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Anthropological contributions to a community-based schistosomiasis control project in northern Cameroun

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Summary This paper describes how anthropological contributions and extensive cooperation between tropical medicine and medical anthropology researchers contributed to a successful community-based cost recovery schistosomiasis control project in northern Cameroun. The project led to increased knowledge about urinary schistosomiasis by local people, significant decreases in prevalence and intensity of the disease, and increased utilization of primary health care centers.

keywords Anthropology and tropical medicine, schistosomiasis control, *S. haematobium*, behavioural and cultural aspects of schistosomiasis control

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Introduction

Tropical disease control projects often use medical anthropologists to conduct KAP (knowledge, attitude and practices) or other social behavioural studies, but these studies are usually advisory. Seldom are medical anthropologists actively involved in decision-making and implementation of tropical disease control and prevention projects. This project was different from many other tropical disease control efforts in that there was regular and extensive collaboration between tropical medicine and medical anthropology researchers. U.S. and Camerounian medical anthropologists and tropical medicine researchers actively assisted and participated in each other's activities. For example, the Camerounian and U.S. snail control biologists and epidemiologists participated in community meetings and helped develop community questionnaires and health education materials, while the U.S. and Camerounian medical anthropologists assisted in the collection and diagnosis of urine and stool samples as well as in the monitoring of snail control efforts. This collaboration was also exemplified in the general administration of the project: the principal investigator was a tropical medicine researcher (B L Cline) and the field director was a medical anthropologist (B S Hewlett). Pat Rosenfield (1992) calls this regular collaboration a 'transdisciplinary' approach and contrasts it with the traditional 'multidisciplinary' approach where researchers work independently and seldom understand or appreciate each other's methods and techniques.

Before describing the Northern Cameroun schistosomiasis control project, it is essential to understand two complementary conceptual orientations, one primarily from tropical medicine and the other primarily from medical anthropology, that unified and motivated the design and implementation of the pilot control project. These were implicit underlying views that influenced and guided day-to-day planning and activities.

The first conceptual orientation emphasized using urinary schistosomiasis as an entry point to strengthening and building the primary health care system. Integrating schistosomiasis control into the existing primary health care system (horizontal rather than traditional vertical control effort) was an

important explicit goal of the project, but implicitly the project was also interested in trying to use urinary schistosomiasis to increase utilization of and trust/faith in rural health care. Utilization rates are often low in rural clinics because health care workers often lack the training, equipment, supplies or medication to diagnose and treat endemic disease. Urinary schistosomiasis is an excellent entry point to build primary health care in northern Cameroun, because it is highly endemic, the symptoms (haematuria and painful urination) are identified by the local people as an illness that needs treatment, the diagnostic techniques are cheap and easy (reagent strips), and treatment (praziquantel) is cheap and effective. Reliable and efficient treatment of a common disease like schistosomiasis builds trust and faith in the local health centre, which can in turn lead to an increase in its utilization, which can result in the increase in money the centre can use to support the diagnosis and treatment of other, less frequent, possibly more severe, diseases. This conceptual orientation was important because it reflected our genuine commitment to enhancing primary health care in general and not just promoting the control of one disease. Health care providers appreciated this orientation and it meant that schistosomiasis project resources (medical personnel, vehicles, etc.) sometimes provided training or support of other pressing community health problems (e.g. venereal disease, mengiococcal meningitis epidemic).

The second conceptual orientation originates in anthropology, but is not entirely new to tropical medicine because its basic tenets were suggested some years ago by Fred Dunn. This view emphasized building upon existing beliefs and institutions and respecting diversity between and within communities (cultural, religious, medical, individual). This orientation may seem intuitively obvious to many, but it has several implications for project design and implementation. It places individuals and communities at the centre of a project. One needs to know communities very well if one is going to build upon and respect what is already there and clearly understand what types of control efforts work and which do not. It means frequent and regular visits to communities. What do elementary school students, parents, teachers and health workers already know about schistosomiasis? What local community organizations (women's groups, church groups, parent/teacher groups) might be able to incorporate schistosomiasis health education into their activities? What community institutions might incorporate or assist with a drug-delivery system? This orientation implies the project would try not to introduce new institutions or positions (e.g. community health workers to provide health education or community pharmacies to provide praziquantel) because it assumes communities already have informal or formal structures to build upon. This conceptual orientation also means working with and responding to diversity in individuals' abilities and personalities; some village chiefs are powerful and can mobilize communities while others are not; some health centre workers respond primarily to material incentives, while others are intrinsically motivated by learning a new technique to diagnose schistosomiasis. This does not mean the project paid some health centre personnel but not others to participate in the schistosomiasis control project; it did mean that project personnel would work with, build upon and respect what existed – some health workers were motivated by having a beer or lunch with project personnel while others were motivated by learning new skills from project personnel.

While these conceptual orientations emphasize decisions from 'below' rather than from 'above', it was clear that political, social and economic decisions in the U.S. and in the Camerounian capital (both very distant from Cameroun communities) dramatically influenced what the communities and project personnel could or could not do. It is our impression that both of the above described orientations contributed substantially to the success of the project and increased the community members' confidence and trust in local health care and the diagnosis and treatment of schistosomiasis.

Study area and ethnographic background

The Cameroun Pilot Control Project

The Camerounian Ministry of Health (MOH) selected Kaele subdivision (population of about 100 000) in the Far North Province for a 'pilot' schistosomiasis control to help it formulate a national plan for the control of schistosomiasis. Kaele is the largest town in the subdivision (population 30 000), situated about 750 km north of Yaounde, the capital of Cameroun. The MOH requested and received technical assistance from USAID to conduct the pilot control and establish a national control programme. Tulane University's School of

Public Health and Tropical Medicine (TU) was already involved with the MOH and USAID in developing the MOH's capacity to conduct research on schistosomiasis and other tropical diseases, so USAID requested that TU provide technical assistance for the Kaele pilot control.

Kaele subdivision was selected because a national survey of 5th grade students indicated that 85% of all schistosomiasis cases were in the North and Far North Provinces (Ratard *et al.* 1990). Subdistrict prevalences for urinary schistosomiasis in school-age children averaged 35%, but Kaele subdistrict had one of the highest prevalences at 55%. The project focused on 14 villages in the subdivision with a health centre or a 'health house.'

The control project consisted of 4 components: health education, snail control, diagnosis and treatment, and cost recovery. The first 3 components were developed to lower morbidity by trying to interrupt the schistosome life cycle at 4 vantage points – diminishing human contact with infected water sources, reducing human urine and faecal contamination of water sources, killing the parasite in the human host through chemotherapy, and removing or reducing the number of intermediate hosts (snails). Elementary school children were selected for health education as this group had the highest prevalence rate. The two overriding goals of the project were: heavy urinary schistosomiasis infection (> 50 eggs/10 ml) should be reduced by 75%, and 70% of the elementary schoolchildren should have an understanding of schistosomiasis transmission. Detailed descriptions and specific objectives of each component are described elsewhere (Cline & Hewlett 1996).

The explicit project design was similar to many other integrative (i.e. horizontal) and comprehensive schistosomiasis control projects, but was relatively unique in that diverse approaches to health education and community involvement were central and perceived as the driving forces for all other components (diagnosis and treatment, snail control, cost recovery); and elementary schoolchildren and other patients had to pay for diagnosis (screening at schools or at clinic) and possible treatment. Other schistosomiasis control projects have targeted schoolchildren, but we are unaware of other control efforts in which students or patients had to pay for diagnosis and possible treatment.

Health education was the central component of the project. Simple, but culturally sensitive and appropriate health education methods were needed to build upon local people's understanding about the transmission of the disease and the availability of new, cheap and easy diagnostic methods and treatments. Local people would not seek treatment or support a snail control programme if they did not understand the consequences of not being treated or perceive the social or economic costs to be greater than the benefits.

The construction of pit latrines and water pumps are other methods to reduce schistosomiasis transmission and were encouraged locally and nationally, but the project was not sufficiently funded to subsidize the construction of these important items. The project worked with UNICEF and Save the Children, both of whom were involved with establishing community cofinanced wells in the region. The project was also involved at 'structural' or outside the community (called extracommunity by Dunn) levels as it aimed at establishing a sustainable regional and national drug delivery (in particular, praziquantel) and reagent strip delivery systems. With the assistance of Mr Kondji Kondji, we also advocated and supported national efforts to increase the training, emphasis and value placed on health education of nurses and physicians. Nurses who ran the primary health care centres had little background in methods, materials or philosophies of health education and often did not feel that health education was part of their job; largely because it was not an integral or valued part of their training as a nurse.

Ecological and cultural overview of Kaele subdivision

Kaele subdivision is located at about 12°N latitude and lies at the very northern limits of the Sudanic climatic zone. The area receives between 900 and1500 mm of rain annually and is 200–500 m in elevation. The landscape is relatively flat with a few basalt outcrops and the vegetation is dominated by thornbrush, semidesert scrub and a few trees (baobob and acacia). The rainy season starts in June and usually ends by late August. Critical and intensive agricultural activities take place during this period. There are few permanent water bodies in the region, but temporary ponds and streams (*maayos*) are numerous during and for some months after the rainy season (Greer 1993). Daytime temperatures are rather mild during the rainy season (25–30 °C), but warmer for the remainder of the year. It can be cool (20 °C) in the months of December and

January and this time of year is often referred to as the dry-cold season. This season contrasts with the hot-dry season that follows in February and March when daytime temperatures are often above 40 °C.

The ecological landscape is relatively homogenous by comparison to the heterogeneous nature of the cultural and linguistic landscape. Three very distinct ethnolinguistic groups – the Guiziga who speak a Chadic language, the Fulbe who speak a West Atlantic language and the Moundang who speak an Adamawan language – are the predominant ethnic groups in the relatively small (70 km by 100 km) Kaele subdivision. The Moundang are the most numerous and the Fulbe a minority (about 25%) among the 100 000 inhabitants of the subdivision. Each village is represented predominantly by one ethnolinguistic group. Fulbe is the *lingua franca*, French is taught in public and private elementary schools and Arabic is taught in the Koranic schools. Most of the Fulbe are Muslim while the majority of the Moundang and Guiziga identify themselves as Christian (Protestant or Catholic). Most Guiziga and Moundang attend private (Catholic or Protestant) or public schools while many Fulbe attend village Koranic schools. Several of the Moundang and Guiziga villages have Catholic or Protestant-supported primary health care clinics. The Fulbe moved into the area in the 1800s as part of a holy war and are the politically dominant group in northern Cameroun, but the Moundang are the politically dominant in the Kaele subdivision. Intermarriage between the different ethnolinguistic groups is relatively common, so there is often an awareness of cultural differences (e.g. different views towards schistosomiasis).

Fulbe houses are usually rectangular and are surrounded by a large wall, while Moundang and Guiziga homes are round and usually do not have walls surrounding them. The lives of men and women are more separate among the Fulbe than among the Moundang and Guiziga. Fulbe women usually do not participate in agricultural tasks because of Islamic restrictions on women's public movements; men and women have separate latrines in the residential compound and men and women wash their own clothes. Women collect the water and firewood in all groups. All groups practice patrilineal descent and patrilocal postmarital residence.

Millet is the principle food crop, supplemented by corn, peanuts and cow peas. Onions are gown in irrigated gardens and, together with cotton, constitute the main cash crops. Goats, sheep and cattle are also kept by many villagers. The Fulbe are the prime cattle producers and onion cultivators, while the Guiziga and Moundang are better known for their cotton cultivation.

Cultural contexts of urinary schistosomiasis

Before control project began, Helen Regis, a TU graduate student in anthropology, conducted a one-year ethnographic study of schistosomiasis in one Fulbe village (Regis 1997). This was part of the first, primarily research, phase of the TU schistosomiasis project. Her detailed ethnographic data provided the basis for more systematic ethnographic studies in randomly selected villages that represented all primary ethnic groups in the subdivision. This paper will summarize some of the local beliefs and practices that were eventually incorporated into the schistosomiasis control effort.

Urinary schistosomiasis is known throughout the area by its most marked symptom, haematuria, and is viewed by all ethnic groups as an illness that needs treatment. The Fulbe call urinary schistosomiasis *cille naange* or sun urine. They explain that when they spend long hours walking or working in the sun, their urine becomes red like the sun. While anyone can get the illness, children are especially susceptible because they spend so much time out in the sun, especially during the hot-dry season, when *cille naange* is said to be most common. Consequently, parents often tell their children to get out of the sun. Some Guiziga and Moundang indicated that staying out in the sun too long could cause red urine (i.e. urine with blood), but they were more likely to suggest that drinking dirty water (i.e. especially, when wells get low during the hot-dry season) or drinking water from two very different sources (e.g. well and temporary pond) as causes of red urine (*tetchoume sjmi* in Moundang; *kwanay babaran* in Guiziga). Guiziga and Moundang also frequently distinguished 'red urine' from 'white urine'. White urine was more painful, more dangerous, sexually transmitted and not as common as red urine. Red urine was much more common, not as dangerous and less likely to be sexually transmitted; it acted slowly as one often continues to be sick even after the hot-dry season when the rains start and there may not be more blood in the urine. Back and kidney pain were also associated with

red urine. Red urine is urinary schistosomiasis and white urine is usually gonorrhea. The Fulbe viewed the disappearance of blood after the hot-dry season as evidence of healing.

All groups felt that children were at a greater risk because they either stayed out in the sun too long or were more likely to drink dirty water or mix water from different sources. Young children (boys and girls aged 4–15) are responsible for grazing goat and sheep herds, usually at temporary bodies of water some distance from the village. Children are likely to be out in the sun for long periods, swim in the temporary bodies of water because it is so hot and drink from them, since no other water sources are available.

A similar situation occurs for the whole family at the end of the rainy season. Dry millet is then planted in fields several kilometers away from the house because it only grows in very specific kinds of soil. Every able-bodied person in the household assists in the planting of this staple crop (children are usually kept out of school to do this). Everyone drinks and bathes in the temporary ponds near the dry millet fields because there are no other sources of water.

People generally distinguish five different types of water sources in the environment: deep wells in the village, temporary shallow wells dug in the dry sand beds of the *maayo*, flowing water in the *maayo* after the rain, low points in the *maayo* that collect water and temporary ponds in depressions in the outlying savanna areas. People tended to prefer to obtain their drinking water from the temporary shallow wells dug in the dry sand beds and preferred to do their wash in flowing water, if possible. Women in all groups did the strenuous task of providing water for the household; many women said this was their most demanding daily task, so efficiency was very important to them –, i.e. locating water sources close to home.

The Fulbe were most likely to build latrines in their compounds, while relatively few Guiziga and Moundang did so; people urinated and defecated in fields close to their home.

Anthropological contributions

Before describing the anthropological contributions to the different components of the project, it is necessary to briefly define and clarify some terms. Anthropologists often talk about doing 'ethnography' – that is, the study of a culture. For this an anthropologist uses several methods (see Koss chapter for more detail) – sometimes qualitative participant observation methods, such as going to the fields with villagers, attending a market-day and informally interviewing people while participating and observing these activities; sometimes precoded standardized questionnaires of a random sampling of villages (KAP studies). In the section that follows, the term 'ethnographic studies' encompasses a range of anthropological methods.

Linking health education to culture and ecology

Local communities were dealing with urinary schistosomiasis long before the TU pilot project started. The role of the project therefore was to build upon existing knowledge and practices related to schistosomiasis rather than to try and completely replace and denigrate indigenous knowledge with a Western biomedical model. Ethnographic studies provided the basis for incorporating local community knowledge and practices into health education. The following list and descriptions summarize the cultural beliefs and practices that were built upon, left alone, or changed.

Cultural knowledge and practices to build upon included indigenous terms for the illness; perception as an illness that needs treatment; haematuria and painful urination seen as the most common symptoms of the illness; children considered at greater risk because of greater exposure to sun or greater chance of drinking dirty water; dirty water seen as cause of the illness; keeping children out of midday sun; recognizing the illness as seasonal; the distinction between red and white urine; the use of latrines by the Fulbe.

All ethnic groups had indigenous terms for the illness, knew the primary symptoms, recognized that it needed treatment and knew that children were at greater risk. This made health education substantially easier, as indigenous terms for the illness could be used in health education discussions, people were already used to seeking traditional treatments for the illness, it was easy for people to see the value of their knowledge, and they already understood why health education targeted school-age children (5–19 years old). This contrasts with other cultures where urinary schistosomiasis is perceived as a normal part of adolescent development and not as

an illness requiring treatment (Huang & Manderson 1992; Kloos 1995).

Local people also described a seasonality for the illness. Most people felt it was primarily an illness of the hot-dry season, because the sun is especially hot during this season or there was a greater possibility of drinking dirty water because of limited water supplies. In order to build upon this, the health education programme and messages were divided into two seasons – the 'season of symptoms' and the 'season of transmission'. The hot-dry season (February-April) was characterized as the 'season of symptoms' and built upon existing knowledge and perceptions that this is the time of year haematuria and painful urination were most common. This is also the time of year many people are most willing and able to purchase praziquantel for treatment because they receive a lump sum cash payment for their cotton harvest. Health education during this season focused on seeking treatment. The second period for health education was at the end of the rainy season (August-September), called the 'season of transmission' because temporary streams and ponds were common and frequently used for planting millet, washing clothes, bathing and swimming. It also coincides with the start of the school year. Health education messages during this time of the year focused on decreasing contamination behaviour.

People knew that children were at greater risk because children spent more time in the hot sun and were more likely to drink dirty water. Consequently, parents understood why health education focused on school-age children and were usually willing to pay for their children's diagnosis and treatment. Fulbe parents also said they tried to keep children out of the midday sun to prevent *cille naange* which often resulted in keeping children away from swimming holes in the middle of the day. This was used in health education as cercariae concentrations are highest then. Moundang and Guiziga were more likely to identify dirty water as a cause of the illness. Health education emphasized their knowledge about the importance of dirty water in the transmission of the illness, but indicated it was from contact with dirty (contaminated by human urine or faeces) water rather than drinking it.

The distinction between red and white urine made by the Moundang and Guiziga was also used in health education, primarily to emphasize the extent of their knowledge, in particular, their ability to recognize schistosomiasis and distinguish it from other types of urinary infections.

Cultural knowledge and practices to leave alone were children swimming in streams and temporary bodies of water and herbal treatments. We decided that decreasing water contact would not be emphasized in health education. It is hot year-round in the arid north and it is not reasonable or feasible to ask people, children in particular, to stay out of the water when the temperature often exceeds 40 °C. The project or community could not provide an alternative to cooling off, bathing and washing clothes, so the health education focused instead on stopping contamination, i.e. urinating and defecating far away from the ponds and rivers. This was especially important in Islamic communities where villagers preferred to clean themselves with water after elimination.

We also decided not to encourage or discourage the use of traditional herbs as it was not possible to investigate their pharmacological components. Villagers noted a variety of herbal treatments for red or sun urine, but tamarind seeds (crushed and boiled) were most frequently mentioned as an herbal treatment, especially among the Guiziga and Moundang. A recent study of traditional plants used to treat urinary schistosomiasis by Zimbabwe healers (Ndamba *et al.* 1994) indicates that plant extracts from other Leguminosae, such as the tamarind tree, were lethal to adult schistosomes. Many of these plants have tannins, which produce a red colour, and the authors suggest symbolic links between tannins and haematuria, the primary diagnostic feature. Many people reported that traditional herbal treatment decreased symptoms, but usually did not cure the illness.

Cultural knowledge and practices needing modification and change were the lack of knowledge about the role of snails as intermediate hosts and the role of water contact; lack of knowledge of the role of excretory behaviour in contaminating water sources with schistosomiasis; perception of the hot-dry season as the primary season of transmission; perceptions of severity, of cost for diagnosis and treatment and of the use of latrines.

While local people had some understanding of the causes, transmission and treatment of urinary schistosomiasis, there were aspects of the disease that people had limited or no understanding. Not surprisingly, none of the groups recognized the role of snails in the transmission of the illness. It was necessary

to add this knowledge if local people were to support a snail control effort. Many people knew dirty water contributed to transmission, but thought it was the drinking of the water rather than standing or swimming in it that transmitted the illness. Many people knew that defecating or urinating in the water could transmit parasitic illnesses, but there was no link between excretory behaviour in or near water sources and urinary schistosomiasis. Health education emphasized urinating and defecating far from water sources and the use of latrines if available. All groups thought the hot-dry season was the most likely season of transmission, so health education was divided into the two explicit seasons already described above. The local perceptions of severity as they influenced treatment-seeking behaviour are discussed in the next section.

Before the project many people did not seek health centre diagnosis and treatment because the health centre did not have the means to diagnose or treat the disease, or because they knew the treatment was extremely expensive. Few health clinics had microscopes and those that did often did not know how to use them. Only two of the villages had praziquantel in their village pharmacies, but it was prohibitively expensive (US$12–US$20 for an adult treatment) for most villagers. Consequently, health education messages emphasized that diagnosis (especially with reagent strips) and treatment (praziquantel in each village pharmacy) were cheap, easy and locally available.

Health education training was provided to all health workers (about 75) and elementary school teachers (about 250) in the subdivision. Teachers were encouraged to work with their local health centre and writing and drawing competitions on schistosomiasis were held to engage students. Extensive community input was used to develop a schistosomiasis flipchart, brochure, poster and curriculum, but the training in the use of the health education materials emphasized the methods of presenting these materials rather than letting the materials speak for themselves –, i.e. adapting the materials to the age, sex and abilities of the group; listening to people's explanations for illnesses, building upon local knowledge and practices and providing simple, clear and culturally sensitive health education messages.

Each health centre also developed written health education action plans for the season of transmission and the season of symptoms. Health education plans helped health centre personnel identify and schedule health education for a diversity of community groups – public, private and Koranic schools, churches, traditional healers, women's groups, cooperatives, traditional chiefs, political leaders, etc.

Anthropological contributions to other components

Anthropological contributions to health education were of primary importance because health education was assumed to be the driving force of other components, but anthropology also contributed to the other components of the study – diagnosis and treatment, snail control, and cost recovery.

Treatment seeking was an area of concern. Diagnosis was cheap (< 0.2 US$) and relatively easy, especially with the reagent strips, but the praziquantel treatment for an adult was more expensive (about US$1.50). The price of praziquantel was based upon what it costs to purchase the drug from a wholesaler and deliver the drug to the community. This was a substantially lower price than previously available, but ethnographic follow-up of untreated cases indicated that perceptions of severity and cost were important considerations in treatment-seeking.

Schistosomiasis was an illness that needed treatment: many said they could eventually die from it if it was not treated, and that they would get treatment as soon as they could afford it. But many people indicated that traditional treatments temporarily relieved symptoms (red urine and/or pain on urination) and some people said symptoms went away on their own after diagnosis. Some mothers mentioned they had five or more children and could not presently afford treatment. While cost was a factor, most said they would obtain treatment (or provide it to their children) after the cotton harvest, the prime cash income activity in the area. Villagers usually received a lump sum payment for their cotton in January or February and this is, in part, why treatment-seeking was emphasized in the season of symptoms; farmers were more likely to have the cash. As mentioned above, this is also the time of year when symptoms are most common.

Severity was also a concern as people were willing to wait months before seeking treatment. Consequently, health education training and materials were modified to discuss the consequences of not being treated. Bladder cancer and possible decreased fertility were mentioned,

but greater emphasis was placed on decreased fertility or potential infertility because cancer is seldom diagnosed in the area and fertility is central to marriage stability and social status (kinship resources, in particular children, are central to economic and social well-being) and is of concern to both men and women.

Ethnographic studies also contributed to the snail control effort. Snail control was attempted late in the project, in part due to fact that many people (Fulbe, in particular) did not link transmission to water. Community-wide health education had to precede any attempt at molluscicide.

Ethnographic studies indicated the fish and snails killed by the molluscicide were not of much economic or social importance. Villagers indicated they were most likely to use the shells of the snails as toys or for washing their pans; the small fish in the ponds were eaten at the end of the rainy season, but they were not regular or important elements of the diet. When the ponds were treated, there were few comments about dead fish or snails.

The greatest concern of local people both before and after molluscicide had to do with the quality and nature of the water. The treated ponds were not sources of drinking water, but could be used for swimming and bathing. Some health workers and villagers were not interested in snail control because of previous negative experiences with DDT treatments of ponds for mosquito control several years ago; it was only after the ponds were treated that people found out that DDT was dangerous to their health and that they should not bathe or swim in this water. Would the molluscicide do the same? Only two villages attempted community-based snail control, and the one with some previous experience with DDT experienced less community support. The community in general wanted snail control, but not as much money was raised to treat ponds and fewer ponds were treated there. Ethnographic studies (participant observation) also indicated the potential transmission importance of ponds near millet fields a few kilometers from the village that were planted at the end of the rainy season. Before this it was assumed that most transmission was taking place in streams and ponds next to the village (water collecting and washing sites). Health education included statements about the risks during this season.

Several of the anthropological contributions to cost recovery have already been described. Ethnographic studies evaluated how much people were willing to pay for diagnosis and treatment and when they were most likely to pay. But ethnographic studies were also important for helping to identify what structures in each community could be built upon to manage the chug delivery and cost recovery systems. Some villages already had small village pharmacies while in other villages health personnel provided drug delivery.

Impact of community-centred health education

Four villages (of the 14 in Kaele subdivision with health centres) were selected as 'assessment' villages. A fifth village in another subdivision was selected as a 'control' for health education. The 'control' village was provided reagent strips and praziquantel at the same price as villages in the assessment villages, and the health centre personnel received the same training as health workers in the assessment villages. The control village also received the health education materials flipchart and poster). School teachers in the village did not receive health education training nor did the health clinic staff develop health education plans for the community. The control village (for ethical reasons) was provided the same capacity for diagnosis and treatment as the assessment villages and therefore it could not serve as a control for the parasitologic impact of diagnosis and treatment.

Tables 1,2,3 summarize some of the significant differences between 'assessment' and 'control' village school-age children's knowledge about schistosomiasis. Table 1 indicates that children in the assessment villages were significantly more likely than control village children to recognize the role of water contact (swimming or bathing in the *maayo*) in contracting the disease, and were less likely to associate it with walking in the hot sun than children in the control village. Drinking dirty water was similarly perceived as a source of the disease in both the control and assessment villages. Table 2 indicates assessment village children clearly understood the role of snails in the transmission of the disease while Table 3 illustrates an increased awareness of the of role of the rains rather than the sun in the transmission in of the disease.

While adults were not targeted as frequently as were children, health clinic staff did include all segments of the community in health education action plans. Children were also encouraged to bring the brochures home and share their information from school with their

Table 1 Children's explanations for the causes of urinary schistosomiasis

	Percentage of children who gave this explanation	
Explanation	Assessment villages	Control villages
Walking in the sun	8.7 (22/252)	41.3 (19/46)
Drinking dirty water	25.0 (63/252)	36.9 (17/46)
Swimming in stream	64.7 (163/252)	13.0 (6/46)
Witchcraft	0.4 (1/252)	8.7 (4/46)

parents and others at home. Tables 4 and 5 indicate adults had a less marked change in schistosomiasis knowledge in comparison to children. Table 4 indicates adults in assessment villages better understood the role of water contact than adults in the control village, while Table 5 indicates an increase in knowledge about the role of the rains, end of rainy season, in particular, in the transmission of the disease while the control village adults were more likely to link the disease to the hot-dry season. Assessment village adults' knowledge of the role of snails in transmission was also double that of adults in the control village (50% to 25%).

Similar patterns in adults' knowledge were found in another small but independent evaluation of the project (Bausch & Cling 1995). Adults in an inadvertently omitted community were significantly less likely to identify swimming in ponds as a risk factor and to identify snails as important factors in its transmission by comparison to adults in the centre of the village.

Table 6 summarizes some of the changes in the utilization of the health centres for schistosomiasis.

Table 2 Children's knowledge of intermediate host for urinary schistosomiasis

	Percentage of children who identified this host	
Intermediate host	Assessment villages	Control village
Mosquito	13.7 (34/248)	26.3 (10/38)
Fly	5.6 (14/248)	39.5 (15/38)
Snail	74.2 (184/248)	18.4 (7/38)
Cow	6.5 (16/248)	15.8 (6/38)
Goat	0.0 (0/248)	7.9 (3/38)

Table 3 Children's knowledge about the season when they would be most likely to get urinary schistosomiasis

	Percentage of children who identified this season of greatest risk	
Season	Assessment villages	Control villages
Hot-dry	16.3 (41/251)	58.7 (27/46)
End of rains	57.3 (144/251)	19.5 (9/46)
Cold-dry	4.3 (11/251)	8.7 (4/46)
Start of rains	21.9 (55/251)	13.0 (6/46)

There was a sixfold jump in the number of reported cases, but even more importantly the total number of consultations at the health centres increased.

Overall prevalence of infection declined from 21% to 7% (67% reduction) in the 4 assessment villages between 1991 and 1993, and the number of heavy infections (> 50 eggs/10 ml of urine) in assessment

Table 4 Adults' explanations for the causes of urinary schistosomiasis

	Percentage of adults who gave this explanation*	
Explanation	Assessment villages	Control villages
Walking in the sun	43.4 (69/159)	60.0 (24/40)
Drinking dirty water	50.9 (81/159)	45.0 (18/40)
Swimming in stream	72.3 (115/159)	37.5 (15/40)
Witchcraft	0.6 (1/159)	0.0 (0/40)

*Adults often gave more than one explanation.

Table 5 Adults' knowledge about the season when they would be most likely to get urinary schistosomiasis

	Percentage of adults who identified this season of greatest risk	
Season	Assessment villages	Control villages
Hot-dry	39.6 (63/159)	80.0 (32/40)
End of rains	26.4 (42/159)	7.5 (3/40)
Cold-dry	3.1 (5/159)	0.0 (0/40)
Start of rains	6.9 (11/159)	10.0 (4/40)

Table 6 Utilization of 9 health centres in Kaelé that had data for both 1990 (before project) and 1992 (one year into project)

Consultations and cases	January–June 1990	January–June 1992	% Change
Total number of consultations	10418	11427	+9.7
Number of schistosomiasis cases diagnosed	167	1260	+654
Percentage of schistosomiasis cases	1.6	11.0	+587

villages declined 65% (23–8) (Cline & Hewlett 1996). In the fortuitous study of the omitted community, the prevalence of schistosomiasis infection in school-aged children in the omitted community was 71% while it was only 7% 2 km away in the part of the village that received health education. High-intensity infection was 1% in the village centre and 26% in the outlying community (Bausch & Cline 1995).

Finally, it is important to point out that local people paid for their diagnosis and treatment. The project did not subsidize diagnosis or treatment, so all costs (with the exception of health workers' salaries) associated with control were supported by the community.

Discussion

Many people from many different disciplines contributed to the success of the Kaele schistosomiasis control project. This paper has highlighted the anthropological contributions and the extensive collaboration between anthropology and tropical medicine researchers.

Philosophical and conceptual frameworks from both disciplines were complementary and provided the motivation and organizational framework for day-to-day activities – build upon what already exists and use urinary schistosomiasis to build PHC. This framework defined the community-centredness of the project. The 14 Kaele communities held meetings at the beginning and various points during the project and a KAP was administered at the start of the project, but no new volunteer positions ('community health workers') were established to help implement the programme. These meetings, the KAP and the establishment of CHWs are often the measures of 'community participation.' But community-centred or community-based means much more than this – in order to respond to communities and incorporate communities into the tropical disease control it means knowing the communities very well and responding to a diversity of political, social, cultural, economic and personality types. This means frequent interactions with various segments of the community. Hielscher & Sommerfeld (1985) have a similar view and state 'There is no single, universal way to motivate community participation. Success largely depends on factors that differ from village to village, e.g. the authority of the village chief, the internal cohesion of the village community, the general economic situation and economic stratification.'

Indigenous knowledge of the Fulbe, Moundang and Guiziga made this urinary schistosomiasis control project relatively easier than others in that all groups had an indigenous term for the illness and perceived it as an illness that needed treatment. Several other African cultures use haematuria, in part, to evaluate the coming of age in men (Bello & Idiong 1982; Nash *et al.* 1982; Akogun 1991). Among the Luguda, a man's family may have to pay 4 times the regular brideprice if he has not demonstrated 'manly [red] urine (Akogun 1991).' These and several other reasons are often given for suggesting that urinary schistosomiasis is not regarded as a priority in many communities (Huang 1992; Kloos 1995). While urinary schistosomiasis is viewed as an illness needing treatment in the Kaele area, it is also true that families have several other health needs besides urinary schistosomiasis and there were several instances where individuals did not seek treatment because of costs (of drug, getting to clinic, other competing family expenses), perceived benefits (would they get reinfected?), perceived severity (will it go away on its own) and the availability of traditional treatments. Discussing possible decreased fertility seemed to engage men and women in health education sessions and reportedly impacted perceptions of the illness.

The project had some rather obvious weaknesses. Firstly, relatively little energy was invested in structural or 'extracommunity' change. Governmental and nongovernmental agencies were approached about

building more wells, construction of latrines was encouraged, and an effort was made at the national level to increase and place greater value on health education in PHC training, but most of the time emphasis was placed on change at the individual and community level. Secondly, with all of the emphasis on community-centredness, we were surprised to discover a community 2 km from a village with a health clinic had been omitted from project activities. The project focused on the centre of the villages – this is where the health clinics and most schools are located. This points to two problems – the project probably did not serve the poorest of the poor and intracommunity political, religious, and other forms of diversity can and does lead to village inequality in health care delivery and services.

This was not the first schistosomiasis project to try and integrate schistosomiasis control into PHC (Siblya 1986), nor was it the first to use health education as the driving force for other components (Tanner 1989; Kloos 1995), but it was is relatively distinct in a few ways.

This project appears relatively unique in that people had to pay for diagnosis and treatment. This meant parents had to pay for the diagnosis and possible treatment for 4 or more children. We are unaware of other African schistosomiasis control projects where this has been attempted. Most projects provide free mass screening and treatment or mass treatment with praziquantel to school-age children along with health education (Chandiwana *et al.* 1991).

Secondly, it is one of the few urinary schistosomiasis projects to try and evaluate the impact of health education. An assumption of the project was that the ability of the community to participate in control activities rested on the delivery of health education. One of the major criticisms of health education in schistosomiasis control projects is that seldom is the impact of health education evaluated (Kloos 1995). This project evaluated health education in two ways – one intentional, one inadvertent – and both were consistent in that villages with community and school health education experienced lower prevalence and intensity of infection. Having cheap and simple diagnostic and treatment methods was not enough to motivate change. These methods of evaluating health education are very limited in that it is not clear what aspects of health education actually contributed to the lower prevalence –, e.g. did it increase treatment-seeking or did it decrease contamination behaviour? We suspect the latter, especially given the short duration of the project, but it will be important in the future to evaluate precisely how health education influences schistosomiasis morbidity.

Thirdly, it is one of the few urinary schistosomiasis control projects not associated with a water development project (i.e. dam construction or irrigation scheme). The temporary ponds and *maayos* are 'natural' parts of the landscape. Water development projects have generally led to relatively recent and dramatic increases in prevalence and intensity of urinary schistosomiasis. The high prevalences in the Kaele region do not appear to be recent and may explain, in part, why local peoples have a relatively good understanding (from a Western biomedical perspective) of the illness –, i.e. the high prevalences do not appear to be a recent development and consequently people have been adapting (biologically and culturally) to the disease for some time.

Finally, it is probably one of the few tropical disease control projects to use aspects of the 'transdisciplinary' approach advocated by Rosenfield (1992). Social scientists, epidemiologists, biologists and tropical medicine researchers with the project actively participated in each other's activities and this led to increased cooperation, better communication and appreciation of each other's methods and techniques. As we become more familiar with each others' disciplines it may be possible to merge theories, concepts and approaches to solve a common problem.

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Factors affecting knowledge of the symptoms of schistosomiasis in two rural areas near Ismailia, Egypt

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Summary

The primary method of control of schistosomiasis in Egypt is through passive chemotherapy, in which people who suspect they have the disease are encouraged to go to their local health unit to be tested and treated. If people are unable to recognize the symptoms of schistosomiasis, this strategy may fail. This paper presents data on local knowledge of the symptoms of schistosomiasis from two areas recently reclaimed from the desert near Ismailia. Using data from free-listing and triadic comparisons, it is shown that schistosomiasis is primarily seen as a urinary disease. Factor analysis performed on a series of 12 questions on the symptoms of schistosomiasis included in a survey demonstrates that responses group into three patterns, the first stressing constitutional symptoms such as weakness, the second stressing abdominal symptoms and the third blood in the urine, burning on urination and blood in the stool. The paper discusses the implications of these findings for efforts to promote regular treatment with praziquantel of people living in or near the Nile Delta who are at risk for intestinal schistosomiasis.

keywords schistosomiasis, Egypt, health education

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Introduction

There have been relatively few in-depth studies on how people perceive schistosomiasis, given the substantial impact the disease has in tropical areas. Studies that have been conducted frequently focus on the one illness term in the local language thought to be closest in meaning to schistosomiasis as defined biomedically, and have examined local ethnomedical knowledge in relation to that term (Kloos *et al.* 1982, 1986; Taylor *et al.* 1987).

The introduction of the drug praziquantel, a low-cost single-dose chemotherapeutic agent effective against all forms of schistosomiasis, has made the study of local perceptions of schistosomiasis a research priority. Whereas previously control programs frequently relied on blanket molluscicide to kill the aquatic snails that are the intermediate host for the disease, treatment with praziquantel is now the cornerstone of control efforts, with molluscicide being used focally, if at all. The primary method of distribution of praziquantel is through passive chemotherapy, in which people are made aware of the symptoms of schistosomiasis, and are encouraged to go to their local health unit to be tested and treated with praziquantel (Webbe & El Hak 1990).

This strategy places the onus on the villager to recognize that s/he may have symptoms compatible with schistosomiasis, or be at risk for the disease due to personal patterns of water contact, and then seek medical care. Since 1989, the Egyptian Ministry of Health has broadcast a series of television spots to raise awareness of the symptoms of the disease and to encourage people to seek testing and treatment (Webbe & El Hak 1990; Mehanna *et al.* submitted).

The effectiveness of passive chemotherapy is vulnerable at several points. First, if people fail to recognize the symptoms of schistosomiasis, they are unlikely to seek treatment for the disease. Secondly, clinic personnel and persons at risk must be sensitive to the tremendous variation which exists in the clinical presentation of schistosomal infection. Finally, equipment for parasitologic diagnosis and a supply of praziquantel must be present in the clinic. This paper examines the first issue, people's knowledge of the symptoms of schistosomiasis.

In Egypt's Nile Delta the epidemiology of schistosomiasis has been changing rapidly in recent years. Urinary schistosomiasis (*S. haematobium*) has declined steeply and even disappeared in many areas, while levels of intestinal schistosomiasis (*S. mansoni*) are generally in slow decline, with numerous remaining foci of intense transmission. In the 1983 Nile Delta schistosomiasis survey Cline *et al.* (1989) found that prevalences of *S. mansoni* and *S. haematobium* were 39% and 5%. In a follow-up survey conducted by Michelson *et al.* in 1990, the prevalence of *S. haematobium* had declined further to 3%, while the prevalence of *S. mansoni* declined to 23% (Michelson *et al.* 1993). Recent studies conducted in the Nile Delta have demonstrated that, although intestinal schistosomiasis is now the predominant form of the disease there, both local people and health personnel still focus on urinary symptoms (El-Katsha & Watts 1995a, b).

The commonly held view that schistosomiasis is a urinary disease has the potential to significantly reduce the effectiveness of a control strategy based on passive chemotherapy in areas like the Nile Delta where intestinal schistosomiasis predominates. People with urinary symptoms who do not have schistosomiasis may receive treatment for the disease, while people with the frequently vague abdominal and constitutional symptoms characteristic of intestinal schistosomiasis may fail to seek treatment. The subtle nature of the symptoms of intestinal schistosomiasis has recently been demonstrated in a study by Parker in the Sudan (Parker 1992, 1993).

This paper will present data from a larger study on the epidemiology and control of schistosomiasis in two areas on the eastern edge of the Nile Delta near Ismailia, Egypt. The social science component of the study examined a wide range of issues such as migration,

access to treatment, and perceptions of other health problems found at the two sites (Mehanna *et al.* 1994). This paper will demonstrate that schistosomiasis is primarily seen as a urinary disease, will examine factors that reinforce this perception, and will discuss the implications of these findings for efforts to promote regular treatment with praziquantel of people at risk for schistosomiasis.

Methods

Study sites

Two recently reclaimed areas were studied, Bitter Lakes and El-Manayef (Mehanna *et al.* 1994; El-Sayed *et al.* 1995). The Bitter Lakes/Sinai site is located 20 km south-east of Ismailia on the east side of the Bitter Lakes, which form part of the channel of the Suez Canal. The population of the study villages in the Bitter Lakes was 2887 in November 1991. The El-Manayef site is located 6 km directly south-west of the centre of Ismailia. Four of the 28 hamlets in El-Manayef, with a population of 2057, were chosen for study. In both areas there are extremely high rates of migration, and the population consists of *fellahin* (peasants) from the Nile Valley as well as recently settled Bedouin.

Qualitative research

The initial phase of qualitative research included semistructured interviews (open-ended but with a set list of topics) on health and illness and on life in the reclaimed areas; free-listing of illness and symptom terms used by the community and exploration of their meaning; and free-listing of community problems. Thirty of these interviews were conducted with residents in El-Manayef and 27 in Bitter Lakes/Sinai. Respondents were chosen on the basis of their familiarity with health and community-wide problems, and their willingness to participate in an extended interview. The data on community problems are reported elsewhere (Mehanna *et al.* 1994).

Triadic comparisons

Based on the list of illnesses generated by free-listing, triadic comparison questionnaires were developed and administered to 89 people (Weller & Romney 1988) to assess how people classify schistosomiasis (bilharzia) and other illnesses. In this technique, respondents were read the names of three illnesses at a time, and asked which one did not belong, or alternatively which two were most similar, and then asked to give the reason for their choice. For example, if the illness terms 'diarrhoea', 'stomach ache' and 'influenza' were presented to a respondent, s/he might respond either that diarrhoea and stomach ache are similar because they both affect the digestive tract, or that influenza is different because it does not affect the digestive tract. The computer programme ANTHROPAC 3.2 (Borgatti 1990) was used to produce individualized questionnaires, each with a randomized list of triads. Triadic comparisons were used to collect this proximity data instead of the more commonly used card-sorting techniques because most respondents were illiterate and it was difficult to represent the different illnesses with a drawing on a card.

Individual survey

A survey to assess various risk factors for schistosomiasis and to quantify findings from the qualitative research was conducted between November 1992 and June 1993, covering all residents 12 years of age or older who could be located and agreed to be interviewed. Questions asked included knowledge and history of schistosomiasis infection; access to television and radio; exposure to Ministry of Health advertisements about the control of schistosomiasis and interpretation of them. In the El-Manayef site 814 surveys were administered, and 1214 in the Bitter Lakes/Sinai site.

Parasitological survey

For quantitative estimation of the egg count, the Kato thick-smear technique was used to examine all stool samples for intestinal schistosomiasis (Barreto *et al.* 1990). Two slides were prepared for each participant. Patients who had schistosomiasis were weighed and treated with Distocide (praziquantel) pills. 1422 stool samples were examined for the El-Manayef site, and 1111 stool samples for the Bitter Lakes/Sinai site. Urine samples were also collected for urinary schistosomiasis, and results are reported elsewhere (El-Sayed *et al.* 1995).

Results

Semi-structured interviews

The local Arabic term used by residents of the two study areas for schistosomiasis is *bilharsiya*, and is often shortened to *harsiya*. For the remainder of this paper, we will use the word bilharzia to refer to the local term for the disease. The word bilharzia is also used on television and radio spots by doctors who describe the disease and its consequences. In interviews bilharzia or *harsiya* was almost always associated with the acute symptoms of urinary schistosomiasis, such as burning on urination and blood in the urine: bilharzia means blood in the urine, and blood in the urine means bilharzia, as illustrated in the following quote:

> 'I had bilharzia 5 times in my life. The first time I was 12 years old and the doctor gave me antibiotics but I was reinfected because I work on the land ... now as soon as I see blood in the urine I go to the clinic and take the pills'.

Some people expressed confusion about situations where a diagnosis of schistosomiasis had been made, but they were not experiencing blood in the urine. Terms that distinguish urinary schistosomiasis (*bawli*) from intestinal schistosomiasis (*ma'wi*) are used by health personnel, but were not used by respondents in these interviews. In talking about intestinal symptoms compatible with intestinal schistosomiasis, there was a tendency for people to see the symptoms as isolated entities, such as nausea (*maghas*), pain in the stomach, pain on defecation, or as types of diarrhoea or dysentery. The term bilharzia was not commonly applied to intestinal symptoms in the two study areas.

A number of general or constitutional symptoms were also referred to such as coughing, itching, nosebleeds, vomiting, pallor of the face, dizziness, lethargy, loss of appetite and weakness. Symptoms typical of liver failure secondary to chronic schistosomiasis mansoni such as jaundice, vomiting of blood and swelling of the abdomen were not mentioned.

Bilharzia was thought to have an extremely wide range of causes. Some of the causes listed, such as using canal water, performing ablutions in the canal, urinating in canals and washing animals and clothing in canals, were the same as those found in epidemiological studies. There were a number of additional causes, however, such as dust, flies, defecating on the road, eating contaminated food, drinking water from the pump, shaking hands, going barefoot and using the same bathroom as someone with bilharzia, although none are mentioned as frequently as contact with canal water.

Many informants stated that the fundamental problem with bilharzia is that there is no way they can avoid contact with canal water. For example, one informant from El-Manayef stated:

> 'My son had bilharzia because he is always in the canal. Yes, to go into the canal is dangerous, but do we have a choice? We even drink from the canal! There is no stand-pipe for clean water close-by, and we have to carry the water a great distance, so it is easier to use the canal.'

A farmer from the Bitter Lakes, whose whole family had had bilharzia more than once explained:

> 'I myself have to go into the canal everyday or else the children will not eat. I cannot go by what the television says regarding bilharzia, because there will be a great problem for me and my children. Who will feed us? So I go get the pill to cure it. We are *fellahin* (farmers) and have to cultivate the land and thank God there is a cure for it.'

Bilharzia is said to be treatable with home remedies or with medicines. One of many herbal remedies described consisted of boiling the dried skin of a pomegranate together with cumin and an herb called *shiikh*, and then drinking the resulting liquid. Many of the Bedouin say that they are not at risk of bilharzia, because they are not farmers.

Free-listing

Free-listing of common health problems was done with 27 respondents in El-Manayef and 22 respondents in the Bitter Lakes, or 49 respondents in total from the two study sites. Thirty-five different health problems were mentioned by more than one respondent, and a further 25–30 conditions were mentioned only once. The free-list for health problems which are common in the area is illustrated in Table 1. Bilharzia (*bilharsiya*) was the most frequently mentioned health problem in both lists. Other commonly mentioned health problems were high fever, cough, influenza, diarrhoea, scabies, headache,

Table 1 Free-listing of Common Health Problems mentioned as having occurred in the household

Name of illness or health problem in English and Arabic	No. of times mentioned				Description of symptoms compatible with schistosomiasis	
	EM $N = 27$	BL $N = 22$	Total $N = 49$	% of total	*S. haematobium*	*S. mansoni*
Bilharzia/*bilharsiya*	17	22	39	80	✓	✓
High fever/*sukhuuniya*	18	12	30	61		
Cough/*kuHHa*	2	13	15	31		
Influenza/*infilwanza*	4	9	13	27		
Diarrhoea/*is.haal*	2	11	13	27		
Scabies/*harsh*	7	11	18	37		
Headache/*Sudaa'*	4	15	19	39		
Saltiness/*imlaaH*	9	0	9	18	✓	
Kidney/*kila*	3	3	6	12	✓	
Eye diseases/*amraaD al-'uyuun*	5	8	13	27		
Dysentery/*duuzuntarya*	3	4	7	14		✓
High blood pressure/*Daght*	3	1	4	8		
Abdominal cramps/*maghaS*	5	9	14	29		✓
Measles/*HaSba*	5	1	6	12		
Chest pain/*wag' eS-Sidr*	3	9	12	24		
Rheumatism/*ruumatizm*	1	3	4	8		
Leg pain/*wag' er-rigl*	5	5	10	20		
Jaundice/*Safra'*	2	0	2	4		✓
Kidney stones/*haSwaa'*	3	0	3	6	✓	
Back pain/*wag' eD-Dahr*	0	6	6	12		✓
Pain on defacation/*ta' niya*	3	3	6	12		✓
Stomach pain/*wag' fom el-ma' da*	3	0	3	6		
Flank pain/*wag' eg-gamb*	4	3	7	14	✓	
'The runs'/*nazilaat ma' wiya*	0	1	1	2		
Dehydration/*gafaaf*	2	3	5	10		✓
Enlarged spleen/*taDakhkhum et-tuHaal*	0	1	2	4		
Asthma/*karshit en-nafas*	1	0	1	2		
Common cold/*bard*	0	2	2	4		
Burning on urination/*Haraqaan el-mayya*	2	0	2	4	✓	
Liver/*kabid*	0	1	1	2		✓
Toothache/*wag' es-siniin*	3	1	4	8		
Constipation/*imsaak*	2	4	6	12		
Worms/*diidaan*	5	2	7	14		✓
Tonsillitis/*el-looz*	1	5	6	12		
Gall bladder/*maraara*	2	2	4	8		✓
Various skin diseases	11	5	16	33		
Others mentioned once	22	18	40	—		

EM, El-Manayef; BL, Bitter Lakes.

saltiness (*imlaaH*), kidney and eye diseases. Similar items appear in the lists generated from the two sites, a notable exception being saltiness which was mentioned and described in detail in El-Manayef, but not in the Bitter Lakes.

The two far right columns of Table 1 indicate those conditions for which, according to descriptions given in semistructured interviews, have symptoms compatible with schistosomiasis haematobium or schistosomiasis mansoni. It can be seen that, in addition to the term

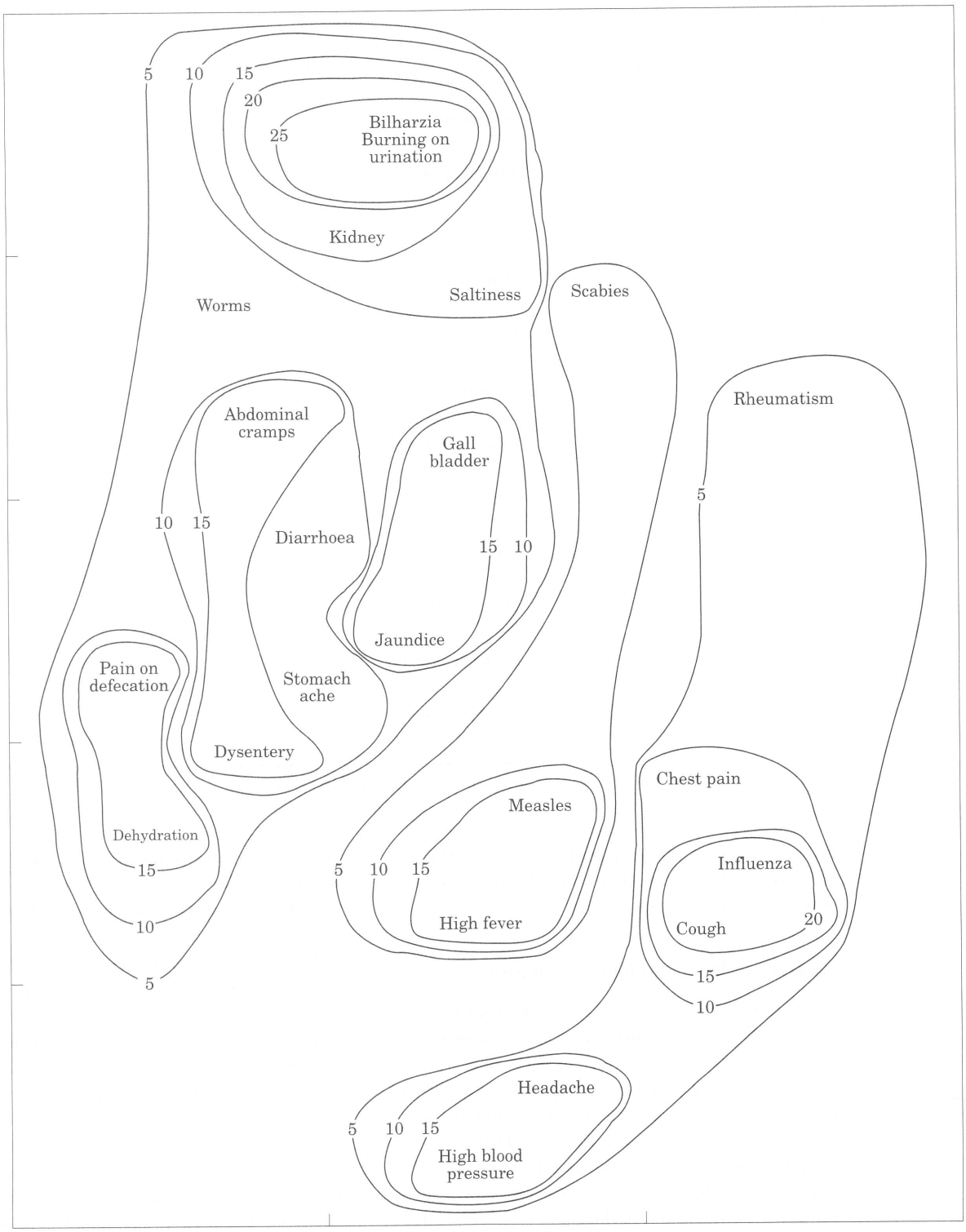

Figure 1 Results of non-metric multi-dimensional scaling (MDS) of data from triadic comparisons of local illness terms.

Table 2 Responses to questions on survey 'How often is each of these a symptom of schistosomiasis?' (N = 2028)

Symptom	Frequency of mention in 12 television spots	Always	Sometimes	Never	Don't know
Weakness	4/12	1270 62.6%	579 28.6%	101 5.0%	78 3.8%
Pale face/paleness	1/12	1223 60.3%	600 29.6%	126 6.2%	79 3.9%
Sleepiness	3/12	1077 53.1%	620 30.6%	224 11.0%	107 5.3%
Diarrhoea	0/12	440 21.7%	614 30.3%	822 40.5%	152 7.5%
Fever	0/12	468 23.1%	702 34.6%	706 34.8%	152 7.5%
Vomiting	0/12	435 21.4%	684 33.7%	780 38.5%	129 6.4%
Pain on defecation	0/12	308 15.2%	766 37.8%	808 39.8%	146 7.2%
Nausea	0/12	865 42.7%	782 38.6%	269 13.3%	112 5.5%
Flank pain	0/12	887 43.7%	752 37.1%	270 13.3%	119 5.9%
Blood in urine	2/12	1071 52.8%	700 34.5%	175 8.6%	82 4.0%
Buring on urination	2/12	1141 56.3%	664 32.7%	145 7.1%	78 3.8%
Blood in stool	0/12*	958 47.2%	743 36.6%	201 9.9%	126 6.2%

*'Mucus in stools' mentioned in one spot.

bilharsiya, at least 5 other named illnesses could be schistosomiasis haematobium clinically, and 9 could be schistosomiasis mansoni.

Grouping of illnesses with triadic comparisons

Triadic comparison questionnaires were made up using 22 of the illness terms generated in the free listing exercise. Illness terms to be used in the triadic comparisons were chosen according to how frequently they were mentioned and whether they could, in some cases, represent clinical schistosomiasis. Fifty questionnaires were administered in El-Manayef and 39 in Bitter Lakes. In each questionnaire respondents were presented a series of sets of three illness terms (triads) such as 'burning on urination', 'measles' and 'headache'. For each triad, the respondent was asked to pick which of the three terms was most different from the other two. This was also phrased as 'which two are most similar'.

Non-metric multidimensional scaling using ANTHROPAC 3.2 was first performed on the proximity matrices created from the triad questionnaires to generate the map shown in Figure 1. Items that are close together on the map tended to be judged as similar when presented to respondents in a triad. The data was first analysed separately for the two sites. When similar results were obtained, analyses were combined. The contour lines in Figure 1 indicate the groupings which resulted from hierarchical clustering, and their relative strengths. The circle around bilharzia (schistosomiasis) and burning on urination at level 25 indicates that

Table 3 Principal component factor matrix with varimax rotation of responses to 10 questions on symptoms of schistosomiasis

Variable: Is 'x' a symptom of schistosomiasis?	Communality: (% variance of original variables explained by the 3 factor solution)	Correlation between original variables and each of the three factors extracted		
		1st factor 'Constitutional symptoms'	2nd factor 'Abdominal symptoms'	3rd factor 'Symptoms with blood'
Weakness	80%	0.88	0.11	0.14
Pale face	74%	0.82	0.14	0.2
Sleepiness	56%	0.69	0.25	0.13
Diarrhoea	53%	0.13	0.71	0.04
Fever	56%	0.05	0.7	0.25
Vomiting	54%	0.19	0.7	0.09
Pain on defecation	48%	0.12	0.68	0.05
Blood in urine	75%	0.2	0.03	0.84
Burning on urination	68%	0.37	0.07	0.73
Blood in stool	60%	0	0.28	0.72
Eigenvalues		3.62	1.43	1.17
% of variance of original 10 variables accounted for by each factor		36.2%	14.3%	11.7%

virtually all respondents thought these two items were more similar to each other than either one was to the third item in the triad, whenever these two items appeared together in a triad. This was the strongest association found between any two items. Other strong associations detected through hierarchical clustering were cough and chest pain at level 23; kidney together with bilharzia and burning at level 19; abdominal cramps and dysentery at level 19; gall bladder and jaundice at level 18; measles and high fever at level 17; dehydration and pain on defecation at level 16; and headache and high blood pressure, also at level 16. Of perhaps greatest significance for this study is the fact that bilharzia is grouped with other conditions affecting the kidneys and the urine, rather than with dysentery and related conditions.

One might expect intestinal schistosomiasis, the predominant form of the disease in the two study areas, to be grouped along with other conditions with abdominal symptoms, such as abdominal cramps, diarrhoea, stomach pain, dysentery, pain on defecation and dehydration. However, no respondents associated these conditions with schistosomiasis (bilharzia).

The three illnesses bilharzia 'burning on urination', 'kidney' and 'saltiness' were grouped together and were all said to produce urinary symptoms such as burning on urination, blood or pus on urination and flank pain. Drinking water which is contaminated or too salty is seen as a cause of these illnesses. The illnesses 'burning on urination' and 'kidney' are thought to be very similar. Burning on urination was said to be caused by bilharzia, and both in turn caused by stones in the urine and salty water. Severe pain on urination, inability to urinate, flank pain and pus in the urine are symptoms of both of the illness 'burning on urination' and of 'kidney'. As mentioned previously, for many respondents burning on urination is virtually synonymous with bilharzia.

It is difficult to find a biomedical equivalent of the local term 'saltiness' (*imlaaH*). The syndrome of saltiness includes all the symptoms of the illnesses 'burning on urination' and 'kidney', but encompasses in addition a range of more generalized symptoms such as abdominal cramps, sore legs, lethargy and tiredness. People in El-Manayef feel that everyone has it to some extent, as shown in this quote from a Bedouin: 'Saltiness here is too much. Everyone has it'. The cause is said to be the salty

Table 4 Bivariate associations with factors created with factor analysis to represent three different types of symptoms of schistosomiasis

Variable	Statistical test (Degrees of freedom for t-test = 2026)	Association with each of the three factors: 1st factor 'Constitutional symptoms'	2nd factor 'Abdominal symptoms'	3rd factor 'Symptoms with blood'
Study site	t-test	Higher in older site t = 10.34 P < 0.001	Higher in newer site t = 11.21 P < 0.001	Higher in newer site t = 12.30 P < 0.001
Arrived > 15 yrs ago	t-test	Lower in recent settlers t = 6.74 P < 0.001	Higher in recent settlers t = 8.29 P < 0.001	Higher in recent settlers t = 6.14 P < 0.001
Age	Pearson's R	Higher in older people R = 0.05 P = 0.034	N.S.	N.S.
Sex	t-test	N.S.	N.S.	Higher in males t = 3.41 P < 0.001
Exposure to television spots	t-test	Higher in exposed t = 2.71 P = 0.014	N.S.	Higher in exposed, N.S. P = 0.12
Prevalence of S. mansoni	t-test	N.S.	Higher in infected t = 2.07 P = 0.039	N.S.
Prevalence of high intensity infection	t-test	N.S.	Higher in high inten. t = 2.31 P = 0.027	N.S.

environment – both the water and food grown with irrigation water are said to have high levels of salt.

Knowledge of symptoms from survey data

Twelve of the most commonly mentioned symptoms of schistosomiasis in semistructured interviews were included in a battery of questions on the large survey administered in the two areas. For each of the 12 symptoms, respondents were asked whether it is always, sometimes or never a symptom of schistosomiasis. Table 2 shows the univariate results for the 12 questions, as well as the frequency with which each was mentioned in the 12 30-second television spots of schistosomiasis broadcast on Egyptian television by the Ministry of Health. There appears to be a strong relationship between the spots and people's knowledge of symptoms. All symptoms mentioned in the spots were said to always be a symptom of schistosomiasis by at least 50% of the respondents. In addition, the symptoms not mentioned in the spots were more likely to elicit a 'don't know' response.

Principal components factor analysis was performed in the next stage of analysis to see if responses to the

symptom questions followed any recognizable pattern. The response 'always' was coded as 2, 'sometimes' as 1 and 'never' or 'don't know' as 0 to make the variables ordinal. Another option would have been to exclude the 'don't know' responses from the analysis. They were coded as 0 so as not to exclude too many cases from further analysis, and because similar results were obtained whether they were excluded or included.

Three underlying variables of factors were extracted as shown in Table 3. Weakness, pale face and sleepiness all were highly correlated (R = 0.69 or greater) with the first factor, meaning that the first factor represents a tendency among respondents to state that constitutional symptoms such as weakness, paleness and sleepiness are always symptoms of schistosomiasis. Similarly the predominantly abdominal symptoms diarrhoea, fever, vomiting and pain on defecation were highly correlated with the second factor, while blood in urine, burning or urination and blood in stool were highly correlated with the third factor. The variables for nausea and flank pain were excluded from the final solution because they were correlated strongly with all three factors, and their elimination made the solutions for each area analysed separately almost identical.

While both types of schistosomiasis occur in Egypt, results of the factor analysis in Table 3 suggest that the intestinal/urinary distinction was not very salient to respondents, as both blood in urine and blood in stool load heavily on the third factor.

The next stage of the analysis was to examine associations between the three factors and variables that might be expected to influence them. Both areas experience high rates of migration. El-Manayef is an older area, with many residents present for 20 years or more, while Bitter Lakes/Sinai is more recently settled, with many residents present for 10 years or less. Table 4 shows that in the older site, and in settlers present for 15 or more years, the scores on the first factor (constitutional symptoms) are significantly higher while scores on the second and third factors are significantly lower. It appears that when people first arrive and settle they see schistosomiasis more in terms of symptoms of acute illness such as diarrhoea, vomiting and blood in the urine. With longer residence they start to focus more on chronic and constitutional symptoms such as weakness and paleness. This is a pattern that might be expected as people acquire greater immunity to the disease.

Men had significantly higher scores than women on the third factor, but otherwise responded similarly to the women. As expected, exposure to the television spots was associated with significantly higher scores for factors 1 and 3, as these represent the symptoms mentioned in the television spots.

Detailed parasitology results are reported elsewhere (El-Sayed *et al.* 1995). In the El-Manayef and Bitter Lakes sites the prevalence of urinary schistosomiasis was 3.3% and 1.7%, respectively, while the prevalence of intestinal schistosomiasis was 49.3% and 40.0%, respectively (El-Sayed *et al.* 1995). Both infection with *S. mansoni* as well as high intensity infection (greater than 100 eggs per gram of stool) were associated with significantly higher scores on the second factor (abdominal symptoms), while no association was seen between the parasitology results and the first or third factors.

Similar results were obtained in multiple regression analysis to those presented in Table 4. In the regression equations for all three factors either study site or time of arrival drops out, while prevalence of high intensity infection drops out in favour of prevalence in the equation for the second factor. The other associations did not disappear in the multiple regression analysis.

Discussion

This paper presents data on local knowledge of the symptoms of schistosomiasis in an area where intestinal schistosomiasis is common, and urinary schistosomiasis uncommon with a prevalence of less than 3%. A key finding was that the local term for schistosomiasis is strongly associated with urinary symptoms, even though intestinal schistosomiasis is the predominant form of the disease in the two study sites. Little distinction is made between urinary and intestinal schistosomiasis. The paper also demonstrates that there are a number of apparent influences on people's knowledge of the symptoms of bilharzia. As shown in Table 4, increasing age and increasing length of residence in the area are associated with respondents stating that bilharzia has constitutional symptoms. Younger, recently arrived people appear to view bilharzia in terms of specific abdominal and urinary symptoms. This may be because younger people with less immunity are more likely to experience the acute symptoms of the disease. Actual experience with the disease, as measured by the prevalence of *S. mansoni* and high intensity infection is

associated with respondents stating that bilharzia has abdominal symptoms, as would be expected in an area where intestinal schistosomiasis predominates.

There are a number of possible explanations for the perception that bilharzia is a urinary illness in the two study areas. First, *S. haematobium* has been the more prevalent parasite in most parts of Egypt until relatively recently, and local knowledge and perceptions have not yet not caught up with the new epidemiological patterns. Secondly, migrants from Upper and Middle Egypt who settle in the Nile Delta or the newly reclaimed areas may carry with them knowledge about the disease they acquired in areas where urinary schistosomiasis is prevalent. Thirdly, health education about schistosomiasis in Egypt has often stressed urinary symptoms, and health personnel more frequently take urine samples, both of which focus people on haematuria and dysuria. Fourthly, the symptoms of schistosomiasis haematobium are more distinctive and easier to describe and remember than the vague and diverse symptoms of the intestinal form. In the Sudan, Parker (1992, 1993) found that the effects of intestinal schistosomiasis were significant but subtle, such as decreased ability to perform agricultural work, a symptom that could easily be attributed to other causes. Finally, kidney stone disease is extremely common, particularly in the newly reclaimed areas (El-Sayed *et al.* 1995). People may misinterpret flank pain, dysuria and haematuria from renal calculi as urinary schistosomiasis. The practical implications of these findings for schistosomiasis control strategies in Egypt are the following:

Content of television spots

Factor analysis showed that there were three patterns of responses on the symptom questions: constitutional symptoms, abdominal symptoms and symptoms with blood. Exposure to the television spots leads to significantly higher scores on the third factor, indicating that the spots reinforce people's focus on urinary symptoms. There is a need for a reorientation of the content of the messages transmitted in the spots to explain that there are two forms of the disease, and to stress the intestinal symptoms of schistosomiasis, especially in the Nile Delta and newly reclaimed areas where schistosomiasis mansoni predominates. The current television spots mention only once in the course of 12 spots that two forms of schistosomiasis exist, and provide no detail regarding the differences between the two. Recommendations on the content of the spots have been provided to the Ministry of Health based on this research.

Appropriate health education for recent migrants

The principal channel of communication used in schistosomiasis control efforts in Egypt in recent years has been television spots. This is not adequate for reaching settlers in areas of land reclamation for two reasons: these areas may not yet have access to electricity (Mehanna *et al.* 1994), and perceptions of schistosomiasis among persons who have recently settled is different from those who have lived for a long time in the area. The recent settlers are more likely to see the disease as one characterized by the urinary symptoms (contained in the third factor), and less likely to be aware of the constitutional symptoms. Together with their poorer access to treatment, this makes them less likely to receive chemotherapy when they need it. In this study mobile teams were used to provide treatment to the recent migrants who live furthest from the main roads and clinics. Appropriate educational messages were conveyed to adults through children who attended special summer clubs during the height of the transmission season. These clubs combined recreational activities such as sports and handicrafts with hygiene education and discussion of behaviours that put people at risk for schistosomiasis. Among topics covered in the hygiene education were the range of symptoms produced by intestinal schistosomiasis, the main form of the disease in the area.

Training of health workers

This study and others have shown that health workers themselves are often unaware of the difference between the urinary and intestinal forms of schistosomiasis. Continuing efforts need to be made to provide training and supervision of health workers to ensure that stool samples are being taken where appropriate for parasitologic diagnosis, and that patients are counselled appropriately. This has been done both as part of this study, as well as in studies in the Nile Delta (El-Katsha & Watts 1995a, 1995b).

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