SCHISTOSOMIASIS-RELATED PERCEPTIONS, ATTITUDES AND TREATMENT-SEEKING PRACTICES IN MAGU DISTRICT, TANZANIA: PUBLIC HEALTH IMPLICATIONS

J. R. MWANGA*, P. MAGNUSSEN†, THE LATE C. L. MUGASHE*, THE LATE R. M. GABONE* and J. AAGAARD-HANSEN†

*National Institute for Medical Research, Mwanza Centre, PO Box 1462, Mwanza, Tanzania and †Danish Bilharziasis Laboratory, Jaegersborg Allé 1D, DK-2920 Charlottenlund, Denmark

Summary. A study on perceptions, attitudes and treatment-seeking practices related to schistosomiasis was conducted among the Wasukuma in the rural Magu district of Tanzania at the shore of Lake Victoria where Schistosoma haematobium and mansoni infections are endemic. The study applied in-depth interviews, focus group discussions and a questionnaire survey among adults and primary school children. The perceived symptoms and causes were incongruous with the biomedical perspective and a number of respondents found schistosomiasis to be a shameful disease. Lack of diagnostic and curative services at the government health care facilities was common, but there was a willingness from the biomedical health care services to collaborate with the traditional healers. Recommendations to the District Health Management Team were: that collaboration between biomedical and traditional health care providers should be strengthened and that the government facilities' diagnostic and curative capacity with regard to schistosomiasis should be upgraded. Culturally compatible health education programmes should be developed in collaboration with the local community.

Introduction

This article explores the ways in which data from social science research can assist public health planning at the district level in rural Africa.

Lay people see their health problems in ways which tend to be different from the biomedical viewpoint. Contrary to modern medicine, which regards 'diseases' predominantly as abnormalities of body functions, lay people conceptualize the conditions as 'illnesses' based on local perceptions of the signs and symptoms, causes, routes of transmission, prognosis and alternative measures for cure and prevention (Eisenberg, 1977; Kleinman, 1980). This somewhat simplistic dichotomy is often expressed as the 'etic' (in this case biomedical) as opposed to the 'emic' (local) perspective (Pike, 1971). Illness reflects the patient's perspective and should be seen in a complex context of cultural, social and economic factors. Illness may be present where disease is absent and vice versa. Eisenberg (1977), for instance, has pointed out that in the West it is possible to feel 'ill' without having an identifiable disease in biomedical terms, and to have a biomedical defined disease without feeling ill (e.g. raised blood pressure, or early carcinoma). Kleinman's concept of 'explanatory models' has played a central role in research within medical anthropology. An explanatory model comprises (1) signs and symptoms by which the illness is recognized; (2) presumed causes of illness; (3) recommended therapies; (4) the pathophysiology of the illness; (5) prognosis (Kleinman 1980, pp. 105–107). Regarding treatment-seeking practices, Kleinman's conceptual framework of the popular, the folk and the professional sectors has provided an important common point of reference for research on medical pluralistic health care systems (Kleinman, 1980).

Up to now, most of the research conducted on schistosomiasis in Mwanza region has been focusing on the epidemiology and control of the infections, whereas the sociocultural aspects of schistosomiasis are not well understood (Huang & Manderson, 1992). Through studies exploring local perceptions and treatment-seeking practices in relation to schistosomiasis, it is possible to gather information for planning and implementation of appropriate control strategies.

Knowledge of local perceptions and practices would be of value for the development of community-based, curative and preventive interventions (Kloos *et al.*, 1982, 1987; Khan & Manderson, 1992) and health education messages based on local perceptions and practices would be more suitable for control programmes than messages relying on biomedical models alone (Robert *et al.*, 1989; El-Katsha & Watts, 1994; Kloos, 1995).

This paper reports on local perceptions, attitudes and treatment-seeking practices related to urinary and intestinal schistosomiasis and implications for the District Health Management Team (DHMT) planning of community-based intervention programmes. Over a period of four years (1995–1999) information was gathered among the Wasukuma at Kahangara ward in the Lake Victoria basin of Tanzania where both *S. haematobium* and *S. mansoni* infections are endemic (Mugashe *et al.*, 1994). Through studies exploring local perceptions of schistosomiasis, it is possible to gather information for planning and implementation of appropriate control strategies.

Methods

Study area and population

The study was undertaken in four villages of Kahangara ward, Magu district, located along the southern shores of Lake Victoria. Most study participants belonged to the Wasukuma ethnic group who speak a Bantu language known as Kisukuma, and constitute the largest ethnic group in Tanzania with a population of about 4 million people. The Wasukuma economy is predominantly based on subsistence farming and livestock keeping. Cassava, millet, maize, yams and rice constitute their food crops, whereas cotton is the main cash crop. Though a good number of people live close to Lake Victoria, only a few are making a living from fishing. The majority of the Wasukuma are Christians, but some are Muslims and a few are animists.

Health status and health care services

The top ten causes of mortality in Magu district for 1998 were malaria, anaemia, diarrhoea, pneumonia, acute respiratory infections, tuberculosis, obstetric emergencies, protein–energy malnutrition, AIDS and accidents. In addition, eye infections, sexually transmitted infections, intestinal worms (including schistosomiasis) and skin infections were frequent and caused substantial morbidity.

Data from a previous survey conducted in Kahangara (Bureau of Statistics, 1992) indicated a prevalence of about 30% and 40% for *S. mansoni* and *S. haematobium* infections, respectively. Mixed infections were found in about 10%. Haematuria due to urinary schistosomiasis was most prevalent among school children. Morbidity due to either of the human schistosome infections has long been documented to be very high in these areas (Webbe, 1962; Rugemalila, 1979; Kitinya *et al.*, 1986). Fishing activities in Lake Victoria are conducive to transmission of schistosomiasis, which in this area is predominantly due to *S. mansoni*. A recent (1996) epidemiological study in Nassa ward of Magu district showed a mean prevalence of *S. mansoni* infection of 89% among school children. The highest prevalence was found close to the lake. Mean prevalence of *S. haematobium was* 37% with the highest prevalence recorded inland (C. L. Mugashe, unpublished data).

In recent years, provision of modern health services has changed and there has been a rapid increase in the costs of health services. Ideally, health services at dispensaries and health centres should be free of charge. However, user charges have been instituted from the level of district hospitals and above to cater for running cost. Private practitioners are operating on a commercial basis. The main problems at government health care facilities are shortage of manpower, drugs and basic supplies, shortage of manpower at tertiary level, and uneven distribution of health facilities, particularly in the rural areas where some of the villages don't have their own dispensary. There are two hospitals in Magu district, one government owned in Magu Township, and another private hospital owned by the African Inland Church of Tanzania located in Mkula ward. There are four health centres located in Nyanguge, Kahangara, Nassa and Kabila wards. There are also 44 dispensaries (37 owned by the government and seven private, owned mostly by religious organizations). Drugs for the district hospitals are mostly purchased through the Medical Stores Department in Mwanza Municipality. Health centres and dispensaries get their drugs from the district hospital through the Essential Drug Programme. Drug kits are supposed to be distributed once every month. However, it is common to find that the supply is erratic and anti-helminthic and anti-schistosomiasis drugs are not included. Over-thecounter selling of medicines, particularly antibiotics, is very common in the area (personal observation), though formally illegal.

Despite the national policy of trying to increase the number of modern health care facilities in terms of dispensaries and health centres, they are by far outnumbered by the traditional health care providers. Traditional healers locally referred to as *wafumu*,

are major health care providers in the area. Ethnographic studies among Wasukuma suggest that misfortunes, including illness and death, are often ascribed to acts of witchcraft and sorcery committed by vindictive or envious relatives and neighbours (Varkevisser, 1973).

Study design and data collection methods

Data were collected during the period 1995–1999. Initial data collection focused on perceptions and attitudes in relation to schistosomiasis, and Focus Group Discussions (FGDs) and In-Depth Interviews (IDIs) with primary school children, fishermen and other key informants were conducted. In total 90 interviewees were purposively sampled: 50 primary school pupils and 40 adults. Pupils were selected with the help of headteachers using school registers from three schools in the ward: 20 pupils from Kahangara primary school (the biggest school), 15 pupils from Shinembo primary school, and 15 pupils from Ijinga primary school. These were from grade 3 to 7. The gender balance was maintained. With regard to the 40 adults, these were selected with the help of village leaders. In each of the four villages ten people were selected, half males and half females. With regard to FGDs, 37 primary school pupils out of the 50 who had previously been interviewed were invited to participate and all 40 adult interviewees were also invited to participate.

At the later stages data collection focused on treatment-seeking practices, particularly concerning schistosomiasis. Data were gathered through semi-structured interview with health care providers from various sectors. Informants for interviews were the health care providers and patients who were available on the days when interviews were conducted. In the government health care facilities two clinical officers and eight nurses were all included in the study. Attendants of the two medical shops (the only shops available in the ward by then) were also included in the study, as were five registered traditional healers in the ward. Exit interviews were conducted with adult patients after consultations with the same health care providers. (The sample included 33 patients: eleven males and 22 females. Eleven patients came out of the health centre, five from medical shops and seventeen from traditional healers.) Furthermore, a questionnaire survey was conducted with school children from the local primary schools and adults. Three hundred and eighty-one respondents were also selected purposively with the help of village leaders from four villages. Of these, 111 were pupils of the four primary schools in the ward who were selected conveniently from the four schools using school registers.

All of the informants were assured that confidentiality would be observed and informed consent was obtained. The medium of communication was Kiswahili, the national language that was understood by all participants.

Thanks to the research team's continuous presence in the study area, a series of sub-studies were conducted during the period 1995–1999. This served several purposes. Partly it allowed a formative process in which new research questions could be pursued based on previous data, and partly it strengthened the validity of the findings by triangulation. Finally, it facilitated the formulation of the questionnaire (which came last) by taking the more qualitative data from the FGDs and the IDIs into consideration.

Focus group discussions (FGDs)

School children in grades 3–6 from four primary schools were purposively selected using school registers and invited to participate one or two days before the FGD through their headteachers. With the assistance of community leaders adults were selected from the community. On invitation, the participants were told that very little was known about the illness problems of the community, and they were told that the investigators were neither interested in testing their knowledge nor comparing it with the information obtained from local health care facilities.

Six locally recruited interviewers – three males and three females with secondary school education - were trained on how to moderate the discussions. Male moderators conducted FGDs with male participants, and female moderators conducted FGDs with female participants. Discussions were held in natural settings, either inside a building or outside under a tree in a quiet and well-lit place. Eighteen FGDs were conducted including 140 people: nine FGDs with school children (four with boys, five with girls), and nine FGDs with adults (six with men, three with women). Each FGD had six to eight participants and the composition of the FGDs took into consideration homogeneity and related aspects (Eriksson, 1988; Krueger, 1988; Morgan, 1988; Dawson et al., 1993). The FGDs explored questions on the common types of illness and their manifestations, and people's perceptions and practices related to specific illness associated with urinary and intestinal schistosomiasis in particular. On average, an FGD took about 90 minutes and was video-recorded to obtain documentation of both verbal and body language expressed by the participants. A Sony Video 8 Handycam camcorder with a Philips stereo microphone was used. The system was demonstrated to the participants before the session (Mwanga et al., 1998).

In-Depth-Interviews (IDIs)

Experienced researchers conducted all interviews. On average, an IDI took about one hour. Sampling was done purposively allowing for a maximum variety of informants within the various categories. Thirty-seven school children (13–17 years, 58% girls) and 40 adults (18–60 years, 58% women) were purposively selected. They were interviewed on themes such as perceptions of common illnesses; signs, symptoms and attitudes in relation to these; and local perceptions and practices in relation to schistosomiasis.

Semi-structured interviews

Seventeen health care providers including clinical officers and nurses at public health facilities and public and private shopkeepers participated. Among the health care providers there were five males and twelve females (age range was between 22 and 55 years). Out of the seventeen, four had secondary education, eleven had at least a primary level and two (both female, traditional healers) had no formal education. Ten were employed at government clinics, five were traditional healers (all of them herbalists), and two ran medicine retail shops. There were no private clinics in this particular area. The health care provider interview included open questions on types

J. R. Mwanga et al.

of health problems in the community and focused on schistosomiasis-related problems. Numbers of clients attending per week, utilization of other alternative health services by the clients or any problems encountered when attending patients were explored. Finally, the interviews focused on the capacity of the various facilities in managing schistosomiasis such as the availability of drugs and equipment for diagnosis.

Client exit interviews

Thirty-three patients (eleven males and 22 females) were interviewed. Of those 27 (82%) were Christians and six (18%) were inclined to traditional beliefs. Age ranged between 15 and 69 years. Twenty-three (70%) had completed primary school, whereas none had completed secondary school education. Of the 33 patients interviewed, 22 (67%) had schistosomiasis-related symptoms (six males and sixteen females). The patients were approached and interviewed immediately after the consultation with the service provider. The interview guide included questions on the health problems that brought them to a facility. The patients were further asked about their feelings during consultation (medical encounters) with health providers, their interactions with the service. Patients were finally asked if the facility in question was able to manage schistosomiasis in terms of diagnosis and treatment.

Questionnaire survey

In the questionnaire survey 381 respondents were interviewed of which 211 (55%) were females. Mean age was 28 years (range 10–75 years). Of the respondents 177 (47%) had completed primary education and seven (2%) had secondary education, whereas 108 (28%) were still in primary schools. The majority (336; 88·2%) were Christians, 38 (10%) were 'traditional believers' and seven (2%) were Muslims. Three hundred and forty-four (90%) belonged to the Wasukuma ethnic group, whereas 37 were Wajita and 'Other' (10%).

The interviewers were four research assistants with secondary school education (two males and two females), recruited and trained on the principles of questionnaire administration. The interviewers participated in pre-testing of the questionnaire. The fact that the study was designed in such a way that open-ended approaches (FGDs and IDIs) were initially applied in 1995, allowed the formulation of the questionnaire to be in accordance with local (emic) terminology. The questionnaire contained closed- as well as open-ended questions on basic demography, history of urinary/intestinal schistosomiasis, treatment-seeking practices, types of treatments locally available, factors that might be constraining the access to health services, preventive measures against schistosomiasis, and willingness to pay for treatment and control of schistosomiasis in the community.

Data analysis

The field notes and transcripts of interviews were typed and transferred to Ethnograph Version 3.0 (Qualis Research Associates, USA) where they were

organized, numbered by sentences, coded and sorted out for interpretable pieces of information. Written transcripts from FGDs were not made. Recorded material from the FGDs was transferred to videocassettes and analysed through playback on the screen, which facilitated retrieval of both verbal and non-verbal responses. Quantitative data from the questionnaire survey were edited in the field for omissions and/or inconsistencies and subsequently entered in the computer using the Epi-Info 6.02 programme for cleaning, validation and subsequent analysis. For comparison and quality assurance of the information gathered, two independent investigators performed data interpretation.

Results

Results from FGDs and IDIs

Symptoms and aetiology. Of the 90 individuals participating in IDIs, 38 (42%) had recently been passing blood in the urine. In Kiswahili, urinary schistosomiasis is known as *kichocho cha mkojo*. A large proportion of members of this community referred to urinary schistosomiasis as 'blood-in-urine symptom'. This condition was said to be very common in the community, particularly among school children. Most interviewees stated that *kichocho cha mkojo* was likely to affect everybody regardless of age or gender, though it was a generally known that school children and fishermen were at a greater risk because they spent a great deal of time in contact with water. Some respondents mentioned other symptoms associated with *kichocho cha mkojo*, including lower abdominal pains, genital itches or pinching like needles, weakness, fever and general malaise. People with *kichocho cha mkojo* were said to have an excessive urge for sweet food items. One typical statement describing the illness was that urinary schistosomiasis could cause pain without the actual passing of blood in the urine.

Though known to exist in the community, the manifestations of intestinal schistosomiasis (*kichocho cha tumbo*) were not clearly explained by most participants. In general many do not realize what illness they suffer from until they are diagnosed at the hospital. Even fishermen, who are most exposed to the infection, were not able to specify symptoms specific to intestinal schistosomiasis. The following type of statement was used to describe the illness:

'Since it is a type of *kichocho*, then even its name is *kichocho cha tumbo*. Like *kichocho cha mkojo*, also this might be contracted sexually.'

During FGDs some adults expressed that they associated noisy abdomen, nausea, flatulence, backache, diarrhoea and blood in stool with *kichocho cha tumbo* (see Table 1). Also, male participants of one FGD felt that *kichocho cha tumbo* can cause impotence. A 36-year-old man remarked:

Kichocho cha tumbo causes backache around the waist, an individual becomes weak and a man cannot erect properly ... he becomes somehow impotent. With such a condition, one cannot win a woman ... However, one can become 'libido' again if treated properly.'

During two FGDs with women, fear was expressed that pregnant women could pass kichocho cha mkojo to newborn babies. Some female interviewees believed

Gastrointestinal symptoms	Urinary tract symptoms	Unspecific symptoms
Nausea Abdominal illness Vomiting Diarrhoea Blood in stool Soft stool Swollen stomach Flatulence	Frequent urination Urge incontinence Painful urination Involuntary urination Blood in urine Terminal haematuria Genital pain, itching	Headache Fever Backache Dizziness Body weakness Tiredness Malaise Sweating at night
Noisy stomach		Lack of appetite Hair discolouration Skin discolouration Yellow eyes

Table 1. Perceived symptoms associated with urinary and/or intestinal schistosomiasis*

*Data are synthesized from eighteen FGDs (nine with children and nine with adults) conducted with a total of 140 participants.

that *kichocho*, particularly of the urinary type (*kichocho cha mkojo*), could cause infertility.

The manifestations of swollen abdomen known as *budumi*, which was said to be common among fishermen or *ihyela*, were not associated with *kichocho* in any way, but were ascribed to witchcraft. A 20-year-old woman lamented in one of the FGDs:

Budumi and *ihyela* are incurable by modern medicine and affect very few unlucky ones ... Such victims might have been bewitched, eaten poisoned food during communal functions or stepped over a bad thing.'

Some study participants believed that urinary schistosomiasis could be transmitted by contact with bloody urine, as a 30-year-old man remarked in one of the interviews:

'We are very careful with people presenting with *kichocho cha mkojo* ... even when we are at the pubs, we avoid sharing latrines with them.'

Most school children perceived the cause of *kichocho cha mkojo* to be linked with taking too much table salt and also with stepping bare-footed on human excreta. When probed further, they claimed to have been told by their teachers. Some participants linked the persistence of the illness in their community to unsafe water for drinking and unprotected water for bathing somehow contaminated with human or animal excreta.

Attitudes. To some school children, *kichocho* was perceived as a shameful and embarrassing condition, to the extent that sometimes the reporting of the illness to parents could be difficult. During one of the interviews a 15-year-old school child remarked:

'I usually pass blood at the end of my urination ... When this happened to me for the first time, I told my brother who helped me to disclose the event to my parents ... I couldn't dare telling them directly ... It was shameful because the blood was coming out of my genitals ... Until now I haven't told any of my friends about my condition because they can laugh at me and make fun of it ... they can nickname me "*DJ wa kichocho*" [literally means disc jockey of schistosomiasis], but I am ready to tell a medical practitioner or a traditional healer, for the sake of seeking help.'

In one of the FGDs, a 13-year-old schoolboy commented:

'Urination of blood is very nasty. You can see one wetting the shorts with blood, which attracts flies all over. One has to stay alone with shame. It is embarrassing.'

Adolescent and adult participants considered both types of '*kichocho*' as sexually transmitted diseases. The patients affected by the illness may feel embarrassed, as opinions from one of the men's FGDs indicated:

'Of course *cha mkojo* is a venereal disease. It affects the genitals. If it is left untreated in childhood, it may develop into *kisumba* manifested by discharging pus when one gets matured'.

This notion is also evidenced in a consensus reached from FGD sessions of adult women and school girls in Kahangara ward:

'Intestinal schistosomiasis is characterized by stomach ache below the umbilicus on the left hand side. It is also characterized by passing loose stool at least three times a day. When it matures, this condition is called *kisumba* in Sukuma language and the affected start passing pus in urine.'

'It is shameful to contract urinary schistosomiasis. For example, a girl is afraid of disclosing the condition to her boyfriend because of fearing to break relationship ... Boys and girls are also afraid of telling their parents fearing to be rebuked that they have already started sexual activity at a tender age ... Therefore, schistosomiasis is a venereal disease and the affected can pass it to his/her spouse. Adults have been shy to tell the doctor fearing disclosure to the public.'

A school girl participating in one of the FGDs in Kahangara confirmed this:

'In most cases those who are infected with schistosomiasis feel shy to tell others about their illness because if they tell someone that they pass blood in urine, then they will be regarded as being promiscuous.'

During IDIs several school children also explained that urinary schistosomiasis is perceived to be a shameful condition. A 13-year-old school boy said:

'Schistosomiasis can cause people to run away from you. When I suffered from schistosomiasis some of my neighbour's children avoided to play with me.'

A 15-year-old school boy re-iterated:

'Schistosomiasis is a shameful disease. Once I suffered from it and told my father only. I did not dare to tell even my mother, sisters and brothers about it.'

This point was confirmed by a 20-year-old woman:

'Schistosomiasis is associated with shyness, avoidance and even being laughed at because people associate the condition with promiscuity.'

Treatment-seeking practices

Blood in the urine was regarded as a normal condition that can either be treated or left untreated for years depending on its severity. Most FGDs with adults indicated that many cases of *kichocho cha mkojo* heal spontaneously without treatment. However, they admitted that the condition is a nuisance and unhealthy if left untreated, and that it deserves attention because it is curable by either traditional or modern medicines. A condition like *budumi*, which was perceived by many adults in this community to be incurable by modern medicine, was regarded as the result of witchcraft, and therefore it is always referred to traditional healers. Believers of the Christian religious faith generally refrained from admitting that *kichocho cha mkojo* and *kichocho cha tumbo* could be treated by traditional medicines, but some individuals admitted to have been receiving this kind of treatment.

Results from health care provider and exit interviews

Through interviews with health care providers at the Kahangara health centre, treatment-seeking practices in relation to schistosomiasis were explored, and it was revealed that on average a total of 40 patients attended daily (this figure could reach 60 patients during periods where drugs were available). Attendants at medical shops confirmed to stock anti-schistosomiasis drugs, and that patients bought the drugs. On average sixteen clients attended per day, whereas traditional healers had an average of eleven clients per day. Both modern and traditional health service providers had similar perceptions of the important health problems in the community and their views reflected their clients' perceived health problems. Interestingly, the health care providers at Kahangara reported that their services were complementary to each other regardless of their orientation, i.e. modern or traditional medicine. One traditional healer, a 50-year-old man, said that he has been referring some cases to a nearby health centre. He also mentioned conditions such as dehydration, tuberculosis and pneumonia as incurable by traditional medicine. Traditional healers dealt mostly with abdominal and infertility problems among women. These problems take a long time to cater for and were often linked to witchcraft. In the same vein, another traditional healer, a 46-year-old man, remarked:

'When I receive patients with symptoms such as deficiency of water, blood, and tuberculosis, I normally refer them to a health centre.'

He further argued that it is common for the people to utilize the traditional services and modern ones simultaneously. Clients also supported this argument. On the other hand, a 35-year-old lady patient interviewed at the traditional healer, remarked:

'I went to Ngudu hospital two months ago. The clinician told me that my illness was traditional in nature (*ugonjwa wa kienyeji*). I contacted two traditional healers before coming to this one. I did not get relief. At the present healer my condition is improving.'

Interviews with health care providers at modern facilities revealed that people are forced to use alternative services when they realise that the stock of drugs has run out at the health centre. Some individuals reported to have visited traditional healers because they think that the illness was a result of witchcraft. For instance, if a child has swollen legs and abdomen (which from a biomedical perspective might be due to malnutrition and other medical causes) he/she is taken to the traditional healer. This is also the case with adults who present with such symptoms. Customers at medical shops underscored the fact that utilization of alternative services depended on severity of illness. Many people prefer to start at a health centre to get a biomedical diagnosis. Traditional healers were of the opinion that it is common to have people using alternative health facilities. In one of the interviews a 46-year-old male healer remarked:

'We healers, be it modern or traditional, we depend on each other in our efforts to treat patients for some illnesses that cannot be cured by medicine from one facility.'

Interviews with biomedical health care providers revealed that health centres and dispensaries cannot manage schistosomiasis to clients' satisfaction because of lack of microscopes for diagnosis of intestinal schistosomiasis and lack of anti-schistosomiasis drugs. On average, there were two cases of schistosomiasis attended to per week and in most cases it was urinary schistosomiasis, as it is easily diagnosed based on symptoms and signs. However, also the traditional healers interviewed claimed to cure schistosomiasis. A 44-year-old male healer said:

'Yes, I can manage schistosomiasis to patients' satisfaction by using an herb known as *Nungu gwa mpando*. I can attend up to five patients per week of both urinary and intestinal schistosomiasis.' (The informant used '*kisambale*', the local Kisukuma term for schistosomiasis.)

In all facilities, patient-provider interaction was reported to be smooth with the exception of very few instances at the public health centre. One patient, a 22-year-young man, remarked:

'There was no privacy during consultation because many patients were also around in the consultation room. This situation hindered me from explaining my illness properly particularly the pain along the urinary tract. There was not enough time to explain my illness and most of the time the provider was busy writing. I was not satisfied with the services provided because I did not get some medicine, particularly one which was supposed to ease pain along my urinary tract.'

Results of questionnaires

Of the 381 questionnaire respondents, 45% were males and 55% females: 184 (48%) were children and adolescents (aged 10-20 years) and 197 (52%) were adults above 20 years of age. During the questionnaire survey, participants were asked about their experience with schistosomiasis. The denominator for most questions was 381. However in a few cases a specific question was not relevant and accordingly the denominator can vary. Table 2 shows the experience of respondents with previous or actual schistosomiasis: 213 (56%) reported never having had schistosomiasis, whereas 162 (43%) said they had suffered from the illness. Only six (2%) were not sure. Two hundred and ninety-five (77%) reported not having schistosomiasis at the time of interview whereas 70 (19%) felt they had ongoing schistosomiasis illness. Fourteen (4%) were not sure. One hundred and twenty-six (78%) reported having suffered from urinary schistosomiasis and 52 (32%) from intestinal schistosomiasis (the figures add up to more than 100% as sixteen people reported suffering from both types of schistosomiasis). Of those who reported to be suffering from schistosomiasis at the time of the interview, 73% (51/70) and 34% (24/70) suffered from urinary or intestinal schistosomiasis, respectively (Table 2). Urinary schistosomiasis was most commonly

							Ag	e group						
	10-	-20	21-	-30	31-	40	41-	-50	51-	-60		60	To	tal
Question	M^{a}	Fa	M	ц	M	ц	М	ц	M	ц	Μ	ц	Mc	Ъc
Do you have														
schistosomiasis (kichocho)	24/88	12/92	9/29	9/51	5/18	3/20	0/12	4/12	3/8	1/14	0/10	2/12	41/165	31/201
right now?	27%	13%	31%	18%	28%	15%	0%	33%	38%	7%	0	17%	25%	15%
Do you suffer from urinary														
schistosomiasis (kichocho	22/23	10/12	4/9	5/9	3/4	1/3		1/4	3/3	0/1		2/2	32/39	19/31
cha mkojo) right now?	96%	83%	44%	56%	75%	33%	0/0	25%	100%	0	0/0	100%	82%	61%
Do you suffer from intestinal schistosomiasis														
(kichocho cha tumbo) right	1/23	2/12	5/9	6/9 ^b	3/4 ^b	2/3		3/4	1/3 ^b	1/1		0/2	$10/39^{b}$	14/31 ^b
now?	4%	17%	56%	67%	75%	67%	0/0	75%	33%	100%	0/0	0	26%	45%
^a M mole: E famole														

M, male; F, female. Some respondents perceived to be suffering from both urinary a

^bSome respondents perceived to be suffering from both urinary and intestinal schistosomiasis. ^cFourteen respondents who answered 'don't know' have not been included in the table.

74

J. R. Mwanga et al.

Table 2. Distribution by age group and sex of questionnaire respondents' answers to schistosomiasis present or not, and which type of schistosomiasis (urinary or intestinal) they perceived to be suffering from at the time they were questioned

Symptom	Urina	ry schistosc	omiasis	Intestinal schistosomiasis			
	Male (<i>n</i> =34)	Female (<i>n</i> =19)	Total* (<i>n</i> =53)	Male (<i>n</i> =13)	Female (<i>n</i> =17)	Total** (<i>n</i> =30)	<i>p</i> ***
Blood in urine	62%	58%	60%	31%	29%	30%	0.029
Dysuria	88%	84%	87%	77%	77%	77%	ns
Blood in stool	41%	37%	40%	85%	35%	57%	0.003
Abdominal pains	68%	79%	72%	100%	100%	100%	0.002
Diarrhoea	32.4%	36.8%	34.0%	69.2%	59.2%	60.0%	0.009

 Table 3. Prevalence of symptoms mentioned by respondents perceiving to be suffering from either urinary or intestinal schistosomiasis

*** χ^2 test of difference between * and **; ns, not significant.

reported among 10-20-year-old respondents compared with respondents older than 20 years (91% vs 54%, p < 0.001). The opposite trend was seen for intestinal schistosomiasis, where only 8.6% among the 10–20-year-olds reported suffering from this condition compared with 60% among the more than 20-year-olds (p < 0.001). Although there was a trend in males reporting higher prevalence of urinary schistosomiasis compared with females and an opposite trend for intestinal schistosomiasis, the differences were not significant. Table 3 shows symptoms perceived by respondents with either urinary or intestinal schistosomiasis at the time of interview. There were no significant differences between males and females except for 'blood in stool', which was less often reported by females perceiving to be suffering from intestinal schistosomiasis compared with males (p < 0.001). Blood in urine was significantly more common among those respondent perceiving to have urinary schistosomiasis compared with those with intestinal schistosomiasis. Blood in stool, abdominal pains and diarrhoea was more common among those perceiving to have intestinal schistosomiasis. Complaints of dysuria were equally distributed among the two groups. In general, respondents in the age group 10-20 years had many more symptoms than respondents in older age groups (data not shown). A few respondents, especially older people, mentioned unspecific symptoms such as headache, dizziness, body weakness, tiredness, malaise, sweating at night and lack of appetite.

Among the age group 10–20 years 56% of the respondents did not know the cause of schistosomiasis, 34% mentioned snails, water and poor sanitation and 10% linked the cause to drinking unsafe water. Among adults 52% of the respondents did not know the cause of schistosomiasis, 39% linked the cause to snails/water/poor sanitation and 9% linked the cause to drinking unsafe water. There were no significant differences between age groups or sex (p > 0.05).

Of the respondents, 341 (90%) reported to have ever received treatment for any disease or illness from public health facilities, 328 (86%) had consulted medical shops, 230 (60%) treated themselves at home by using local herbs and 134 (35%) reported to have gone for treatment at private dispensaries. Traditional healers (in most cases herbalists) had been consulted by 123 (32%) for various illnesses. Altogether 68 (17%)

		Age group							
Response to the question: 'Where do you prefer to go	10-20		≥21		То	Total			
for treatment?	Male	Female	Male	Female	Male	Female			
Using traditional herbs	26/88 30%	20/96 21%	25/82 30%	46/115 40%	51/170 30%	66/211 34%			
Visit herbalist or traditional	20/88	18/96	20/82	30/115 26%	40/170 24%	48/211			
Buy medicine from a medical	2376 74/88	87/96	70/82	94/115	144/170	181/211			
shop Visit a private health facility	89% 49/88	90% 51/96	77% 45/82	82% 45/115	85% 94/170	86% 96/211			
Visit a public health facility	56% 86/88	47% 93/96	55% 75/82	39% 113/115	55% 161/170	45% 206/211			
·····	98%	97%	91%	98%	95%	98%			

 Table 4. Treatment-seeking practices among 381 questionnaire respondents who perceived to suffer from schistosomiasis

stated that they had ever been treated by religious prayers. Twenty-eight (8%) had been treated by local injectionists and 26 (7%) of the respondents reported having never sought any other kind of treatment. Thirty-four (9%) reported knowing anti-schistosomiasis herbs, and 24 (6%) reported having used some of these herbs to treat themselves. Table 4 shows where the respondents would prefer to go for treatment of their present condition. All age groups above 20 years were lumped together as there are very few people in the age groups above 21–30 years. A public health facility or a drug shop was definitely the preferred option and there were no major differences between sexes or age groups.

Willingness of the respondents to participate in controlling schistosomiasis was high: 341 (89.5%) were willing to participate in planning of control and 359 (94.2%) to participate in health education; 345 (90.6%) would mobilize fellow villagers in the control of schistosomiasis; 337 (88.5%) were willing to share the costs of diagnosis and treatment of schistosomiasis, 348 (91.3%) to share the costs for the supply of safe water and 342 (89.8%) of respondents were willing to share the costs of building safe latrines.

Discussion

The symptoms recorded during FGDs, and which from a biomedical point of view were associated with either urinary or intestinal schistosomiasis, were not different from those recorded in the questionnaire. Many of these manifestations are commonly reported from elsewhere in sub-Saharan Africa (Sukwa *et al.*, 1985; Gryssels & Polderman, 1991). Symptoms like abdominal pain, blood in stool and diarrhoea could, from a biomedical perspective, be related to intestinal schistosomiasis. Other symptoms such as blood in urine (terminal haematuria), dysuria/irritating

or burning urination and colic during or after urinating are biomedically relevant to urinary schistosomiasis. As recorded through FGDs and IDIs, there appears to be some overlap between symptoms related to urinary or intestinal schistosomiasis and this might explain why symptoms biomedically associated with urinary schistosomiasis were recorded by some people who perceived that they suffered from intestinal schistosomiasis and vice versa. However, the highly significant differences in perceived symptoms indicate that people are able to differentiate the two conditions. It might also play an important role that epidemiologically the two infections co-exist and a substantial number of people in the study area were actually double-infected (C. L. Mugashe, unpublished data). However, in the present study dysuria was reported with the same frequency among respondents perceiving to suffer from urinary or intestinal schistosomiasis. The reason for this finding remains unclear, but could be due to the fact that dysuria was maybe understood as a more diffuse lower abdominal condition.

The participants also reported a number of symptoms that were not specific to either urinary or intestinal schistosomiasis. For instance, mild headache, fevers, dizziness, sweating at night, lack of appetite and signs of malnutrition, were associated with *kichocho cha mkojo* by the participants. However, many of these symptoms are related to general ill health and could be due to chronic schistosomiasis or other disease conditions.

In the study communities both urinary and intestinal schistosomiasis were associated with venereal diseases. Symptoms such as burning urination, painful urination and genital pain/itching, which characterize urinary schistosomiasis, are not differentiated from those of gonorrhoea. However, the fact that each of the conditions has its own local term, i.e. kisambale for schistosomiasis and kasogone for gonorrhoea, indicates that local people can differentiate the two, but some similarities in symptoms lead them to believe that both the conditions are sexually transmitted. The belief among some of the female interviewees, that urinary schistosomiasis can lead to infertility, is supported by published data (Feldmeier & Krantz, 1993). The feeling that the illness could also affect marriage or sexual life (Raikes et al., 1992; Feldmeier et al., 1995) was also expressed in this community, particularly among male participants who feared the effects of impotence. Furthermore, the perception that schistosomiasis is sexually transmitted has also been reported from Nigeria and Cameroon. In South-eastern Nigeria for instance, the main symptom of urinary schistosomiasis, gross haematuria, is perceived as an indicator of sexually transmitted disease (Nwaorgu, 1992). In the study communities schistosomiasis, especially urinary, was considered to be shameful for both males and females and likewise for both children and adults. Particularly among adults, schistosomiasis was associated with sexually transmitted diseases, while school children found it embarrassing as it could expose them to crude jokes and being isolated by friends.

The use of a combination of modern and traditional treatment is known from many parts of Africa. This has also been found in other studies on schistosomiasis in Upper Egypt and Kenya (Kloss *et al.*, 1982, 1987). This indicates that any meaningful treatment campaign has to take into consideration why and where people seek treatment and for which symptoms. The problematic relationship between biomedicine and local traditions of health care have been reported by other studies in Africa. In many societies the relationship between the two has long been rather hostile. Some argue that local medical traditions have a unique and intrinsic value and advocate for collaboration with local biomedical practitioners, who tend to be outsiders. Pillsbury (1982) described some early attempts at co-operation between local healers and biomedical practitioners but came to the conclusion that genuine co-operation to any significant degree was extremely rare. However, in the present study such hostility was not observed between community health workers and traditional healers. On the contrary, the relationship between traditional healers and modern health care providers was good. Traditional healers command respect in the communities in which they live and they are frequently consulted for different illnesses. As Kloos *et al.* (1987) in Kenya, this study found that medical herbs were used by more than half of the study population, though few knew specific herbal treatments for symptoms associated with schistosomiasis.

The discussion on whether co-operation is desirable and feasible is ongoing. Some believe that the underlying theoretical concepts are so different that co-operation is practically impossible. Others have taken a more pragmatic view and have appealed for co-operation because of the mutual benefits involved. A more general point emphasized by the majority of authors is that practitioners of the local and biomedical traditions should have more mutual understanding and respect for each other. One way of asserting how to integrate the two traditions is recognition. The government of Tanzania has recognized the contribution of the traditional sector of medicine to the health of its people by issuing permits to practise, albeit some still operate clandestinely. The present study has demonstrated that both traditions peacefully co-exist in communities of Sukumaland. Another issue that points towards how possible integration can be reached is that in the present study, traditional healers were open to the fact that they can manage some ill-health conditions but there are other conditions that they cannot manage and hence refer people to hospitals. This being the case, the two traditions complement each other and this could be the starting point for the integration of the two traditions.

The results of the present study could be of use in improving treatment control programmes for urinary and intestinal schistosomiasis in several ways. The results from the health care provider interviews would be of relevance to the District Health Management Team (DHMT) in Magu district. The data showed that mutual referrals take place between the traditional healers and the formal government health facilities. This interaction between the two sectors of the health care system should be looked into more so that patients with specific ailments are referred to and cared for by the most appropriate service providers. However, there is no point in referring the schistosomiasis patients to (government) clinics if the facilities are not prepared to cater for them. The present findings indicate that diagnostic equipment (e.g. microscopes) is not sufficient at the government clinics, that privacy for patients is lacking and drugs are often not available. Furthermore, user fees are sometimes prohibitive for low-income groups of the population. On the other hand the results of the survey indicate that people prefer to go to a public health facility, which would be one more reason for strengthening the diagnostic and treatment capability of these facilities.

Health education forms an important part of control programmes for schistosomiasis. Seen from both biomedical and sociomedical perspectives, a number of 'messages' would be relevant among the Wasukuma. The 'messages' should: (1) counteract the shame and embarrassment associated with the symptoms, at least among some groups (the school children and young men), so that the problems can be brought into the open and addressed appropriately; (2) encourage patients with relevant symptoms (as expressed in local terms) to seek treatment at the local clinic; (3) explain precautions to avoid transmission i.e. construct and use latrines and minimize water contact. Health education should be conveyed in such a way that it reduces risk behaviour and promotes appropriate treatment-seeking practices. The design of the teaching material is important, but far from the only precondition for success. The terminology should of course be in harmony with locally used words, and illustrations should conform to the local conventions of visual presentation (Haaland, 1984). The traditional top-down approach in which factual knowledge is passively conveyed to a 'target group' is not likely to succeed as it is based on at least two dubious assumptions: firstly, that the passive mode of learning serves the purpose of transferring new knowledge in a sustainable way (Jensen & Schnack, 1994); secondly, that new (and from a biomedical perspective more 'correct') knowledge will be transformed into changed (more health promotive) practices (Yoder, 1997). It is recommended that the DHMT liase with professional health communicators skilled in more innovative approaches, who can advise on how best to plan and implement the health information activities. Active participation of the community when addressing public health problems such as schistosomiasis has been shown to be important for success (Stone, 1989). From that perspective it was encouraging that close to 90% of the informants in this study indicated an interest in participating in various aspects of a schistosomiasis control programme and even in contributing to the funding.

Acknowledgments

The authors acknowledge the National Institute of Medical Research (NIMR), Mwanza Centre and the Danish Bilharziasis Laboratory (DBL), Denmark, for practical support throughout the study. They also thank the people of Kahangara, Magu district, as well as the local staff of the Ministry of Health and Ministry of Education for their co-operation. The study was funded by the Danish Bilharziasis Laboratory (DBL), Denmark.

References

Bureau of Statistics (1992) 1988 Population Census Mwanza Regional Profile. President's Office, Planning Commission.

Dawson, S., Manderson, L. & Tallo, V. L. (1993) *A Manual for the Use of Focus Groups.* International Nutrition Foundation for Developing Countries, Boston.

Eisenberg, L. (1977) Disease and illness: Distinction between professional and popular ideas of sickness. *Culture, Medicine and Psychiatry* 1, 9.

El-Katsha, S. & Watts, S. (1994) A model for health education. World Health Forum 15, 29-33.

Eriksson, C. (1988) Focus groups and other methods for increased effectiveness of community interventions – A review. *Scandinavian Journal of Primary Health Care*, supplement 1, 73–80.

- Feldmeier, H. & Krantz, I. (1993) A synoptic inventory of needs for research on women and tropical parasitic diseases. 1. Application to urinary and intestinal schistosomiasis. *Acta Tropica* 55, 117–138.
- Feldmeier, H., Poggensee, G., Krantz, I. & Helling-Giese, G. (1995) Female genital schistosomiasis: New challenges from a gender perspective. *Tropical and Geographical Medicine* 47, supplement 2.
- Gryseels, B. & Polderman, A. M. (1991) Morbidity, due to schistosomiasis mansoni, and its control in sub-Saharan Africa. *Parasitology Today* 7, 244–248.
- Haaland, A. (1984) Pre-testing Communication Materials with Special Emphasis on Child Health and Nutrition Education. UNICEF, Rangoon.
- Huang, Y. & Manderson, L. (1992) Schistosomiasis and the social patterning of infection. Acta Tropica 51, 175–194.
- Jensen, B. B. & Schnack, K. (1994) Action competence as an educational challenge. In Jensen,
 B. & Schnack, K. (eds) Action and Action Competence as Key Concepts in Critical Pedagogy. Royal Danish School of Educational Studies, Copenhagen, pp. 5–18.
- Khan, M. E. & Manderson, L. (1992) Focus groups in rapid assessment procedures for tropical disease research. *Health Policy and Planning* 7, 56.
- Kitinya, J. N., Laurèn, P. A., Eshleman, L. J., Paljärvi, L. & Tanaka, K. (1986) The incidence of squamous and transitional cell carcinomas of the urinary bladder in northern Tanzania in areas of high and low levels of endemic S. haematobium infection. Transactions of the Royal Society of Tropical Medicine and Hygiene 80, 935–939.
- Kleinman, A. (1980) Patients and Healers in the Context of Culture. University of California Press, Berkeley.
- Kloos, H. (1995) Human behaviour, health education and schistosomiasis control: A review. *Social Science and Medicine* 40, 1497.
- Kloos, H., Ouma, J. H., Kariuki, H. C. & Butterworth, A. (1987) Coping with intestinal illness among the Kamba in Machakos, Kenya and aspects of schistosomiasis control. *Social Science and Medicine* 24, 383–394.
- Kloos, H., Sidrak, W., Michael, A. A. M., Mohareb, E. W. & Higashi, G. I. (1982) Disease concepts and treatment practices relating to *S. haematobium* in Upper Egypt. *Journal of Tropical Medicine and Hygiene* 85, 99–107.
- Krueger. R. (1988) Focus groups: A Practical Guide for Applied Research. Sage, London.
- Morgan, D. L. (1988) Focus Groups as Qualitative Research. Sage, London; Newbury Park, CA.
- Mugashe, C. L., Malenganisho, W. L. & Gabone, R. M. (1994) Relative contribution of Lake Victoria and inland water bodies to transmission of schistosomiasis mansoni in Kahangara ward, Mwanza Region. Proceedings of the 12th NIMR Annual Joint Scientific Conference, 21–23 Feb. 1994. National Institute for Medical Research, Arusha, Tanzania.
- Mwanga, J. R., Mugashe, C. L., Magnussen, P., Gabone, R. M. & Aagaard-Hansen, J. (1998) Experience from video-recorded focus group discussion on schistosomiasis in Magu, Tanzania. *Qualitative Health Research* **8**, 707–717.
- Nwaorgu, O. C. (1992) Schistosomiasis and women in Amagunze Southeastern Nigeria. Manuscript presented at WHO and NORAD Meeting on Women and Tropical Diseases, Oslo, Norway, 28–30 April 1992.
- Pike, K. L. (1971) Language in Relation to a Unified Theory of the Structure of Human Behaviour. Mouton & Co, The Hague, pp. 37–72.
- **Pillsbury, B.** (1982) Policy and evaluation perspectives and traditional health practitioners in National Health Systems. *Social Science and Medicine* **16**, 1825–1834.
- Raikes, A., Shoo, R. & Brabin, L. (1992) Gender-planned health services. Annals of Tropical Medicine and Parasitology 86, supplement 1, 19.

- Robert, C. F., Bouvier, S. & Rougemont, A. (1989) Epidemiology, anthropology and health education. *World Health Forum* 10, 355–364.
- Rugemalila, J. B. (1979) The impact of urinary schistosomiasis on health of two community populations living in endemic areas in Tanzania. *Tropical and Geographical Medicine* 31, 375.
- Stone, D. (1989) Cultural crossroads of community participation in development: a case from Nepal. *Human Organisation* 48, 206–313.
- Sukwa, T. Y., Bulsara, M. K. & Wurapa, F. K. (1985) Evaluation of selected symptoms in the diagnosis of *Schistosoma mansoni*. *Tropical and Geographical Medicine* 37, 295–297.
- Varkevisser, C. M. (1973) Socialization in a Changing Society: Sukuma Childhood in Rural and Urban Mwanza, Tanzania. CESO Molrnstraat, The Hague.
- Webbe, G. (1962) The transmission of *S. haematobium* in an area of Lake Province Tanganyika. *Bulletin of the World Health Organization* 27, 59.
- Yoder, P. S. (1997) Negotiating relevance: belief, knowledge, and practice in international health projects. *Medical Anthropology Quarterly* **11**, 131–146.