure. While hospital medicine was said to be effective, it was also described as less accessible for most people due to poverty or because the dispensary has no medicines. The people interviewed were also aware that even after treatment, re-infection is likely as long as they continue working in the same infected water.

They furthermore explained that the evil spirits, said by a traditional healer to be the cause of the disease, were responsible for the well or bore-hole being dirty. Most open wells and bore-holes are filled with dirty water when it rains. The protected wells including the pumps installed through the project were said to be safe.[6]

There are however disease conditions for which traditional medicine was said to be more effective. *Kibishi,* the general term for STDs mentioned earlier, was described as a condition for which traditional medicine is effective. The type of treatment given depends nevertheless on what is believed to be the cause. If the symptoms present as pain when urinating, it is believed to be caused by too much heat which may result from working long hours in the hot sun. For this condition, the treatment described involved making the patient urinate until a dark worm passes out. Men in focus group discussions and traditional healers interviewed were especially conversant with this condition and its treatment.[7] The second type was said to be gonorrhoea where the patient seemed to have pus in urine. According to one healer, treatment depends on the symptoms presented:

> I treat according to the way he or she presents the condition to me… pus in urine, then I know it is gonorrhoea… pain when urinating, then I know it is due to the long stay in the sun… Even for that condition I have treatment.

Cancers are also believed to be more responsive to traditional medicine. It was said that people with cancer should avoid operations, a treatment option believed to make the cancer spread all over the body. According to the health centre staff, some women had refused the project screening and treatment for fear of being diagnosed as having cancer.[8]

*Kilawalawa* or infection of genitals in children was another widely discussed condition. The symptoms were said to be a rash around the genital area causing scratching for which clitoridectomy was believed to be the appropriate treatment. Interestingly, hospital treatment was said to be the care option sought for clitoridectomy. One traditional healer had this to say when asked about *kilawalawa*:

> It was traditionally treated but as people are now getting knowledge of going to the hospital, then they do take their children to the hospital for treatment…Kilawalawa is something that is inside…it is within the body.

A TBA reasoned about *Kilawalawa* in the following way during an interview:

> When she falls sick, and you circumcise, you will not have made a mistake. This is taken to hospital and I have not seen anyone do it at home. When the child falls sick, she is taken to hospital and when she is examined she is found with infection.[9]

### *Making sense of urinary schistosomiasis symptoms*

Given the importance of symptom recognition in disease management, our question was whether women, especially in this highly endemic area, could identify schistosomiasis symptoms. This was described as difficult and seemed easier for men than it was for women. The men, including traditional healers, all who were men, said that if blood trickled after urinating, this was schistosomiasis. Women also indicated that the consistency and flow of the blood and sensation from schistosomiasis and menstruation are different:

> The schistosomiasis blood is usually in drops and whenever you pass them out, there is burning sensation unlike in menstruation where the blood is thick and when it flows out it does not burn.

A major reason for the difficulty in distinguishing the symptoms of schistosomiasis from those of STDs was however said to be the stigma surrounding the latter. During a focus group discussion women described the secrecy and implication for disease diagnosis in the following way:

> There are other diseases like syphilis and gonorrhoea, but such diseases are never mentioned. So when a person goes for treatment, she will never say where she is suffering from.

The silence and lack of communication between spouses was said to constitute another problem and made it difficult to identify symptoms openly, as indicated by a woman group participant:

> It's very difficult to tell because when your partner discovers that he has the disease, he goes for treatment and thereafter turns against you and accuses you of being unfaithful.

Many women were said to have refused to undergo the gynaecological screening according to the project protocol because of the stigma and the fear of being tested for STDs, especially AIDS. Others were said to have refused the tests and treatment for fear of having their reproductive capacities terminated. There were rumours that uteruses were being removed. While the fear of being tested for STDs or having reproductive capacities terminated were mentioned as reasons for not accepting the screening and treatment offered by the project, another and interesting reason was mentioned. In the focus group with women who had refused to be treated although their tests were showing signs of schistosomiasis infection, one woman said she refused because she did not have any symptoms, nor did she feel unwell. She said she had just been told she had the disease, although she herself did not experience it. This reaction is similar to what was said by a man in a focus group discussion:

> …I remember having schistosomiasis when I was a little child of school age. I had, I had so much pain! I needed to hold on to some support when urinating. One thing that surprises me these days is that recently we were screened and found to have the disease. Now my dear professionals, I want you to help me here. How is that in those days, I experienced such pain and these days I don't even know that I have the disease, though I am told and I know that I have it….It seems that the schistosomiasis of these days is a different type, or is it still the very old one?

## Discussion and conclusions

This paper is based on qualitative data and a limited sample of research participants, a common approach in qualitative research. As such we cannot claim to represent the broader picture of people's perceptions to urinary schistosomiasis and the health care behaviours. Qualitative methods are nonetheless suited for a problem such as the current one, where little is known, not to mention the sensitivity and stigma mentioned above. Moreover, qualitative methods are flexible and as is evidently clear from this research, they enhance reflection, while method and research participant triangulation helped generate different aspects or dimensions of the research problem. In spite of this, we faced some problems and although they were not unique to this study, discussing them here is appropriate.

In spite of the flexibility of qualitative methods, capacities for such research may be limited also due to professional training. In this research, we worked with public health nurses whose main training and practice is health education. During fieldwork a great deal of effort was made to restrain the public health nurses who conducted the focus group discussions from diverting the discussion sessions into health education lectures. One way we dealt with the problem was to continuously stress that people in the village had knowledge equal or more important than professional knowledge. We did so even at the risk of contradicting a group that had presented itself as a team concerned with and knowledgeable about health. In addition, our emphasis on local knowledge could have been construed as a refusal to offer them what they expected and are used to getting from educated health professionals.[10] These expectations were explicitly expressed by the research participants in this study in ways similar to those reported by Yelland and Gifford (1995).

Schistosomiasis is a disease that is preventable and treatable. However, the context within which control would have to take place in the area studied is complex. Being a disease associated with farming, or what Hughes and Hunter (1970) once called a disease of development, the introduction of irrigation schemes may be carried out without much consideration for the human costs, which makes prevention all the more of a challenge. Contact with water is central in farming, and in domestic chores such as washing clothes and fetching drinking water, while children swim in the schistosomiasis-infested river. In addition, the small plots of land where rice is grown are perceived to be unsuitable and too far from land suitable for latrine construction. Only two thirds of the households were observed to have latrines (Poggensee 2000). The right medicines too are frequently unavailable, the treatment of water is difficult, in a situation where the snail or the intermediate host has a favourable habitat in the irrigation canals. The risk of infection and re-infection high is thus high.

The way schistosomiasis was described and compared to malaria, the way people reasoned around their actions and the care they seek suggest that schistosomiasis is not categorised under the 'illnesses of man' or those diseases believed to be caused by evil eye or witchcraft (Feierman 1985, Appiah-Kubi 1981, Onuaha 1981). The attempt by one healer to associate schistosomiasis with *majini* (evil spirits) did not stand the test. This is not to say that culturally rooted ideas about the disease were not observed. The belief that pain when urinating is caused by the heat of the sun can be said to be part of the cultural ideas about disease causation, a rationality that seem to reflect the conditions under which women and men work in the fields. However, while culture constitutes the means by which people and groups evaluate and make sense of the world, we view it in its dynamic form where actors therein shape and reshape their ways of seeing as they interact with each other fusing existing ideas, discourses and practices. While the characteristics of FGS, its endemic nature, slow progression and link to livelihood may have been used to make sense of the disease, symptom presentation is problematic, not only because they are not specific, but more significantly because they can be confused with STDs which are highly stigmatised. A number of questions could be asked. Is this a cultural definition or is it an interpretation of disease in contexts where cultural boundaries are increasingly blurred? Is it a disease recently introduced with developments in irrigation for rice production from which few can escape due to poverty?[11] Is it a combination of these and the developments in biomedicine and public health and its introduction in the area? The biomedical discovery of the causal link between disease agents, behaviour or lifestyle and ill-health has transformed disease from an ever-present danger into a risk related to lifestyle and therefore an individual's choice. The responsibility for disease prevention and health promotion is ultimately shifted to the individual. It is then assumed that increased knowledge about the causal links would enable individuals make rational decisions to avoid the risks. Public health education is based on this assumption (Caplan 2000, Tierney 1999, Flick 1998, Bunton et al 1995) and health educators are trained to get the message of individual responsibility in disease causation and prevention.

There seems however to be a paradox: while individual responsibility is emphasised, health education rarely takes account of the dynamics in the social life of the people which is what matters in their actions and interpretation of incoming information. On the contrary the current form of health education leaves the people highly aware of the transmission routes as well as the preventive actions they can take, a knowledge that leaves them more dependent on the professionals, but makes less sense to their lives. This is a point that the participants in this study seemed to be making, a phenomenon common in other interventions such as AIDS control (Poppen and Reisen 1997).

Control of urinary and female genital schistosomiasis is complex due to a number of its characteriatics and the context within which it occurs. Because of the similarity with STD symptoms, schistosomiasis has entered the realms of shame and stigma, complicating not only symptom recognition, but also actions taken for prevention as well as seeking care. Moreover, apart from being shameful, symptoms such as blood in urine may have different meanings for boys and for girls. In studies in Nigeria, Amazigou (1994) observed that for the boys it is viewed as a sign of adulthood. For the girls, lower abdominal pain, bleeding after sexual intercourse, which can be caused by FGS, may be regarded as symptoms of STDs. Such STD-seeming symptoms can may lead girls not to seek treatment - as was evidently clear from the women in this study who refused to be screened. In the long run, this could lead to complications in their reproductive system, translating into infertility and more social stigma.

Although the flow and consistency of blood was said to help distinguish FGS from other symptoms in women and men, the local belief that pain when urinating is caused by the heat of the sun may delay diagnosis and treatment. This is a rational explanation in an area where women and men work long hours in the fields under the hot sun. Furthermore, since the disease is highly prevalent, not as fatal as malaria, but associated with the basic livelihood of the people, infection and re-infection must be expected. Consequently, people in this area seem to have resigned themselves to the fact that schistosomiasis will always be with them and neither traditional nor hospital medicine is currently considered effective.

Additionally, the quality of care in public health facilities seems also to affect what care is sought and the faith people have in particular care options.[12] Such is the case with cancer and the observed belief that it should not be taken to hospital and that an operation should be avoided to prevent it spreading over the entire body. While partly explaining the ideas held about the diseased body, the fear of operation may just be an expression of the experiences of the people of the public health facilities. A cancer that requires operation is perhaps already spread over the entire body and cancer patients may not survive the operation largely due to the poor state of quality of care. This could be the basis for such a belief. Nevertheless, the belief has implications for urinary schistosomiasis, now known to affect the female reproductive tract and may present itself as cervical cancer or may even be causative to cancer (Feldmeier 1995).

Our study has added to the increasing evidence of the importance of gender roles and inequalities in explaining the pattern of disease among women and men (WHO 1998, Annandale and Hunt 2000, Lorber 1997). The possibility that the different farming and household roles could expose women and men to different rates of infection suggests not only the need for further research but that health education should avoid lecturing communities about how schistosomiasis is caused without linking this to the different gender roles.

In conclusion, there is clearly need for contextual understanding. In turn this would require reorientation in health promotion and preventive work to enable those in charge to question assumptions, knowledge and perspectives (Cant and Sharma 1999, Hertz 1997). More often than not, these are projected on to the communities even when the aim may to give voice to community members (Cooke and Kothari 2001). Moreover, given that the high risk of exposure is not just sheer contact with infected water, but may also be a matter of gender dynamics in this area, interventions would need to be gender-sensitive.

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## Notes

1. According to a household survey carried out by the research team, the two villages had 2 471 and 1 283 inhabitants respectively with a third of the households having no latrines. Two springs provide water for a traditional irrigation scheme that enables the people to grow rice in small plots of land as a cash crop and to irrigate maize fields. In both villages about half of the households own plots of land in the irrigated fields. However, significantly more members of the households in one village work in the rice fields as both owners and hired hands. People from the other village tend to hire seasonal workers to cultivate their fields. A health centre serves the two villages and there are two primary but no secondary schools.
2. By the time of this study the committee had not accomplished much. The male participants in the two focus group discussions indicate having little knowledge about the committee and neither had they any idea of any meeting having taken place.
3. Both schools had received a water pump and latrines had been improved through the project. By the time we arrived in one school late afternoon, the pupils were scrubbing the floors of the latrines. The nurse field assistants and the health centre guide made a note to the teachers that this was not the appropriate time for scrubbing. They also noted that the scrubbing brushes were short and the pupils were stepping on the dirty water as they did not wear shoes.
4. This is not to say that there were no problems or biases related to using a village health centre staff as a guide As the public heath representativeat the centre, she often drifted into health education about water and latrine use. Being an insider, she also acted in a way an outsider might consider confrontational with the respondents, possibly jeopardising an interview situation. The

problem was minimised partly by not letting the field guide conduct interviews and partly through reflection at the end of each day. During the reflection meetings, it was stressed that this was not an occasion for health education, but for inquiry.
5. The villagers' use of the latrines could not be ascertained as such a task would have required more elaborately organised observations.
6. This dispelled the fears among the nurses/field assistants that the people were against the project water scheme.
7. As one traditional healer described the treatment, he demonstrated with his finger the length of the worm which usually passed out.
8. Similarly a child with convulsion (*degedege*) or malaria should not be given an injection. It was said this may kill the child.
9. This is a condition where a great deal of eradication campaigns have been going on nationally and internationally. That people reason in this way may be a reaction to these campaigns.
10. The first author (BMA), who was present in all the group discussions and individual interviews, was introduced as a very learned professor. This could be problematic because of increasing social distance. It was obvious in this case that there were expectations that the professor should offer more than just interviews. The social distance arising from such an introduction could not be gauged during the interview but was hopefully minimised by adding that the professor was only a professor of books, and not a professor of social life in the same way as the people in the village were. It was stressed that for the professor and indeed the research team to offer any useful information and education, they had to first be educated by the people
11. Some research participants indicated they had stopped rice farming to avoid infection while data from the two villages showed different patterns of infection with more prevalence in the village more involved in rice farming for their families or as labourers for others (Poggensee 2000).
12. A number of examples of such fusion were noted in this study. Female circumcision has for example, been turned into a disease that justifies the operation taking place in health facilities, a process which may have started with the early Christian missionary activities which advocated among others that the operation be done in the clinics to avoid infections (Ahlberg et al 2000).

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