

Perceptions and practices on schistosomiasis among communities in Ukerewe district, Tanzania

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Abstract: A study on perceptions and practices related to schistosomiasis was conducted among adult people in Ukerewe Island, in north-western Tanzania where *Schistosoma mansoni* infection is endemic. Focus group discussions and semi-structured interviews involved a cross-section of people in 12 villages. In addition, unstructured observations were conducted. The study participants unanimously agreed that schistosomiasis is a chronic illness affecting their health. In this community schistosomiasis-related symptoms were associated with a sexually transmitted disease locally referred to as *ekitelanzila*. Symptoms such as swollen abdomen were associated with witchcraft and taboos such as smelling, seeing or killing a python. Treatment-seeking practices revealed existence of medical pluralism. Community's awareness of preventive measures to be taken against schistosomiasis was not reflected in their health habits. In this paper findings on schistosomiasis-related perceptions and practices, and implications for health education intervention are presented and discussed.

Key words: perceptions, practices, schistosomiasis, health education, Tanzania.

Introduction

People in developing countries carry a heavy burden of diseases including schistosomiasis. Diseases have been shown to negatively affect socio-economic and cultural development (Nokes & Bundy, 1994; Bundy & Guyatt, 1996). However, affected populations do not always perceive diseases as health problems (Kamunvi & Ferguson, 1993; Kloos, 1995). Thus, the incentive to change behaviour or to invest in control intervention could be minimal. Although there is no direct link between increased knowledge of the disease and behavioural change, the possibility of any disease control programme succeeding is highest in cases where the target population perceive the disease as a health problem (Olsen *et al.*, 2001).

Through studies for instance, those exploring local perceptions and practices in relation to schistosomiasis, it is possible to gather information for planning and implementing appropriate health education intervention (Kloos *et al.*, 1982, 1987). Health education messages based on local perceptions and practices would be more suitable for control programmes than messages relying on biomedical model alone (Robert *et al.*, 1989; El-Katsha & Watts, 1994; Kloos, 1995).

This study was undertaken to determine local perceptions and practices related to urinary and intestinal schistosomiasis among the communities of Ukerewe Island of Lake Victoria, Tanzania and try to point out implications for the local authority planning of a community-based health education intervention programme.

Materials and Methods

Study area

The study was carried out in Ukerewe district, the main Island on the Lake Victoria, in north-western Tanzania. The district extends between latitude 1°40'S to 2°10'S and longitude 32°30'E to 33°30'E over an area of 6,400 km². Administratively, Ukerewe district is divided into four divisions, 24 administrative wards and 74 villages. The district is densely populated with more than 300 people per km².

The Island is predominantly inhabited by *Wakerewe* who live in compounds or homesteads known as *kaya*. A single *kaya* is usually comprised of an extended family of a senior man, his wife/wives, sons and their wives as well as their children and relatives. An acre or more usually separates one *kaya* from another. Several *kaya* in close proximity form neighbourhood, which play an important role in socio-economic support.

Economically, most of the inhabitants derive their livelihood from agriculture, fishing and livestock keeping. Livestock keeping (cattle, goats and sheep) always goes together with crop production (cassava, sweet potatoes, maize and rice) within the framework of individual *kaya*. Thus, land, lake, livestock and labour constitute the main components of the economic system of the population, the basis of which is agriculture founded on family labour.

Study design

A cross-sectional study was undertaken among conveniently selected study participants between May and June 1999. Focus group discussions (FGDs), semi-

structured interviews (SSIs) and observations were conducted with adult men and women in twelve villages of namely Bulamba, Hamuyebe, Mahande, Halwego, Chamuhunda, Mukunu, Kameya, Nakamwa, Murutilima, Kaseni, Namasabo and Mtoni.

Focus group discussions

The focus group discussion guide in *Kiswahili*, the national language, was pre-tested before being used in the field. Participants of FGDs were selected with the assistance from village leaders. Twenty-one focus groups were held with a total of 215 participants (Table 1). Slightly more than half of those who participated in FGDs were previously interviewed (face-to-face interview using SSI schedule). The size of a focus group ranged between 6-12 participants. The composition of focus groups took into consideration homogeneity and other related aspects emphasised in the FGD literature (Khan & Manderson, 1992); Dawson *et al.*, 1993; Mwanga *et al.*, 1998).

Focus group discussions were held in natural settings, both inside a building and/or outside under a tree shade (if weather allowed) where privacy could be maintained. A moderator and a recorder facilitated the FGDs. The FGD guide explored issues on local perceptions and practices regarding common illnesses in general and schistosomiasis in particular. Efforts were made to encourage every participant to speak freely and spontaneously and the information collected was treated with utmost confidentiality and anonymity. The discussion lasted between one and two hours including introduction at the beginning and questions and answers at the end of the sessions. The FGDs were tape-recorded using SONY stereo cassette-recorder WM-D3 Walkman Professional, Japan. Informed consent was sought before the tape recording gadgets were used.

Semi structured interviews

The semi-structured interviews schedule also in *Kiswahili* with the same topics as for FGD guide (to allow for methodological triangulation) was also pre-tested before being used in the field, among the conveniently selected sample of 114 adults in the villages (Table 2). The schedule contained hints, which allowed for probing and prompting. On average an interview lasted between 30 and 45 minutes. Interviews were documented manually (notes were taken during the interview) and reports were made immediately after the interviews. These were edited in the field for omissions and/or inconsistency and were back-translated into English and typed.

Unstructured observations

Unstructured observations were made throughout the study and relevant observations were noted down. Field notes were made immediately after observations and translated into English.

Data analysis

Then transcripts of FGDs, reports from SSI and field notes from observations were transferred to a computer programme Ethnography Version 3.0 (Qualis Research Associates, USA) where the data were organised, numbered by sentences, coded, categorised and sorted out into interpretable pieces of information and subsequently interpreted.

Results

A total of 215 people (115 males and 100 females) participated in the study. Study participants were almost divided into two equal half 115/215 (53.5%) males and 100/215 (46.5%) females. Their age ranged from 19-81 years (mean age for males = 47 years; females = 45 years). A good number of participants, 172/215 (80%) was between 20 and 49 years old. With regard to education, 129/215 (60%) of the study participants had at least primary education. Ninety per cent (194/215) of the study participants were peasants.

All 114 interviewees and 215 participants of focus groups unanimously agreed that schistosomiasis was a chronic health problem affecting the people in Ukerewe Island. The study revealed that in most cases participants had local perceptions of what causes schistosomiasis, its symptoms and modes of transmission. One interviewee, a 48 years old man from Bulamba village said: "*Yes, schistosomiasis is a problem in this area. Water from the lake and rivers is infested with snails. Growing of paddy in bunds from dusk-to-dawn also allows ample time for people to get infected.*"

In addition, in one focus group of male participants in Mahande village a participant remarked: "*It is true that schistosomiasis is a chronic health problem in this island because we do not have sources of clean and safe water. The main source of water, Lake Victoria is not safe. It is not unusual that people defecate and urinate indiscriminately into or near the lake. Some people do not use latrines, when it rains, all the excreta is washed into the lake.*"

The study also revealed that in this community schistosomiasis-related symptoms were associated with a sexually transmitted disease locally referred to

as *ekitelanzila*. There was a consensus during all 21 focus groups as indicated in remarks of one participant, a 35 years old lady from Hamuyebe village who said: "*Ekitelanzila means discharging blood and pus from the male or female genitals. Schistosomiasis is associated with venereal diseases and dirty water.*"

risk of getting infected. My wife and I once suffered from schistosomiasis and got cured. However, my wife still complains of abdominal pains and nausea. I think this problem is a sequel of venereal disease which I had during my youth."

Table 1: Distribution of Focus Group Discussion participants by sex and village

Village	No. of FGD Conducted	No. of Participants		Total
		Male	Female	
Bulamba	2	8	5	13
Hamuyebe	2	8	12	20
Mahande	2	10	4	14
Halwego	2	12	12	24
Chamuhunda	2	12	10	22
Mukunu	2	12	12	24
Kameya	1	6	6	12
Nakamwa	2	12	11	23
Murutilima	1	6	6	12
Kaseni	2	12	10	22
Namasabo	2	12	9	21
Mtoni	1	5	3	8
TOTAL	21	115	100	215

Key: FGD= focus group discussion

Furthermore, some of the study participants characterised schistosomiasis with symptoms, which from biomedical point of view could be associated with urinary and/or intestinal schistosomiasis. One interviewee, a 40 years old man from Chamuhunda village said: "*Ekitelanzila is characterised by abdominal pains (below the umbilicus), diarrhoea, passing blood and fat in stool, hard stool, noisy stomach and tiredness. With regard to urinary tract the affected person experiences difficulties in urination, itching, backache, headache, dizziness and passing blood in urine*".

Almost all the study participants perceived themselves to be at a considerable risk of getting infected with schistosomiasis. One of the participants (a 28 years old man) of a focus group of men from Murutilima village, said: "*Personally I am at greater*

Furthermore, some of the study participants believed that drinking and bathing dirty water infested with snails causes schistosomiasis as one interviewee, a 24 years old young man from Namasabo village said: "*Ekitelanzila is contracted by drinking water indiscriminately particularly for fishermen. This disease also affects those who take bath in the lake, rivers as well as in water ponds, which human beings share with livestock.*"

Some of the study participants associated schistosomiasis-related symptoms with witchcraft and contravening of taboos. This is evident in a consensus reached during many FGD sessions as remarked by the previous participant: "*The disease is also characterised by a swollen abdomen locally believed to be associated with killing or seeing a dead python. It is also caused by witchcraft.*"

Table 2: Distribution of in-depth interviews participants by sex and village

Village	No. of Male interviewees	No. of Female interviewed	Total number of interviewed
Bulamba	11	5	16
Hamuyebe	3	8	11
Mahande	5	5	10
Halwego	4	4	8
Chamuhunda	4	4	8
Mukunu	3	5	8
Kameya	4	2	6
Nakamwa	3	3	6
Murutilima	3	3	6
Kaseni	11	4	15
Namasabo	9	3	12
Mtoni	6	2	8
TOTAL	66	48	114

In the same vein, when asked what causes schistosomiasis one interviewee, a 36 years old man from Murutilima village said: *“to eat a bad thing, to eat in a house where someone was stabbed to death, to kill a person, to kill a python, to see a dead python, and to smell a python. Burning a house or having a house gutted down by fire.”*

In seeking treatment for schistosomiasis-related symptoms, the study participants reported interplay of the popular, folk and modern sector of health care. A 24 years old young man from Bulamba village said: *“When I became ill I went to a private dispensary where the illness was diagnosed as schistosomiasis. Medicine (praziquantel) was prescribed and I went to buy drugs for schistosomiasis. However, people consult traditional healers or modern doctors depending on their beliefs in illness causation. I believe that the real cure for schistosomiasis comes from hospital. There is a tendency towards seeking treatment from different sources. Traditional healers also claim to cure schistosomiasis.”*

Similarly, another participant (50 years old) of male focus group from Mukunu village remarked: *“Frankly speaking I suffered from schistosomiasis as I explained before. I went to the hospital and the illness was diagnosed, treated and got cured. I suffered again and went to the hospital and got cured.”* Another participant of the same focus group, a 45 years old man said: *“Treatment of schistosomiasis depends on belief of the affected. There are some people who believe that the disease is not cured by medicine from the hospital. Such people, once they contract schistosomiasis end up seeking help from traditional healers. Personally I believe that hospital treatment is the best of all. I once suffered*

and used traditional medicine for three months without relief. Later on I went to the hospital and got cured.”

A focus group discussion of men from Chamuhunda village revealed quite interesting pattern of treatment seeking practices as one participant remarked: *“We, people of Ukerewe are guided by traditional customs of respecting pythons. When one suffers from distended abdomen or swollen legs, these symptoms are associated with smelling a python, seeing a live or dead python, or killing a python. Because of these strong traditional beliefs people who present with schistosomiasis-related symptoms consult their traditional healers first.”*

All the study participants reported some form of preventive measures undertaken to avert the disease despite some problems they encountered. One participant of a focus group of women from Kaseni village, a 19 years old young lady remarked: *“On prevention I think perhaps it is better to fetch water and take it home and boil before taking bath. Frankly speaking, we at home don't boil water before drinking and taking bath. Normally we let it settle in the vessel, then use the portion which is clean judging from the naked eyes and discard the portion with mud.”*

A 45 years old female interviewee from Halwego village remarked: *“I refrain from promiscuity. I also boil and filter water before drinking. I continue taking bath in the lake or rivers. Nowadays it is difficult to boil water for taking bath because vessels for water fetching and storage, and fuel for heating are costly.”*

These findings were also supported by observations that in villages located on shores of Lake Victoria men, women, children and toddlers were all at various times along the shore and in the lake, at different points for various water contact activities. Women, girls and toddlers were separated from men

and boys in some places only ten metres apart. While men and women were bathing near the shores, boys and girls were swimming in the lake. Some women and girls were washing toddlers, clothes and dishes while others were fetching water. One interviewee, a 20 years old lady from Nakamwa village had these to say: "Those who fish by using chemicals like Thiordan pollutes water. Fishermen also plunge into the lake fish, which they previously caught but did not dry up properly. They also defecate and urinate into the lake. I have no idea how to protect myself because I live in risky environment. I have no alternative but to take bath in the lake. I have to work on rice fields and wade across water. Even fetching water from the lake and take bath at home is risky. I tell you water in the lake is dirty."

Apart from many study participants, who had problems with regard to prevention against schistosomiasis, the study also revealed that some of them reported a number of important measures which they undertake against schistosomiasis such as maintaining environmental hygiene and observing general cleanliness such as to boil water before taking bath, to refrain from defecating and urinating into or near sources of water, to use latrine, to wear shoes and other hygienic habits.

Discussion

The *S. mansoni*-related morbidity on Ukerewe Island and the presence of its snail intermediate host has been previously reported (Magendantz, 1972; Kardorff *et al.*, 1997). Recently Muro *et al.* (2000) reported the prevalence of *S. mansoni* to be as high as 90% in six Lake Victoria onshore villages in Ukerewe Island. Similarly, the findings of this study have also indicated that intestinal schistosomiasis is a chronic health problem among the people of Ukerewe Island. However, the disease is locally perceived to be a sexually acquired infection with symptoms similar to those of gonorrhoea.

Similarly, in their recent study among communities of Magu district, Mwanga *et al.* (2004) found that both urinary and intestinal schistosomiasis were associated with venereal diseases. Symptoms such as burning urination, painful urination and genital pain/itching, which characterise urinary schistosomiasis, were not differentiated from those of gonorrhoea. Furthermore, the perception that schistosomiasis is sexually transmitted has also been reported from Nigeria and Cameroon. In South-eastern Nigeria for instance, the main symptoms of urinary schistosomiasis, gross haematuria, is perceived as an

indicator of sexually transmitted disease (O.C. Nwaorgu, unpublished). Moreover, rural people in Cameroon attributed haematuria to overexposure to the sun, sexual intercourse and overcrowding, causing many of them not to seek treatment in local clinics (Robert *et al.*, 1989).

Although from biomedical point of view, a few of the study participants correctly pointed out causes of schistosomiasis, some of them pointed out totally unrelated causes and implicated witchcraft and other causes related to their traditional customs such as taboos associated with python and many others. Furthermore, though known to exist in the community, the manifestations of intestinal schistosomiasis were not clearly explained by most participants. Sometimes it was difficult for them to distinguish between urinary and intestinal schistosomiasis related symptoms.

Given the fact that Ukerewe Island is known to harbour snails (intermediate hosts of intestinal schistosomiasis), it is not surprising that all participants echoed the fact that they were at considerable risk of getting infected with schistosomiasis. It can be argued that the study population has no alternative sources of clean and safe water. Lake Victoria, unprotected wells and rivers coupled with unsanitary water use habits, put the people at greater risk of schistosomiasis infection. Although keeping people away from contact with potentially infective water is difficult because their lives are at stake, they can be educated on how to minimise possibilities of getting infected.

What came out quite clearly from this study is the importance of relating treatment-seeking practices with explanatory models and disease aetiologies. The findings suggest that there was no linear pattern of treatment-seeking practices concerning schistosomiasis among the participants. Some people might start with popular sector (home-based treatments) where almost 80% of treatments take place (Kleinman, 1980), then go to the traditional healers and end up in seeking help from the hospitals. The vice versa was also true. Furthermore, there was a tendency among the study participants to criss-cross the sectors in a bid to shop around for treatment.

Participants' treatment-seeking practices in relation to schistosomiasis in this study revealed a multiplicity of health systems (medical pluralism). This is not surprising in this part of the world with multiplicity of aetiologies and therapies. Moreover, the use of combination of modern and traditional treatment of schistosomiasis is known from many parts of Africa including Egypt and Kenya (Kloos *et al.*, 1982, 1987). This implies that any meaningful

treatment campaign has to take into consideration as to why people seek treatment where they seek and for which symptoms. This is important because although in other communities, illness beliefs are not good predictors of patterns of resort (health-seeking strategies) of patients and their families as shown by these findings as previously pointed out by Sargent & Johnson (1996).

Generally, many participants were aware of preventive measures to be undertaken to avoid getting infected with schistosomiasis although a few of them were desperate and did not know what to do. Furthermore, this study revealed that the hygienic habits of study population in relation to water put them at risk of acquiring schistosomiasis. Although some of participants reported to take some form of preventive measures, it seems that there was a gap between the reported preventive measures undertaken and the actual practice as observed in this study. It is the perception of many participants that water in the lake is not safe, but it seems that people do not take enough precautions to avert schistosomiasis. This attitude towards schistosomiasis infection is counterproductive and need to be discouraged through health education.

Basing on the findings of this study, the following are implications for implementation of effective health education intervention on schistosomiasis in the study community: Any meaningful health education intervention should be built around what people already know about schistosomiasis (background/informal knowledge). It is now generally accepted that health education messages derived from the biomedical model alone are incomprehensible to many people in schistosomiasis endemic areas (Robert *et al.*, 1989). As suggested by Hubley (1986), communities should not be blamed for their traditional health beliefs and considered, as barriers to health promotion. Many beliefs are harmless and health educator should build on those that may be beneficial.

In conclusion, it is recommended that community-integrated and action-oriented health education intervention on schistosomiasis is urgently needed in the study community. This would create conducive environment from which genuine participation of a wider community in learning and development of action competence could result. Thence, a wider community will be empowered to take actions directed at changing not only lifestyles

but also adverse living conditions for better life in the villages.

Acknowledgements

The author would like to thank the people of Ukerewe Island for their generosity and co-operation. This study received funding from World Health Organization Special Programme for Research and Training in Tropical Diseases.

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