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The social context of schistosomiasis and its control

An introduction and annotated bibliography

Birgitte Bruun
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Foreword by
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Special Programme for Research & Training in Tropical Diseases (TDR) sponsored by
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Birgitte Bruun[1]
Jens Aagaard-Hansen[2]

Foreword by
Susan Watts[3]

[1] Medical anthropologist, DBL – Centre for Health Research and Development, University of Copenhagen, Copenhagen, Denmark

[2] Medical doctor and medical anthropologist, DBL – Centre for Health Research and Development, University of Copenhagen, Copenhagen, Denmark

[3] Scientist, World Health Organization Regional Office for the Eastern Mediterranean, Cairo, Egypt

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FOREWORD

Schistosomiasis is widely recognized as a disease that is socially determined. An understanding of the social and behavioural factors linked to disease transmission and control should play a vital role in designing policies and strategies for schistosomiasis prevention and control. To this must be added the awareness that schistosomiasis is also a disease of poverty. It still survives in poverty-stricken, remote areas where there is little or no safe water or sanitation, and health care is scarce or non-existent. For a variety of complex reasons, many of which are addressed in this book, the disease is particularly prevalent in sub-Saharan Africa, and persists in certain areas of rural China. This concern for human behaviour in an environment of poverty echoes the concerns of the new research priority for "diseases of poverty" identified by the Special Programme for Research & Training in Tropical Diseases.

Schistosomiasis is recognized by the World Health Organization as a neglected tropical disease. However, it does not survive in tropical areas because of their unique climatic characteristics but because of poverty and neglect on the part of local, national and global actors.

Among its other merits, this book brings to our attention one of the most pressing dilemmas in the field of public health. In the case of schistosomiasis, most so-called integrated approaches have neglected preventive strategies in favour of treatment. If we opt for a truly integrated approach, we need to update strategies that have often focused on spreading messages forbidding certain behaviours. Such strategies are often not based on an understanding of local rationales for such behaviours. Rather, they originate in top-down policies designed by health policy-makers and managers who rarely visit affected populations or make an effort to understand the local social context of disease transmission and control. This approach (in Africa at least) had its origins in colonial policies based on the assumption that "experts" knew best and needed to tell "ignorant" locals how to protect themselves against disease.

This book reminds us of the need for grounded social science research to improve both preventive and curative approaches to schistosomiasis control. Exclusive reliance on mass distribution of anthelminthic drugs for schistosomiasis, as for

onchocerciasis, lymphatic filariasis and soil-transmitted helminthiasis, without prior social research and community mobilization may prove ineffective. It is acknowledged that preventive chemotherapy does need to make a special effort to reach vulnerable populations, and social science research can help in identifying these groups and ways in which to reach them. Nevertheless, undue reliance on the curative approach to tackle schistosomiasis (made possible by work in the Bayer AG laboratory in Wuppertal, Germany, in 1972 and tested in clinical trials in 1979) has its limitations. The cure-rate is somewhat less than 100%, and mass treatment is likely to miss a disproportionate number of infections because it fails to reach children not in school. Infected people can continue to excrete schistosome eggs into local water sources (lakes, rivers and canals) where farmers, children and adolescents playing or swimming, and women carrying out domestic tasks can be infected. Thus, reinfection rates remain high, and are likely to continue so if the behaviour associated with disease transmission does not change. Given the inadequacy of health systems in impoverished rural areas in sub-Saharan Africa, and the ending of donor-supported programmes in countries such as China, drug provision may not reach all who need it, or, once introduced, it cannot be sustained. In such conditions, the likelihood of a resurgence in schistosomiasis cannot be ruled out; indeed, this has recently been noted in China.

The great virtue of this book is that it presents a micro as well as a macro view of schistosomiasis. It presents evidence for the complexity of the behaviour of people in endemic areas exposed to schistosomiasis, and of health personnel who provide schistosomiasis control services. This evidence, in turn, suggests ways in which preventive programmes can be updated and made relevant to real-life situations in remote rural areas by using the insights of social scientists – medical anthropologists, health geographers, sociologists and others – whose skills enable them to explore the social context of schistosomiasis transmission and control at the micro level, in the setting in which the infection is transmitted and where efforts are made to control it. From this perspective there is no "quick fix", which highlights the importance of a schistosomiasis control policy that allows scope for local-level decision-making rather than depending on a "one-size-fits-all" strategy.

This gap in the knowledge base at the micro level is addressed by several of the research findings reviewed in the present volume, especially those in Chapter 3. Coming out of this is the unsurprising conclusion that local people exposed to

infection often view their behaviour as unavoidable. For example, farmers in Egypt do not see any realistic alternative to entering infected canals when watering their fields. Similarly, village women continue to fetch water from infected sources or use these sources for domestic tasks because they have no satisfactory source of safe water from a protected source, through a tap close to their home, or better still, in their own home. Similarly, their behaviour is influenced by the absence of a suitable drainage system for sullage (waste domestic water) or an on-site safe source of sanitation.

Preventive strategies that are soundly based on an understanding of the social context of schistosomiasis can also have an impact on childhood diarrhoea and on other diseases that are a target for preventive mass therapy. Effective actions on hygiene behaviours at the household level, and on safe water and sanitation should go hand in hand with curative approaches. These strategies will also have a beneficial impact on the general rural environment, and on women and girls who otherwise must spend many hours every day collecting water of uncertain quality from distant sources. But governments must have resources to operate an efficient health system that incorporates preventive as well as curative strategies. To achieve these ends, ministries of health need to extend their narrow remit and collaborate with other actors. These should include ministries responsible for issues such as water and sanitation, education, agriculture and finance, as well as other organizations – governmental and nongovernmental – that have an interest in the health and well-being of the rural population.

This book increases our understanding of the complex and multifaceted contexts within which schistosomiasis is transmitted and within which it is controlled – *or not controlled*. But when one third of the planet's population lacks safe water and sanitation, the forces of globalization, which also act as social determinants of health, must also be considered. Globalization impacts on health and the schistosomiasis situation in the form of externally imposed health priorities that focus on treatment and cost recovery for primary health care in poor countries, and at the country level, on poor management and on neglect of health and welfare programmes in the interests of increasing defence spending and/or the amount of money going into the pockets of interested parties – citizens and non-citizens – as a result of poor governance.

CHAPTER 1

INTRODUCTION

Main points

- *Social science research can offer insights into the dynamics of schistosomiasis transmission and control that complement studies in biomedicine and biology. These insights are useful in planning, implementing, monitoring and evaluating public health interventions.*
- *The transmission and control of schistosomiasis is best conceptualized in an eco-bio-social perspective.*
- *Social science methods and perspectives should not only be applied in research and implementation at community level, but also at health systems and policy development levels.*

Transmission of schistosomiasis is the result not only of interplay between humans, snails and parasites, but also of complex demographic, environmental, biological, technological, political, socioeconomic and cultural processes.

Schistosomiasis poses a public health challenge, but for several reasons it is not necessarily considered a priority in national and local health policies and programmes: schistosomiasis is widespread, but only a few people notice the symptoms and even fewer react in response to them; relatively inexpensive and safe medication is available and has been used with success (disregarding high reinfection rates); and the spread of schistosomiasis is very closely tied to factors beyond health authorities' traditional sphere of influence. The fact that the infection[1] is mainly found among people with very limited access to decision-making processes at both local and national levels further contributes to the limited attention given to the infection.

[1] In relation to a parasitic disease, the correct medical term would be infestation, but this book will follow common usage in the literature and use the term infection.

Global prevalence of schistosomiasis[a]

Estimates of morbidity and mortality from schistosomiasis vary considerably. Some are listed here.

About 779 million people – more than 10% of the world's population – were at risk of being infected with schistosomiasis in mid-2003.

Approximately 200 million people in tropical and subtropical zones are infected with schistosomiasis. According to a recent estimate, 207 million people were infected by mid-2003.

About 120 million people infected with schistosomiasis are estimated to be symptomatic; 20 million develop severe disease.

Schistosomiasis is endemic in 76 countries and territories. Active transmission is reported from 67 countries and territories. Of these, 46 are in Africa.

Even though the more pathogenic type of schistosomiasis is found in Asia (caused by *Schistosoma japonicum*), most of the severe cases occur in Africa, due to lacking morbidity control.

Africa is estimated to account for 85% of all schistosomiasis transmission globally and there is a growing discrepancy between sub-Saharan Africa and the rest of the world in terms of transmission and control.

[a] Source: Chitsulo et al., 2000; Engels et al., 2002; WHO, 2002; Steinmann et al., 2006.

This book focuses specifically on the sociocultural contexts that enable or constrain the transmission of schistosomiasis and influence access to preventive and curative measures. These contexts have been described and analysed within the social science disciplines of anthropology, ethnography, sociology, economics, political science, demography, communication, education and others. These disciplines share an emphasis on understanding how human practices in a given context both shape and are shaped by a vast array of influences (Williams et al., 2002). This book takes perspectives and insights from anthropology, particularly medical anthropology, and sociology as a main starting point, but reference will also be made to epidemiological and public health studies.

The overall intention of the book is to contribute to cross-disciplinary approaches to research on the design, implementation and evaluation of national schistosomiasis control strategies and programmes in endemic regions. Its specific aims are to:

- bring together existing knowledge about sociocultural aspects of schistosomiasis transmission and control;
- offer suggestions for operational implications of insights provided by the social science perspectives for planners and implementers of schistosomiasis control programmes at various levels;
- suggest directions for future social science research in the field of schistosomiasis.

The book is aimed at two main audiences:

- planners and implementers of schistosomiasis control interventions with little or no background in social sciences, who wish to integrate insights from social science into their programming;
- researchers planning to conduct social science research in relation to schistosomiasis transmission and control.

Many of the observations and suggestions will be relevant whether schistosomiasis is addressed in isolation or as one of several health problems in an integrated approach.[2]

Organization of the chapters

The social contexts of schistosomiasis transmission and control can be analysed from many angles: at individual and household levels as well as at community level, across sectors, and at the level of national priority setting and international funding priorities. In this book, these levels have been divided into three chapters dealing with the macro, micro and intervention perspective.

[2] In the literature, the term integrated control refers to three different forms of organization: (i) several control measures are integrated into one programme, i.e. health education, sanitation, treatment, snail control; (ii) control efforts are integrated into primary health care structures; and (iii) control, e.g. treatment, of schistosomiasis is integrated with (often vertical) control of other infections. This book uses the term in the final sense.

- Chapter 2 on macro-perspective studies introduces the reader to the relatively limited number of studies on the social aspects of schistosomiasis transmission that are produced as a result of structural factors at a global and national level.
- Chapter 3 on micro-perspective research sums up the main findings from studies of water contact, infective behaviour, local knowledge of symptoms, risks and treatment-seeking practices. Most of what has been published in anthropology and sociology about schistosomiasis falls under this chapter heading.
- Chapter 4 on the intervention perspective summarizes social science studies on diagnosis, access and adherence to treatment, health education and community involvement in schistosomiasis control programmes. So far, the literature on these topics has been relatively limited. The chapter closes with a discussion of social science views on schistosomiasis in a health-systems perspective.

This organization is not meant as a way of confining certain topics to specific analytical levels. On the contrary, some of these themes (e.g. gender and impact measurement) cut across the conceptual division of the chapters.

The social sciences among other disciplines in public health

The nature of schistosomiasis invites a broad range of disciplines to study aspects of the infection and changes in its distribution from their own perspective. The various social sciences have mainly been involved in studies of perceptions and behaviours, health education, community participation and, to a certain extent, the economic aspects of control programmes. An important contribution of these studies is the recognition of the complexity of schistosomiasis as a public health problem.

Anthropology, and to a certain extent sociology, has often been associated with micro-perspective studies of "exotic" beliefs, and with findings that do not appear applicable in other settings. These disciplines have also been regarded as instrumental in making local communities collaborate with control programmes. But the theoretical positions, methods and inclusive perspectives of anthropology and sociology have more to offer (Manderson, 1998). For example, they can provide an

understanding of water contact patterns beyond the registration of correlations between water contacts and reinfection. They can reflect on the complexities in sustaining the results of interventions in different settings. They can provide insights into the dynamic links between schistosomiasis, poverty and political economy at all levels. The disciplines have the conceptual capacity to critically analyse how control policies may be linked to dominant political and institutional agendas, and how such policies may feed back into the process whereby certain areas become schistosomiasis endemic and others do not. Furthermore, the disciplines have the capacity to look not only at the beliefs and behaviour of people affected by the disease, but also the beliefs and behaviour of programmers, policy-makers, public health specialists, researchers and field workers who are all "natives" in a multicentred culture of international health. Here they follow trends, position themselves in relation to authorities, struggle to raise and spend funds and to carve out a career path. These understudied social processes influence the way programmes are designed, implemented and evaluated and thereby the distribution of schistosomiasis. In other words, the disciplines have the capacity to explore the social roots – or the social production – of schistosomiasis. The link between ill-health, inequity and social exclusion has been increasingly acknowledged by global actors in recent years and attention to the social determinants of health is, for example, the basis of the formulation of the Millennium Development Goals (Watts, 2006; Irwin et al., 2006).

The contribution of social sciences will not make schistosomiasis research and control any simpler – but then again, it never was simple. Schistosomiasis is a complex phenomenon that cannot be addressed with technical fixes or magic bullets (Reich, 1988; Cline, 1995) and it appears that interventions need to shift from product-based to knowledge-based approaches, i.e. a thorough understanding is required of the biogeography, epidemiology and social context of the infection in its specific settings. Socioeconomic aspects also play an important role (Rosenfield, 1986).

Recognizing that biological, social, political and cultural factors all contribute to the formation of specific endemic profiles (Barbosa, 1998:59), Farmer (1999) has suggested that a biosocial approach should be applied to researching the diseases that afflict the worlds' poor and marginalized. Barbosa & Coimbra Júnior (1992) have observed that since many of the tropical diseases are more related to social strata than to climate (as originally implied in the term tropical), there are often

strong reasons for including social dynamics in the framing of these public health challenges. For this reason, biosocial research, as opposed to basic or operational (and traditionally more biological) research, should draw from several disciplines across the natural/social science divide.

An implication of this perspective is the move away from a focus on the risk of individuals to social vulnerability, which directs attention to the social factors and structures of inequity that make some groups or individuals more vulnerable to infection than others (Porter, Ogden & Pronyk, 1999:325). Responsibility for the infection is no longer that of the individual only – it also has a societal basis (ibid.:326). This societal basis may be enabling or constraining with regard to infection.[3]

This book offers a view of schistosomiasis less as a disease occurring in individuals exposed to a parasite transmitted by a freshwater snail, and more as a disease *produced* at local level by individuals' meaningful daily habits that are formed in social relationships influenced by national and international political choices, including choices made in control programmes.

Previous reviews of literature on schistosomiasis

The literature on schistosomiasis infection in humans has been dominated by pathology, epidemiology and physiology.

> **Selected references: previous natural science bibliographies**
>
> Hoffman DB, Warren KS (1978). *Schistosomiasis IV. Condensations of the selected literature 1963-1975. Vols I/ and II.* Washington, DC, Hemisphere Publishing.
>
> Warren KS (1973). *Schistosomiasis – the evolution of a medical literature. Selected abstracts and citations 1852-1972*. Cambridge, MA, Massachusetts Institute of Technology Press.
>
> Warren KS, Newill VA (1967). *Schistosomiasis: a bibliography of the world's literature from 1852 to 1962*. Cleveland, OH, Western Reserve University Press.

Social and economic aspects of the infection have received comparatively little attention. In 1979, Dunn published a review of the few behavioural studies that had been carried out in relation to the epidemiology and control of parasitic diseases, and proposed a set of research objectives for behavioural scientists and

[3] An alternative distinction between the concept of risk and the concept of vulnerability is proposed by Sutherst, who suggests that risk denotes the assessment of danger that disregards societal responses as opposed to vulnerability, which takes account of individuals' and societies' resilience and capacity to avert danger (Sutherst, 2004:141).

educators, which would be instrumental in control programmes (Dunn, 1979). In 1992, Huang & Manderson published a more critical review of articles relating to the social patterning of schistosomiasis, primarily based on literature from studies in Africa (Huang & Manderson, 1992). Social themes were identified in studies of the link between schistosomiasis and economic development entailing water resources development and in water contact studies that provided details of social factors, including the identification of age, sex, religion and occupation as risk factors. The authors called for research on the social contexts of water use, the intersection of social and economic activities on community involvement in interventions and household/community costs of infection (rather than only measurements of working capacity and impact on productivity). Huang & Manderson (2005) have recently published a similar review on *Schistosoma japonicum* infections.

Selected references: previous social sciences reviews

Dunn FL (1979). Behavioural aspects of the control of parasitic diseases. *Bulletin of the World Health Organization*, 57(4):499-512.

Huang Y, Manderson L (1992). Schistosomiasis and the social patterning of infection. *Acta Tropica*, 51(3-4):175-194.

Huang YX, Manderson L (2005). The social and economic context and determinants of schistosomiasis japonica. *Acta Tropica*, 96(2-3):223-231.

Brief overview of the medical aspects of schistosomiasis

Geographical distribution and prevalence

The geographical distribution of schistosomiasis is changing. Some countries in Latin America and Asia and most countries of the Caribbean and the Middle East have brought down the prevalence of schistosomiasis and prevented severe morbidity from the infection through a concerted public health effort. But in many of these countries, there are still endemic regions and a potential for resurgence exists.

In sub-Saharan Africa, prevalence levels, particularly of *S. mansoni*, have increased due to water resources development projects, population increase or displacement, migration and competing priorities in the health sector. Chitsulo et al. (2000) and Engels et al. (2002) have provided a country-by-country analysis. There are no survey data to show whether global prevalence levels have changed over the

past 50 years (Chitsulo et al., 2000:41; WHO, 2002:23; Mascie-Taylor & Karim, 2003:1921-1922) and estimates are weakened by a lack of recent data from several endemic countries.

The five kinds of human schistosomiasis and their distribution

The difference between the *Schistosoma* species is principally related to the different intermediate and definitive hosts that they infect, their morphology and their final location within the human host. The first three species listed in the table below are the most common.

Overview of human *Schistosoma* species

***Schistosoma* species**	**Location in human host**	**Distribution**
S. haematobium	Genitourinary	Endemic in 53 countries in Africa and the Middle East.
S. mansoni	Intestinal	Endemic in 54 countries in Latin America, the Caribbean, Africa and the Middle East. In many areas in Africa and the Middle East, *S. mansoni* is moving into areas where previously only *S. haematobium* existed.
S. japonicum	Intestinal	Endemic in Cambodia, China, Indonesia and the Philippines. It has also been reported from Lao People's Democratic Republic.
S. intercalatum	Intestinal	Endemic in 10 countries in central Africa.
S. mekongi	Intestinal	Endemic in Cambodia and Lao People's Democratic Republic.

S. japonicum infection is a zoonosis (the parasite has a range of mammals as definitive hosts), which greatly complicates efforts to control the disease in humans.

As with most other literature on schistosomiasis, the majority of social science studies on schistosomiasis deals with *S. haematobium* and *S. mansoni* and less with the other three species.[a] This bibliography reflects this bias.

[a] It has not been possible to review the extensive Chinese and Japanese literature on schistosomiasis for social science studies.

Parasite life-cycle

Adult worms live in blood vessels around either the intestines or the urinary bladder. Together, male and female worms produce between 50 and several hundred eggs per day (up to thousands for *S. japonicum*) that are passed out with faeces or urine. Miracidia, the first larval stage, emerge from the eggs if they reach water. For the next 6-12 hours, they are able to bore into the intermediate host, a snail, which has to be of one of a limited number of species suitable for the specific type of schistosome. After a period of multiplication of 4-7 weeks in the snail, the next larval stage, the cercariae, emerge and are now able to infect humans (or other animals). A single miracidium can develop into as many as 100 000 cercariae. Up to 48 hours after leaving the snail, the cercariae are capable of boring through the skin of the definitive host and transform into schistosomula that migrate through the lungs and liver where they mature. After 6-12 weeks, they pair and move via blood vessels to their final position, where they begin to produce eggs. An average couple will produce eggs for 2-5 years, but have been known to live for up to 30 years (Hornstein et al., 1990).

Disease progression

Schistosomiasis infections are often asymptomatic, and if there are symptoms they may be difficult to discern from concurrent diseases. The invasion, migration and maturation of the parasite induce acute schistosomiasis. Acute urinary schistosomiasis may lead to fever, dysuria and haematuria, whereas intestinal schistosomiasis may cause fever, abdominal pain, bloody diarrhoea and tender hepatosplenomegaly. If not treated, symptoms of chronic schistosomiasis may emerge after 5-15 years. The chronic phase can be divided into early and late stages.

Pathological effects of the infection mainly stem from host immunological reactions to eggs that are not successfully channelled out of the host body, but deposited in the tissues or passed by the blood vessels to the liver, where they are enmeshed in granuloma. Thus, the encapsulated eggs may cause splenomegaly, hepatomegaly and bleeding from oesophageal varices, depending on their location. Urinary schistosomiasis may lead to dysuria and haematuria in both the acute and chronic stages. In the later stages, calcification of the bladder wall, bladder stones, bladder carcinoma, hydronephrosis and renal failure may occur. Intestinal schistosomiasis may lead to portal hypertension in the late stages.

Furthermore, schistosomes may infect the nervous system, and both female and male genital schistosomiasis reduce fertility.

There is generally a good correlation between intensity and severity of infection and it has been estimated that 1 out of 10 infected people will develop severe schistosomiasis and 1 in a 100 infected people (in areas without access to treatment) may die from the disease. Death from schistosomiasis is most often caused by *S. mansoni* or *S. japonicum*, the latter being considered to cause the most severe pathogenic damage. Chronic or temporary morbidity, such as hepatomegaly, splenomegaly, anaemia and growth stunting, are more common outcomes of the infection (WHO, 2002:4) and thus of greater public health importance. Recently, attention has been directed to less well-recognized (subtle) pathology associated with schistosomiasis (King, Dickman & Tisch, 2005).

Treatment

Praziquantel administered according to body weight is an effective single-dose drug for all schistosomiasis infections. It was patented in 1979 and became inexpensive during the 1990s when patents expired. Despite the wide use of praziquantel in mass treatment campaigns over a number of years, there is no mechanism available for monitoring signs of schistosome resistance to praziquantel in humans. The issue of resistance development has received attention since studies from Senegal showed low cure-rates for *S. mansoni* infections (WHO, 2002:14-15; Mascie-Taylor & Karim, 2003:1922), and the subject continues to be controversial. Previously, oxamniquine was used for the treatment of *S. mansoni* and metrifonate was used for treatment of *S. haematobium*, but these alternatives are no longer available. Artemisinins have shown promising anti-schistosomal effects on immature worms (not adult worms and eggs), but should only be used in areas where there would be no risk of interference with malaria treatment. Initiatives to develop vaccines has been taken, but so far no vaccine candidate has successfully reached beyond clinical trials. In 2001, resolution WHA54.19 by Member States of the World Health Organization (WHO) declared that all States in infected regions should regularly reach and treat at least 75% of all school-age children at risk of morbidity due to schistosomiasis and soil-transmitted helminth infections by 2010.

Historical trends in schistosomiasis control[4]

The history of schistosomiasis control has changed with new understandings of the social dimensions of disease and their interactions with technical innovations. Furthermore, changes in research and control programmes have also been inextricably linked to "outside" factors, such as imperialism, war, development policies and institutional changes in medical schools and research institutions. Throughout the history of control, there has been a tendency to focus more on biological than social factors in the transmission of schistosomiasis (Sandbach, 1976:275).

Schistosomiasis in antiquity and older history

It is likely that schistosomiasis developed around the same time as human populations shifted from hunter-gatherer communities to agricultural settlements (Sandbach, 1976:261). It has been suggested that the infection first evolved around the River Nile (Nozais, 1987; Nozais, 2003). In 1910, Ruffer was the first to find schistosome eggs in Egyptian mummies, dating from 1250 to 1000 BC – this became the beginning of paleoparasitology as a discipline (Cox, 2002). Later immunological methodology made it possible to detect schistosomiasis in mummies as old as 5200 years (Lewin, 1977; Reyman, Zimmerman & Lewin, 1977; Miller et al., 1992:555; Bouchet et al., 2002).

For many years, the ancient Egyptian word *aaa,* initiated by a hieroglyph depicting a discharging penis, was interpreted as the word for haematuria, but this interpretation has been questioned (Jordan, 2000).

Several autopsies of Egyptian mummies have shown that the parasite existed during different periods, but it was probably not very widespread. Many years later, Napoleon Bonaparte's soldiers who were stationed in Egypt from 1799 to 1801 suffered from severe haematuria (Sandbach, 1976:262-262; Cox 2002).

S. japonicum eggs have been identified in mummified bodies from ancient China (2100 BC) (Jordan, 2000). In Japan, a disease known as Katayama disease, which affects people, cattle and horses through abdominal swelling, wasting and rashes on the legs, was first described by Fujii in 1847 (Cox, 2002:601).

4 This section on the history of schistosomiasis control draws heavily on Sandbach's detailed and critical article from 1975 (Sandbach, 1975).

Schistosomiasis has never been sustained in Europe, but *S. mansoni* eggs have been found in a latrine dating from 1450 to 1500 in Montbéliard, France, probably stemming from southern visitors or slaves (Bouchet et al., 2002).

Grove has compiled a detailed account of the history of schistosomiasis; Foster, Goodwin and Hoeppli have each produced shorter overviews. Farley has analysed schistosomiasis in the context of British and American imperialism (references below are from Cox, 2002).

- Farley J (1991). *Bilharzia. A history of imperial tropical medicine*. Cambridge, Cambridge University Press.
- Foster WD (1965). *A history of parasitology*. Edinburgh, Livingstone.
- Goodwin L (1996). Schistosomiasis. In: Cox FEG, ed. *The Wellcome Trust illustrated history of tropical diseases*. London, The Wellcome Trust:264-273.
- Grove DI (1990). *A history of human helminthology*. Wallingford, CAB International.
- Hoeppli R (1973). Morphological changes in human schistosomiasis and certain analogies in ancient Egyptian sculpture. *Acta Tropica*, 30:1-11.

In 1851, the German physician Theodor Maximilian Bilharz first identified the schistosome worm; the disease was named after him (bilharzia).[5] General consensus about the life-cycle, the various species and their intermediate hosts was not reached until 1913 after convincing experiments by the Japanese researchers Keinosuke Miyairi and Masatsuga Suzuki (on *S. japonicum*) and the British researcher Robert Leiper in 1915 (on *S. haematobium*) (Sandbach, 1976:268; Jordan, 2000; Mahmoud, 2004). Grove (1986) has outlined the history of the diagnostic method of identifying eggs in faeces.

Preventive measures replaced by technical solutions

During the late 18th century and early 19th century, before fully understanding the life-cycle of schistosomes and the role of snails, preventive measures focused on sanitation and on preventing contact with infected water through education. This was in line with a general public health approach that was based on an

[5] In 1965, WHO formally adopted the term schistosomiasis for the infection in both humans and other animals.

understanding of ill-health as a result of poor living conditions and other social factors. Another line of thought, however, considered that social change and education would hardly be effective and preferred technical solutions (Sandbach, 1976:272).

Technical solutions were further supported by three trends: (i) the germ theory of disease evolved in the second half of the 19th century; (ii) breakthroughs in drug development encouraged biochemical and physiological approaches to illness; and (iii) the medical and biological sciences became increasingly specialized.

The history of schistosomiasis research and control is closely associated with colonialism and war. According to Sandbach (1975:517), the first control programme was initiated in 1913 in Egypt where both local people and stationed soldiers were heavily infected.[6] The first programmes focused on snail control and their impact was measured by the percentage of snails killed rather than by reductions in the number of infections (Jordan, 2000:25). Mass treatment with tartar emetic was also an element, but around the 1930s, surveys in Egypt showed no impact of mass treatment, which contributed to a decrease in this type of intervention. At the same time, there was a growing interest in community development and in the economic situation of people infected with the parasite. Sanitary methods, which are theoretically the most effective methods of helminth control, were implemented in Egypt in the 1930s. The results of this intervention have frequently been referred to as ineffective (Jordan & Rosenfield, 1983:318; Sturrock, 2001:18) and the intervention was not further promoted as a control strategy. The contemporary institutional development of medicine did not encourage health education, and chemical snail control soon became the chosen intervention again.

After Leiper elucidated the life-cycle of the *Schistosoma* parasite during the first years of the First World War, snail control and mass treatment became the chosen control measures. Together with recommendations on a number of environmental control measures (which, however, were not widely implemented), Leiper considered it possible to eradicate the disease without the cooperation of the infected individuals by destroying the intermediate snail hosts (Jordan, 2000:25-26).

[6] Jordan & Rosenfield (1983:327) mention the 1930s as the time of the first control programmes; Barbosa & Coimbra Júnior (1992:217) mention 1922 and that mollusciciding was initiated in the 1940s.

The conceptual heritage of focusing on technical solutions still plays a major role in priority setting today.

The first control programme that integrated research and systematic moitoring of its effects was implemented in Leyte in the Philippines from 1953 to 1962, with assistance from WHO (Blas et al., 1989).

A public health priority

The first assessment of the global distribution of schistosomiasis and other worm infections (Stoll, 1999) and the fact that western soldiers were posted in China, the Philippines and the Pacific Islands during the Second World War made schistosomiasis a priority in the international health community (Sandbach, 1975:518). Israel, Japan, Puerto Rico and the former Venezuela[7] initiated national control programmes during or soon after the war. Based on rather loose (and, according to Sandbach, possibly exaggerated) estimates of the economic loss due to schistosomiasis, the first World Health Assembly in 1948 decided to establish an expert committee to deal with schistosomiasis alone and not in conjunction with other parasitic diseases[8] (Sandbach, 1976:266). The policy of the newly formed WHO was influenced by previous experience in Egypt and snail control was recommended as the most important single method of preventing schistosomiasis. The development of more powerful molluscicides kept optimism high without much experimental evidence that this approach could reduce the prevalence of schistosomiasis.

During the 1960s, enthusiasm for this approach declined with an increase in interest for the environment and concern about the effects of chemicals (Sandbach, 1975:518). Environmental measures of snail control, such as keeping canals free of weeds, were also applied. They were demanding, however, in maintenance and could be costly when lining canals with cement, and they were mainly successful in the context of wider agricultural development projects (Jordan & Rosenfield, 1983:314).

[7] Now the Bolivarian Republic of Venezuela.

[8] An option that receives new attention today.

Neglect of social aspects

The social aspects of water contact, and differential risk for men, women, children and people of various occupations, had been described already in 1888 and in 1905 (Sandbach, 1976:269). More social epidemiological observations were published in the 1940s by Mozley, who noted how schistosomiasis was linked to the living conditions of the poor in former Rhodesia,[9] and by Blair, who stressed the need for improved water supply and sanitation (cited in Husting, 1970:5). These fields of knowledge were, however, largely neglected during the period following the discovery of the parasite life-cycle. They were rediscovered and emphasized only in the mid-1960s, when Farooq & Mallah (1966) and Farooq et al. (1966a, 1966b) published a series of articles from one of the first comprehensive studies of schistosomiasis that included sociological aspects of transmission in Egypt (the Egypt-49 project). One article documented how occupation, education, religion and washing habits were correlated with infection. Other articles discussed patterns of water contact, the presence of household latrines and infection.

During the 1960s, schistosomiasis again received new attention as a public health problem that should be addressed by national health authorities and international organizations. Again, great optimism prevailed that technical progress in diagnosis and epidemiological techniques made during the 1960s would be matched by practical achievements in the field in the 1970s (Husting, 1970; Southgate, 1970). Snail control was still a preferred strategy, together with mass treatment,[10] and actually played a crucial role in schistosomiasis control in China (Cheng, 1971; Utzinger et al., 2005), whereas sanitary measures and health education was much less represented in control projects (Sandbach, 1975:518). This happened at a time when attention to community development and social conditions increased in the wider field of international health. Less developed countries became independent from their colonizers, an interest in economic growth emerged, cost-benefit analyses were developed, the costs of medical science increased, and the radical shifts in health policies in China and Cuba led to increasing concern

[9] At that time, the territory of Rhodesia was divided into Northern Rhodesia (now Zambia) and Southern Rhodesia (now Zimbabwe).

[10] Mass treatment was not always risk free. Apart from drugs that were complicated to administer due to their high levels of toxicity, mass inoculation with antimonial compounds for the treatment of schistosomiasis in Egypt from 1961 to 1986 was linked to a higher prevalence of hepatitis C (Goldstein, 2001).

with social and economic factors in the assessment of health programmes. In the mid-1970s, Sandbach argued for less focus on snail control and increased focus on sanitation and for incorporating findings about social factors and water contact into control strategies (Sandbach, 1975:519).

A move to a holistic approach

Following the Alma-Ata Declaration of 1978, there was a drive towards integrating the prevention and treatment of schistosomiasis into primary health care using a holistic approach (implementing several types of interventions simultaneously) that should be backed by national political commitment and knowledge produced by collaborating researchers from several disciplines (Mata, 1982). The WHO Expert Committee on Epidemiology and Control of Schistosomiasis in 1978 asserted that "comprehensive understanding of environmental, demographic, social, human behavioural and economic factors in schistosomiasis is essential for the design of control programs that are successful in the long run" (cited in Kloos, 1985:609).

In 1979, praziquantel was approved for humans and made generally available for selective and mass treatment during the 1980s. This was followed by a WHO strategy focusing on treatment in 1984, which had become feasible due to the availability of safe and effective single-dose medicine. Treatment campaigns were initiated in numerous endemic areas, often involving substantial external funds. It was expected that an initial reduction in prevalence levels would enable national health authorities to take over implementation in a maintenance phase. However, transmission and reinfection persisted at high levels in many areas and most donor-funded vertical control initiatives initiated during the 1980s proved to be unsustainable after funding was phased out (Engels et al., 2002:139).

As a consequence, WHO in 1991 reinforced its 1984 recommendation to shift from transmission control (focusing on the prevalence of infection) to morbidity control (focusing on the intensity of infection). Furthermore, it was recommended that programmes should shift from vertical implementation to implementation through primary health care structures. Around the same time, the price for praziquantel fell from US$ 3.00 to today's less than US$ 0.07 per tablet (excluding distribution costs, etc.), due to expired patents.

From transmission control to morbidity control policies

Recognizing the diverse epidemiological profiles of the infection, it has been suggested that a distinction should be made between strategies for morbidity control, infection control and transmission control, which are built on a concept of staged control towards elimination (Coura, 1995; Engels et al., 2002). Following a recommendation by the WHO Expert Committee on the Control of Schistosomiasis in 1984, the strategy for schistosomiasis control at the global level was adjusted from transmission control to morbidity control (WHO, 1985). In 1991, the WHO Expert Committee on Schistosomiasis observed that programmes had placed "increased emphasis on the role of health education and safe and adequate domestic water supply, as well as sanitation, in the maintenance of control of schistosomiasis" (WHO, 1993).

More recent policy recommendations include a resolution in 2001 by the World Health Assembly (WHA54.19) encouraging synergies between helminth control and other control programmes for communicable diseases. In 2004, a resolution by the Partners for Parasite Control proposed that the control of parasitic worm infections should be incorporated into a multidisease control approach, together with tuberculosis, malaria and HIV/AIDS (WHO, 2005).

Several studies calculate the costs of treating various target groups using different strategies (Guyatt et al., 1994; Guyatt & Tanner 1996; Guyatt 2003; Mascie-Taylor & Karim, 2003:1922). The availability of inexpensive and safe drugs has greatly facilitated, if not spurred, the current WHO strategy. Nonetheless, the challenge remains of establishing measures and structures that will prevent reinfection and sustain the lower prevalence and intensity levels after treatment.

Selected references: the history of discovering and controlling schistosomiasis in China, Japan, the Philippines and the Mekong River basin

China

Cheng TH (1971). Shistosomiasis in mainland China. A review of research and control programs since 1949. *The American Journal of Tropical Medicine and Hygiene*, 20(1):26-53.

Utzinger J et al. (2005). Conquering schistosomiasis in China: the long march. *Acta Tropica*, 96(2-3):69-96.

Japan (specifically on the history of schistosomiasis research and eradication)

Ishii A, Tsuji M, Tada I (2003). History of Katayama disease: schistosomiasis japonica in Katayama district, Hiroshima, Japan. *Parasitology International*, 52(4):313-319.

Minai M, Hosaka Y, Ohta N (2003). Historical view of schistosomiasis japonica in Japan: implementation and evaluation of disease-control strategies in Yamanashi Prefecture. *Parasitology International*, 52(4):321-326.

Tanaka H, Tsuji M (1997). From discovery to eradication of schistosomiasis in Japan: 1847-1996. *International Journal for Parasitology*, 27(12):1465-1480.

The Philippines

Blas BL et al. (1989). Epidemiology and control of schistosomiasis in the Philippines: progress report as of 1987. *Memórias do Instituto Oswaldo Cruz*, 84(Suppl. 1):105-116.

Blas BL et al. (2004). The schistosomiasis problem in the Philippines: a review. *Parasitology International*, 53(2):127-134.*Memórias do Instituto Oswaldo Cruz*, 84(Suppl. 1):105-116.

Mekong River basin

Ohmae H et al. (2004). Schistosomiasis mekongi: from discovery to control. *Parasitology International*, 53(2):135-142.

CHAPTER 2

THE MACRO PERSPECTIVE: BROAD SOCIAL DYNAMICS INFLUENCING THE DISTRIBUTION OF SCHISTOSOMIASIS

Schistosomiasis has been described as a "three factor disease" involving schistosomes, snails and humans (Kloos, 1985:609). However, this conceptualization of transmission may seriously limit an understanding of the processes that lead to "endemization". Endemic areas emerge in conducive social complexes where cultural processes interact with bioecological processes (Barbosa, 1995), and they are often largely determined by social disparities (Farmer, 1999:4). Each case of schistosomiasis, transmission is enabled by the interrelated effects of broader environmental, climatic, biological, political, demographic, economic, social and cultural trends. Furthermore, programmes for disease control are influenced by policies and priorities of resource allocation.

This chapter focuses particularly on the factors that have roots in social determinants at the macro level. The most well-documented factor is living near water resources development projects, but migration has also received some attention in the literature, often in connection with studies of urbanization. Studies of these factors are often heavily inspired by the epidemiological approach of measuring univariate associations at a given point in time. A few studies, however, incorporate observations about the relations between infection and processes of poverty, marginalization and social change, which profoundly influence vulnerability and equity in access to services. Furthermore, some studies place these observations in an account of specific historical circumstances. Insight into what has been termed "the politics of disease" or "the political economy of disease" highlights that the distribution of infection is not "natural", but socially produced within certain power relations (Vaughan, cited in Huang & Manderson, 1992:176). Wider social, economic and political factors influence how areas become and stay endemic as well as the ways that results of various control efforts are more or less sustained. To the extent that gender relations can be considered a factor operating at a structural level, relevant studies are also included in this chapter.

Studies of the link between water resources development projects, infection and equity

Main points

- *Not only environmental changes, but also social changes linked to water resources development projects may contribute to increased inequity and risk of infection.*
- *Those who gain economic benefits from water resources development projects are rarely those who are exposed to its health hazards.*

Both large- and small-scale water resources development projects are often established to satisfy agricultural production and energy needs for growing populations. Such initiatives for human and economic development, unfortunately, often lead to increased morbidity for local populations (Traoré, 1989; Watts & el Katsha, 1995; Parent et al., 1997).

Schistosomiasis can be regarded as one of the most sensitive and obvious indicator diseases of environmental change following the establishment of lakes, waterways, dams, irrigation schemes and reclamation projects in many areas of the world. If preventive measures and health services are insufficient or non-existent, infections appear a year or two after the change and the new symptoms are often recognized by the local population. Changes in the health and nutritional status of people living near new water resources development schemes can be used as simple indicators of how people adapt to the new environment in general (Parent et al., 1997).

Accurate and valid data on disease prevalence before and after the development of water resources are rarely available. Governments are often not interested in publishing figures showing that health has deteriorated following initiatives for large-scale water resources development (Hunter, Rey & Scott, 1982:1128). Nevertheless, the available literature convincingly documents the link between water resources development and the spread of schistosomiasis. Evidence for the link has been particularly persuasive from Africa (e.g. Kloos et al., 1980). A study

that discusses this link more in detail can be found in a recent meta-analysis of 24 studies (including 35 datasets) from Africa (Steinman et al., 2006). The same review estimates that of the 779 million people worldwide at risk of infection in mid-2003, 13.6% were at risk because they lived near large dam reservoirs and irrigation schemes.

Large-scale water resources development schemes receive most of the attention when it comes to increased risk of schistosomiasis. But taken together, small local impoundments constructed for fishing, water supply, cattle and livestock watering, irrigation and flood control may play an even more significant role in disease transmission. These smaller schemes, which are often created for the benefit of locals, as opposed to the larger schemes (Waddy, 1975:39), rarely include plans for adjusted health-care needs (Hunter, Rey & Scott, 1982:1132). The increase of diseases due to small dams for agricultural development, such as those established in Upper East Region in Ghana, is not transient, but permanently entrenched in the regional disease ecology (Hunter, 2003:231).

Discovering the link between water resources development and schistosomiasis

Alarming rises in the prevalence of schistosomiasis were first documented in connection with a low dam irrigation scheme at Aswan in Egypt in the early 1930s (Hunter, Rey & Scott, 1982:1128). In the early 1960s, the drastic impact of a large dam on the prevalence of schistosomiasis was documented from the Akosombo dam in Ghana (WHO, 2002:38). Following the establishment of the Aswan High Dam in Egypt (in 1970), the closure of the Diama dam on the Senegal River (completed in 1985) and Manantali dam on the Bafing River in Mali (completed in 1988), it was not only observed that the prevalence of schistosomiasis rose, but also that there was a shift from *S. haematobium* to massive outbreaks of the more severe intestinal infection with *S. mansoni*, which is harder for locals to detect (WHO, 2002:39).

The Three Gorges Dam in southern China, to be finalized around 2010, is expected to increase the transmission of *S. mansoni* by preventing the annual flushing of snails (Li et al., 2000).

Even though there is massive evidence of increases in infection in connection with water resources development projects, a study from Mali, however, shows how prevalence may not necessarily rise as a result of water resources development (Traoré, 1995). Patterns of infection after the establishment of dams and irrigation schemes may differ markedly between population groups due to various social factors, including traditions of agriculture and/or fishing as the main source of subsistence.

A study from the State of Bahia, Brazil, showed that prevalence of *S. haematobium* infections did not increase with expansion of irrigation systems. Due to investments in advanced technologies for irrigation and agriculture, farmer's direct contact with water was reduced. In areas of the state where irrigation was not mechanized, prevalence rates were higher (Martins Jr & Barreto, 2003).

Effects on health status

Environmental change due to irrigation schemes and its consequence for snail populations can be complex and does not always lead to increased transmission (Kloos, 1985:620). But several studies have observed the paradox that even though dam and irrigation projects are often established to increase agricultural production, the health and nutrition of the farmers' families often worsen. This is linked to an increase in diseases directly associated with water bodies, such as malaria, schistosomiasis, other parasitic infections and diarrhoea. This may be due to increased numbers of vectors, changes in dietary intake or new patterns of incomes and expenditures at the household level. Migrants coming to the area may bring other communicable diseases, with human immunodeficiency virus (HIV) infections and other sexually transmitted infections as particular problems.

Family structures and gender roles may be altered, with consequences for health, which is also linked to the location and accessibility of new homes and essential infrastructure, such as schools, health centres and roads (Parent et al., 1997).

In short, water resources development projects do not only change the environment, but also affect the social structures in which health and well-being are produced. It should be taken into consideration that different social changes and types of risk appear in different phases of water resources development:

(i) when a water resources development project is constructed; (ii) immediately after its completion; and (iii) in the normal operation of the scheme (Hunter, Rey & Scott, 1982:1127).

Effects on equity

The risks and benefits of economic development stemming from water resources development are not equally distributed. In fact, social and economic inequity is often further increased by such schemes – people in towns and participants in the wider national economy enjoy electricity, waged employment and other economic benefits generated by the scheme, while people living at the lakeside suffer from increased disease burden and are often worse off than before (Hunter et al. 1982:1136). "Thus, ironically, economic activity, under the banner of 'development', is creating ill health, which is a strange form of societal self-abuse" (ibid.:1135). Following this perspective, and recognizing the overwhelming documentation of how the emergence of endemic areas is linked to water resources development, the changing geography of schistosomiasis can be interpreted as a management failure rather than as increased risks due to environmental change (Bergquist, 2002:309).

In general, health risks are greater in highly endemic areas of disease with economically weak populations (Hunter, Rey & Scott, 1982:1131). People moved from land that was submerged or requisitioned are affected by economic and social disturbances during the years between abandonment of cultivated lands and adaptation to their new situation. Even when resettlement programmes are implemented, changes in lifestyle make children and pregnant women particularly vulnerable (ibid.:1127). Another population group that is rarely included in studies or public health measures is people living outside the defined water resources development project areas, who may, nevertheless, be affected by changes in the environment and in schistosomiasis transmission (Kloos, 1985:611).

Dunn (1979:508) proposes that results of studies of behaviour should be made available to planners before the design and construction of water resources development projects. Hunter, Rey & Scott (1982) and Mouchet & Carnevale (1997) argue for policies to incorporate health protection in planning and costing of water resources development projects. The latter article provides detailed

suggestions on how to implement and monitor such policies through integrated multisectoral planning. See also Chapter 4 for recommendations regarding health impact assessment tools.

The changing global climate

Another macro context for analysing the spread of schistosomiasis and other vector-borne infections is global climate change (Mouchet & Carnevale, 1997). In a framework for an integrated assessment of the impacts of different "global change drivers", Sutherst (2004) proposes that factors such as land use; water storage and irrigation; industrial, agricultural and chemical pollution; trade and human movements as well as urbanization have the potential, together with climate change, to influence the spread of vector-borne diseases.

Sutherst suggests that adaptation and successful control in different countries and community groups will depend on three capacities (apart from the availability of appropriate technology):

- effective surveillance for feedback and motivation for change
- community ownership of control measures
- viable public health infrastructure for service delivery.

Adaptive capacity is linked to social and economic development and stability (ibid.:165).

Implications for planning and implementation of control programmes

- Planners and managers should ensure that health impact assessments are conducted in relation to water resources development projects, taking broader equity aspects into consideration.

Directions for social science research

- How do different households and groups manage the short- and long-term social and economic changes as well as the new health hazards that are related to water resources development projects?

Studies of links between schistosomiasis, mobility and urbanization

Main points

- *Studies of the links between schistosomiasis and mobility such as labour migration, tourism or conflict focus on how infection is spread to new environments and populations. Some studies analyse this movement in terms of social vulnerability.*
- *Studies of the links between schistosomiasis and urbanization focus on how urban areas without adequate safe water supply, sewage and sanitation infrastructure can become transmission sites. Some studies relate these observations to sociopolitical factors.*

Mobility

Different patterns of mobility lead to different forms of vulnerability to schistosomiasis. In general, water resources development projects and the intensification of agriculture often lead to changes in mobility patterns as they attract construction workers, farmers and fishermen, who settle more or less permanently in the area (e.g. Traoré, 1989, in Mali). Mobility of individuals or entire families may be related to availability of land, access to paid labour, or the opportunity to escape social pressure in their home village. The mobility may be seasonal, over long or short distances for paid work or for new grazing fields for livestock. Or it may be caused by disaster and conflict, which again entails different social dynamics (Kloos et al., 1980; Kloos, Desole & Lemma, 1981; Mehanna et al., 1994).

There can be high rates of mobility over short distances between rural areas, which may influence the distribution of schistosomiasis and reinfection rates. For example, a rural area of north-eastern United Republic of Tanzania was characterized by an unusual non-focal distribution of the infection. Researchers examined the role of mobility in the emergence of this pattern and found that the total population exchange was more than 60% – mainly from one rural area to another – between 1969 and 1971. The main motives for migration for women were marriage and divorce. Death and disease, coupled with fear of witchcraft, were very common reasons as well, but the most frequent motivation for both

emigration and immigration was environmental factors, such as shortage of land, infertile soil and insufficient water supply. Ruyssenaars, van Etten & McCullough (1973) discuss the role of emigration in the spread of schistosomiasis to previously non-endemic districts in the area. Studies from China describe similar scenarios. Additional factors in the endemization of new areas in China are infected livestock brought by migrants as well as certain aquatic plants that unfortunately serve as good breeding sites for host snails (Huang & Manderson, 2005:225-226).

The link between schistosomiasis and people's movements can be analysed in the context of broader political and economic changes, such as the historical introduction of *S. mansoni* to Latin America with African slaves, where their poor living and working conditions created an environment favourable for transmission (Loureiro, 1989). Another analytical entry point to understanding the link between mobility and infection can be the micro perspective, where the exploration of individuals' and families' motives for moving can illuminate how they may be vulnerable to infection (see Chapter 3). Disch et al. (2002) provide an example from Brazil of the impact of mobility on the results of a control programme.

Mobility linked to water resources development

Migration in connection with the establishment of dams may lead to overcrowding, rising costs of living, commercial speculation, prostitution and other social problems. Inadequate relocation schemes, loss of usual sources of income, unemployment, social insecurity and insufficient family budget have consequences for educational, hygienic and nutritional conditions (Hunter, Rey & Scott, 1982:1127). New project sites and unplanned settlements may not be included in schistosomiasis control programmes and officials may not even have accurate estimates of the size of the population in the area (Mehanna et al., 1994:287). It seems that such changes have not resulted in as negative health outcomes in Latin America as elsewhere because preventive health services have been in place and because project planners have contributed financially to control efforts (Hunter, Rey & Scott, 1982:1131).

In a study of the prevalence of a range of helminth infections in the Awash Valley in Ethiopia, ecological and cultural changes during the previous 20 years were analysed (Kloos, Desole & Lemma, 1981). It was observed that even though pastoralists had been pushed into closer contact with more intensely endemic

areas, they still had a lower prevalence of most parasites and less than half as many multiple infections compared with settlers, subsistence farmers, indigenous farm labourers and migrant farm labourers. Hookworm and *S. mansoni* infections were the infections with the greatest variation among the ethnic groups and between pastoralists and farm labourers.[11] As women did not work in irrigated fields, prevalence was higher in men. Since the 1950s, the area had undergone profound environmental and cultural change due to the construction of high dams, irrigated agriculture occupying the best grazing lands and serious droughts in the early 1970s. Loss of livestock and human life caused survivors to move nearer to irrigation schemes and almost all seven ethnic groups in the area had changed from exclusive semi-nomadic pastoralism to living from a mix of animal husbandry and farming. Competition for the remaining grazing land was intense between the groups.

Urban to rural mobility

Growing weekend tourism of middle-class urban residents visiting rural areas in the vicinity of Belo Horizonte in Brazil leads to exposure of new sections of the population (Enk et al., 2004). The proposed solution involves collaboration between owners of resorts, local health authorities and specialists of different scientific and technical areas to develop health education, sanitation measures and assistance to local health services, and involvement of the local political authorities, the local community and individual owners to not only improve health, but also preserve the environment. Comprehensive control efforts should become a matter of public state policy in order to secure "economic stability on a large scale and sustainable basis and not only punctual and restricted to limited areas in consequence of scientific investigations" (ibid.:107).

Rural to urban migration

A study of the infection trends between 1950 and 1990 measured the impact of control interventions in counties of Bahia, Brazil, through an analysis of figures

[11] Again the distribution of parasites was also closely related to environmental factors. An epidemiological study by Kloos et al. (1977) showed that Afar semi-nomads living in a swamp and lake area were generally more infected with *S. haematobium* than Afar farmers living in a nearby, but drier area of the Awash Valley, before two dams were established during the 1960s. *S. mansoni* had not been identified in the area prior to the projects, but 11 years later, *S. mansoni* was common among migrant farmer labourers in the valley. At the same time, the transmission of *S. haematobium* declined more than 50% among pastoralists between the 1960s and the 1970s because swamps had decreased in number and size due to the up-river dams (Kloos, 1985:618).

for population mobility, water and sanitation, treatment coverage and prevalence levels. Apart from a reduction in the overall prevalence from 15.6% to 9.5%, the analysis showed that there had been no changes in the overall spatial distribution of schistosomiasis and that long-term reduction of prevalence in some areas showed no links to the mass treatment campaigns that had been implemented since 1975. Instead, migration in combination with increased access to piped water supply and sanitation, changes in the ecosystem that influenced local fauna, and changes in water contact habits explain the reduction of prevalence. These were, however, also the factors behind the rise in prevalence in some counties, where new transmission sites had appeared. The analysis concluded that in this environment, control strategies based on repeated mass treatment would be relatively expensive, compared with more permanent changes in the environment, combined with health communication to increase the effectiveness of control interventions (Carmo & Barreto, 1994).

A case-control study assessed the relationship between migration from rural to urban areas and schistosomiasis in São Lourenço da Mata, north-eastern Brazil. People born in this urban area and migrants coming from other endemic areas had the same probability of being infected, whereas migrants coming from non-endemic areas would only have the same probability of being infected as people born in the urban area after five years of living in the town. The study data could not explain this observation, but the authors suggest that either the migrants from non-endemic areas had different water contact patterns than locals and migrants from endemic areas, or their contact with water took place where there was no transmission. The paper draws attention to the distinction between structural and socioeconomic reasons for migratory movements and individual migrants' specific motivations to move, which is relevant for a proper understanding of migration and risk (Ximenes et al., 2000).

It has been suggested that control programmes in areas where conflict and other factors can disrupt control programmes should include environmental management components to sustain the impact of chemotherapy and delay return to high prevalence rates (Bos & Mills, 1987:162). Only one study of schistosomiasis in conflict areas was found (Wilcocks, 1962, cited in Sandbach, 1976:265), which focused more on the biomedical interrelation between schistosomiasis morbidity and malnutrition among fishermen on Lake Albert in eastern Africa during times of conflict.

Urbanization

Urban populations are projected to grow globally. Over the next 25 years, the number of people will double in Africa, almost double in Asia and grow by almost 50% in Latin America and the Caribbean (WHO & UNICEF, 2000). This urbanization process will often happen in an unregulated way, which will put pressure on the infrastructure of towns and cities – not least in peripheral slums and squatter areas, where labour migrants often settle.

Inadequate sewage systems and lack of latrines and piped water create local transmission sites that are sometimes compounded by lack of political will to improve the situation for people living in these areas (Saker et al., 2004). Large slum and squatter areas around towns and cities are characterized by overcrowding and very poor standards of hygiene. Transmission of worms is often particularly intense in the marginalized communities living in these areas, but they are rarely included in control programmes (WHO, 2002:28). Furthermore, settlers in these areas are often "illegal" and thus without the necessary papers to access local health services if they notice symptoms of infection. "Urban schistosomiasis" has been observed since the mid-1960s (Bradley, 1968), and has been documented in several later epidemiological studies.

In Paracambi, Brazil, an analysis of different sections of the town and its suburbs showed that a few people living in a densely populated area had high intensities of infection (Soares et al., 1995). The area was characterized by streams running through many backyards that were used for disposal of waste materials, and by the absence of treated water, which led to use of natural and untreated sources. According to the authors, control measures in such situations would include investment in sanitation and chemotherapy, synchronized with snail control. Individual household initiatives to improve water quality and sanitation were limited by the cost of installing and maintaining clean water supply and septic tanks and by the attraction of water sources for leisure activities.

It is important to take three factors into consideration when analysing schistosomiasis in urban areas.

- There is a high mobility of people between urban and rural areas (Mott et al., 1990).

- Transmission is usually higher in less developed parts of cities (Ernould et al., 2000).
- Health-care facilities are often more numerous in urban areas than in rural areas, but are still stratified according to the socioeconomic level of different quarters (ibid.).

Some studies of urban schistosomiasis apply "neighbourhoods" as a basic unit of analysis, while Cadot et al. (1998) propose to work with "points", in a more detailed mapping of the spatial distribution of risk of infection, since transmission is usually so focal.

In a study from urban São Paulo, Brazil, da Silva (1985) observes that previous studies had exaggerated the role of migration in their analysis of how transmission of schistosomiasis was established. Instead, the pattern of urban growth into the surrounding lowlands, as opposed to previous expansions in more elevated areas, made the establishment of transmission foci possible.

A study in urban Niamey, Niger, described the trends in the distribution of schistosomiasis among schoolchildren in relation to water contact as well as seasonal travel. It was observed that the prevalence had fallen from 24% to 16% compared with a relatively similar survey in the school population in the same area nine years earlier. The study linked this observation to the rapid growth of the city during the previous nine years and suggests that urbanization is not beneficial for transmission. It was furthermore observed that the distribution of parasites depended on the school's location in relation to water sources rather than whether the quarter was richer or poorer, or the type of school (public or private, secular or Koranic). Prevalence of infection correlated with living in a traditional area of Niamey with no piped water. Even though this fact does not necessarily indicate the origin of infection in areas where seasonal mobility of the population is high, the elevated risk of infection in areas where recent migrants had settled near the river, compared with new settlements further away from the river, indicated that infection was locally contracted rather than imported. The article concluded that regular primary school health programmes will suffice to control morbidity given the moderate transmission in Niamey and that peripheral villages should be included in rural control programme activities (Ernould et al., 2000).

A second study of schistosomiasis in Niamey, Niger, showed that the decisive risk factors were the very focal water contact patterns (with river and water canals) in the periurban areas, whereas trips to rural areas did not play an important role (Ernould et al., 2003).

Barreto (1991) has conducted a study from an urban area in Bahia, Brazil, showing how lower levels of infection among children were closely associated with longer duration of residence in the urban area compared with recent immigrant children from rural areas.

Migrants may bring the infection to periurban areas, where the parasite life-cycle can be established and maintained. For example, infections with *S. mansoni* were identified in children who had never left urban Addis Ababa, Ethiopia. These infections were traced to their swimming in a depression created by people digging for construction materials and filled with river and rain water that was also used for recreational purposes by migrants (Birrie, Medhin & Redda, 1996).

Results of a sociodemographic survey combined with mapping of water sources, a parasitological survey, clinical examination and water contact interviews in a suburban area of Belo Horizonte, Brazil, showed that infection was closely associated with recreational water contacts by boys between 10 and 19 years of age (Firmo et al., 1996). A similar finding was made by Amorim et al. (1997) from Bela Fama, a suburb of Nova Lima, Brazil, where most households have piped water.

Effect on snail populations

People's mobility may also affect snail populations. In central Africa, urbanization and deforestation can have an effect on the distribution of *S. intercalatum* and *S. haematobium* respectively. *S. intercalatum* is often found in newly urbanized areas and its territory is therefore expanding, but since the host snail of *S. haematobium* coming from the desert area to the north is better adapted to the deforested environment, *S. haematobium* appears to be slowly taking over (Ripert, 2003).

Ollivier, Brutus & Cot (1999) have analysed data over a period of 20 years on the spatial distribution of schistosomiasis in Madagascar. The authors are able to conclude how *S. mansoni* has been able to spread due to a mix of biological and

social reasons. *S. mansoni* has apparently become more resistant to colder waters over the period and the establishment of irrigation schemes in the highlands has attracted people from infected areas, who have settled in the outskirts of towns where there is no sanitation infrastructure.

Social class or status

Some researchers argue that it is more accurate to understand the social production of schistosomiasis in relation to social class or status rather than to urbanization. Loureiro (1989) argues that prevalence of schistosomiasis should be seen as a marker of the risk levels that various social groups are exposed to. People's social position conditions their material situation and thus the disease is mostly found among the poor and underprivileged. This is true for poor people living in both rural areas and urban peripheries. They often share conditions such as lower levels of education and unemployment as well as lack of sanitation, housing, transport and access to health facilities. Their point is not that lack of education or poor housing will automatically lead to infection, but that if infective snails are present in local waterways, it will most likely be members of the poorer households who are infected.

An unusually detailed epidemiological analysis of socioeconomic determinants of schistosomiasis in the mainly urban area of São Lourenço da Mata, Pernambuco, Brazil, showed a significant household aggregation of schistosomiasis. Families having higher levels of household consumption and whose members had jobs of higher status were associated with lower risk and intensity of infection. The analysis was based on the assumption that disease is not an individual biological phenomenon, but rather a social and biological phenomenon that occurs within specific social settings. Apart from data on the theoretical reduction in the probability of infection if water supply and sanitation was improved, possible control efforts were discussed in relation to wider policy changes regarding the continuing decentralization of the health sector, community involvement, general socioeconomic development in the country, urban underemployment and access to land and education (Ximenes et al., 2003).

Implications for planning and implementation of control programmes

- Control programmes should adapt to the mobility patterns (e.g. due to nomadism, conflict situations, labour migration) of the target population when planning, monitoring and evaluating interventions.
- Health impact assessments should become an integrated part of urban planning.

Directions for social science research

- What are the social and economic determinants of vulnerability to infection at the individual, household and community level, and how do they interact with determinants that are significant at the national level?
- How can control programmes be designed in such a way that different mobile populations (rural-to-rural or rural-to-urban migrants, cyclical migrants or nomadic peoples, refugees from disaster and conflict areas) get better access to services?
- How does the distribution of rural and urban schistosomiasis develop over time and what social factors are involved in the changes?

Studies of schistosomiasis and gender

Main points

- *The common assumption that men and boys are more heavily infected and affected than women and girls in endemic areas is not always correct.*
- *The social aspects of female and male genital schistosomiasis – particularly with regard to consequences, illness perceptions and social factors influencing access to treatment – have only been very sporadically researched.*

Because gender relations have such profound impact on exposure and access to treatment in many societies, and because the social mechanisms behind this impact are often perceived to be so "natural" that they become "invisible", this section will highlight some structural dimensions of gender in schistosomiasis. Some of the observations below will be discussed in more detail in the relevant chapters to come.

Sex, gender and vulnerability to schistosomiasis

There are no global figures on the distribution of schistosomiasis by sex. From the scattered surveys available, it seems that men and women are infected in equal numbers, but that women are generally more intensely affected by the disease than men (Vlassoff & Bonilla, 1994:38). This appears to have little to do with genetic, biological and immunological differences between the sexes. There are indications that men and women react differently in terms of biological and immunological response to infection (Booth et al., 2004). Even though research on these differences has not been exhausted (Feldmeier & Krantz, 1993; Michelson, 1993), the sometimes considerable local differences in prevalence and intensity observed between men and women can be explained very convincingly by differences in the social and occupational roles taken up by men and women. Social factors related to gender do not only have implications for exposure patterns (Michelson, 1993), but also for perceptions of illness and involvement in decision-making regarding access to treatment and its use. Women may be used to ignoring feelings of weakness and symptoms of disease longer than men in an attempt to meet other household members' expectations of them as mothers, housekeepers and farmers or small-scale business women. Furthermore, they may not be allowed to seek treatment or incur any expenses related to health without permission from their husband or father. While both men and women in endemic areas frequently suffer from structural inequalities and poverty, women are often particularly disadvantaged if they at the same time are ascribed a lower social status and depend economically and socially on men (e.g. Danso-Appiah et al., 2004, on fathers in Ghana as financial providers and gatekeepers to health care; Manderson & Huang, 2005). This is the reason why social science literature on gender and schistosomiasis has mainly addressed the situation of women.

Sex and gender

The terms sex and gender were introduced as variables in health research in order to bring attention to the impact of gender on health status, outcomes and health-seeking behaviour. The two terms makes it possible to distinguish analytically between biological and physiological traits (sex), and sociocultural roles that men and women are socialized to perform (gender).

When the roles of men and women are no longer seen as primarily based on their biology, but on economic, historical and sociocultural processes, it becomes possible to both analyse and question structural differences in men and women's entitlements with regard to access to information, general resources, health-care services and treatment. Different patterns of vulnerability to infection and different ways of interpreting and responding to disease and suffering become visible. Similarly, different expectations of men and women's contributions to preventive measures and in caring for the sick become obvious (Vlassoff & Manderson, 1998:1012). These differences are not determined by nature, but are deeply sociocultural and therefore changeable over time. They change with social, economic and technological conditions as well as institutional and legal environments. In spite of this capacity for change, a gender analysis will very often reveal skewed power relations and structural inequalities between men and women. This has a myriad of differentiated consequences for the health of women and men in many settings in developing countries (Vlassoff & Bonilla, 1994).

Gender-specific aspects of schistosomiasis are an area that is yet to be systematically researched. In 1993, Feldmeier & Krantz devised a comprehensive and systematic inventory of research needs and priorities in relation to determinants of female morbidity, which they then tested by matching it with existing knowledge of schistosomiasis among women (Feldmeier & Krantz, 1993). They pointed to a number of areas characterized by an acute lack of biomedical knowledge on women's health, including the essential areas of diagnosis and treatment, and of the interactions between environmental and socioeconomic variables specific to women. Among other factors, the authors summarized women's knowledge and water contact, attitudes of society towards people with the disease, factors in women's readiness to be treated and the role of women in transmission of schistosomiasis.

Diagnosis and morbidity assessment

A paper by Feldmeier, Poggensee & Krantz (1993) focuses on gender-related biases in the diagnosis and morbidity assessment of schistosomiasis in women. The paper is based on the premise that efficiency of a diagnostic tool is influenced by sociocultural factors, which implies that validation of diagnostic techniques should include considerations of sociocultural factors (for details, see the sections on diagnosis and treatment in Chapter 4). Systematically going through studies of women's participation in diagnostic surveys, the authors observe that when women's level of participation was high it was often linked to a community-based type of control operation and the main reason given by women for their involvement was that they were concerned about the health of their family. The most important constraining factors for women's participation were household obligations, market/agricultural activities and lack of education.

Involving women

Vlassoff & Bonilla (1994) go further into an analysis of gender aspects of the infection by applying a framework that incorporates three important dimensions of gender roles, i.e. "economic-productive", "social-reproductive", and "personal", showing how these overlap with biological and psychological states of health and disease. They examined existing evidence of gender differences in the economic, social and personal determinants and consequences of tropical diseases using malaria and schistosomiasis as examples. The review concludes with the observation that knowledge is still incomplete regarding this important public health issue, that women are far too rarely involved in planning and implementing interventions and that they are often the last to benefit, if at all, from projects and programmes. They suggest that making an effort to involve women would strengthen the health system at local level.

Dias (1996:252) suggests that more attention should be given to the role of women in prevention of schistosomiasis, as they are often responsible for both family health care and guiding children's sanitation habits. Michelson (1993:495-496) refers to studies that show how women may govern the acceptance or rejection of changes in behaviour or technical innovations regarding water supply and sanitation in households.

Gendered risk

A later paper by Vlassoff & Manderson (1998) presents the advantages of combining a gender-sensitive approach with anthropological enquiries and draws out the consequences of such analyses for the design of interventions and control strategies. Using examples from research on urinary schistosomiasis, malaria, leprosy, leishmaniasis and onchocerciasis, the paper discusses data on the implications of gender on prevalence and distribution, determinants and consequences of diseases. One such determinant is the division of labour by gender. Since Dalton's pioneering study of water contact patterns and division of labour by gender and space (Dalton, 1976; see the section on studies of water contact and social determinants at local level in Chapter 3), gender differences in exposure patterns have been observed in epidemiological studies, but patterns are very heterogeneous and generalized assumptions may lead to inaccurate estimates of disease prevalence, especially in women. A thorough understanding of the division of labour between men and women in endemic areas should have consequences for the way prevention measures are developed.

Watts et al. (1998) point to the potential importance of attention to the gendered use of space, i.e. potential differences in men and women's use of space, and how this may shift in relation to time of day, season, activity and water contacts and thereby influence risk of infection. A study from Nigeria shows how the expectation that women and girls should bathe in shady sections of rivers and streams, where cercarial density is very high, exposes them to infection (Amazigo, Anago-Amanze & Okeibunor, 1997).

An interesting perspective on gendered risk is presented in a study by Noronha et al. (1995). In a small town in Bahia, Brazil, women (often employed as cleaners, saleswomen or manicurists) had a schistosomiasis prevalence of 18% whereas men (often working as mechanics, salesmen, farmers and tradesmen) had a prevalence rate of 30%. When enquiring about perceptions of health and illness in general, women were thought to be more ill than men due to an idea of women being physically weaker than men and often suffering from various symptoms related to menstruation and pregnancy. But parasitic infections in particular were associated with men and their freedom to move everywhere, including "dirty" places (forests, mud, streams and rivers) that are perceived as risky in terms of parasitic infections. Thus, *the enactment of local gender roles* puts men and women at different

risk levels. On the one hand, men's freedom and the expectation that they will move around is a threat to their health, because they often rest and swim in the river. Young women, on the other hand, are not supposed to expose themselves to male eyes by bathing or swimming in streams and pools. Thus, women, who are expected to "be good", are also protected from parasite infection by this moral aspect of the female gender role. The authors suggested that moral values in male and female gender roles should play a role in risk assessments.

In schistosomiasis, a gender approach would both note the patterning of infection and its association with occupation and activities, and question how gender roles determine differential exposure to infested areas. It would raise further questions regarding men and women's knowledge and perceptions about disease and treatment and factors affecting treatment seeking, including access and ability to pay. The use of a gender framework also raises the possibility of under-reporting or hidden manifestations of the disease, such as genital schistosomiasis in females and males (Vlassoff & Manderson, 1998:1012).

School-based screening

In a study to explore and revise the protocol for school-based screening in Egypt, el Katsha & Watts (1998) pointed out the need for a gender-sensitive approach. School-based screening poses particular problems if enrolment of boys and girls is skewed, but can also relate to differences in girls' willingness to participate. There is no standardized solution to such issues, which are best addressed through consultations with local students, teachers and health personnel. In Egypt, girls' participation was low because they lacked privacy when providing specimen samples and did not like to queue with boys in the health clinic carrying a container with visible contents. To minimize the girls' embarrassment and to facilitate their asking questions, the revised protocol recommended separation of boys and girls throughout the procedures, with the implication that female teachers should be trained to educate and supervise the students regarding schistosomiasis, testing and gender aspects of the infection.

Schistosomiasis can contribute to anaemia, which is of particular concern in young pregnant women, who are in the age group where peak prevalence and intensity of schistosomiasis is often found (Leenstra et al., 2004). A mainly epidemiological

study of sociocultural and nutritional risk factors of adolescents and young pregnant women between 11 and 22 years of age in a schistosomiasis-endemic area in Egypt showed that both groups had water contact as part of household activities and work in fields, but their status as married or unmarried – rather than pregnant or not – meant that there was some variation in the type and frequency of exposure (el-Sahn, Darwish & Soliman, 1992).

Genital schistosomiasis

Eggs and also adult worms may be present in the tissues of reproductive organs in both men and women. Prevalence and morbidity of these manifestations of schistosomiasis are seldom researched and yet to be evaluated systematically in terms of public health impact and priority in most endemic areas.

Female genital schistosomiasis

Female genital schistosomiasis was first described in Egypt in 1899, but was largely neglected until the 1990s, when the HIV/AIDS (acquired immunodeficiency syndrome) epidemic made it relevant to explore how damage to the vaginal epithelium from the excretion of schistosomiasis eggs might increase vulnerability to HIV (Feldmeier et al., 1995; Poggensee & Feldmeier, 2001). In 1997, the Gender Task Force of the Special Programme for Research & Training in Tropical Diseases (TDR) listed female genital schistosomiasis as a high research priority.

Although research on women's health in the tropics has essentially looked only at their reproductive health (Vlassoff & Bonilla, 1994:40), there has been remarkably little research on female genital schistosomiasis. The few available studies indicate that this manifestation of the infection is by no means rare (Feldmeier et al., 1995; Poggensee, Feldmeier & Krantz, 1999) and that it contributes significantly to gynaecological morbidity (Michelson, 1993:497; Feldmeier, Poggensee & Krantz, 1993:159-162; Ali, 2001) to the extent that it should be categorized and addressed as a reproductive health problem (Talaat et al., 2004).

Studies of the link between female genital schistosomiasis and infertility are very limited, as are studies of women's perceptions of the symptoms, the social implications of the symptoms (including infertility) and the misinterpretation of

the symptoms as resulting from a sexually transmitted infection (E. Anyangwe, O. Njikain & L. Kouemeni, unpublished data, 1992).[12] Studies of women's access to and ways of seeking treatment for the symptoms are very scarce (Ali, 2001).

Clinical aspects of female genital schistosomiasis

Both eggs and adult worms of mainly *S. haematobium* but also *S. mansoni* (Poggensee, Feldmeier & Krantz, 1999) and *S. japonicum* (Qunhua et al., 2000) have been found in the vulva, cervix, uterus and Fallopian tubes. Four population-based studies in Africa revealed a high prevalence of female genital schistosomiasis, of between 30% and 75% (cited in Poggensee, Feldmeier & Krantz, 1999:378). In a community study in Egypt, 50% of 86 women were affected (Talaat et al., 2004).

Symptoms are often nonspecific and may include irregular menstruation and intermenstrual bleeding, chronic pelvic and abdominal pain, pain during sexual intercourse, increased vaginal discharge and post-coital bleeding. Lesions may grow for months or years and may be painful in case of ulceration or secondary infection.

Female genital schistosomiasis facilitates the transmission of sexually transmitted infections and alters the disease progression of these infections (Leutscher et al., 1998; Poggensee & Feldmeier, 2001). The role of female genital schistosomiasis in connection with cervical and other cancers, ectopic pregnancy, abortion, infertility and pregnancy-related disorders has been explored in a few studies (Feldmeier & Krantz, 1993; Feldmeier, Poggensee & Krantz, 1993; Michelson, 1993; Ali, 2001).

Female genital schistosomiasis may easily go undiagnosed. Urine analysis reagent sticks to detect haematuria failed to identify more than half of the infected women enrolled in a study of genital schistosomiasis (Feldmeier & Krantz, 1993:129-130; Poggensee, Feldmeier & Krantz, 1999:381). Women with genital schistosomiasis may not excrete eggs in urine and therefore standard parasitological methods of detection may not be valid. As there are no immunological or biochemical methods for detecting genital schistosomiasis, vaginal biopsy is the chosen method.

[12] *Urinary schistomiasis in women. An anthropological and descriptive study of a holo-endemic focus in Cameroon*. Manuscript presented at the WHO and NORAD Meeting on Women and Tropical Diseases, Oslo, Norway, 28-30 April 1992.

Male genital schistosomiasis

While studies of both the medical and social aspects of female genital schistosomiasis are few, male genital schistosomiasis is even less described – even though the establishment of prevalence rates is much less invasive and laboratory intensive for men than for women (semen sample versus vaginal biopsy). Male genital schistosomiasis was first observed in 1944 but did not receive much attention until the 1990s (Richens, 2004). Symptoms are less diverse than in women. The risk of transmitting HIV may be increased (Leutscher et al., 2000; Leutscher et al., 2003). A community-based, cross-sectional study conducted in a village in Madagascar showed that 43% of 44 semen samples contained eggs of *S. haematobium*. This result indicates that this expression of the infection is not uncommon.

Implications for planning and implementation of control programmes

- Data in control programmes should be gender disaggregated and sensitive to possible differences in men and women's daily activity patterns.
- Control programmes should address local gender-related patterns of exposure, contaminating behaviour and access to treatment.
- Screening for genital schistosomiasis should be considered.

Directions for social science research

- What are the gender-related factors at play in the local maintenance of the infection? How do shifts in gender roles and occupation affect exposure patterns?
- How do gender relations in the household, including resource allocation, domains of authority and division of labour, influence access to treatment?
- How can acceptable tools for diagnosis and screening of genital schistosomiasis in both men and women be developed, adapted and validated?

Studies of health and socioeconomic impact of schistosomiasis

Main points

- *Assessing the impact and disease burden of schistosomiasis is complicated and common estimates remain inconclusive. Assessments of health impact are often based on clinical epidemiological data and do not incorporate gender-disaggregated measurements of functional disability.*
- *Assessments of socioeconomic impact are often limited to relatively context-free analyses of productivity and income. This approach does not take account of long-term effects or compensation strategies by individuals and households.*
- *Both health and socioeconomic impact assessments are usually extrapolated from observations of individuals. Impact assessments at household and community levels might offer valuable input to priority setting in public health.*

Compared with many other tropical infections, schistosomiasis is characterized by low mortality rates and very inconclusive morbidity estimates. It has been asserted that schistosomiasis follows malaria as the most important tropical disease in terms of endemicity and public health importance on a global level (Chandiwana & Taylor, 1990). A report by the WHO Expert Committee states that socioeconomic impact of schistosomiasis is second only to malaria (WHO, 1985). These observations are based on epidemiological figures on prevalence, but extrapolating impact of infection on complex measures such as health, disability and productivity from prevalence data is complicated (Prescott, 1979).

In 1992 and 1993, Parker suggested that the priority given to schistosomiasis as a public health issue at international and national levels had mainly been based on epidemiological information alone (Parker, 1992, 1993). Parker challenged the assumption that scientists know enough about the impact of schistosomiasis to characterize it as a major public health problem and asserts that this gap in knowledge is most acute with regard to the impact of infection in women.

Similarly, based on an analysis of workers' productivity, it has been suggested that the disease is not always of serious public health concern (Sandbach, 1976:275).

Measuring morbidity

Standardized morbidity measures at population level have become central for measuring the impact of interventions and the relative burden of disease.[13] This has proved difficult in the case of schistosomiasis due to the many nonspecific symptoms of the infection (Morrow Jr, 1984; Tanner 1989a:146; Michaud, Gordon & Reich, 2004) and the highly heterogeneous morbidity patterns in different communities, which are related to, but not determined by, the different species of schistosomes, as well as age, sex, socioeconomic status, nutritional status and concomitant parasitism of the person affected (Tanner, 1989a:143; Parker, 1993:483; Parraga et al., 1996; Assis et al., 2004; Michaud, Gordon & Reich, 2004; King, Dickman & Tisch, 2005). Even though morbidity in individuals can be measured with increasing accuracy by ultrasound and some of the most obvious clinical signs of schistosomiasis (such as hepatomegaly, splenomegaly, intestinal disease, fibrosis and bladder calcification) have been studied, there is no simple relationship between infection, intensity, "obvious" morbidity, "subtle" morbidity and (subjectively experienced) disease or disability in schistosomiasis. A further complication is the lack of conceptual clarity in the terms morbidity and health impact. Even if there were agreement on definitions of morbidity and mortality in relation to schistosomiasis and they were measured and defined as health impact, this definition of health would be quite restricted to physical features. Patients' perceptions of the infection, damage due to the migration of the parasite in the body, infertility, and increased vulnerability to sexually transmitted infections in women have not been studied as thoroughly (Polderman, 1995). Studies of the effect of infection on daily activities are even rarer. In other words, epidemiological

[13] *Direct morbidity:* non-fatal health outcomes resulting from pathological changes and clinical manifestations induced by schistosome egg deposition in tissues (Michaud, Gordon & Reich, 2004:22)
Indirect morbidity: includes (i) nutritional consequences of schistosomiasis infection (anaemia and growth retardation) and (ii) functional consequences (educational impairment and productivity loss). The term is not clearly defined in the literature and it embraces some ambiguities about boundaries and causal relationships with schistosomiasis. This ambiguity is due to both the non-specific nature of the consequences of schistosomiasis and their complex interactions with other diseases (ibid.:22).
Disability: an umbrella term for impairments, activity limitations or participation restrictions (defined in the *International classification of functioning, disability and health* (WHO, 2001). See Parker, 1992:878, for a critical introduction to the discussion of disability in relation to schistosomiasis.

measures of impact are often limited to biomedical aspects, thus defining health in a relatively narrow way (Parker, 1992:878; Parker, 1993:484).

When designing interventions and policies in public health, evaluations of cost have an increasingly influential, if not determining, role in priority setting. A recurring question is how to define and measure various types of impact and benefits at individual and community levels (Dunlop, 1984; Rosenfield, Golladay & Davidson, 1984), and not least, how to do it in a gender-sensitive way (Parker, 1993:482). Researching the relation between infection, behaviour and productivity, or economic and social vulnerability, is perhaps even more complex than researching the relation between infection, clinical manifestation and health (Barbosa & Pereira da Costa, 1981).

Several studies have attempted to measure impact on physical fitness, working ability and productivity of individuals. Unfortunately, the contribution of such studies to the assessment of impact has often been rather one-dimensional. Physiologists measure disability in terms of indices of work capacity and physical fitness, clinicians and epidemiologists measure in terms of reported symptoms, and others may measure running performance, educational achievement or productivity of individuals (Parker, 1992:878). Placing data on, for example, absenteeism and earnings in the context of local social worlds would enable a more informative analysis of the economic consequences for a household with infected member(s) (Parker, 1993:484).

In a review of physical fitness, working capacity and productivity, Tanner (1989a) found conflicting results between 16 studies involving adult patients with schistosomiasis haematobium, mansoni and japonicum. Not all studies showed a decrease in fitness or working capacity and results were incomparable due to differences in study methodologies, patients' age and intensity of infections. Based on this review, Tanner points to difficulties in measuring variables such as annual loss at both country and community levels. Studies of market productivity among individual infected workers (sugar-cane cutters, canal cleaners), for example, should also include data about the total output of production at the production-unit level to illuminate whether schistosomiasis diminishes the output or leads to the employment of more workers to carry out the same work (Tanner, 1989a:145).

Socioeconomic consequences

Prescott (cited in Huang & Manderson, 1992:188-189 and in Parker, 1993:484) reviewed studies of socioeconomic consequences of schistosomiasis in 1979 and found that they are often biased towards relatively healthy workers, economic effects are measured at the individual and not household level, long-term economic consequences are not adequately studied and economic consequences for infected women engaged in domestic work are not studied. Furthermore, observations of economic performance are often interpreted without reference to local settings and insights, and thus lack in-depth understanding of the meanings of data for people's lives (Parker, 1993).

As pointed out by Prescott, the economic and social consequences of schistosomiasis have often been investigated at the level of individuals. The importance of measuring socioeconomic impact at household level is underlined by Popkin (1982), Herrin (1986), Tanner (1989a) and Parker (1993:484). Popkin (1982:533) proposes that impact be measured and quantified at household level using a microeconomic perspective. Integrated household survey questionnaires on health, agriculture, economy and demography of households allow more complete empirical analyses of complex household issues. Herrin (1986) proposes a conceptual framework and research strategy to analyse social and economic aspects of schistosomiasis. The framework includes three levels: (i) decision-making at household level; (ii) the physical, social and economic environment of the community; and (iii) changes in the environment stemming from national policies and programmes or from natural forces. The framework, which requires quite intensive data collection, should be applied by a multidisciplinary team.

Impact of infection on women

The lack of studies regarding impact of infection on women has been observed (Feldmeier & Krantz, 1993:131). The only study retrieved was Parkers' exploratory study of the productivity of women infected with *S. mansoni* in Sudan. The study convincingly shows that infected women pick the same amount of cotton as uninfected women, but in a shorter time (Parker, 1992). The hypothesis is that the infected women realized that they were not able to pick cotton for as long as other women (none of them were aware of their infective status on the day of observation), and instead they made an effort to pick sufficient cotton

(equalling cash income) in a shorter time. They spent much less time on personal care or collecting weeds for goats. Parker reports on previous observations of domestic work and on the way heavily infected women seem unaffected in their daily activities. For this reason, it is inappropriate to rely on epidemiological information when determining to what extent schistosomiasis presents a public health problem (ibid.:888).

Selected references: exploring the relationship between schistosomiasis and cognitive development and school performancea

Bhargava A et al. (2005). Modeling the effects of health status and the educational infrastructure on the cognitive development of Tanzanian schoolchildren. *American Journal of Human Biology*, 17(3):280-292.

de Clercq D et al. (1998). The relationship between *Schistosoma haematobium* infection and school performance and attendance in Bamako, Mali. *Annals of Tropical Medicine and Parasitology*, 92(8):851-858.

Jukes MC et al (2002). Heavy schistosomiasis associated with poor short-term memory and slower reaction times in Tanzanian schoolchildren. *Tropical Medicine & International Health*, 7(2):104-117.

Kvalsvig JD, Becker PJ (1988). Selective exposure of active and sociable children to schistosomiasis. *Annals of Tropical Medicine and Parasitology*, 82(5):471-474.

Nokes C et al (1999). Evidence for an improvement in cognitive function following treatment of *Schistosoma japonicum* infection in Chinese primary schoolchildren. *The American Journal of Tropical Medicine and Hygiene*, 60(4):556-565.

Stephenson LS (2001). Optimising the benefits of anthelmintic treatment in children. *Paediatric Drugs*, 3(7):495-508.

[a] For older references, see Huang Y, Manderson L (1992). Schistosomiasis and the social patterning of infection. *Acta Tropica*, 51(3-4):189).

Ranking the severity of infection

Social aspects of infection have been measured by asking individuals to rank the severity of schistosomiasis. However, this approach does not indicate the impact of infection and how people cope with it. Ranking has played a different role in studies from the United Republic of Tanzania, where it was used to screen communities. It was found that teachers' ranking of schistosomiasis among the top five diseases in their areas actually correlated with higher prevalence in their areas (see the section on social factors in relation to diagnosis and screening in Chapter 4 for studies using this method for screening communities).

Ranking exercises

Programmes that involve local communities in control efforts have sometimes been preceded by studies of how communities rank schistosomiasis in terms of severity to assess people's motivation for participating (Tanner et al., 1986; Siziya & Mushanga, 1996) or as a preliminary way of assessing the prevalence of infection in an area (Lengeler et al., 1991b; see also the section on questionnaires used for community diagnosis in social factors in relation to diagnosis and screening in Chapter 4).

Depending on the definitions and dimensions of severity implied in the studies and the methods of enquiry, the studies give an indication of how people compare the infection with other health problems. Data are often disaggregated by age, gender and level of education (Amazigo, Anago-Amanze & Okeibunor, 1997). Schistosomiasis often ranks low (e.g. Kamunvi & Ferguson, 1993, in rural Kenya), but people living with an infected household member more often tend to label red urine a health problem (Taylor et al., 1987, in rural Zimbabwe). In rural Malawi, the correlation between individuals' perceived risk judgement of schistosomiasis (in terms of level, seriousness, predictability and controllability) and their reported adherence to prevention guidelines was stronger than the same correlation for malaria. The correlation was stronger among educated people and among women (who were more in contact with water) than men (Ager, 1992). MacLachlan & Namangale (1997) compared measured perceptions of AIDS and malaria with schistosomiasis and common cold as "contrast" diseases.

Parker (1993:485) questions the value of asking people to rank schistosomiasis among other diseases in terms of severity when it is not specified whether the possible answers (e.g. mild/serious, on a scale from 1 to 5) are related to perceived damage to an organ, a set of organs, general well-being or social relations. Asking locals to rank diseases usually provides an overall insight into what could be called individuals' "cognitive map" of local ailments. If researchers probe into the parameters of severity that people apply in their responses, information becomes richer, but it cannot be assumed that there is a linear relation between people's cognitive maps of ailments and the way they seek treatment, adhere to treatment or to what extent they would be active in unspecified control efforts.

Stigma attached to infection

A rarely researched indicator, stigma attached to infection, has been studied in the Philippines, where Herrin (cited in Parker, 1993:485-486) administered a questionnaire to both infected and non-infected people on possible social consequences. The study showed that people considered it shameful to be infected or to have an infected family member and that the expected consequences of infection would be different for men (who would not be able to "make progress in life") and women/mothers (who would not be able to carry out domestic duties). Furthermore, non-infected participants perceived the impact of infection as more serious than infected participants. Unfortunately the study did not explore correlations between perceptions and age and sex, and did not mention prevalence and intensities of infection.

Implications for planning and implementation of control programmes

- Resource allocation for schistosomiasis control should be based on a sufficiently multifaceted and comprehensive picture of the burden of disease.

Directions for social science research

- What methods can be developed to assess the socioeconomic impact of the infection on individuals, households, communities and societies in a gender-sensitive way (domestic work and women's farming often being economically invisible)?
- What are the social and economic impacts of chronic disease and genital schistosomiasis? What role does stigmatization play?

CHAPTER 3

THE MICRO PERSPECTIVE: COMMUNITY DYNAMICS INFLUENCING THE DISTRIBUTION OF SCHISTOSOMIASIS

The distribution of schistosomiasis in endemic areas is usually focal and intimately linked to the distribution of the intermediate host snails. Furthermore, the density and infectivity of cercariae depend on water temperature and velocity of flow, time of day and intensity of light, among other variables. Seasonality is another factor depending on environmental setting. These biological and environmental prerequisites for infection are further complicated by the myriad of local social factors involved in the final pattern of who gets infected and to what extent. Studies from widely different endemic areas have shown that prevalence and intensity of schistosomiasis are often age-dependent, that they may differ considerably between men and women, and that infection is unevenly distributed within a community with the majority of individuals harbouring light infections and a minority having heavy infections (Anderson & May, cited in Feldmeier & Krantz, 1993:121). This chapter includes studies of water contacts, infective behaviour, local knowledge of risk and symptoms, as well as health-seeking behaviour. In short, we refer to this as the "micro level" (in accordance with Barbosa, 1995).

Studies of water contact and social determinants at local level

Main points

- *Water contact studies are mainly epidemiological in design. Their documentation of correlations between infection, types of water contact and demographic characteristics have pointed to the wide variety of social aspects in schistosomiasis transmission.*
- *Analysing water contact behaviours in the wider social contexts of people's intentions can be useful input for control programmes. This would include studies of the way people "balance" priorities and perceived risks as well as their gendered habits.*

Even though water contact does not automatically lead to exposure to cercariae, considerable academic energy has been invested over the years in studying correlations between infection and water contact, which remains the single most important variable determining the prevalence of the infection. Along with age, water contact patterns are also often the most important factor with regard to the intensity of the infection. In relation to interventions, studies of water contact patterns have been carried out to guide the choice of control measures, including the introduction of alternative water supplies and sanitation, and locations as well as to evaluate the effectiveness of control programmes (Kloos, Gazzinelli & van Zuyle, 1998; Ximenes et al., 2001:14). This section will not include references to the many general studies on water use and hygiene that are nevertheless very relevant for an understanding of the transmission of schistosomiasis. For a selection of relevant articles on this important topic, readers are referred to the bibliography in el Katsha & Watts (2002).

Epidemiological surveys have documented how individual infections and water contacts are often correlated with a range of social and demographic factors, such as age, gender, education, occupation, ethnicity, religion, housing, hygiene, village size and house location. It remains problematic to predict indicators for water contact patterns across cultural, social and economic contexts – even within the same village. The extraordinary variety of social factors involved in water contacts have been reviewed by Huang & Manderson in 1992, mainly based on studies from Africa, and again in 2005, based on studies from China (Huang & Manderson, 1992; Huang & Manderson, 2005). To illustrate this variation, the following section briefly refers to a few of the observations from epidemiological studies of individual water contact. It closes by presenting an approach to water contact studies that applies households as the basic unit of analysis (rather than individuals) and an anthropological study of water use as an inherently social phenomenon.

One of the first major epidemiological studies pointing to the significance of water contact behaviour in relation to schistosomiasis infection was reported from Puerto Rico in 1961 (Pimentel et al., 1961). A more frequently cited, pioneering study was published by Farooq & Mallah (1966) from Egypt, which was among the first to systematically observe water contacts and their seasonal variation. Rée (1982) and Husting (1970) provide additional references on early water

contact studies. The identification of correlations between water contact and schistosomiasis infections became more nuanced when water contact activities were categorized as domestic ("housekeeping") or economic (related to income generation) in Dalton's study from Saint Lucia (Dalton, 1976) and the observation that people use different water contact sites for different purposes (Husting, 1970). The latter study was among the first to provide anthropological insights into the social pattern of water use, and to implicitly question the categories used in epidemiological data collection. It showed how men and women's water contact patterns were "linked" (e.g. women would wash clothes and bathe children and themselves at the same time) and inseparable from their gendered tasks, and how boys and girls changed water contact behaviour as they grew up to take adult roles. Dalton & Pole (1978) have studied the relation between type of water contact and infection in Saint Lucia. Barbour (1985) conducted a re-analysis of Dalton & Pole's data, arguing that age and sex were the only significant factors in predicting infection, not type of water contact.

Selected references: studies of water contact

This summary lists some of the most cited water contact studies in the literature. Some studies describe water contact only, while others relate water contact patterns to various quantitative measures of infection (prevalence and intensity) or to demographic characteristics of the affected populations.

Butterworth AE et al. (1984). Immunity after treatment of human schistosomiasis mansoni. I. Study design, pretreatment observations and the results of treatment. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 78(1):108-123.

Chandiwana SK (1987a). Seasonal patterns in water contact and the influence of water availability on contact activities in two schistosomiasis-endemic areas in Zimbabwe. *The Central African Journal of Medicine*, 33(1):8-15.

Chandiwana SK (1987b). Community water-contact patterns and the transmission of Schistosoma haematobium in the highveld region of Zimbabwe. *Social Science & Medicine*, 25(5):495-505.

Chandiwana SK, Woolhouse ME (1991). Heterogeneities in water contact patterns and the epidemiology of *Schistosoma haematobium*. *Parasitology*, 103(Pt 3):363-370.

da Silva AA et al. (1997). Water-contact patterns and risk factors for *Schistosoma mansoni* infection in a rural village of northeast Brazil. *Revista do Instituto de Medicina Tropical de São Paulo*, 39(2):91-96.

Dalton PR (1976). A socioecological approach to the control of *Schistosoma mansoni* in St Lucia. *Bulletin of the World Health Organization*, 54(5):587-595.

Dalton PR, Pole D (1978). Water-contact patterns in relation to *Schistosoma haematobium* infection. *Bulletin of the World Health Organization*, 56(3):417-426.

Ernould JC, Labbo R, Chippaux JP (2003). Evolution de la schistosomose urinaire à Niamey, Niger [Course of urinary schistosomiasis in Niamey, Niger]. *Bulletin de la Société de Pathologie Exotique*, 96(3):173-177.

Etard JF, Borel E (1992). Contacts homme-eau et schistosomiase urinaire dans un village mauritanien [Man-water contacts and urinary schistosomiasis in a Mauritanian village]. *Revue d'Épidémiologie et de Santé Publique*, 40(4):268-275.

Farooq M, Mallah MB (1966). The behavioural pattern of social and religious water-contact activities in the Egypt-49 bilharziasis project area. *Bulletin of the World Health Organization*, 35(3):377-387.

Fulford AJ et al. (1996). Water contact observations in Kenyan communities endemic for schistosomiasis: methodology and patterns of behaviour. *Parasitology*, 113(Pt 3):223-241.

Husting EL (1970). Sociological patterns and their influence on the transmission of Bilharziasis. *The Central African Journal of Medicine*, July(Suppl.):5-10.

Husting EL (1983). Human water contact activities related to the transmission of bilharziasis (schistosomiasis). *The Journal of Tropical Medicine and Hygiene*, 86(1):23-35.

Kloos H et al. (1983). Water contact behavior and schistosomiasis in an upper Egyptian village. *Social Science & Medicine*, 17(9):545-562.

Kloos H et al. (1990). Water contact and *Schistosoma haematobium* infection: a case study from an upper Egyptian village. *International Journal of Epidemiology*, 19(3):749-758.

Kloos H et al. (2006). Combined methods for the study of water contact behavior in a rural schistosomiasis-endemic area in Brazil. *Acta Tropica*, 97(1):31-41.

Klumpp RK, Webbe G (1987). Focal, seasonal and behavioural patterns of infection and transmission of *Schistosoma haematobium* in a farming village at the Volta Lake, Ghana. *The Journal of Tropical Medicine and Hygiene*, 90(5):265-281.

Kvalsvig JD, Schutte CH (1986). The role of human water contact patterns in the transmission of schistosomiasis in an informal settlement near a major industrial area. *Annals of Tropical Medicine and Parasitology*, 80(1):13-26.

Loroni-Lakwo T et al. (1994). Transmission of *Schistosoma mansoni* in Rhino Camp, Uganda. *East African Medical Journal*, 71(3):165-166.

Mota E, Sleigh AC (1987). Water-contact patterns and *Schistosoma mansoni* infection in a rural community in northeast Brazil. *Revista do Instituto de Medicina Tropical de São Paulo*, 29(1):1-8.

Ofoezie JE, Christensen NO, Madsen H (1998). Water contact patterns and behavioural knowledge of schistosomiasis in south-west Nigeria. *Journal of Biosocial Science*, 30(2):245-259.

Pimentel D et al. (1961). Aspects of schistosomal endemicity in three Puerto Rican watersheds. *The American Journal of Tropical Medicine and Hygiene*, 10:523-529.

Rée GH (1982). Schistosomiasis and human behaviour. *Ecology of Disease*, 1(2-3):131-133.

Sama MT, Ratard RC (1994). Water contact and schistosomiasis infection in Kumba, south-western Cameroon. *Annals of Tropical Medicine and Parasitology*, 88(6):629-634.

Tayo MA, Pugh RN, Bradley AK (1980). Malumfashi Endemic Diseases Research Project, XI. Water-contact activities in the schistosomiasis study area. *Annals of Tropical Medicine and Parasitology*, 74(3):347-354.

Tiglao TV, Camacho AC (1983). Water contact behaviour among humans in Leyte, Philippines. *The Southeast Asian Journal of Tropical Medicine and Public Health*, 14(1):18-24.

Useh MF, Ejezie GC (1999). Modification of behaviour and attitude in the control of schistosomiasis. 1. Observations on water-contact patterns and perception of infection. *Annals of Tropical Medicine and Parasitology*, 93(7):711-720.

Wu Z et al. (1993). Factors contributing to reinfection with schistosomiasis japonica after treatment in the lake region of China. *Acta Tropica*, 54(2):83-88.

Validity in studies of water contact

During the 1980s and 1990s, it was debated in the literature whether direct observation or self-reporting through questionnaires was the most reliable method for producing accurate data on risk behaviour (Huang & Manderson, 1992:181). This debate was part of a wider discussion concerning immunological reactions to schistosomiasis, which had potential implications for vaccine development: could lower egg loads in adults than in children be ascribed to less water contact or to the fact that adults had developed an immunological response to the infection?[a]

Observational studies have been regarded as more valid than interviews of reported water contact, but they may entail their own biases. People may change habits when they are observed and it may be impossible to cover all water sources in an area. Kvalsvig & Schutte (1986) present a cost-effective method for determining the most important water contact activities in relation to transmission. Fulford et al. (1996) and Kloos et al. (2006) have discussed the strengths and weaknesses of direct observation and interview methods.

[a] Today it is generally acknowledged that water contact is not the only relevant factor for explaining adults' lower susceptibility to pathology.

Social determinants at local level

The following summary of selected findings related to social determinants mainly stems from water contact studies.

Age and gender

Water contact is intimately linked with the different social roles and practices of men, women, boys and girls in particular locations. Whereas age is often related to intensities of infection, with older children having the highest intensities, gender is a poor indicator for predicting risk across areas and regions. Among Afar semi-nomads in Ethiopia, men do their own laundry, but women are still more at risk because they collect swamp plants for food and mats (Kloos et al., 1977). In Brazil, moral notions of proper womanhood keep girls and women away from places that are considered "dirty", such as rivers and streams, which protects women from infection (Noronha et al., 1995). Even though young women in particular may spend more time in contact with water in communities in Kenya, the time of day and degree of immersion reduce gender differences in exposure to infection (Fulford et al., 1996). Ofoezie, Christensen & Madsen (1998) made similar observations from south-west Nigeria. Kloos et al. (2006) discussed methods to eliminate gender bias in recording of water contacts (see the section on studies of schistosomiasis and gender in Chapter 2).

Occupation

Occupation is often a valid predictor of risk, taking focality of transmission and age into account (Huang & Manderson, 1992:180-181). Various forms of fishing and farming pose risks (Loroni-Lakwo et al., 1994; Watts & el Katsha, 1997). A study from Brazil shows the link between economic survival and particularly men's contact with water as part of agriculture (da Silva et al., 1997). Tayo, Pugh & Bradley (1980) showed how fishing by young men accounted for the majority of contamination and exposure in northern Nigeria.

Ethnicity and religion

Epidemiological studies sometimes point to ethnicity as a risk factor, but such a pattern often points to an underlying division of labour between ethnic groups (e.g. Fenwick et al., 1982). The seclusion of women in some Muslim communities leads to women's lower rates of schistosomiasis due to less exposure to water sources (Michelson, 1993). If water used for daily ablutions by Muslim men is infectious, they may have higher prevalence than women (Kuntz, 1952). A study from a Muslim community in northern Nigeria showed that activities involving contamination and exposure were almost exclusively carried out by men (Tayo, Pugh & Bradley, 1980).

Education

There have been few studies on the correlation between education level and infection and results are contradictory (Farag et al., 1997). A study from Kumba in south-western Cameroon observed that infected people had more knowledge of the infection than uninfected people in the same area (Sama & Ratard, 1994). This could be interpreted as a case of health communication that has worked under conditions that have not allowed people to change habits. A study from Santo Antonio de Jesus, Bahia State, Brazil, indicates that an increase in the education level of the head of household was strongly associated with a decrease in the prevalence and intensity of infection in the household (Barreto, 1991).

Socioeconomic status

Results of studies on the relation between socioeconomic status (defined and measured in many different ways) and water contact or infection are conflicting. A study from Côte d'Ivoire shows that while the general population in areas with piped water, less crowding and better housing was less infected than the population in crowded areas without piped water and good housing, the prevalence in children between 10 and 14 years of age was still high due to their playing in infested water (Fournet, N'Guessan & Cadot, 2004).

Location of households in relation to water sources may play a role (Mota & Sleigh, 1987). A detailed epidemiological study was carried out in São Lourenço da Mata, Brazil (Ximenes et al., 2001). It showed that leisure water contact, particularly swimming, was the only type of water contact significantly associated with schistosomiasis among people between 10 and 25 years of age, and that a decrease in water contact was associated with better socioeconomic conditions (ibid.:20). As school attendance is not compulsory in Brazil, young people from poorer families may be engaged in physical labour, and thus more tempted to cool off in the river. The authors draw attention to the dominant ideology of individuals being responsible for their own health, which sees individuals as independent decision-makers. Even though individuals can make choices regarding, for example, exposure, many settings do not promote and enable such choices (ibid.:20).

A survey among schoolchildren in a rural area in Côte d'Ivoire by Raso et al. (2005) observed that there was no relation between prevalence of *S. mansoni* infection and socioeconomic status as defined by household assets. However,

poorer children had higher frequencies of light infection, whereas there was no significant association between socioeconomic status and moderate or heavy infection. This finding is similar to those from studies from Brazil (Kloos, Gazzinelli & van Zuyle, 1998; Bethony et al., 2001), but behavioural, ecological and other factors specific to each site are assumed to play important roles in the distribution of infection.

Epidemiological studies, including water contact studies, can be useful as a starting point for screening of infections in the area or for monitoring individuals' change in water contact behaviour over time in the same location, but observations often have limited predictive value across cultures and regions. Furthermore, these data often provide little information about underlying social dynamics and local motives and meanings related to water contact, which is necessary when designing locally compatible control programmes.

Spatial analyses of the distribution of schistosomiasis

Due to the usually focal nature of transmission, spatial analyses are particularly relevant when studying schistosomiasis. Microgeographical studies can visualize the complex links between a number of variables such as transmission sites, water contact sites, snail habitats, location of housing and infection at individual (prevalence and intensity) and household level (density of infection) in different areas (Kloos et al., 1983; Barreto, 1991; Kloos et al., 1997; Kloos, Gazzinelli & van Zuyle, 1998; Lwambo et al., 1999; Kloos et al., 2001).

Applications of geographic information systems (GIS) are currently powerful means of risk mapping for whole populations (Bergquist, 2002:310; Handzel et al., 2003; Clennon et al., 2004; Simoonga, 2006). Wu et al. (1993) conducted a study that included an analysis of the role of distance between house and snail habitat in reinfection patterns in China. Huang & Manderson (2005:227) report similar observations in China.

Spatial studies have also been carried out at regional level. Martins Jr & Barreto (2003) produced a spatial profile of correlations between irrigation systems and the spread of *S. haematobium* infections at state level in Bahia, Brazil, and Ollivier, Brutus & Cot (1999) mapped the spatial distribution of the infection in Madagascar in relation to several factors, such as labour migration, urbanization and water resources development projects.

Households as basic unit of analysis

Acknowledging that individual water contact is embedded in wider social processes, households have been introduced as a basic unit of analysis. Studies from Brazil showed that households, as a composite measure of the social determinants influencing water contact, accounted for between a quarter and a third of the variation in faecal egg excretion measured in three faecal samples per participant (Bethony et al., 2001) and water contacts per week (Bethony et al., 2004).

Households, as a unit of analysis, may be most relevant in Brazil, where individual household water supply and ownership of land and water leads to greater focalization of exposure risk compared with African settings where communal ownership of land and water sources does not limit people's movements in the same way (Kloos, Gazzinelli & van Zuyle, 1998). Similarly, Jiang et al. (1997) have analysed the factors involved in family clustering of *S. japonicum* infection in China, which can be interpreted as a result of the shift from collective to family-based production. Ellis et al. (2006) have pointed to genetic factors in familial aggregation of infection with *S. japonicum* in China.

Whenever households are used as a unit of analysis, it is important to define whether the unit is delineated as a physical structure, a kinship locus, a social organization or an economic unit. It is equally important for an analysis to consider migrants away from home as well as labourers living with their employers when defining the household (Bethony et al., 2001:136-137).

Water contacts as integrated part of social activities

Watts et al. (1998) have applied an approach to water contact behaviour that leaves the banks and brinks of water sources to analyse water contacts as an integrated part of social activities in a village in an irrigated area of Morocco. Water-use activities are seen as processes that take place in a social, spatial and temporal context, rather than merely a series of discrete activities performed by individuals (ibid.:756). Taking account of gender relations and family members' roles in the household, the study focuses on three elements of analysis: (i) the household (as a basic locus for the production of health and the power relations, knowledge and strategies that influences the health of each family member); (ii) the time geography (mapping of who goes where at what time); and (iii) the

gendered use of space. The study shows how the composition of a household and its resources influence the patterns of risk for each family member. Situating detailed observations of movement in and out of the house and activities associated with water collection, water contact and water use in the daily life of family members, it became possible to understand the extensive flexibility and variability in water use and water contact (ibid.). The study is an example of the way social science studies can feed into a larger cross-disciplinary research project, such as in Morocco, in which it was an objective to introduce environmental interventions and monitor impact on snail populations and human water use and water contact. The detailed observations formed a baseline for changes in water use and water contact behaviour.

The approach suggested by Watts et al. can be applied to illuminate how water contact is often a well-informed matter of managing a balance of risk and benefits. Women in Egyptian villages who are well aware of the risk of schistosomiasis may still prefer to go to the canal to wash grains. This task, which would take two days at the water tap at home, takes two hours in the local canal. Women from households with septic tanks may still go to the canal to keep down the bills for emptying the tanks (el Katsha & Watts, 1997: 851). The approach can also highlight the way water sources are social arenas. In Egypt, for example, teenage girls do not only help out with dishwashing at the canal, but they also display part of their skills as future housewives in making kitchen utensils shine and by stacking them nicely (ibid.: 851).

Implications for planning and implementation of control programmes

- Looking at water use from a household and community perspective – as opposed to individual-level – may provide new input to the design of control programmes.

Directions for social science research

- What new insights can be obtained from applying the household – as opposed to individual behaviour – as the main unit of analysis in relation to various aspects of transmission?

Studies of infective behaviour

Main points

- *Very few studies have systematically explored the role of contaminating behaviour in transmission.*

Epidemiological studies have shown that only a small portion of an infected population is responsible for the majority of eggs excreted into the environment (Feldmeier & Krantz, 1993:133). When a limited group of community members dispose faecal material near or in water, it presents a hazard for all community members in contact with the water. The privacy associated with human urination and defecation has limited studies of the segment of the transmission cycle related to infective behaviour.

From the few studies on this particular topic and scattered observations from others, it appears that age and gender play an important role in infective behaviour. A large part of contamination stems from children, who often have high intensities of infection and who urinate and defecate in water during play (Ouma, 1987). Sow et al. (2004) investigated hygienic practices of schoolchildren and mothers with infants in relation to defecation in a village in northern Senegal. They found that more than two thirds of schoolchildren rarely or never used latrines (latrines were available to 90% of the village population). Children's reasons for not using them included that they were not available, they were dirty, occupied or distressing or that they used the latrines at school. The study also observed that 24% of the children defecated near or in water.

Adults may also prefer to relieve themselves near water in order to wash afterwards, particularly if the location offers privacy (Fenwick, Cheesmond & Amin, 1981). A systematic study of excretion behaviour and its effect on transmission of *S. mansoni* in the Gezira irrigated area of Sudan suggested that privacy was more important to adults defecating than access to water for washing bodies or hands afterwards. A total of 93% of recorded defecation episodes took place far from water sources (Cheesmond & Fenwick, 1981). The same study observed that only 31% of men and women washed after excretion, and that women tended to wash by pouring water from a jar onto dry ground, as opposed to some of the

men who washed directly in the canals. Nevertheless, the study concluded that contamination from washing after defecation was limited.

A study from Cameroon briefly observes how different ethnic groups have different preferences with regard to the location of defecation and norms of decency (Robert, Bouvier & Rougemont, 1989a:359). Ouma (1987) studied the transmission of *S. mansoni* in an endemic area of Kenya with special reference to the role of human defecation behaviour and sanitary practices.

Implications for planning and implementation of control programmes

- The fact that a few highly infectious individuals can contaminate a whole locality poses a challenge for control, particularly where prevalence levels are low.
- Programmes for construction of latrines should be evaluated with regard to use.

Directions for social science research

- In spite of methodological difficulties, there is a need for more knowledge about local variations in preferences and habits in this largely unexplored area. Findings would also be of use in relation to other health problems, such as diarrhoea and dysentery.

Local perspectives on symptoms, risks and treatment-seeking practices

Main points

- *Quantitative and qualitative studies of local knowledge, perceptions and practices are usually descriptive and focus on risks, signs of morbidity and treatment-seeking practices. Only a few studies interpret data with reference to theories of knowledge and practice.*
- *Quantitative and qualitative studies of local knowledge are often carried out to provide baseline data, but some are also used as input to the development of health education messages or as an integrated part of community involvement.*

Studies of local perspectives on schistosomiasis are often based on a primary health care approach and on the assumption that control programmes should relate to local conditions to be effective (e.g. Dunn, 1979; Taylor et al., 1987; Gazzinelli et al., 1998; Danso-Appiah et al., 2004). Local perspectives and conditions are defined and explored in varying detail. Quantified surveys of knowledge, attitudes and practices (KAP) are mainly carried out to provide baseline data at the beginning of control programmes, sometimes in conjunction with prevalence or morbidity studies and other assessments. The majority of these studies measure local knowledge and risk perceptions against biomedical knowledge of the infection and the parasite life-cycle.[14] Studies applying an open-ended and qualitative approach often explore more fully the variety and dynamics of local priorities from the actors' point of view. Data may be analysed with reference to wider social, political and historical contexts as well as theories of practice and the dynamics of social change. Furthermore, these studies sometimes offer insight into the understudied social dynamics in the interfaces between local communities and the institutions that implement control programmes (discussed in the section on community involvement in schistosomiasis control in Chapter 4). The section closes with a brief discussion of the apparent discrepancy between knowledge and behaviour commonly observed in these studies.

Interpretation of symptoms

Local knowledge of S. haematobium *infection*

When studying local interpretations of the symptoms of urinary schistosomiasis, a classic observation is that red urine is seen as a normal and rather harmless phenomenon, a rite of passage, for young boys (Hunter, 2003:231, in northern Ghana) or a sign of manhood (Akogun, 1991, about the Song people in Nigeria). But in areas with a higher prevalence, blood in urine and pain when urinating can also be seen as a serious problem (Clark, Appleton & Kvalsvig, 1997, in KwaZulu-Natal, South Africa; Hewlett & Cline 1997:A29-A30, in northern Cameroon).

[14] In many studies, there is an implicit hierarchy between scientific knowledge of schistosomiasis and the "misconceptions", "irrational", "inadequate", and "false" beliefs and myths of the "ignorant" locals. The validity of medical sciences is not disputed here, but limitations in the biomedical viewpoint can be a barrier to understanding the fuller picture of coexisting explanatory models and the dynamics of knowledge. Furthermore, it is misleading if this terminology implies that more education will solve the problem of transmission.

The interpretation of identical clinical symptoms may vary with gender. Bloody urine may be seen as a sign of a sexually transmitted infection or infertility in women in Cameroon and south-east Nigeria (Nwaorgu, 1992, and Anyangwe et al., 1993, cited in Feldmeier, Poggensee & Krantz, 1993:144). In a Muslim community in Nigeria, women's movements were restricted so that they were not exposed to infected waters. Blood in urine was regarded exclusively as a male disorder, though some equated haematuria with women's menstruation (Bello & Idiong, 1982; Pugh et al., 1978, cited in Michelson, 1993:495).

Among people in rural Mali, where the prevalence of infection with *S. haematobium* was relatively low, there was no local term for the schistosomiasis symptom complex. The various symptoms of the infection were regarded as unrelated. Red urine was associated with several different afflictions, syndromes and causes, including hard work, eating certain foods, sexual intercourse and flies. The process of labelling symptoms and classifying them into illness entities was sometimes repeated if treatment failed. Symptoms could be reclassified several times and new forms of treatment tried out until it was considered adequate (Hielscher & Sommerfeld, 1985).

In Upper Egypt, men considered schistosomiasis, known as *harzia* from the previously common term bilharzia, a serious disease that weakens people, eats the liver and causes blood loss, bladder stones, calcium disease and other afflictions. At the same time, many considered the disease a children's disease. People would give widely varying responses to the question of cause, but the higher the level of education, the fewer different causes were mentioned (Kloos et al., 1982).

In north Cameroon, the Fulbe relate red urine, *cille naange* ("sun urine"), to long exposure to the sun, which is particularly common for children. People from other ethnic groups more often related red urine to drinking dirty water or water from very different sources (also more common for children). They would also distinguish red urine from white urine, which was more often related to sexually transmitted diseases. These and other bits of local knowledge (e.g. staying out of the sun and water holes during midday in order to avoid infection) were systematically used as a basis for the design of health communication (Hewlett & Cline, 1997).

In Nigeria, red urine, *ogbodu*, was seen by many (irrespective of educational level) as a sign of a venereal disease; a sign of maturity or a result of a curse (more among people with no formal education); malaria fever, witchcraft or dirtiness, but water contacts or snails were not mentioned (Amazigo, Anago-Amanze & Okeibunor, 1997).

Local knowledge of* S. mansoni *infection

A study from Kenya reports on the widespread knowledge of skin rashes that appear in connection with contact with stream water (possibly due to cercarial penetration of the skin). These symptoms were seen as seasonal, being most common during the dry season when transmission was highest in the area. Locals, however, did not associate these rashes with stomach aches or worm infections (Kloos et al., 1987).

A study from the State of Espirito Santo, Brazil, elucidated very well how people actively develop their understanding of schistosomiasis in a dynamic process based on a mix of existing and new knowledge. People mentioned a range of symptoms of infection by *S. mansoni* – mainly weakness, fatigue and inability to work as hard in daily routines. A total of 22% of people interviewed referred to serious cases when answering questions about symptoms, even though prevalence levels had only been medium in this area. Among the serious symptoms, the *barriga d'água* ("water belly") had most impact on people's accounts. The form of diagnosis influenced the understanding of the parasite (if it had been diagnosed via blood samples, it was considered to live in blood vessels). People were aware that worms can live for a long time in the body, and that the infection can become serious if it is not detected early enough. They were also aware that the infection could be treated to avoid the serious sequelae.

The local term for the illness was *doença do caramujo* ("the snail disease"). Many people did not distinguish between the snail and the parasite, but based on the way they had understood the federal public health agency's information, one third of the informants thought of the infection as caused by water snails entering the body. At the same time, they found this information absurd, because the snail is too big to penetrate the skin. This mystery cast doubt on the existence of the illness and the researchers were repeatedly asked to explain how the snails could enter people's bodies. People themselves had hypotheses that the snail could

be swallowed by accident, even though they knew that health workers wanted them to say that the disease-causing agent enters through the skin. People then assumed that if it could enter through the skin, it must also be able to enter through the mouth – a route of disease transmission that they were much more familiar with (Rozemberg, 1994).

In preparation for a survey to be used as baseline information on household KAP and water contact studies as well as subsequent health education, Gazzinelli et al. (1998) explored teachers' and students' understanding of transmission, causes, prevention and therapy of schistosomiasis in a rural area of the State of Minas Gerais, Brazil. The local term for the disease, *xistose*, which was not considered serious, referred to worms that entered the body when it was in contact with dirty water or when eating unwashed fruits and vegetables, raw pork or fish from contaminated water. Kissing or touching infected people was also mentioned as well as walking without shoes in dirty places. Students and teachers listed stomach ache, diarrhoea, blood in stools, enlarged belly, headache and dizziness as possible symptoms of infection, as well as pain in the legs, weakness, fever and white spots on the body (ibid.).

Local knowledge of* S. japonicum *and* S. mekongi *infections

It has not been possible to locate any studies published in English of local perceptions of *S. japonicum* infections, but in Guangxi, China, where schistosomiasis was eradicated in 1989, a series of qualitative data collection methods were applied between 1993 and 1996 (in-depth interviews, a KAP survey, focus group discussions followed by community feedback) to provide information about the possible roles of communities in maintenance strategies (Sleigh et al., 1998b). The study showed how older generations linked eradication of schistosomiasis with clear differences in health status, work capacity and social mobility (infected men could not enrol in the army; matchmakers could not find brides willing to move into areas known for schistosomiasis). Younger generations were less knowledgeable of schistosomiasis and its consequences, but were interested in learning more. The success of the control programme was to a large extent based on mobilization of local communities (for snail surveillance, ditch maintenance, clean water supply and sanitation, etc.), which would seem unrealistic today, because people's attitudes have changed from the collective effort of the past for the common good to a more individualistic approach.

In an article presenting clinical cases from northern Cambodia, Biays et al. (1999) include data on local perceptions and treatment of severe infection with *S. mekongi*. Four different local terms existed for describing the severe symptoms of the infection. These four terms were seen as separate diseases ascribed to various factors, such as poisoning of river water due to gold mining up the river, the use of human faeces as manure in rice fields or revenging forest spirits. Some people observed that the diseases had increased in frequency 20 years previously, when a group of people had been relocated to the area by the military regime at the time. The study does not provide information about prevalence then and 20 years later, so it is not possible to draw any conclusions about whether there had in fact been a change in prevalence. The illnesses are usually treated by calling and making offerings to spirits, by various types of herbal treatment, by burning the skin of the patient around the affected areas or through a mix of Buddhist and animist ceremonies.

Local knowledge of mixed infections

In areas with mixed infections, there is often a marked difference in local knowledge of the two infections (Sangho et al., 2002). This may be because the symptomology of *S. haematobium* infection is more distinct than that of the infection with other schistosome species. Sometimes infection with *S. haematobium* is more common and sometimes public health education and health personnel have been geared towards *S. haematobium* to the extent that symptoms of infection with *S. mansoni* are not recognized (el Katsha & Watts, 1995a). The lack of recognition of *S. mansoni* infections may be reflected at the professional health-care level in case records and health information systems that do not distinguish between infections with *S. haematobium* and *S. mansoni* (Danso-Appiah et al., 2004).

In the Magu District near Lake Victoria, in the United Republic of Tanzania, infections with both *S. haematobium* and *S. mansoni* are found. Applying a combination of qualitative and quantitative methods, Mwanga et al. (2004) studied local perceptions of and attitudes to symptoms associated with both infections in this district. Both types of schistosomiasis are associated with sex and promiscuity, as well as infertility for women and impotency for men (ibid.:69-71), which is partly why people in the study area find blood in urine, *kichocho cha mkojo*,

shameful. Young boys and girls, who are most likely to be heavily infected and who pass blood in urine, are particularly ashamed to disclose their symptoms to friends and adults.

In Cameroon, different ethnic groups have settled at a newly established hydro-electric dam where both *S. haematobium* and *S. mansoni* are found. They associate the infection and/or red urine with drinking lake water, sexual intercourse or overexposure to the sun. Some associate the infection with pains in the lower abdomen, pain when urinating or changes in the colour of urine to white or red. The terms used for blood in urine or in stools are associated with several illnesses related to genitourinary symptoms and diarrhoea (Robert, Bouvier & Rougemont, 1989b).

Limitations of knowledge, attitudes and practices (KAP) surveys

KAP surveys seem to be one of the most widely used contributions of the social sciences to public health. The questionnaire-based surveys provide insight into the distribution of normative knowledge (but not necessarily attitudes and practices) regarding predefined issues in a given population, which can be useful as a source of baseline data for post-intervention evaluation. But depending on the purpose of KAP surveys, the following limitations to the interpretation of data may apply.

- KAP surveys provide snapshots of the distribution of normative or desired knowledge, attitudes, and reported practices of individuals. However, when actual practices unfold, normative knowledge and attitudes only figure as one factor among others and they are best described after extensive observations of events and naturally occurring discussions analysed in the context where they arise (Yoder, 1997:141). Factors at household, community and national levels may also influence health-seeking behaviour, and even internationally driven policies, such as cost-recovery schemes, may play a role (Danso-Appiah et al., 2004) that is difficult to capture in a KAP study. The social desirability of behaviours and attitudes related to hygiene and health-seeking practices may influence men and women's different responses in questionnaires (Taylor et al., 1987; Kloos et al., 2006:39).

- The quantifiable and predefined variables used in many KAP studies form the basis of a static and simplified understanding of social and cultural aspects of schistosomiasis. "A sense of process is not conveyed in this work and the context is lost. Above all, the techniques are too insensitive to describe health and illness from the actor's point of view" (Parker, 1993: 486), which is the central entry point for understanding health-seeking practices and the way they may change over time.
- KAP studies are not always based on a thorough exploration of local terms and categories for signs and symptoms that can be associated with schistosomiasis or other biomedical disease entities. Even if there is a local term for red urine, it should not be assumed that local images of its causes and symptoms correlate with the biomedical images of schistosomiasis on a one-to-one basis. This may seriously distort interpretations of questionnaire results. The formulation of survey questions and the interpretation of the findings should be informed by specific information about local disease categories (Hewlett & Cline, 1997). The different implications of referring to signs and symptoms as opposed to the local or even biomedical disease label should be considered in the design and interpretation of questionnaires.
- A danger in studies of local knowledge is that they produce an image of the problem as a matter of lack of knowledge or education (e.g. Ukwandu & Nmorsi, 2004). They fail to include social and economic underpinnings of the problem at community, regional, national and international levels (Kloos et al., 1987:383; Kloos, 1995:1498). Furthermore, the focus on an individual's knowledge facilitates a view of infection as something that can be blamed on that individual. This obscures the social, economic and political basis of health (Crawford, 1977; Barbosa, 1995:157; Farmer, 1999:85), which includes the importance of poverty, the low priority given by communities and national health planners to the control of specific diseases, the inefficiency of the health services and the lack of political will and community participation, all of which are beyond the control of individuals at risk (Kloos, 1995:1498).

Prevention, treatment-seeking practices and the balancing of risks

People's perception of risk, diagnosis and cause of illness change and may be influenced by the perceived effect of treatment. In the course of trying out different treatment options for various symptoms (Hielscher & Sommerfeld, 1985),

people will adjust their understanding of their disease and its cause based on their experience of symptoms and the effect of treatment. This process is also influenced by what people hear about the infection from relatives, neighbours, health personnel and mass media. This and other factors influence the way people diagnose ailments and balance risks in their daily routines.

Few studies explore in depth the dynamics of coexisting concepts and treatment practices in a pluralistic health-care system.[15] Danso-Appiah et al. (2004) observed with concern how people in a village in Ghana combined self-treatment (with pharmaceuticals) with visits to health clinics for symptoms that could be related to schistosomiasis. More than 90% of those who treated themselves did not take praziquantel. This has implications for shifting from vertical programmes to integrating schistosomiasis into regular health services in Ghana, which would rely on passive case detection.[16]

Many different perceived causes of symptoms may be considered in the process of deciding on a diagnosis that relates to different forms of prevention and treatment. Aryeetey et al. (1999) described how people in villages in southern Ghana related red urine to eating sugar cane, sexual intercourse with an infected person, or bathing and drinking in ponds or rivers. If treatment was considered necessary, it was sought from drug peddlers or shops. Herbs prepared at home by the elders might be tried out. The choice of treatment depended on the interpretation of symptoms and their cause, but also on convenience and access to social and economic resources.

In Upper Egypt, higher levels of education were related to the reporting of fewer different causes of infection with *S. haematobium* (Kloos et al., 1982), but the level of education was not significant in patterns of using modern or (the more easily available) traditional treatment. Most people had taken both.

Symptoms of both *S. haematobium* and *S. mansoni* infections were considered normal in Magu District, United Repulic of Tanzania, and it was expected that

[15] Pluralistic health-care systems have been defined as consisting of at least three "sectors", i.e. the popular sector embracing practices of self-treatment, the folk sector consisting of traditional specialists, and the professional sector based on biomedical knowledge (Kleinman, 1980).

[16] Active case detection implies that health-care personnel reach out to target groups. Passive case detection implies that infected people themselves seek testing and treatment in health-care facilities.

they would disappear without treatment. A swollen abdomen was considered to be caused by bad will or witchcraft, which should be treated by traditional medicines. Traditional medicine and biomedicine coexisted in the district and their practitioners referred patients to each other (Mwanga et al., 2004).[17]

Danso-Appiah et al. (2004) looked at determinants for passive case reporting in existing health-care delivery systems in Ghana, where vertical programmes were to be integrated into the regular health services. Among the observations, teenagers (mainly boys, and particularly those not attending school), who usually had a high intensity of infection, were expected to begin paying for their own health-care needs. This might delay or rule out their visits to health centres, particularly if symptoms were regarded as mild.

In a study from Cameroon conducted by Robert, Bouvier & Rougemont (1989b), people were well aware of ways to prevent a range of diseases related to the drinking of contaminated lake water, but they were not familiar with the role of snails in the life-cycle of schistosomiasis and, thus, not aware of the risk of contact with water. Symptoms could be treated with herbs, by going to the local health centre or a combination of both.

In rural Minas Gerais, Brazil, children and teachers all knew of biomedical treatment of *xistose* (the local term most equivalent to the biomedical disease entity schistosomiasis), which was available in local pharmacies after being tested. People tended to seek treatment in health centres only for serious gastrointestinal problems or bloody stools, because it was difficult to get appointments, or because transport and waiting times made access difficult (Gazzinelli et al., 1998).

In the State of Espirito Santo, Brazil, people might look for the free-of-charge and guaranteed biomedical *remédio de caramujo* ("snail medicine") once they had been diagnosed with *S. mansoni*. People said that even though the medicine could not remove the disease, it could ensure that the disease would not become

[17] In Zimbabwe, plant medicines used by traditional healers have been tested for efficacy. Researchers asked 286 traditional healers about their knowledge of signs and symptoms of urinary schistosomiasis and for a fee they gave the names of the plants they used for treating the infection. The eight most commonly mentioned plants were tested in male hamsters and three were found to be lethal to adult worms (Ndamba et al., 1994). It is not known to what extent traditional medicine used in the communities may influence prevalence and intensities of infection.

serious. People who were not checked regularly and who did not take treatment were considered to be in danger of serious disease (Rozemberg, 1994).

In two villages in Minas Gerais, Brazil, people were well aware of schistosomiasis and its relation to water contact. Perceived risk was not associated with water contact, however, but rather with symptoms of the infection. People tended to distinguish between minor symptoms (skin rash associated with water contact) and major symptoms of *xistose* (leg pains, weakness, weight loss, swelling of abdomen, vomiting and bloody diarrhoea). Schistosomiasis was on the one hand seen as serious, but on the other hand as harmless, if treatment was taken at an early point. This view did not appear to reduce water contact (possibly also due to broken water pumps and the convenient location of some water sources) (Uchoa et al., 2000).

A study from a small town in Bahia, Brazil, further explored the intersection of individuals' *experience* of risk and being infected with parasites as opposed to their quite extensive *knowledge* of transmission and prevention of parasitic infections, which stemmed from health education. Young people's accounts of the transmission cycle and risk factors were fairly close to the biomedical model and they reported that they had their information from teachers and doctors. The authors interpreted young people's firm statements in this regard as indications of a strong medicalization of health, which may be connected to the younger generations' faith in science, "progress" and technologies, including modern pharmaceuticals. The authors interpreted this as an expression of medical doctors' monopoly of "correct" knowledge (Noronha et al., 1995). The authors observed that even though young people were aware of risk factors and pointed to the importance of consulting their doctor, they did not translate their knowledge into practice. Instead, it seemed that the enactment of local gender roles played a part in putting men and women at different risk levels (see also the section on studies of schistosomiasis and gender in Chapter 2). In spite of a relatively successful transfer of biomedical knowledge regarding schistosomiasis through conventional health education, there was still a discrepancy between knowledge and local practices.

The summaries above are examples of informants' "irrational" perceptions of the infection, which have consequences for the way people may or may not change behaviour and seek treatment. Systematic study of these perceptions (e.g. many

people thought the infection was a worm eating them from their insides; a native chief assumed that the pills for treatment turned into worms inside his body, because worms came out when defecating; a wealthy and influential woman who became dizzy after taking the pills effectively warned everybody in her village against the pills; a young girl left the risk of getting infected in God's hands) provides important insight for control. By including these subjective, symbolic, irrational, theological and mythological experiences into the epidemiological description of the infection, it becomes easier to understand the complexity of the transmission cycle and its constantly changing image in communities (Coura-Filho, 1996).

Hielscher & Sommerfeld (1985) describe how local concepts of red urine were mixed with biomedical concepts and treatment practices of schistosomiasis in rural Mali. In an area of relatively low prevalence, red urine was interpreted according to a range of disease labels and it was not usually treated with biomedical medicine. In a nearby area with a functioning irrigation scheme, red urine was more often interpreted in a way that would entail consultations with the professional biomedical sector. The study shows how people looked for treatment on a trial-and-error basis and it closes by drawing attention to the many factors that influenced diagnosis and choice of treatment, which was not only a matter of disease categories, but also perceptions of what types of medicine match which symptoms, the different forms of trust involved in the various sectors (i.e. popular, folk and professional), and not least the economic and social resources available to the person affected and his or her family.

Kloos et al. (1987) take a pragmatic view of conditions and resources in rural communities in Kenya that may be built upon in prevention and control of the transmission of *S. mansoni* infection. People reported being treated for intestinal illness at hospitals, health centres and clinics, by traditional healers or with home remedies or shop medicines. Almost half of the people interviewed reported using more than one type of medical service apart from control project services. Home remedies were most often used for newly arising stomach aches, diarrhoea and vomiting, and if these failed, people would look for other options. People with chronic symptoms would seek assistance both in the biomedical health-care system and with traditional healers, depending on convenience, type of payment requested and advice from others.

For studies of local knowledge regarding plants that can be used as molluscicides, see the section on snail control (in community involvement in schistosomiasis control in Chapter 4).

Several studies from areas where control programmes have run for many years have observed a correlation between knowledge of schistosomiasis and behaviour. Umeh, Amali & Umeh (2004) measured, among other factors, the correlation between knowledge of urinary schistosomiasis and prevalence in rural Nigeria and suggest that health education would be a cost-effective intervention to reduce incidence. In contrast, other studies show an association between individuals' infection and their higher levels of knowledge about the infection (Sama & Ratard, 1994; Wagatsuma et al., 2003). Kloos et al. (1982) observe how people in Egypt are very aware of safe and unsafe water contact. The authors note parents' ambivalence in wanting children to stay away from the water, but at the same time teaching them to swim.

The health belief model claims that there is a direct relationship between knowledge and behaviour. Although it has been shown repeatedly that behaviour and behaviour change is only related to knowledge in a very complex way, it remains the predominant conceptual framework for health education and promotion (Yoder, 1997). Research on local perceptions of illness is useful for understanding the logic of actions, but it cannot be expected to predict individual behaviour (ibid.:138). Action is influenced by power relations and situated in specific contexts of coexisting and sometimes contradictory concerns and priorities. For this reason, researchers need to maintain a focus on social processes rather than on static beliefs and cultural markers (ibid.:141). Knowledge and perceptions are situational and without much meaning when they are seen in isolation from the moment they are articulated.

For the same reason, it is a mistake to assume that behaviour change can or will come about only by designing culturally appropriate health education messages. It makes a great deal of sense to interpret observations of behaviour and social factors with reference to the meanings and significance they have for the people at risk of infection, and to design control efforts on the basis of local conditions (Parker, 1992; Hewlett & Cline 1997; Watts et al., 1998), but identifying local idioms and using them in health education is not a magic bullet automatically

leading to impact. Behaviour is linked to but not determined by knowledge or culture. People must have attractive alternatives to be able to change behaviour (Coura-Filho, 1998). See also the study by el Katsha & Watts (1997) mentioned in the section on water contacts as integrated part of social activities above.

In the Zona da Mata region of Pernambuco, Brazil, public institutions tended to regard the failure to reach programme goals as individuals' cognitive weaknesses or collective cultural backwardness. Since no evaluations were carried out, there were no opportunities to get feedback from people. The authors' semi-structured interviews with local people revealed that none had participated in meetings about health, but people were quite aware of risks related to river water. To bridge the discrepancy between official health messages and daily necessity, people applied their own strategies to minimize risk, such as to wash clothes in the river, but not bathe in it; to bathe in the river, but not to drink from it; or to stay only in shallow water near the brink. The authors interpret these practices as an expression of survival techniques rather than ignorance or indifference to risk (Acioli & de Carvalho, 1998).

Implications for planning and implementation of control programmes

- Control programmes should be aware that KAP surveys are not always appropriate and that it would sometimes be an advantage to supplement such surveys with qualitative methods of enquiry.
- The various elements of a control programme should take local perceptions and practices into account.

Directions for social science research

- An understudied topic (so far only studied sporadically in Brazil) is the social dynamics at play when implementers of interventions meet and interact with local communities (see also the section on community involvement in schistosomiasis control in Chapter 4).
- How can long-term studies of social *processes* rather than snapshot studies of local knowledge contribute to improving control programmes?

CHAPTER 4

THE INTERVENTION PERSPECTIVE: SOCIAL ASPECTS OF CONTROL POLICIES AND INTERVENTIONS

In theory, the life-cycle of schistosomiasis can be broken at several stages – see, for example, MacDonald's modelling of the "break point" of schistosomiasis transmission, a threshold level of exposure below which the infection would die out (MacDonald, 1965) – but in practice few control programmes have been able to reduce prevalence and incidence of schistosomiasis permanently (Robert, Bouvier & Rougemont, 1989a:355). However, schistosomiasis has been controlled in China (Sleigh et al., 1998a; Utzinger et al., 2005) and the disease has been eradicated in Japan (Minai, Hosaka & Ohta, 2003) – both successful before the advent of praziquantel.[18] Apart from technical and managerial aspects, many social factors are involved in the, sometimes inadvertent, changes that control programmes bring about.

In practice, the major operational component in morbidity control today is targeted chemotherapy focusing on school-age children and other high-risk groups (adolescents and those whose occupations involve contact with infectious water – fishermen, farmers, irrigation workers, women doing domestic tasks) to lower the intensities of infection (see box *From transmission control to morbidity control policies* in Chapter 1). Depending on reinfection rates, treatment once a year or every six months is recommended. Chemotherapy as the main intervention has gained considerable impetus after the patents related to praziquantel were lifted and the drug became available at an inexpensive price in the 1990s. In this context, many forms of preventive measures are no longer considered cost effective.

A few countries (such as the Islamic Republic of Iran, Lebanon, Thailand and Turkey) have focused on transmission control for some years. This often encompasses broader preventive interventions that are also recommended by WHO (1993),

[18] Puerto Rico, former Venezuela (now the Bolivarian Republic of Venezuela) and many of the Caribbean islands were also successful in reducing prevalence through a combination of environmental management, sanitation and public health initiatives before the advent of praziquantel.

i.e. provision of safe water supply and sanitation, environmental management, health communication and focal snail control (Chitsulo et al., 2000:48). Each of these operational components has social aspects that have been discussed in the literature. This chapter highlights the social elements in diagnosis, access and adherence to treatment, the establishment of safe water supply and sanitation, health education and community involvement in schistosomiasis control programmes, as presented in the literature. It closes with a discussion of the contribution of the social sciences to the study and control of schistosomiasis in a health systems perspective.

Social factors in relation to diagnosis and screening

Main points

- *Social, cultural and economic factors' influence on the validity of individual and population-based diagnostic and screening methods is understudied.*

The standard clinical diagnosis of schistosomiasis infection is based on the detection of eggs excreted in urine for *S. haematobium* and in stools for intestinal strains. Furthermore, diagnosis can be established by detection of schistosome-specific pathology using clinical, biochemical or immunological disease markers. These diagnostic techniques are often regarded as part of a purely technical endeavour handled by health professionals and laboratory experts. Diagnosis can, however, also be viewed as an "interface" between the infected individual, the infected community and the health-care system represented by health professionals and researchers (Feldmeier, Poggensee & Krantz, 1993:162), where many sociocultural and economic factors, including gender relations, influence the validity and efficiency of these methods. This interface has only been researched very sporadically and the acceptability of different diagnostic methods has been a neglected area compared with logistic and technical issues in diagnosis (ibid.: 143).

Sociocultural and economic factors in diagnosis[19]

Diagnosis is mainly based on urine or stool specimens, but blood samples may also be required in some settings. People may be reluctant to comply

[19] See also the section on studies of schistosomiasis and gender in Chapter 2.

and women and girls in particular may be embarrassed to handle bodily specimens in public (Feldmeier, Poggensee & Krantz, 1993:152; el Katsha & Watts, 1998:658). Urine and faeces, but particularly blood, may be ascribed cultural meanings that prevent people from providing specimens. Furthermore, myths and rumours about the use of the specimens may circulate in communities (Feldmeier, Poggensee & Krantz, 1993:143). Reluctance can be interpreted in the context of local cosmologies, but could also very well be seen as a form of local resistance by people with little influence on decisions made regarding an intervention that has perhaps not been properly introduced in the community. The mode of approaching people, the extent of reluctance and its implications for findings are very rarely addressed in studies (Kloos et al., 1977; Kloos, Desole & Lemma, 1981; Traoré, 1989).

Gender-related biases

With particular regard to gender-related biases in diagnoses, Feldmeier, Poggensee & Krantz (1993) have provided a comprehensive overview of biological/immunological, sociocultural, educational and economic factors to consider in assessing the validity of diagnoses of schistosomiasis. For example, errors can occur at a demographic and sociocultural level (women are underrepresented, either by lack of attention to the sampling of participants or to women's sociocultural or economic circumstances, which may hinder involvement), or at a technical level (in terms of gender-related differences in sensitivity or specificity of diagnostic methods). With regard to cultural and educational factors that may influence women's involvement in screening investigations, stigma may be attached to haematuria and embarrassment to blood, urine and stool specimens. Women may lack decision-making powers and freedom of movement in relation to participation in surveys or trips to health facilities. They may lack time due to household chores, lack means of transportation appropriate for women, and have lower levels of education and awareness of symptoms than men. They may fear side-effects of treatment (so may men), have low expectations of the quality of care available from public health-care providers and let the gender of health personnel influence their willingness to participate – either men or women may be most preferred depending on context (ibid.:147-152). In areas where women are secluded, there may be systematic underreporting of women in morbidity surveys (Vlassoff & Bonilla, 1994:43).

Women may be unable to participate in screening initiatives due to their workload. The time lost for farming, small-scale business or domestic chores forms a considerable non-monetary, but tangible cost. There is often very little flexibility regarding these chores in poor households, and even less in households headed by women (Feldmeier, Poggensee & Krantz, 1993:147-152)

A meta-analysis of 35 epidemiological studies on prevalence and/or incidence showed the following tentative results: women and girls are underrepresented in studies where samples are collected at schools and particularly at hospitals. Studies where samples were collected at health centres were too few to draw any conclusions. Women were overrepresented in studies where samples were collected in households, because research assistants would typically visit households during their working hours, when working men would be away from their homes (ibid.:147-152). In areas where women in particular are expected to be among the most heavily infected, it is pertinent to evaluate barriers to women's participation in screening exercises.

Regarding detection of pathology, there are a number of biological differences, such as menstruation, vaginal infections, circumcision or other causes of bleeding that may complicate the use of urine analysis reagent sticks as an indirect diagnostic means among women of reproductive age. Norms of women's mobility during menstruation may also skew their participation in screenings. Ultrasonography, which is the gold standard for detecting severity of pathological changes, and manual palpation require prolonged physical contact between patient and researcher. The abdomen must be uncovered and in case of *S. haematobium* the pubic area too. Women and girls may find this intervention uncomfortable and avoid the examination (ibid.:157-159). Once it is introduced to participants, however, all groups alike may find it interesting to be examined by ultrasonography.

A rare study from the United Republic of Tanzania systematically asked schoolchildren and adolescents about their experience after being examined by ultrasonography (Hatz, 2001). The children and adolescents did not fear the examination in general, but girls were more worried and felt more ashamed than boys. The individual behaviour of the different doctors appeared to be more important to the children than the gender of the doctor (although the youngest girls more often preferred a female doctor) or whether the doctor was African or European (ibid.). Privacy,

the presence of a relative or other close person, and people's opportunity to choose either a male or female researcher may facilitate their participation in the diagnostic procedures.

Diagnosis of genital schistosomiasis

The diagnosis of genital schistosomiasis poses particular challenges. Talaat et al. (2004) have made a detailed report of the way researchers in a cross-disciplinary, community-based study of female genital schistosomiasis in Egypt worked with local men and women and responded to local needs, concerns and requests. The particularly sensitive aspects of genital schistosomiasis contribute to possible biases in diagnosis and call for collaboration between biomedical, technical and social sciences in assessing the acceptability and validity of diagnostic tools. It is not possible to predict factors contributing to gender-related biases in diagnosis of genital schistosomiasis from one time and place to the next – ethnographic or sociomedical studies are needed prior to interventions, to incorporate findings into intervention design (Feldmeier, Poggensee & Krantz, 1993:163).

Mode and consequences of making test results available

An understudied area at the interface between researchers/implementers and communities is the way test results are made available to people during prevalence surveys and how this affects subsequent patterns of exposure and treatment-seeking practices. People are often interested to learn their individual test results, but this feedback (and treatment options made available inside or outside the local health infrastructure, with or without cost-sharing) is not always built into survey designs. Apart from being unethical, it also forms a lost opportunity for health communication, and it may hamper future research projects in the area that assumes people's willingness to participate. A variant of the same problem is people's unwillingness to participate in general surveys. Traoré (1989) observed how the population near a hydroelectric dam in Mali were tired of being surveyed for the previous eight years on their economic, social and health conditions. They simply did not see the benefit of the surveys and consequently the levels of participation were low.

Importance of dialogue

In circumstances where control programmes have been implemented for many years and where people do not experience symptoms, it may be difficult to keep

mobilizing people for surveillance. Pressure to participate can be met by hidden resistance, such as submitting animal faeces or specimens from other people for testing. A study conducted in a rural area in Brazil, where people were given the choice between diagnosis based on a stool sample, a blood sample or both, documents how this choice, coupled with discussions of collective responsibility for good health, made interest and participation increase (Gonçalves et al., 2005). Furthermore, the study underlines how the deliberately established dialogue between researchers and locals led to mutual commitments, which had consequences for the way researchers handled test results in the local community and the acknowledgement of people's right to refuse to participate. Yuan et al. (2005) conducted a study of the way multimedia used in health education of schoolchildren in Hunan, China, significantly increased their willingness to submit stool samples and adhere to treatment.

Link between screening and health education

A largely unexplored area is the link between screening and health education. Much screening is carried out in schools in collaboration with the education system, but little experience with opportunities for health communication has been documented. El Katsha & Watts (1998) have conducted an interesting action research study on the translation of screening policies into action at primary health care level in rural Egypt, including ways of integrating screening in schoolchildren with health education in a context of limited health system resources. See also Guo et al. (2005) for a study of the way health education combined with passive case detection was well received in an area in China used to frequent mass treatment campaigns.

Community diagnosis through screening with questionnaires

Parasitological surveys are often costly and time consuming and (particularly for *S. haematobium*) people's own knowledge of signs and symptoms as recorded in questionnaires has proved a valid and very cost-effective way of identifying and monitoring hot spots of transmission at community level. Questionnaires aimed at schoolchildren were tested by the renowned Red Urine Study Group in Cameroon, Congo, Ethiopia, Malawi, former Zaire,[20] Zambia and Zimbabwe in the early 1990s

[20] Now the Democratic Republic of the Congo.

and then introduced as a screening method for infections with *S. haematobium* in possible high-prevalence areas (Red Urine Study Group, 1995). The method was shown to be a reliable and inexpensive procedure at community level (but not individual level), which could be managed in collaboration with the local education system. Infections by *S. mansoni* and *S. japonicum* can be screened in this way too, but not with the same accuracy due to their nonspecific symptoms (WHO, 2002:19). However, a consistently high negative predictive value in these questionnaires might be used to exclude areas without *S. mansoni* (Magnussen, 2003). For *S. mekongi*, the inclusion of a question regarding the presence of rocks in rivers has proved a useful indicator, together with questions of signs and symptoms (WHO, 2002:20). Used as a first step, questionnaires can assist in stratifying an area into low-risk and high-risk communities, which can then be covered accordingly by the most cost-effective treatment strategy, i.e. either treatment through existing services or special programmes (Tanner, Lengeler & Lorenz, 1993:521).

Selected references: studies using questionnaires for individual and community diagnosis

This list summarizes studies that discuss and use questionnaires for individual and community diagnosis, sometimes in conjunction with parasitological analyses of urine and/or stool samples to check their validity.

***S. haematobium* infections**

Ansell J et al. (2001). The effects of sex and age of responders on the reliability of self-diagnosed infection: a study of self-reported urinary schistosomiasis in Tanzanian school children. *Social Science & Medicine*, 53(7):957-967.

Campagne G et al. (1999). Evaluation preliminaire des indicateurs utilisables au cours d'un programme de lutte contre la bilharziose urinaire au Niger [Preliminary evaluation of usable indicators during a control program for urinary bilharziosis in Niger]. *Médecine Tropicale*, 59(3):243-248.

Jemaneh L, Shewakena F, Tedla S (1996). The use of questionnaires for the identification of high risk areas for urinary schistosomiasis: the Ethiopian experience. *Ethiopian Medical Journal*, 34(2):93-105.

Lengeler C et al. (1991a). Community-based questionnaires and health statistics as tools for the cost-efficient identification of communities at risk of urinary schistosomiasis. *International Journal of Epidemiology*, 20(3):796-807.

Lengeler C et al. (1991b). Rapid, low-cost, two-step method to screen for urinary schistosomiasis at the district level: the Kilosa experience. *Bulletin of the World Health Organization*, 69(2):179-189.

Lwambo NJ et al. (1997). Control of *Schistosoma haematobium* morbidity on Pemba Island: validity and efficiency of indirect screening tests. *Bulletin of the World Health Organization*, 75(3):247-252.

Mafe MA et al. (2000). Control of urinary schistosomiasis: an investigation into the effective use of questionnaires to identify high-risk communities and individuals in Niger State, Nigeria. *Tropical Medicine & International Health*, 5(1):53-63.

N'goran EK et al. (1998). Identification rapide par questionnaire des principaux foyers de bilharziose urinaire au centre de la Cote d'Ivoire [Use of a questionnaire for quick identification of the principal foci of urinary bilharziasis in central Ivory Coast]. *Médecine Tropicale*, 58(3):253-260.

Onayade AA, Abayomi IO, Fabiyi AK (1996). Urinary schistosomiasis: options for control within endemic rural communities: a case study in south-west Nigeria. *Public Health*, 110(4):221-227.

Randrianasolo BS et al. (2002). Validation de la méthode du questionnaire pour identifier les zones hyperendémique de la bilharziose à *Schistosoma haematobium* à Madagascar [Validation of questionnaire methods to identify *Schistosoma haematobium* bilharziasis hyperendemic zones in Madagascar]. *Archives de l'Institut Pasteur de Madagascar*, 68(1-2):59-62.

Stothard JR et al. (2002). Urinary schistosomiasis in schoolchildren on Zanzibar Island (Unguja), Tanzania: a parasitological survey supplemented with questionnaires. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 96(5):507-514.

van der Werf MJ, Borsboom GJ, de Vlas SJ (2003). No effect of recall period length on prevalence of self-reported haematuria in *Schistosoma haematobium*-endemic areas. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 97(4):373-374.

***S. mansoni* infections**

Brooker S et al. (2001). The potential of rapid screening methods for *Schistosoma mansoni* in western Kenya. *Annals of Tropical Medicine and Parasitology*, 95(4):343-351.

Hailu M, Jemaneh L, Kebede D (1995). The use of questionnaires for the identification of communities at risk for intestinal schistosomiasis in western Gojam. *Ethiopian Medical Journal*, 33(2):103-113.

Lima e Costa MF et al. (1998). Questionnaires in the screening for *Schistosoma mansoni* infection: a study of socio demographic and water contact variables in four communities in Brazil. *Revista do Instituto de Medicina Tropical de São Paulo*, 40(2):93-99.

Raso G et al. (2004). Multiple parasite infections and their relationship to self-reported morbidity in a community of rural Côte d'Ivoire. *International Journal of Epidemiology*, 33(5):1092-1102.

Utzinger J et al. (1998). *Schistosoma mansoni*, intestinal parasites and perceived morbidity indicators in schoolchildren in a rural endemic area of western Côte d'Ivoire. *Tropical Medicine & International Health*, 3(9):711-720.

Utzinger J et al. (2000a). Simple anamnestic questions and recalled water-contact patterns for self-diagnosis of *Schistosoma mansoni* infection among schoolchildren in western Côte d'Ivoire. *The American Journal of Tropical Medicine and Hygiene*, 62(5):649-655.

Utzinger J et al. (2000b). Rapid screening for *Schistosoma mansoni* in western Côte d'Ivoire using a simple school questionnaire. *Bulletin of the World Health Organization*, 78(3):389-398.

***S. japonicum* infections**

Tan H et al. (2004). Rapid screening method for *Schistosoma japonicum* infection using questionnaires in flood area of the People's Republic of China. *Acta Tropica*, 90(1):1-9.

Zhou H et al. (1998). Diagnosis of schistosomiasis japonica in Chinese schoolchildren by administration of a questionnaire. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 92(3):245-250.

***S. mekongi* infections**

Urbani C et al. (2002). Epidemiology and control of mekongi schistosomiasis. *Acta Tropica*, 82(2):157-168.

***S. intercalatum* infections**

Arene FO, Ukpeibo ET, Nwanze EA (1989). Studies on schistosomiasis in the Niger Delta: *Schistosoma intercalatum* in the urban city of Port Harcourt, Nigeria. *Public Health*, 103(4):295-301.

Mixed infections

***S. haematobium* and *S. mansoni* infections**

Booth M et al. (1998). The use of morbidity questionnaires to identify communities with high prevalences of schistosome or geohelminth infections in Tanzania. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 92(5):484-490.

Lengeler C, Utzinger J, Tanner M (2002a). Questionnaires for rapid screening of schistosomiasis in sub-Saharan Africa. *Bulletin of the World Health Organization*, 80(3):235-242.

Lengeler C, Utzinger J, Tanner M (2002b). Screening for schistosomiasis with questionnaires. *Trends in Parasitology*, 18(9):375-377.

Lengeler C et al. (2000). Simple school questionnaires can map both *Schistosoma mansoni* and *Schistosoma haematobium* in the Democratic Republic of Congo. *Acta Tropica*, 74(1):77-87.

Tanner M, Lengeler C, Lorenz N (1993). Case studies from the biomedical and health systems research activities of the Swiss Tropical Institute in Africa. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 87(5):518-523.

Questionnaires on *S. mansoni* in Brazil

Studies using questionnaires to predict infection with *S. mansoni* in Brazil have tended to include more parameters, including water contacts and sociodemographic variables. They are less simple and rapid than diagnostic tools, but may provide more sophisticated insights into the factors enabling transmission.

Barreto ML (1991). Geographical and socioeconomic factors relating to the distribution of *Schistosoma mansoni* infection in an urban area of north-east Brazil. *Bulletin of the World Health Organization*, 69(1):93-102.

Barreto ML (1993). Use of risk factors obtained by questionnaires in the screening for *Schistosoma mansoni* infection. *The American Journal of Tropical Medicine and Hygiene*, 48(6):742-747.

Firmo JO et al. (1996). Urban schistosomiasis: morbidity, sociodemographic characteristics and water contact patterns predictive of infection. *International Journal of Epidemiology*, 25(6):1292-1300.

Lima e Costa MF et al. (1987). Water-contact patterns and socioeconomic variables in the epidemiology of *schistosomiasis mansoni* in an endemic area in Brazil. *Bulletin of the World Health Organization*, 65(1):57-66.

Lima e Costa MF et al. (1991). A multivariate analysis of socio-demographic factors, water contact patterns and *Schistosoma mansoni* infection in an endemic area in Brazil. *Revista do Instituto de Medicina Tropical de São Paulo*, 33(1):58-63.

Lima e Costa MF et al. (1998). Questionnaires in the screening for *Schistosoma mansoni* infection: a study of socio demographic and water contact variables in four communities in Brazil. *Revista do Instituto de Medicina Tropical de São Paulo*, 40(2):93-99.

See also Chitsulo L, Lengeler C, Jenkins J (1995). *The schistosomiasis manual*. A guide for the rapid identification of communities with a high prevalence of urinary schistosomiasis, for district health management teams, disease control programme managers and community health workers. Geneva, World Health Organization, Special Programme for Research & Training inTropical Diseases (Social and Economic Research. Methods for Social Research in Tropical Diseases No. 3).

Implications for planning and implementation of control programmes

- It may be important to consider whether previous screening programmes, research studies and control programmes (also those not related to schistosomiasis) influence compliance with screening.
- It may be relevant to involve local authorities as well as local health and education facilities in the planning and implementation of screening programmes.
- Mechanisms should be put in place for informing people individually and discretely of their test results and subsequent access to treatment should be assured.
- Diagnosis and screening should be conducted in a gender-sensitive way.

Directions for social science research

- Which gender-related factors influence the acceptability of screening and diagnostic procedures? How do various factors in client-provider interaction influence acceptability?
- How does individual feedback on test results affect treatment-seeking behaviour and exposure patterns?
- How can social science methods contribute to the further development of tools for screening for *S. mekongi* and *S. intercalatum* infections?

Treatment – equity in targeting, access and adherence

Main points

- *Typical definitions of target groups for mass treatment may exclude relevant subgroups.*
- *Few studies have systematically documented and analysed issues related to adherence.*
- *Socioeconomic and cultural factors (including user fees and perceived quality of health-care services) influence access to treatment.*

A key component of control programmes today is chemotherapy. Most control programmes operate with one of three approaches to treatment:

- mass treatment of whole populations without individual diagnosis;
- selective treatment of groups defined by age or occupation without individual diagnosis;
- selective treatment of individuals upon diagnosis. Case detection by the control programme can be active or passive.

Equity in targeting treatment

Limited resources allocated to schistosomiasis control increase the importance of targeted treatment. The choice of strategy is based on the local transmission pattern, available resources and the weighing of costs of case detection versus cost of treatment, where calculations of costs may or may not include logistics, training, storage (e.g. of drugs, diagnostic materials) and other elements of delivery systems (Jordan & Rosenfield, 1983:317; Guyatt et al., 1994; Guyatt & Tanner, 1996; Guyatt, 2003). Even though the convenience of new, inexpensive, rapid and field-applicable diagnostic techniques played an important role in the initiation of several control programmes in sub-Saharan Africa (Chitsulo et al., 2000:47), the availability of praziquantel after 1979, and particularly after the patents expired in the 1990s, made mass treatment more cost effective than selective treatment in high-prevalence areas (e.g. Talaat & Evans, 2000, on out-of-school children in Egypt).[21] The price of individual treatment is, however, still very high when

[21] The same development has contributed to the shift away from identifying sites of transmission, and consequently from snail control, as a component of control programmes in high-prevalence areas.

looking at available per capita health expenditure in sub-Saharan Africa (Guyatt et al., 1994; WHO, 2002:11). Currently, the low cost of praziquantel means that treatment without prior diagnosis is a cost-effective option in areas with high transmission levels, because the cost of diagnosis may be disproportionately high (WHO, 2002:25). However, in low-prevalence areas, the issue of the cost and ethics of mass treatment versus selected treatment based on individual diagnosis has been raised (Rabello, 1997).

With technical developments of diagnostics and drugs, treatment quickly became the backbone of control programmes and other interventions became less emphasized. Even though the risk of chronic disease may be reduced with repeated treatment, it is debated whether intensive and repeated treatment will be effective in the long run without also interrupting or slowing down the transmission cycle in areas of different environmental, epidemiological, socioeconomic and political situations (e.g. Gryseels, 1989). For this reason, there are recurrent concerns that international funding agencies will not continue to fund mass treatment campaigns and that coverage and frequency of treatment campaigns will decline due to lack of funds (Leonardo et al., 2002).

Target groups for treatment, including mass treatment

Current strategies for selective mass treatment have developed in a balance between the need for regular treatment due to high reinfection rates and the cost of interventions (Chandiwana & Taylor, 1990, in Zimbabwe). WHO identifies school-age children, adolescents and those whose occupations involve contact with infectious water (fishermen, farmers, irrigation workers, women doing domestic tasks) as high-risk groups that should be the main target group for treatment campaigns (WHO, 2002:25). This identification of high-risk target groups has given rise to the following considerations for researchers.

- Prevalence and intensity of infection is often higher among children than among adults (and thus children account for a larger part of the contamination) and reinfection rates are also often higher in children than in adults. For logistic reasons, treatment is often targeted at children attending school. If the proportion of non-attending children – who may or may not have a higher prevalence and intensity of infection (e.g. Husein et al., 1996; Useh & Ejezie, 1999b; Fentiman, Hall & Bundy, 2001) – is high, coverage may

be increased through community delivery of drugs (Olsen, 1998, in Kenya; Mafe et al., 2005, in Nigeria). In areas with high levels of school attendance, community leaders and teachers can be contacted and schoolchildren can be informed about the next deworming campaign and invited to bring their siblings. Talaat, Omar & Evans (1999) showed that particularly girls and younger children benefited from this approach in Egypt. Operational problems included teachers' concern about the discipline of non-enrolled children and lack of clean water for swallowing tablets (Montresor et al., 2001, on anthelminthic treatment in Zanzibar).

- Recent studies have shown that preschool children, and even infants, are also infected (Mafiana, Ekpo & Ojo, 2003; Odogwu et al., 2006). This is of interest for studies of morbidity dynamics and reduction of contamination, but should this also have consequences for the targeting of control programmes?
- For many years, pregnant and lactating women have been excluded from treatment campaigns for lack of knowledge about the effects of praziquantel on the fetus and infant. Since many women in some countries are either pregnant or lactating during most of their reproductive years, they have been practically excluded from treatment. In China, Egypt and the Philippines, lactating women have been asked to refrain from breastfeeding for 24 hours after having taken praziquantel (WHO, 2002:10). A risk-benefit analysis indicated that treatment should be recommended (Olds, 2003) and this is now supported by WHO (2002:9).

With the WHO recommendation to integrate schistosomiasis control with the control of soil-transmitted helminths (WHO, 2002), the identification of target groups and how to reach them needs further consideration (see box *Target groups for treatment, including mass treatment*).

Equity in access to treatment

Not much has been written on equity in access to treatment of schistosomiasis. A study from Cameroon observed how inclusion of villages or areas in intervention projects was partly a matter of intracommunity political and religious priorities, which lead to inequity in health-care delivery and services (Hewlett & Cline, 1997:A35). The issue of overall geographical accessibility of more remote areas

in the distribution of resources and technical assistance for control is rarely addressed, but poses a potential equity issue (Kloos, 1995). At community level, women's access to treatment may be hampered by lack of access to cash and possible restrictions on their movements hindering visits to health facilities for health problems that are not considered life-threatening. Women may wait longer than men in reporting illness, due to a mix of guilt, feelings of responsibility as well as preference for self-treatment and consultations with traditional specialists (Vlassoff & Bonilla, 1994:46). Muela, Mushi & Ribera (2000) discuss the complexities in assessing the affordability of basic health care in the United Republic of Tanzania. Yu et al. (2001) studied the way willingness and ability to pay for schistosomiasis control has changed with institutional changes of the control programme in China.

Adherence to treatment

It has been proposed that morbidity control requires less involvement of local populations than transmission control (Tanner et al., 1986), but adherence to treatment depends on many social factors that have rarely been studied systematically in relation to praziquantel.

Readiness to participate in chemotherapy will depend on social and cultural perceptions of what is considered proper, and thus be influenced by such factors as whether the drugs are recommended by a male or a female person, by a foreigner or a local inhabitant, by a member of the national health service or by somebody highly ranked socially. In addition, the classification of illnesses is known to vary widely between cultures and societies, and it is often believed that only some classes of diseases can be relieved through cosmopolitan, western-style drugs (Barley, 1983, cited in Feldmeier& Krantz, 1993:132).

These factors may influence men and women differently (Nwaorgu, 1992, cited in Feldmeier & Krantz, 1993:132; see also the section on studies of schistosomiasis and gender in Chapter 2). Although adverse effects of praziquantel are far less serious than those of the previously used drugs, people's experience of adverse effects may play a role in their adherence to chemotherapy. Rozemberg (1994) analysed how people in Brazil find themselves choosing between symptoms of schistosomiasis and perceived side-effects of praziquantel. Furthermore, adherence

to treatment should be interpreted in the light of the fact that people often alternate between or combine drugs obtained through formal health-care providers and informal sources, such as drug peddlers and traditional herbalists (Kloos et al., 1982; Mwanga et al., 2004; see also the section on local perspectives on symptoms, risks and of treatment-seeking practices in Chapter 3).

Adherence and health-seeking behaviour is not only related to level of knowledge or education and money for transport, but also to the anticipated quality of the medicine and the health care offered by the programme or at the health facility. User fees are often a barrier, but not necessarily. In a highly endemic area in north Cameroon, a control programme with health communication as a key element successfully introduced user fees for subsidized praziquantel (Cline & Hewlett, 1996; Hewlett & Cline, 1997).

In China, it had been observed how adherence declined in areas where frequent mass treatment had been carried out. Comparing coverage in a village where health education sessions had encouraged people to seek treatment themselves with a village where the usual "active" mass treatment was carried out showed no statistically significant difference in the coverage of infected people (Guo et al., 2005). Furthermore, the costs of interventions were significantly lower in the village that received health education and offered treatment to those who sought it compared with the village receiving mass treatment. Even though there was not a 100% coverage rate of infected people in the village receiving health education, the approach was well received by people and should be considered in a maintenance and consolidation phase of a schistosomiasis control programme.

Implications for planning and implementation of control programmes

- Epidemiological profiles of target groups should be supplemented with other relevant data as a basis for choosing appropriate control strategies, such as previous control programmes, local health infrastructure and local people's ability to pay.
- Control programmes should explore and monitor people's reasons for adhering to or rejecting treatment ("sociovigilance").

Directions for social science research

- How can social research enhance the identification of the most vulnerable groups and define strategies to ensure access to chemotherapy?
- Which factors (at household, community and other levels) are related to adherence and treatment-seeking practices in various case detection and drug distribution modalities?
- What factors influence gender differences in access to information and treatment in various endemic areas?
- How does the total cost of treatment (including consultation, transport and loss of time and income) influence individual and household decisions to seek treatment?

Safe and adequate water supply and sanitation

Main points

- *The establishment of safe and adequate water supply and sanitation facilities at household and village levels has an effect on domestic utilization patterns, but the relation to prevalence of schistosomiasis remains complex.*

With the current focus on morbidity control there is less focus on interventions related to safe water supply and sanitation, which, in theory, could contribute to controlling transmission of all helminths and many other infections.[22] Since schistosomiasis is water transmitted, as opposed to soil-transmitted helminth infections, there is disagreement about the importance of sanitation for this specific infection. Nevertheless, safe water supply and sanitation have the potential to go far beyond control and prevention of schistosomiasis by addressing the root causes of many other diseases resulting from substandard living conditions

[22] An estimation of disease burden (measured in disability-adjusted life years, DALYs) from insufficient water, sanitation and hygiene (including contact with schistosome-infested waters) at global level suggested that 4% of all deaths and 5.7% of the total disease burden can be attributed to these largely preventable conditions (Prüss et al., 2002).

(Asaolu & Ofoezie, 2003:291). However, these interventions have rarely been seriously considered in schistosomiasis control programmes (Jordan & Rosenfield, 1983:318; Schall, 1995:229), particularly in rural areas (Sturrock, 2001). One reason may be that they appear more expensive than other types of interventions. Sanitation is often considered too costly, but it is unknown what proportion it would make up compared with the sums that have been spent on classic control measures during the history of schistosomiasis control (Barbosa, 1995). Studies exploring the effect of installing safe water supply, sanitation and drainage on behaviour and infection rates show varying results that may be due to technical differences, such as the many different engineering solutions to ensuring safe water supply and sanitation in widely differing environments. Variations may also be due to the different indicators used when assessing impact (e.g. behaviour change, trends in prevalence over shorter or longer times). Differences in evaluation results may also be due to the wide variety of social settings and dynamics involved, which impede comparison. The observations summarized in the following two subsections are by no means exhaustive and are not meant as a thematic review. Instead they point to the variety of findings in relation to schistosomiasis, suggesting that recommendations regarding the installation of water supply and sanitation should depend on assessments of local conditions, taking equity issues into account.

Safe and adequate water supply

In one of the earliest studies of the link between environmental factors and infection, Farooq et al. (1966b) recommended that access to safe water should be prioritized as a preventive measure in Egypt. The provision of piped water in households can change water contact behaviour (Jordan et al., 1982, in Saint Lucia). A study of an intervention in Kenya that installed community standpipes and a shower unit at the local school observed that the new water sources had a great influence on some villagers' water contact behaviour and very little on the rest of the villagers (Noda et al., 1997:124). The intervention did not include health education as such, but the researchers observed that bathing decreased and people began to wash more at river banks and less in streams. The authors interpret this positive change as a consequence of the intervention process itself, which encouraged people to reflect on risk and take the precautions that were possible for them (ibid.:125). Chimbari et al. (1992) made a similar observation

from Zimbabwe. Ximenes et al. (2001) showed how piped water in the house was strongly correlated with less leisure water contact for young people in a town near Recife, Brazil. But the opposite observation has also been made. This has been reported by Firmo et al. (1996) from a suburb of Belo Horizonte, Brazil, and Amorim et al. (1997) from a rural and an urban area in the State of Minas Gerais, Brazil. The quality of water for drinking and washing clothes that is provided by safe sources plays a large role in level of use (Chimbari et al., 1992). Convenience of location, break down of pumps, privacy to bathe, availability of washing slabs and a chance to socialize are also factors involved in people's choice of water sources for different purposes (see the section on water contacts as integrated part of social activities in Chapter 3). El Kholy et al. (1989) conducted a study of the effects of borehole wells on water use in a high-prevalence area in Kenya, which showed no short-term effect on the transmission of *S. haematobium*, but a significant number of households changed to borehole water for drinking, cooking and dish washing.

Sanitation

Improved sanitation is considered more effective than reducing general contact with infected water (Espino, Koops & Manderson, 2004:26). But the provision of latrine facilities does not imply that they are always used by everybody as intended (Asaolu & Ofoezie, 2003). Small children may avoid using latrines for fear of falling into them, older people for conservative reasons, people working in their fields will not return home in the middle of the day to relieve themselves and latrines in the fields may not be conveniently located nor well maintained (Chimbari et al., 1992, in Zimbabwe; see also the section on studies of infective behaviour in Chapter 3). There was no correlation between the presence of a latrine and lower levels of infection in Zimbabwe (Taylor et al., 1987). Kvale (1981) showed that in a Brazilian town, where sanitary facilities were limited, there was no significant difference in prevalence between people from households with septic tanks and people from households without such facilities. A survey of infections in two villages in Egypt showed that overall infection levels were higher in the village without a sewage system. When measured at household level, there was a statistically significant relationship between infection levels and the absence of sewerage connections, but in the better drained village, there was no similar significant correlation. Even though only a third of households were

connected to the sewerage system in this village, the system had contributed to lowering the water table to the benefit of the general village environment (el Katsha & Watts, 1997:850).

Implications for planning and implementation of control programmes

- It should be ensured that the construction of water and sanitation infrastructure is based on knowledge of local preferences and use patterns.
- It should be explored how and where water and sanitation interventions can support treatment campaigns that follow the growing trend towards integrated control programmes targeting more than one type of disease.

Directions for social science research

- Which are the social processes of relevance to feasible water and sanitation programmes at the community level?

Health communication in relation to schistosomiasis

Main points

- *Health communication in control programmes has been characterized by a wide variety of approaches and methods as well as organizational and managerial set-ups.*
- *Health communication is rarely systematically evaluated for effect and impact.*

Health education efforts in relation to schistosomiasis are characterized by very diverse approaches that have been more or less adapted to local sociocultural and environmental conditions (Guiguemdé, 1989). Kloos (1995), Schall (1995) and Yoder (1997) have provided elaborate reviews and critiques of common concepts and models for health education. Summarizing their points, health education has often been seen as "health instruction", a one-directional, technical instrument, often with a moralistic content, for making individuals comply with interventions.

More rarely, health education is viewed as health communication – highlighting the *dialogue* between individuals, communities and institutions with different agendas, needs and priorities. Thus, health education can be framed as an issue of depositing technical information in passive individuals, as illustrated by Sow et al. (2003) in Senegal and Guanghan et al. (2000) in China, or it can be regarded as a question of how to persuade while still respecting individuals' freedom of decision and choice (Ximenes et al., 2001:14).

Alternatively, it can be seen as a broader transformative and communal process, building on local conditions. Some researchers take a step further and see health communication as creating "a critical perception of the social, cultural, political and economic forces that structure reality" so that people will be encouraged to "take action against those forces that are oppressive. Infectious disease education programmes could benefit from a new set of models focusing on collective empowerment and community mobilization" (Porter, Ogden & Pronyk, 1999:326). This approach to mobilizing critical citizenship (Gazzinelli et al., 1998:847) and fostering a sense of active responsibility for health resonates with the set of values put forth in the Alma-Ata Declaration on community involvement in primary health care (WHO, 1978) and is particularly strong in the literature from Brazil. Here, the educational philosopher Paolo Freire has profoundly influenced the approach to learning and development with his "pedagogy of liberation", in which people are encouraged to look for "the problem behind the problem" (Freire, 1970). Even though social transformation may not be the aim of health communication, broader issues, such as socioeconomic conditions and political influences at national and international levels, as well as health services use and administrative constraints in the local community, have been acknowledged sporadically in the design and evaluation of health communication initiatives (Kloos, 1995; da Silva et al., 2002).

Unfortunately, health education is often characterized by a very vague and conceptually unclear form with no clear objectives (Kloos, 1995:1498). Appropriate theoretical foundations are not developed or applied and the common focus on knowledge of individuals (e.g. Ribeiro et al., 2004) is often not sufficient to make people change behaviour and break the transmission cycle of schistosomiasis (Noronha et al., 1995). Furthermore, without the means for behaviour change (e.g. safe water supply and appropriate sanitation), health education may only

have limited impact on prevalence and intensity levels. Likewise, in areas where water contacts are part of occupational exposure, health education on treatment will be more relevant than messages on prevention. Li et al. (2000:280) observe that in the Dongting Lake region, China, 98% of human water contact exposure is the result of occupational exposure and that health education has been one of the most effective elements of the integrated approaches for schistosomiasis control.

Methods for health education have reflected the more or less explicit concepts and approaches summarized above, and involved different local stakeholders to varying extents. It seems that control programmes have mainly relied on community members' passive cooperation or even enforced active participation in external professionals' short-term interventions (Kloos, 1995:1501). In this regard, health education in relation to schistosomiasis is another example of the organizational, managerial and financial problems in translating the values of the primary health care approach into action (ibid.:1500-1502). Similar observations have been made about discrepancies between the rhetoric of health education and social change in Brazil (Schall, 1995:229).

Adapting to local conditions

In his comprehensive review of literature on health education in relation to schistosomiasis, Kloos (1995) observes that health education began to acknowledge local sociocultural contexts in the 1970s, when large-scale snail control was abandoned and the impact of interventions began to depend more on collaboration with local communities. He notes that education activities need to incorporate sensitivity to differences between medical and popular knowledge. Interpretations and representations of illness can vary considerably from one social context to another (Alves et al., 1998; see also the section on local perspectives on symptoms in Chapter 3). To understand behaviour, it is necessary to first understand how this behaviour makes sense to the person observed (Noronha et al., 1995). At the same time, it is important to acknowledge that health education is a dynamic social process.

One of the most thoroughly documented processes of adapting health education to local conditions is the study by Hewlett & Cline (1997) from northern

Cameroon. The researchers systematically explored local ideas and terms for blood in urine and its many causes, its seasonality, its prevention and treatment and its relation to other symptoms. Water contacts, agricultural practices and sanitation facilities were explored together with gender roles and variations between ethnic groups. On the basis of this information, health education activities were designed to relate to local knowledge and practices. Among other aspects, the severity of symptoms was emphasized to encourage treatment, particularly at the time of the year when symptoms were most common and people had access to cash from selling their agricultural produce. People associated symptoms with the hot dry season when symptoms would be most common. In health education, the researchers characterized this season as the "season of symptoms" and introduced the concept of "season of transmission", i.e. the end of the rainy season, when transmission was high and when education messages focused on limiting contaminating behaviour. Infertility, which was a concern in the community, was also emphasized as a risk of not treating the infection. Since the control project was based on passive case detection and cost-sharing, the researchers also explored how much people would be willing to pay for treatment. Staff in the local health centres and school teachers were involved in the programme. The impact of the health education was measured using several variables. Knowledge improved, particularly among children, who were more targeted with health education. The number of reported cases at the health centre grew sixfold and the overall prevalence fell from 21% to 7% between 1991 and 1993.

In Egypt, a study focused on socioeconomic conditions in reclaimed and endemic areas through qualitative free-listing and a survey of paired comparisons of importance of different community-wide problems. This method gave a good basis for qualified reflections on how health education could be carried out in an area with a highly heterogeneous and mobile population with little sense of community and very few shared concerns (Mehanna et al., 1994:296).

Other authors suggest building messages that take into account the fact that many people do not know the life-cycle of schistosomes, but they do associate blood in urine or diarrhoea with dirty water and other hygiene-related contacts (Taylor et al., 1987; Ndamba, Chandiwana & Makaza, 1989; Gazzinelli et al., 2002).

Hygienic and preventive behaviours are connected to basic cultural ideas of what is "dirty" and what is "clean" and how men and women handle these differently (Noronha et al., 1995). In settings where blood in urine or stools is recognized, but schistosomiasis is not, health education messages could embrace a number of urogenital and diarrhoeal diseases, including schistosomiasis, to address a fuller range of people's concerns (Robert, Bouvier & Rougemont, 1989a:363). Such educational messages should form part of intersectoral activities, such as digging latrines, building a water supply system in the communities and landing stages for boats at the waterfront. At the same time, it is observed that these initiatives will not have any impact if people's own prioritized needs have not been addressed, which may include basics such as food, housing and clean drinking water. Robert, Bouvier & Rougemont (1989b) provide an example of a cross-disciplinary assessment of health and health education needs in northern Cameroon.

El Katsha & Watts (1994) developed a model for health education in Egyptian villages that was not only directed at reducing levels of schistosomiasis, but also reflected local concerns regarding childhood diarrhoea, eye diseases and environmental sanitation. With a focus on social processes, the model was developed and thoroughly tested with the involvement of community members at all stages as well as local health staff and government agencies at local levels. The model, which was based on training and active involvement of nurses and local health promoters, included links between environmental sanitation, waterborne disease transmission through contact with canal water and other health-related practices (e.g. water and food storage, infant feeding, hand-washing, food preparation, latrine cleanliness and kitchen hygiene). Training schedules, monitoring routines and resource needs were developed and adjusted with local conditions in mind.

Making a case for linking helminth control and "health-promoting schools", Taylor et al. (1999) explored risk factors for schistosomiasis and other helminth infections among schoolchildren in KwaZulu-Natal, South Africa. In a staged approach, where a quantitative survey was preceded by qualitative studies, the authors organized findings using Green et al.'s health promotion model, which labels factors for improving health as predisposing, reinforcing or enabling

(Green et al., 1980). According to the authors, potential predisposing factors included perceived symptoms, sanitation, washing of hands, effects of dust, preparation of food, geophagy and recognition of the helminth infection. Water contacts, lack of safe water sources, health-seeking behaviour and interest in health communication were included among enabling factors. On the basis of this clustering of factors, it was possible to measure and monitor their role in transmission in a systematic way.

In Minas Gerais, Brazil, a critical pedagogical approach, inspired by Paulo Freire, was implemented in schools to stimulate the development of conscious citizenship. This form of pedagogy teaches children to take an active part in their everyday life and the social and political context where they live. Priority focus is given to students' experience of daily conditions and a participatory construction of knowledge. Researchers and teachers of four schools agreed on a partnership on health, which included teacher training in both schistosomiasis and problem-solving pedagogy, a kit with information folders, samples of molluscs, worms, tongs and gloves. Invited experts gave lectures and teachers were encouraged to ask questions, to maintain a dynamic learning process. Discussions and investigations led to debate about wider issues such as the local environment, domestic refuse, and risk of deforestation and what can be done about it. After the course, teachers developed a large variety of projects with students, and researchers were able to follow and stimulate the development of the work for a year after the intervention. The 33 teachers who participated in the course became key resource people, who were both better equipped to teach about schistosomiasis and more confident about their own ability to improve their own and their students' health conditions (Massara & Schall, 2004).

Mwanga (2004) studied a community-integrated and action-oriented health education intervention on schistosomiasis and other illnesses among children of primary school age in Magu District, United Republic of Tanzania.

Health education materials

Some studies have evaluated materials used in health education. In Cameroon, classic drawings of the parasite life-cycle, with references to laboratories, the global extent of the infection and various water contact activities, were not understood by the locals (Robert Bouvier & Rougemont, 1989a). In a review of information and education materials used in the state of Minas Gerais, Brazil, since the 1960s, Schall & Diniz (2001) observed that factual errors were repeated for decades in leaflets, pamphlets and posters that were distributed in relation to screening and treatment activities, but never evaluated for impact in a population with low literacy levels. Furthermore, the information provided did not illustrate how to improve the local environment or what to expect from local health services.

The impact of watching an educational video and reading a comic book developed for schoolchildren in China was evaluated through a pre- and post-test questionnaire and observations of water contacts. The study showed that children had increased their knowledge about the infection and how to avoid unsafe places for water contact, which was reflected in their actual water contact pattern two months later (Yuan et al., 2000).

A paper from rural Suriname gives a detailed account of the production and showing of an educational video on schistosomiasis to schoolchildren and the way the process gradually involved teachers, parents and local authorities. The paper makes very useful observations regarding the strengths and limitations of showing videos to schoolchildren as a teaching tool (Locketz, 1976). Rigau-Pérez & Pereira Díaz (1996) have provided a historical view of health education related to schistosomiasis in Puerto Rico based on slides produced by the United States Centers for Disease Control and Prevention that were used in the 1950s.

Comparing the impact of different types of health education interventions

In general, there is less information about the effect of health education on disease control than there is about the effect of sanitation (WHO, 2002:42; Asaolu & Ofoezie, 2003). Studies of the impact of health education usually measure changes in knowledge and sometimes also reported changes in practices

(Gwatirisa, Ndamba & Nyazema, 1999; Garba et al., 2001), but more rarely linkages to prevalence (Huang & Manderson, 1992:187). When lower prevalences are observed, it is, however, often difficult to assess how health education and other components in control programmes each contribute to improvements over time. There are discussions about the validity of different modes of assessing change due to health education. Some scholars ascribe more validity to quasi-experimental research set-ups where change can be measured as a function of different interventions in separate settings, preferably including a control setting. Others prefer to study and document change processes through qualitative case-studies. Depending on the purpose and paradigm of the research, both approaches can contribute new insights.

School-based health education

School-based health education has expanded children's knowledge of schistosomiasis in Nigeria. On the basis of the diagnostic tool PRECEDE[23] for planning health education, Ekeh & Adeniyi (1988) evaluated the level of impact on the control of malaria, dracunculiasis, schistosomiasis and onchocerciasis in school settings and found a positive effect. The baseline survey results were reported in 1986 (Ekeh & Adeniyi, 1986). The study raises the question of impact in the home environment, which cannot be taken for granted (Lansdown et al., 2002). Other studies measuring impact of school-based health education on children's knowledge and practices in various ways have been presented by Schall et al. (1993) in Minas Gerais, Brazil, and Yuan et al. (2005) – using multimedia – in Hunan, China.

A study of the impact of health education in primary schools in rural United Republic of Tanzania showed that behaviour change was still evident a year after all project activities had ended. The project introduced active teaching methods, where children were encouraged to make up plays and songs, write essays, and otherwise be actively involved, with particular emphasis on schistosomiasis, other helminth infections and general health education over a period of one school year. The project was evaluated by a pre- and post-intervention questionnaire, focus group discussions and recurring observations of practices throughout the

23 The original PRECEDE model of health promotion and evaluation was developed by Green and colleagues in 1980 (Green et al., 1980). It evolved into the PRECEDE/PROCEED model in the 1990s. See Taylor et al. (1999) and Kloos (1995) for applications of the model in schistosomiasis control.

project. All findings were compared with similar schools not involved in the project. In the intervention school, changes were evident in children's knowledge of health and school environments improved considerably. There were mixed experiences with children acting as change agents regarding health and hygiene habits in their homes. Costs were minimal: expenditures were limited to workshop costs, and parents contributed to improvement in the school latrines (Lansdown et al., 2002).

A study running over 10 months in rural Cameroon compared children's awareness of schistosomiasis and prevalence of infection in: (i) schools with no health education; (ii) schools receiving predesigned control procedures for schistosomiasis; (iii) and schools where children were asked to design their own control procedures with assistance from the researchers. The children who were involved in designing control programmes had the largest increase in awareness and the largest decrease in prevalence – particularly the age group of 10-14 years (Lucien, Nkwelang & Ejezie, 2003). Unfortunately, the study does not describe how the children went about designing health education materials, to what extent the lower prevalence among them was due to treatment or changed behaviour and why older children were more reluctant to go to the health centre for treatment.

In Egypt, a survey to evaluate health education in the fifth grade of six paired primary schools (intervention and control) was carried out one month and one year after a three-day health education session carried out by local, trained teachers. Compared with the baseline, scores for knowledge and attitude were significantly improved after one month and it also appeared that the health education intervention could account for the variation in knowledge scores after one year (Kotb et al., 1998).

Village-based health education

Leaving the school setting, a study rigorously compared the impact of three different approaches to health education on infection rates in Ghanaian villages over three years. The three approaches to health education were: (i) none; (ii) intensive health education by trained community members who went from house to house twice a week for 18 months, explaining about schistosomiasis and how to control it. In addition, local committees for safe water supply, provision of sanitary facilities and environmental management of the water contact sites were

formed;.and (iii) less intensive health education using existing local institutions and their leaders, who were trained to use provided health education materials. The study found that the area receiving the most intensive health education and community mobilization had a lower prevalence of infection than the other two. (Nsowah-Nuamah et al., 2001). A study by Aryeetey et al. (1999) reports from the same intervention on changes in people's KAP during the intervention. It concluded that without a reliable alternative water supply, changes in knowledge and awareness did not make a sustained difference.

Hu et al. (2005) conducted a similar study focusing on the role of health education for water contacts and adherence to treatment in the Poyang Lake area, China. Short- and long-term effects of health education were compared in six villages receiving three different types of interventions aimed at schoolchildren, women and men. The study observed that health education had an impact on infection among children and women, but not among men.

Mass media-based health education

In Egypt, where prevalence is high, passive case detection is the predominant mode of schistosomiasis control. The strategy is to make praziquantel available in all clinics in Egypt and to broadcast television spots to make people aware of the symptoms of schistosomiasis and to encourage them to seek treatment at clinics. The success of the strategy is based on the assumption that three steps take place: (i) people receive information about symptoms, risk situations and treatment options; (ii) people recognize themselves as being infected or at risk of infection and they seek testing and treatment; and (iii) staff at health facilities test and treat people presenting at the clinics. Since not all Egyptians have access to television and levels of illiteracy may be high, the assumptions behind this strategy might need reassessment, particularly in newly reclaimed areas where access to information is very limited and where health facilities are lacking (Mehanna et al., 1994:295). Another observation regarding the mass media-based social marketing strategy in Egypt is that the various health messages appear to make people take more medication instead of changing behaviour (Kloos, 1995). Hubley, 1986, (cited in Kloos, 1995:1503), has listed the major reasons for failure in evaluating health education interventions.

Generating feedback on health education interventions

Feedback on such interventions does not necessarily have to wait until evaluations have been carried out at the end of the programmes. It is often recommended to include continuous feedback from communities, local authorities, particularly health authorities, and technicians through community meetings and other initiatives in the design (Tanner et al., 1986; Barbosa, da Silva & Barbosa, 1996) and monitoring of control programmes (Tanner & Degrémont, 1986). This can be seen as a way of mobilizing local people, but also as a means of monitoring whether health education reaches people at all (e.g. da Silva et al., 2002). However, actual experience with generating such feedback from the beneficiaries or partners is rarely documented.

Implications for planning and implementation of control programmes

- It should be ensured that health communication materials are compatible with local perceptions and practices, including local terminologies.
- Health communication programmes should be properly evaluated based on appropriate indicators (e.g. increase of knowledge, improved prevention and treatment practices or lower intensity/prevalence of infection).

Directions for social science research

- Which health communication approaches are most appropriate, effective and efficient in various settings?
- What are the methodological and theoretical strengths and limitations in quasi-experimental designs versus qualitative process studies when evaluating the impact of schistosomiasis health education?

Community involvement in schistosomiasis control

Main points

- *Experience with community involvement in schistosomiasis control is relatively limited.*
- *Interventions involving communities are characterized by very different images of what communities are and what their role should be in control efforts.*
- *The link between community involvement and sustainability of control efforts is often emphasized but less often documented beyond the intervention phase.*

Community involvement was one of the principles – if not the core principle – of the primary health care framework formulated at the Alma-Ata conference in 1978 (WHO, 1978). Since its inception, however, there has been an inherent paradox in the concept of community involvement: it should both empower people and communities to act on their needs (an end in itself) and facilitate an improvement in health status towards health for all (an instrument for public health "outsiders"). This paradox has often been translated into a practice where community involvement, which ideally would be driven by communities, is often initiated and driven by external agencies, who steer by outputs rather than the quality of processes, and are not necessarily inclined to let go of their authority and influence (Espino, Koops & Manderson, 2004).

It has been noted specifically for schistosomiasis control that community involvement should not be seen as another isolated "weapon" in the arsenal for schistosomiasis control, but as a platform for building new knowledge and practices on the basis of the accumulated knowledge of locals (Barbosa, 1995:155). It has also been observed, however, that community involvement sometimes becomes pure rhetoric and is only "used to indicate a 'modern' view in coping with the non-confessed failures of the classical methods in controlling schistosomiasis" (Barbosa & Coimbra Júnior, 1992:218).

Images of community

The term "community" is widely used but is rather ambiguous.

- There is not necessarily a precise overlap between "communities", geographical location and populations vulnerable to infection, as defined by epidemiological methods (Espino, Koops & Manderson, 2004).
- People targeted in interventions may have their own priorities that control programmes are not sensitive to.
- We have naively addressed the community as an empty vessel that eagerly waits to imbibe the science-based knowledge that we preach and have expected [the community] to adapt and conform to our objectives for environmentally acceptable behaviours... (Nathan, cited by Cline, 1995:5).
- Do poor, disadvantaged or marginalized groups and individuals have the resources to organize themselves (Espino, Koops & Manderson, 2004)?
- People living in urban areas or settlements around newly established water resources, such as dams and irrigation schemes, may have very little sense of community or belonging. Natives, newcomers and seasonal migrants may not relate much to each other (Mehanna et al., 1994) and may even be in competition for resources (Kloos, Desole & Lemma, 1981).
- Power relations within communities or geographical areas may reflect quite heterogeneous interests. What appear to be village or community priorities might be the priorities of a select group within the community (Loureiro, 1989). Certain ethnic or occupational groups, women, young people or marginalized groups may not have been heard in the community consultation. Do interventions even maintain unequal power relations?
- It can be argued that control interventions create new social relations and thereby new communities. Expanding the notion of community to include implementing agencies and their local representatives (workers and volunteers within the health, environment and agriculture sectors) makes it possible to analyse power relations between old and new communities and the reasons why activities may or may not be sustained when the new community is dissolved due to the ending of the project or lack of outside resources (Espino, Koops & Manderson, 2004:11).

There is no single, universal way to motivate community involvement. 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 (Hielscher & Sommerfeld, 1985:481). Furthermore, it is a misconception if primary health care-based control programmes are regarded as requiring less intensive field activities (e.g. Chandiwana, Taylor & Matanhire, 1991, on working with communities in integrated control in Zimbabwe). Community involvement and self-reliance is an intensive process that needs substantial input from functioning support systems (Kloos, 1995). Local representatives need to be involved in decision-making in order to ensure legitimacy. Finally, authorities should not use references to community involvement to shed their responsibilities and blame communities if expected results are not achieved.

There is a basic and often unresolved tension between the need for quick results to show to donors and the long-term and often slow build up of local capacity, which may be more sustainable. A central observation is that recognition of local priorities plays a vital role in the success of any control strategy at primary health care level (Tanner et al., 1986) and some have suggested that health planners and implementers should look systematically for resources and opportunities already present in the communities, upon which control programmes could build (Kloos et al., 1987; Hewlett & Cline, 1997). From a very comprehensive community-based study of schistosomiasis in Egypt, el Katsha & Watts (2002) argue that a bottom-up participatory approach, supported by cross-disciplinary research, is necessary to control the infection. According to Dias (1998), common problems with community participation in a health-sector perspective include the following:

- the contradiction between the medical perspective on governments' health systems (curative, disease focused and hierarchical) and the preventive and collaborative spirit of community participation;
- the way public health authorities regard community participation as a supplement;
- the complexity of health programmes cannot always be "solved" by community participation as an approach;
- the timing and duration of programmes are not flexible;

- programme or policy priorities do not always resonate with popular concerns;
- the way funding is distributed sets priorities instead of reflecting them;
- uniting local programmes with larger-scale governmental structures is complicated.

A classic set of considerations regarding horizontally implemented community participation in schistosomiasis control was based on activities in the Ifakara Division of the United Republic of Tanzania (Tanner et al., 1986). Urinary schistosomiasis was recognized by the local communities, but issues related to sanitation had a higher priority among local concerns. Water supply, sanitation, environmental management and health education were planned to build on local participation, as well as to increase capacity for morbidity control at the local village health post. Village health volunteers played a central role in mediating the needs of the communities and the resources of the control programme. Continuous monitoring of water contact, snail occurrence, environmental change and infection level (prevalence, incidence and morbidity) by village health volunteers was built into the programme and reported to the district, regional and national levels, which in turn gave feedback to the community – encouraging continuous community involvement (Tanner & Degrémont, 1986).

In another project, communities were invited to elect a water and health committee in an irrigation scheme in Kenya after one month of health education. This committee made decisions and oversaw all operations in the project from initiation to completion, which included clearing of canals and construction of wells, bathing facilities and latrines. The committee decided to raise funds for water supply and sanitation facilities through household contributions, and also received material and technical assistance from the National Irrigation Board and the Ministry of Transport free of charge. Chemotherapy for schistosomiasis was carried out after a good part of the facilities were in place. The study underlines the multisectoral approach and the way local and outside resources complemented each other in the implementation of the project (Katsivo et al., 1993b).

Committees established for a specific purpose by an intervention may not survive beyond the end of the project. Instead of setting up such committees, an alternative is to work through existing structures. The often cited study by Hewlett & Cline

(1997) from northern Cameroon provides a detailed example of an intervention to control urinary schistosomiasis that built on already existing formal or informal structures in the village. These included women's groups, church groups, parents' or teachers' groups and community health workers. Individuals and communities were placed at the centre of the intervention and diversities between and within communities were acknowledged. The authors noted that the intervention entailed frequent visits to the community, approaches were adapted to both powerful and less powerful village headmen, and health personnel were motivated in various ways. The distribution channels for praziquantel were adapted to local conditions, either by including it in existing village pharmacies or providing it through local health personnel. Health education and community involvement were placed as the driving forces for all other components, such as diagnosis and treatment, snail control and cost recovery. The cost recovery component was unique (Cline & Hewlett, 1996).

In 1987, a government control programme (Northeast Endemic Disease Control Program, supported by the Brazilian Ministry of Health and World Bank) in a town in Pernambuco, Brazil, intended to build on community involvement. Popular education, mass media campaigns and participatory investigations were applied as health education measures. An evaluation of the discourses and practices of the intervention showed that there was no encouragement of citizenship, defined by the authors as critical involvement in local democratic knowledge-sharing, decision-making and planning processes. Local health workers reported that their main role was to persuade people to seek treatment and avoid water contact. They addressed public authorities and leaders, churches, associations and schools, but had problems in reaching their goals because of lack of materials, people's dissatisfaction with mass treatment and lack of alternatives to contact with the river water. Furthermore, the messages delivered by health personnel did not relate to the concrete reality of people's everyday lives, and people were often more occupied with meeting their basic needs of food, work, housing and sanitation than with changing daily habits. People had no alternatives to the river for water sources and so the goal of the education strategies became limited to making people seek treatment. Community mobilization was reduced to making people turn up for meetings and lectures. The authors conclude that community mobilization is reduced to rhetoric in national documents; it is not implemented

on the ground where mass treatment remains the standard intervention (Acioli & de Carvalho, 1998).

In the State of Bahia, Brazil, a study was carried out to understand the processes whereby individuals construct popular views and meanings related to schistosomiasis and the implications of these meanings for community participation in control efforts. The authors show that since people with schistosomiasis often do not experience symptoms, it is usually the social context of the disease that makes the infection more or less important to people. In other words, it is the totality of the intervention (not only the contents of health education messages) that may – or may not – mobilize people to take preventive and curative action (Alves et al., 1998).

A study of the effectiveness of health education in a community in Minas Gerais, Brazil, combined anthropological and epidemiological methods in evaluating the impact of a control programme running over 10 years (*Programa de Controle da Esquistossomose/Programa de Controle das Doencas Endemicas do Nordeste*). The programme was conducted by the Brazilian Ministry of Health and included snail surveillance and control, free-of-charge treatment of all 7-14-year-old children and all infected adults, as well as person-to-person explanation of the transmission cycle and preventive measures. A village where the community had been mobilized to participate in additional health education activities was compared with a similar village without this mobilization component. The community mobilization component, defined by the Brazilian Ministry of Health, intended to increase both villagers' and health workers' understanding of the links between living conditions, the environment and infection. The authors conclude that long-term effectiveness should be built on health education that continuously takes local views and behaviours into account, as well as improved sanitation and community treatment (Uchoa et al., 2000). Santana et al. (1997) describe an epidemiological study from Bahia, Brazil, which shows how a decrease in prevalence was largest in an area where chemotherapy and snail control was combined with health education, but where differences in prevalence could not be correlated with behaviour changes within the communities. The authors point to the need for qualitative evaluation research as well as cost-benefit and cost-effectiveness analyses for decision-making regarding control strategies.

To remedy ineffective schistosomiasis control programmes in Brazil, Coura-Filho (1996) suggests an increased focus on local variations and an acknowledgement of the individuality of community members. The author suggests that previous resistance to treatment of schistosomiasis can be met by programmes based on community involvement. Such programmes should recognize that people's constructions of health and illness are fragmented and have emerged from scientific information that has been adapted to subjective, cultural imagination and magical aspects. These aspects are real to those who experience them and should be decoded by health workers in order to find a shared language and to establish contact. The federal government should provide the necessary material conditions for forming citizenship with the collective will to control schistosomiasis (ibid.).

The same author reports from a control project carried out in Taquaraçu de Minas, Minas Gerais, Brazil, between 1985 and 1995, which had three phases. In the first phase, a local commission was formed by elected members of the local community, researchers and a public health supervisor as part of the newly introduced unified health system, *Sistema Único de Saúde*, in Brazil. Volunteers were trained in registration, stool sample collection, notifying people with positive stool samples about treatment options and the establishment of small dams for raising fish and ducks for biological snail control. In the second phase, stools were examined and infected people were treated. In the third phase, prevalence and intensity of the infection were measured. Prevalence levels had been reduced sevenfold to 4.3% and intensity was also reduced significantly. The commission was pivotal in developing and implementing an alternative model for schistosomiasis control, which was appropriate to the local circumstances. It should, however, also be mentioned that a newly established commission can develop into a parallel local power structure, which may collide with other local or higher-level power structures (Coura-Filho, 1998).

Promising modes of community participation in morbidity control?

School-based programmes

Teachers' role in administering questionnaires for community diagnosis should be emphasized as a form of community participation involving non-specialists (see box on questionnaires in the section on social factors in relation to diagnosis and screening, earlier in this chapter). Teachers have also been dedicated to

individual diagnosis and treatment of urinary schistosomiasis in schoolchildren. In a project to control both malaria and schistosomiasis, head teachers and selected "health teachers" in Mwera Division, United Republic of Tanzania, were trained in diagnosis of urinary schistosomiasis and treatment. They were also provided with health education materials and improved school latrines. With a minimum of training, the teachers were efficient in implementing the programme, even though coverage varied over the five-year period (Magnussen et al., 2001).

A similar set-up was evaluated in Nigeria. A study of the acceptability of a school-based schistosomiasis and soil-transmitted helminthiasis control programme showed that children, adults and various local authorities were positive towards a school-based control programme, but that they also had valid concerns regarding affordability, management and sustainability of the programme. The study recommended that a training workshop should be held for teachers to meet the concerns of community members, but also noted how health staff and officials in the state ministries of health and education maintained that health staff should be responsible for diagnosis and administering drugs (Nwaorgu et al., 1998).

Two governmental school-based health programmes in Ghana (involving 75 schools) and the United Republic of Tanzania (involving 30 schools) were evaluated after the first round of treatments. Children's, parents' and teachers' perceptions were explored to assess factors related to the sustainability the programme. The evaluation revealed concerns about communication between the schools and the families: not all parents, particularly in Ghana, knew which illness the children were treated for in school. Teachers were generally satisfied with their new role, although it had to be balanced with their many other tasks. About a third of the parents reported that their children had experienced side-effects due to treatment. In Ghana, disagreements arose regarding who should pay for the treatment of the 18 children who were taken to a clinic for treatment of side-effects. Both parents and children were very pleased with the programme and the opportunity to obtain good treatment without losing time and money in going to the clinics. Most parents expressed willingness to begin paying for continuation of the programme, but many teachers doubted whether all would actually do this – also referring to the risk of inequity – since poorer families could hardly afford school fees in the first place. The authors closed by noting that not only local communities needed to be positive about the programme for sustainability, but also district

and national authorities, who could use studies such as these for planning, cost analysis and impact epidemiology (Brooker et al., 2001a).

Community-directed treatment

A new approach to morbidity control has been developed in Uganda, in which community members organize and effectuate the distribution of medication for deworming after collecting the drugs from central stocks. The approach, developed for the distribution of ivermectin for onchocerciasis, is called community-directed treatment, to underline the active participation of locals, as opposed to their often nominal involvement in the much broader category of community-based interventions (Katabarwa et al., 2005).

A study from Uganda evaluated integrated, community-directed treatment (praziquantel for schistosomiasis, invermectin for onchocerciasis and mebendazole for soil-transmitted helminthiasis) in comparison with routine community-directed distribution of ivermectin and school-based treatment of helminthiasis. The integrated approach, which included more people in decision-making processes, had a higher coverage than routine community-directed treatment of onchocerciasis, because parents brought their children for treatment of soil-transmitted helminths and the children then also received treatment for onchocerciasis. The coverage of children was higher in the integrated, community-directed treatment scheme compared with school-based treatment, because out-of-school children were also reached. A drawback in the integrated, community-directed treatment scheme was that drug shortages occurred more often than in the two other schemes, because non-targeted groups were also treated (Ndyomugyenyi & Kabatereine, 2003).

A study of the roles of the drug distributors or health workers in community-directed treatment schemes of ivermectin for onchocerciasis in Uganda showed that the health workers who were involved in other health and development activities performed better in terms of coverage than those who were only involved in onchocerciasis control. The longer a person had been involved in the scheme, the more responsibilities they tended to have. Female distributors performed better inside their own communities, neighbourhoods and kinship groups than male distributors, who were sometimes asked to cover other areas (Katabarwa et al., 2005).

Snail control and environmental management

As noted previously, during the first half of the 20th century, there was a strong emphasis on snail control together with mass treatment. One of its advantages was that it did not require the cooperation of the locals (Leiper, 1915, and WHO, 1950, cited in Sandbach, 1975:522-523). But with the transition from area-wide chemical control to focal snail control backed up by environmental management, community involvement became a desired component in snail control. In 1982, it was observed that community involvement in snail control seemed essential, but it was often neglected. Barriers were reported to be high illiteracy rates, hostility between villagers and local authorities (Kloos, 1985:622) and other social and political factors (WHO, cited in Rée, 1982:132). Furthermore, the effects of the chemicals were not proportional to their high costs. Nevertheless, snail control is considered the key to the ultimate elimination of schistosomiasis in China (Utzinger et al., 2005) and in Morocco (Laamrani et al., 2000b), mainly through environmental management (Ault, 1994).

Exploring the ecology of snails in local settings can be the entry point for community involvement. In the Akka oasis in Morocco, a participatory rapid appraisal identified several methods for schistosomiasis control, which included posting a doctor in the area, reinforcing collaboration between village committees and spring committees, and weed removal from transmission sites. Motivated by the rapid appraisal, farmers themselves took the initiative to intensify weeding, which led to a substantial reduction in density of snails and their egg masses. At some point, the community itself suggested that trachoma control be integrated with schistosomiasis control. The authors conclude that the early involvement of locals in problem definition and identification of counter measures stimulated the development of locally appropriate interventions for control (Laamrani et al., 2000a; Boelee & Laamrani, 2004).

Since the mid-1980s, efforts in snail control have also involved locals in the cultivation and management of plant molluscicides that would be less expensive than synthetic molluscicides. The soap berry plant (*Phytolacca dodecandra*) in particular had proved relatively effective as a molluscicide in laboratory settings.

The processing and application of the soap berry plant was tested in Ethiopia, where the plant is known as *endod*. Both occasional spraying and the use of *endod* soap for washing clothes were tested and it appeared that spraying would be the least labour-intensive method of control in that setting (Erko et al., 2002). Esser, Semagn & Wolde-Yohannes (2003) present a study from Ethiopia of local perceptions of the plant and its many uses, as well as people's reported willingness to cultivate the plant for medicinal use, including for schistosomiasis control. Clark, Appleton & Kvalsvig (1997) conducted a study from KwaZulu-Natal, South Africa, of local perceptions of blood in urine, people's limited access to western medication, and their interest in cultivating plants for molluscicides.

In Zimbabwe, a KAP study explored local knowledge of both schistosomiasis and the soap berry plant. A large majority of study participants agreed that schistosomiasis was a problem, but none of them knew the role of snails in the transmission of the infection. Although they did not previously know of the plant as a molluscicide, a high proportion of people were willing to grow the plant after a brief explanation of its use. A local concern, however, was the necessary allocation of scarce land to growing the plants (Ndamba, Chandiwana & Makaza, 1989).

A study from a rural area in Zimbabwe explored why only a few households were willing to actively participate in cultivating and applying the soap berries for schistosomiasis control when 97% of respondents in an initial survey had stated their willingness to join in activities (Gwatirisa, Ndamba & Nyazema, 1999). The reasons included the perceived low value of the project, the lack of tangible benefits, inaccessible fields and weak leadership. The level of involvement, plot care and factors motivating people in community involvement were analysed in the context of the local historical roots of community involvement and its political history in the country (Ndekha, 2001; Ndekha et al., 2003).

Evaluating planned and unplanned community participation in schistosomiasis control

One of the very few evaluations of community involvement in control programmes was carried out at the end of a five-year control programme in a Kenyan irrigation scheme. Alternative water sources, bathing and laundry facilities, treatment and health education were introduced. The study documented how villagers

appreciated the project activities, but that about half would have liked to have been even more involved in project management. Many heads of households felt that they now saved time with the new facilities and they found their children to be healthier. However, some were concerned about the future maintenance of the facilities. The study notes that discussions about the steps to be taken in the running of control projects should involve locals in a continuous fashion and not just at the beginning of the project. The mechanism for dialogue should also be flexible enough to accommodate inevitable changes in organization and management of the programme (Katsivo et al., 1993a).

Unplanned interaction between locals and implementers and its implications for practices is an unexplored area. Noda et al. (1997) observed how changes in water contact practices in a Kenyan village were much more drastic than the installation of five water standpipes and a shower unit could account for. Health education was not included in the project, but bathing in the river decreased significantly and people began washing clothes in the river instead of in the streams (ibid.:125). Chimbari et al. (1992) observed how people's knowledge of symptoms and causes of schistosomiasis was fairly extensive even though there was no health education intervention in a project in Zimbabwe. Short talks on the life-cycle of schistosome parasites given before collection of urine and stool specimens as well as answers to people's questions during snail monitoring activities had given people new knowledge of the infection. Sow et al. (2003) observed how epidemiological research activities over the previous seven years in Senegal were the main sources of knowledge regarding schistosomiasis in a community, followed by information from friends and relatives. Similarly, it has been observed that women generally maintain a higher and more constant level of enthusiasm in surveys and control projects than men (Feldmeier, Poggensee & Krantz, 1993:165). It may be worthwhile researching how men and women engage differently in non-planned aspects of control interventions in order to further increase the efficacy of control programmes.[24]

[24] Staff of public health offices in 24 endemic areas in Africa and South America reported that men and women participated almost equally in control measures in 13 (54%) of the programmes. Of the 11 (46%) programmes where involvement was unequal between genders, women were overrepresented in 4 whereas men were overrepresented in 7. The overrepresentation of women was usually linked to interventions at community level and explained by their concern for the health of their families. Staff of public health offices characterized educational and economic factors (and to a much lesser extent sociological and ethnic factors) as the most hindering factors in men and women's equal involvement in control measures (Feldmeier, Poggensee & Krantz, 1993:146).

One of the few more elaborate studies of the interaction between local residents and control interventions was conducted in the State of Espirito Santo, Brazil. Here, people in endemic areas regard schistosomiasis as a problem that the federal public health agency (*Superintendência de Campanhas de Saúde Pública Ministério da Saúde*, SUCAM) brought with their different modes of testing for the infection and the free-of-charge medicine for treating it. The SUCAM control programme also carried out health education sessions in the community, but the way people were cast as passive recipients made them relate to the sessions as a kind of punishment after a hard working day. Only very few people mentioned transmission sites and sanitation as another area of intervention (Rozemberg, 1994). If treatment was the preferred response to infection over time, chemotherapy might come to be seen by the locals as the only solution to the complex of biological, environmental and social factors involved in the transmission of schistosomiasis.

Implications for planning and implementation of control programmes

- Community participation components should be facilitated in a way that takes intracommunity dynamics into account and genuinely allows the community (however defined) to participate in decisions.
- Collaboration between education and health-sector staff in school-based treatment programmes should be developed and strengthened.

Directions for social science research

- How can community-directed drug distribution, as piloted in Uganda, be scaled up?
- How can the impact of community participation on the sustainability of programmes after the end of control activities be evaluated and documented? What role does interaction with programme staff and decision-makers play?
- How do the dynamics of the new "communities" that emerge as a result of control or research interventions (i.e. the social dynamics emerging between target groups, local intervention managers and technicians, national and international stakeholders) relate to sustainability of programme results?

Schistosomiasis control in a broader health systems perspective

Main points

- *Looking at schistosomiasis control from a health systems perspective (including processes of resource allocation, priority setting, human resources and management) offers new perspectives on efficiency and sustainability of control strategies.*
- *Socioeconomic and cultural factors influence the management and sustainability of schistosomiasis control programmes as well as case management in primary health care settings.*

There is a growing sense that advances in drugs, vaccines and diagnostics are not enough to improve health on their own, but that the systems in which these technical means are implemented need scrutiny (Liese, 1986). The emergence, resurgence and persistence of schistosomiasis is closely linked not only to large-scale forces such as economic and environmental changes, but also to the organization and management of control programmes and their interaction with health systems in general. The organization of services, resource allocation and financing mechanisms directly influence transmission and control of schistosomiasis (e.g. Xiang et al., 1998, for an example from China). Political priorities within a ministry of health, inefficiencies and waste of resources in a health system profoundly shape the conditions for sustainability and for the application of well-known or new technologies. It has been suggested that successful schistosomiasis control depends on political commitment, allocation of resources and a long-term strategy (Giboda & Bergquist, 2000). Similarly, failures of disease control, such as for schistosomiasis and malaria, are in fact failures of implementation and maintenance (Rosenfield, 1983). This section summarizes observations regarding social and cultural aspects that influence the organization of control programmes, the capacity and skills of health staff, priority setting in the health sector and coordination between sectors.

Control strategies and the organization of control programmes, including availability of drugs

The relationship between the organization of health systems and the formation of strategies for control is complex. It has been suggested that policy models do not generate practices, but rather that policy models are sustained by practices (Shiffman, Beer & Wu, 2002). In this light, control practices have sustained a range of vertical, horizontal and integrated policy models for control – often in various hybrid forms. Utzinger et al. (2004) describe a study of a community outreach programme in a public-private partnership with the Chad-Cameroon petroleum development and pipeline project, which included control of schistosomiasis.

For many years, the control of schistosomiasis was practised as vertical programmes with separate budgeting, often supported by donor organizations. The vertical programmes produced rapid results, which were, however, not sustainable due to a combination of rapid reinfection, low adherence after repeated treatment campaigns, and the high costs of control programmes, which could not be met by deteriorating health systems. Furthermore, vertical approaches have been criticized for being governed by centralized, interventionist and medicalized logistics that are implemented uniformly in different endemic regions (Barbosa, 1998:59) and for wasting resources when many vertical programmes run in parallel in the same areas (Porter, Ogden & Pronyk, 1999).

Passive case detection, based on people's self-reporting, has been considered a less expensive strategy based on the integration of schistosomiasis control into the regular health services. More active versions of control at primary health care level have combined treatment campaigns with improvements of water supply and sanitation and other control efforts in endemic areas. It has been argued that the starting point of such interventions should be based on local concerns and priorities (Tanner, 1989b). Schall (1998) has described a model of the levels involved when health education is incorporated in a control programme.

In countries without schistosomiasis control programmes, equipping health-care facilities for passive case detection is the only option. In the context of integrating schistosomiasis control into regular health services in Ghana, a study explored and described decision-making processes for obtaining health care in

relation to symptoms suggestive of schistosomiasis (Danso-Appiah et al., 2004). The prevalence of schistosomiasis was quite high in the study area (*S. haematobium* infection: 70%, *S. mansoni* infection: 78%). Most people with blood in urine or painful urination did nothing, while people with blood in stools and abdominal pain treated themselves, usually with pharmaceuticals. Lack of money and not judging the symptoms serious enough were the two main reasons for not seeking treatment (ibid.). It is a challenge for schistosomiasis control that many people with blood in urine do not seek treatment or self-medicate with herbs or pharmaceuticals. This challenge is further aggravated if schistosomiasis is not acknowledged at community level (Tanner et al., 1986; Gazzinelli et al., 1998), for example, in low prevalence areas and in areas where intestinal schistosomiasis is predominant.

Since control strategies have effectively shifted from transmission control to morbidity control in many settings, new observations regarding the classical distinction between vertical and horizontal approaches can be made. Morbidity control has the potential to be more vertical than transmission control, because it does not include preventive measures, such as environmental management and health education (Tanner et al., 1986). Mass treatment campaigns targeted at schoolchildren and other high-risk groups borrow traits from vertical programmes, including their weaknesses regarding sustainability and lack of local ownership. Some observe that schistosomiasis control must be integrated into the health-care services at district level and that intersectoral coordination is necessary for sustainability (Magnussen, 2003:244). A particular combination of vertical and horizontal approaches has emerged in community-directed treatment schemes (Katabarwa et al., 2005:321), which appear to combine the strengths of decentralized or localized interventions (Barbosa, 1998:59-60) with the strengths of vertical programmes.

More recent recommendations speak of integrated control of schistosomiasis and soil-transmitted helminthiasis. Due to resource constraints and because tools and target groups of these diseases are similar, the World Health Assembly decided in 2001 to promote integrated control programmes in highly endemic areas (resolution WHA54.19). Technical and policy publications discuss schistosomiasis and other parasitic diseases in combination (WHO, 2002; WHO, 2005). Morbidity control is currently the first objective for both schistosomiasis and soil-transmitted

helminthiasis. The high-risk groups largely overlap and can be reached through the same channels of education and health systems with extended community outreach where populations are severely affected and underserved. Both types of infections can be prevented by improved hygienic conditions coupled with health education (WHO, 2002:25).

In areas where transmission is under control or elimination has been successful, there is still a need for strategies to survey and register incidence and deal with chronic infections (Giboda & Bergquist, 2000). It has been suggested that community involvement is central to surveillance when only a few transmission foci are left (Dias, 1998). In China, the possible role of communities in maintaining the control of schistosomiasis was explored using questionnaires as well as other qualitative methods (Sleigh et al., 1998b).

Another study from China examined how the provision of schistosomiasis control, delivered through dedicated schistosomiasis stations, has adapted to increased exposure to market forces. It concluded that a combination of less rigorous supervision and a greater reliance on user payment and market mechanisms has severely compromised the provision of schistosomiasis control. The radically increased reliance on revenue earning through the 1980s and onwards has led to a situation where the focus has shifted from preventive services aimed at populations to curative services aimed at individuals against a fee. "Reducing the prevalence and incidence of schistosomiasis would be irrational behaviour from a short and medium term profit perspective" (Bian et al., 2004:S91-S92) and the question is whether it is time to integrate schistosomiasis control with other health services in the area (ibid.). Yu et al. (2001) have discussed equity in access to treatment in the decentralized health-care system in China, and Liese (1986) has focused on single-purpose versus multipurpose public health services in a health system, using schistosomiasis as an example.

Capacity and skills of health staff

Training of staff at local, district and central levels is a key but often overlooked component of control programmes (Christensen, Simonsen & Furu, 1989). An important aspect is health staff's and technicians' ability to detect infections, particularly in their intestinal form (de Vlas et al., 2004). Few studies have focused

on social and management aspects of diagnostic systems. A study from Egypt tested the quality of diagnosis in six rural health units, where schistosomiasis control had been integrated into primary health care for many years, and found that technicians' skills varied considerably as did their opportunities and willingness to update their skills. The policy of the central ministry of health was that everybody attending rural health units should be tested for *S. haematobium* and *S. mansoni*, but only those requesting tests were examined (Sayed et al., 2000). To maintain technicians' interest and have a system of quality control in low transmission areas, it has been suggested that known positive stools be introduced among the many negatives (Jordan & Rosenfield, 1983:326). With increasing prevalence of *S. mansoni* infection in the Nile delta, a readjustment of protocols for diagnostic and treatment services was needed, including training of staff to test for and follow-up the disease (el Katsha & Watts, 1995b).

In two villages in Menoufia governorate, Egypt, primary health care teams were trained and equipped to carry out adequate case finding, recording, treatment and follow-up. Community representatives were involved, in collaboration with local health-care teams. The three-year project was evaluated on the basis of impact on community compliance with testing and treatment as well as prevalence, intensity, incidence and reinfection levels. Prevalence levels fell after the first year, but reinfection levels were persistently high in spite of different environmental conditions in the two villages. Compliance rates of diagnosis and treatment increased, although some villagers, particularly women, were still reluctant to be tested. The authors conclude that the wide variety of water contacts and the quality of tap water also needs to be addressed to reduce reinfection levels (Khairy & Farag, 1995).

A quantitative study from Ghana, where there is no national control programme for schistosomiasis, showed that the probability of undergoing treatment with praziquantel upon noticing blood in urine or stools was very low (4.4% and 1.4%, respectively). Even if drugs were available at all levels of the health-care delivery system and health education was carried out to encourage treatment seeking, the probability of being treated might not exceed 30%. The study concluded that additional control activities, especially for high-risk groups, were still needed for control to have an effect (de Vlas et al., 2004). A paper reporting from the same study remarks that if passive case detection remains the national strategy for

schistosomiasis control, it will be necessary to improve availability of praziquantel in endemic areas and to train staff in case detection and management (van der Werf, Borsboom & de Vlas, 2003).[25]

A study from Mali (which has had a national schistosomiasis control programme since 1982) shows that 85% of cases presenting with blood in urine would receive praziquantel from health-care staff whereas only 19% presenting with blood in stools would receive praziquantel (Landouré et al., 2003). In Mali, the policy concern appears to be the cost of diagnosis and treatment at the health centres, which may be part of the reason why only an estimated 50% of people registering blood in urine will seek treatment (van der Werf et al., 2004). Passive case detection is most effective for morbidity control in areas with very high prevalence levels and where most cases of both blood in urine and blood in stools are caused by schistosomiasis (ibid.). Such a situation is described in northern Senegal, where the health system has successfully invested in capacity-building to handle the high prevalence due to the newly established dam in the area. Health staff still prefer to have diagnoses confirmed by laboratory tests, even though the prevalence is so high that it has been recommended to base treatment on symptoms alone. This increases the cost of treatment (transport and testing), which may deter some people from seeking treatment. The authors recommend that the intervention be evaluated again in some years to assess its sustainability (van der Werf et al., 2002).

In Morocco, where the national goal is now to eliminate schistosomiasis, it is an issue to keep up health staff's motivation for surveillance and case detection. The local epidemiological capacity needs to be high as surveillance will have to be maintained for many years. The cost of finding the last case in Morocco will be disproportionately high, but worthwhile (Laamrani et al., 2000b).

Upgrading of health personnel's capacity for schistosomiasis control can be an entry point to increasing overall use of and trust in local health-care facilities (Hewlett & Cline, 1997). By the end of an intervention project in northern

[25] Upgrading the capacity of health workers may not be sufficient for better case detection. Treatment-seeking behaviour in households and communities is also influenced by factors related to national and international policy and funding trends, such as cost recovery systems, etc. (Danso-Appiah et al., 2004:785).

Cameroon, there had been a 20% increase in use of the health-care centres and the percentage of consultations for schistosomiasis had increased from 1-2% to 11% (Cline & Hewlett, 1996).

Not only health-care staff, but also health communicators need to be included in training. For several years, mass media health education campaigns and health workers in Egypt continued focusing on infections with *S. haematobium* and ignored infections by *S. mansoni* even though the proportion of infections with *S. mansoni* was growing (el Katsha & Watts, 1995a; Mehanna et al., 1997).

Priority setting in the health sector

It has been suggested that politicization of health may be the most important force in the mobilization of public health programmes (Mata, 1982:877). This is particularly relevant when it comes to resource-demanding approaches, such as implementation of several types of interventions simultaneously. The author suggests that the necessary political will for comprehensive programmes, such as schistosomiasis control, could be mobilized by an outspoken scientific community and pressure by the affected populations.

The safety, efficacy and low price of praziquantel has undoubtedly played a role in the current visibility of schistosomiasis as a public health problem. In other words, the availability of a solution has promoted the relative visibility of the problem among other problems. At the same time, the availability of this particular technical solution may also have undermined the political will to continue classic prevention efforts (entailing complex social processes). However, reductions in drug price do not ensure access to treatment, let alone equity in access (Reich & Govindaraj, 1998; WHO, 2002:12). Closely related to the issue of equity in access is the question of user fees for treatment, which may relieve the state's burden of providing health care, but which does not necessarily increase funds for other public health measures (Reich, 1988:96).

Acknowledgement of both the complexity in priority setting and the need to address the root causes of ill health has led to new forms of bridging institutional and academic disciplines. It has been proposed that "thinking in terms of infectious disease policy rather than disease-specific interventions will draw

attention to the social, cultural, economic and political dimensions of health, will lead to the creation of effective multidisciplinary teams, and to the development of interventions which work across social sectors" (Porter, Ogden & Pronyk, 1999:326). Instead of fighting causes that impede health, health is seen as something to be *produced* through affirming skills and concepts that advance it – proaction instead of reaction (ibid.:322). This implies a shift away from biomedical programme approaches towards a process-oriented policy approach. This argumentation has been summarized as a paradigm shift in disease control (ibid.) and is outlined in Table 1.

Table 1 – The paradigm shift in disease control[a]

From: current public health orientation	To: infectious disease policy
Disease specificity and verticality	Integrated/horizontal linkages
Standardization of interventions	Flexibility/context sensitivity
Short-term orientation	Longer-term objectives/sustainability
Emphasis on product/targets	Emphasis on process
Limited to health sector	Linking multiple sectors
Focus on individual "risk"	Understanding social vulnerability: risk in the context of everyday life
Operating without reference to global processes	Taking globalization as referent and context
Working on behalf of populations	Working in partnership with communities

[a] Reproduced, by permission of Oxford University Press and the authors, from Porter J, Ogden J, Pronyk P (1999). Infectious disease policy: towards the production of health. *Health Policy and Planning*, 14(4):322-328.

Coordination between sectors

It has been suggested that lack of knowledge is no longer the problem in schistosomiasis control. Instead, the lack of *coordination* of knowledge and its application to environmental and social problems needs attention. Particularly intersectoral coordination and cross-disciplinary analysis in health, education and irrigation/water sectors would serve development planning. "[W]earing blinders [blinkers]of sectoral dominance results in asymmetrical allocations of priorities and financial resources that lead to failure and negative outcome" (Hunter, 2003:232).

In Brazil, intersectoral collaboration appears to have been successful though costly (Jordan & Rosenfield, 1983:327), but in Egypt it has been observed that because schistosomiasis control falls under different directorates and ministries with little integration at regional, district and village levels, control is not effective (el Katsha & Watts, 1997:853). Intersectoral coordination is also needed for prevention:

> Short term economic benefits of resource development generally carry more weight in political decision-making than the adverse health effects such projects may have in the medium and long term. This problem is particularly acute in the case of water resources development projects which can often promote the prevalence and incidence of certain vector-borne diseases such as schistosomiasis and malaria. And while the agricultural sector is usually strengthened by production increase resulting from water resources development, the health sector may ultimately have to pick up the bill for disease control programmes which become necessary as a consequence (Bos & Mills, 1987:160).

This division of benefits and burdens between different sectors has been labelled and criticized as "institutional separatism" (Hunter, Rey & Scott, 1982:1136). Hunter et al. (1993) have provided a guide on intersectoral collaboration in water resources development projects. The WHO publication *Guidelines for forecasting the vector-borne disease implications of water resources development* by Birley (1991) deals with similar issues.

Implications for planning and implementation of control programmes

- Control programmes should be aware of their relationship with the wider health system at local level of influence.
- Case finding and management of schistosomiasis at primary health care level, particularly in areas where *S. haematobium* and *S. mansoni* coexist, should be improved.
- Control programmes should explore how they can best work together with other programmes and initiatives, such as the healthy child initiative, health promoting schools, etc.
- The social aspects of intersectoral health impact assessments in relation to water resources development projects should be further strengthened.
- Community reactions (including negative reactions) towards interventions should be systematically monitored (sociovigilance).

Directions for social science research

- The knowledge and attitudes of health personnel is an understudied topic. Do they recognize infections and are they equipped to track possible shifts in the prevalence of different types of schistosomiasis? Do they have the necessary equipment and skills to diagnose the disease accurately? What incentives and disincentives are there for health personnel in various institutional and epidemiological settings to engage in schistosomiasis control?
- What are the political and administrative structures under which control programmes operate and how do they influence implementation?
- How can health impact assessment techniques be incorporated into multisectoral programme development?
- What are the common short- and long-term trade-offs between the often competing concerns in relation to health, economy, environment and sociocultural conditions when large dam or irrigation schemes are planned?
- What factors and processes are involved when planners at various administrative levels define target groups and suggest treatment strategies? To what extent does the notion of equity in access play a role at the various levels?
- Which are the important financial and managerial contextual factors for the success and sustainability of control programmes (e.g. cost, distribution and availability of drugs in the periphery, public expenditure/out-of-pocket payment, vertical/horizontal programmes, coordination with national health systems and form of community involvement)?

CHAPTER 5

CONCLUSION

This book has aimed to:

- bring together existing knowledge about sociocultural aspects of schistosomiasis transmission and control;
- offer suggestions for operational implications of insights provided by the social science perspectives for planners and implementers of schistosomiasis control programmes at various levels;
- suggest directions for future social science research in the field of schistosomiasis.

Reflecting a broad range of social science studies and their interfaces with studies in epidemiology and public health, the book cites a very heterogeneous collection of studies that reflect many levels of analysis – altogether 378 publications, of which 67 have been annotated (see Annotated bibliography). We have chosen to be inclusive in the selection of references (as can be seen by the boxes containing selected references, which serve as springboards into related themes) and transparent in our search and selection criteria (as described in Annex 1).

Often social science studies are associated with the community level, but in order to highlight how wider contextual factors influence transmission, we have grouped studies according to the macro level (describing the *broad* social dynamics influencing the distribution of schistosomiasis) and the micro level (describing the *community* dynamics influencing the distribution of schistosomiasis). We have also provided a separate chapter on the intervention level, in order to point to sociocultural aspects of *control policies and interventions* that are often underexposed.

Lessons learnt from the social sciences regarding transmission and control of schistosomiasis

> *"Human behaviour is at the heart of prevention, treatment and control of tropical diseases" (Cline, 1995:3)*

The role of humans in the transmission of schistosomiasis has been recognized ever since the transmission cycle was first described in the early 20th century. However, social and behavioural aspects of schistosomiasis have received relatively limited attention in research and control efforts. Not until the 1980s and 1990s did it become possible to speak of a body of social science literature on schistosomiasis, which is mainly focused on African and Latin American settings. This literature has largely revolved around issues relevant to operations. However, in recent years interest has increased in the conditions and policy environments that allow infections to persist and spread in the first place, and research has been conducted also in Asia. The growing focus on the wider social contexts of schistosomiasis is part of a broader trend that relates to many other infectious diseases in developing countries (e.g. Farmer, 1999; Heggenhougen, Hackethal & Vivek, 2003). This focus on the social contexts and determinants of infection and equity in health has renewed the need for insights from social science.

The exact contribution of social sciences to schistosomiasis as a public health issue may be elusive to many. On the one hand, some planners and researchers find it difficult to understand how these disciplines can make a difference to the health status of people living in endemic areas, while on the other hand, Leighton, somewhat provocatively, noted that "the administrator uses social science the way a drunk uses a lamp post; for support rather than illumination" (quoted in Yoder, 1997:132). Yoder continues,

> *Indeed, in the setting of international health programs, administrators use evidence of local beliefs to explain behaviour far more often than insights offered by ethnographic research showing the complexities of decisions about treatment choices or the use of health services* ... (ibid.:132).

Insight into the social dynamics and social change related to schistosomiasis can provide information about many concrete issues in control as well as a basis for broader reflections on priorities and approaches.

An observation often heard from the social sciences is that control programmes should not only be adapted to local epidemiological profiles, but also to social, cultural, economic and political conditions. Below we will elaborate on this point in relation to schistosomiasis.

Standardization of programmes and tools can assist in quality assurance, but it can also hinder innovation and sensitivity to local conditions. There is no "one-size-fits-all" programme. Even with adaptation of global strategies to national conditions, there will be local conditions at district and community level that will challenge national programme design and management. The effect of tools depends strongly on economic, social, cultural and political forces (Reich, 1988:92) and as Kloos (1985) observed, "There is no 'typical' schistosomiasis endemic area or community, and it is unlikely that a blue print for an effective control protocol applicable to all areas will ever be developed".

Infection is closely linked to social conditions and lifestyles, which can differ tremendously with age, gender, ethnicity, religion, location, socioeconomic status and other factors. Wider sociopolitical and economic factors as well as patterns of inequity play a large role in the production of endemic areas and affected populations. Standard perceptions about target groups (e.g. women or schoolchildren) are too simplistic and should be modified according to local circumstances.

The history of schistosomiasis control (Chapter 1) shows how intervention approaches have changed over time. Invention of new technologies, discovery of subsequent shortcomings and changes in policy-makers' and funding agencies' attention have influenced control strategies. There has been a tendency to narrow down interventions when new technologies have become available (i.e. various forms of molluscicides and chemotherapy). But due to the complexity of schistosomiasis transmission, single intervention magic bullets have not proved effective in the long run. Among the complexities are the conditions under which people in very different endemic areas manage various risks and concerns related to health and water contacts. This complexity invites an exploration of more comprehensive packages of interventions. Programmes consisting of several components developed with community participation may be better suited for sustainable impact in many settings. However, such comprehensive approaches

call for more flexible management and monitoring structures than most countries and funding agencies choose to prioritize at present.

Future directions for social sciences research

From a macro perspective, it has become clear that we need more knowledge of the social determinants of health as they manifest themselves along lines of social, cultural and economic factors. Issues such as migration, urbanization and gender issues in relation to vulnerability are prominent.

At a more practical level, there is still a need for more social science research within areas such as access to safe water and sanitation and appropriate health communication. Sociocultural aspects of diagnostics as well as access and adherence to treatment should also be further investigated. In addition, the neglected area of contaminating behaviour needs more emphasis.

The control of schistosomiasis is channelled through institutions that condition programmes in ways that are rarely made explicit and even more rarely researched.

Processes of policy-making, planning, resource allocation, health personnel characteristics and management influence schistosomiasis control just as much as concrete technologies. This is the field of health systems research, the importance of which is gaining general recognition (Global Forum for Health Research, 2005). In this regard, research on community involvement in control programmes and challenges to intersectoral collaboration are also key research priorities.

In his presidential address given before the annual meeting of the American Society of Tropical Medicine and Hygiene in 1994, Cline observed that

> *ours is an impatient society that supports, encourages, and rewards a quick fix approach to biomedical research. More than we recognize, funding, role models, and professional incentives are driven by anachronistic images evoked by the likes of Pasteur and Fleming, of instant solutions to health problems emerging from the laboratories of towering intellects* (Cline, 1995:6).

He continues,

> *The slow fix I envision ... urges us to use endemic communities to permit scientists of diverse disciplines to interact creatively, to formulate and address scientific questions that range from the basic biology of parasites to the upstream and downstream determinants essential to the prevention and control of tropical diseases. The slow fix I envision avoids the unproductive debate on basic versus applied research and urges it to be transformed into a basic and applied context. The slow fix I envision challenges us to develop a clearer vision of, and effective advocacy for, optimal research strategies. The slow fix I envision also provides the setting in which the tropical public health scientists and practitioners of the future will mature and flourish. Paradoxically, I believe a slow fix research strategy, intimately connected to communities suffering from tropical diseases, will often be more effective than a quick fix approach* ... (ibid.:7).

ANNOTATED BIBLIOGRAPHY

Acioli MD, de Carvalho EF (1998). Discursos e práticas referentes ao processo de participação comunitária nas ações de educação em saúde: as ações de mobilizaçao comunitária do PCDEN/PE [Discourses and practices concerning the social participation process in health education activities: community mobilization in the PCDEN/PE. Programa de Controle das Doencas Endemicas do Nordeste/Pernambuco]. Cadernos de Saúde Pública*, 14(Suppl. 2):59-68*

Because this important Portuguese paper offers a rare analysis of the discrepancy between control programme discourses and how they are understood by the locals, a detailed summary is given.

In 1987, a government control programme, *Programa de Controle das Doencas Endemicas do Nordeste* (North-east Endemic Disease Control Programme), supported by the Brazilian Ministry of Health and World Bank, in a town in Pernambuco, Brazil, was intended to build on community participation. Popular education, mass campaigns and participatory investigations were applied as health education measures. An evaluation of the discourses and practices of the intervention showed that the actual result of the government's practices of community involvement was limited to mobilizing people to adopt certain preventive practices and to use public health services. There was no encouragement of citizenship, defined by the authors as critical involvement in local democratic knowledge-sharing, decision-making and planning processes. These processes are in fact highlighted in government strategy papers, but because of the institutional culture of the health sector, biomedical approaches and mass treatment became the practical articulation of the intentions.

This conclusion was based on an interpretation of institutional documents and discourses by the federal public health agency, *Superintendência de Campanhas de Saúde Pública Ministério da Saúde*, *Fundação Nacional de Saúde* and the Ministry of Health, and semi-structured interviews with community-based health agents and the general population. Local health workers reported that their main role was to persuade people to seek treatment and avoid water contact. They addressed public authorities and leaders, churches, associations and schools, but had problems in reaching their goals because of lack of materials, people's dissatisfaction with mass treatment and lack of alternatives to contact with the river waters. Furthermore, the messages delivered by health personnel did not relate to the reality of people's everyday life, and people

were often more occupied with meeting their basic needs of food, work, housing and sanitation than with changing daily habits.

The authors discuss community mobilization within programmes that have specific goals and that aim to change historically embedded habits and practices (such as water contact). These programmes are often designed without an understanding of local daily life and without taking the local material, social, psychosocial and cultural reality into account (where water contact is needed for food, hygiene and recreation).

Institutional practices, based on vertical programmes and medication, did not enable real participation in the programme, but reproduced a discrepancy between discourse and practice – between maintaining hegemonic social control and stimulating community autonomy, the latter being historically rooted in the Brazilian state.

The *Programa de Controle das Doencas Endemicas do Nordeste* could be regarded as an exercise in democracy – part of a re-democratization of Brazilian society in the 1980s – which collided with an institutional culture that is centralized and technocratic. In this regard, doctors and health personnel are stewards of the dominant groups, in line with Gramsci's theories of hegemony, and people's reinterpretation of the dominant discourse (i.e. bathing in the river, but only near the brink) can be seen as contra-hegemony.

The authors conclude that within the institutional framework of the health sector, treatment strategies are prioritized according to a traditional biomedical solution model. This is far from democratization of knowledge. An example of the fact that the educational measures employed were not suitable is that one of the most important measures was handing out flyers and folders even though 50% of the population was illiterate.

Community mobilization was reduced to a question of making people turn up for meetings and lectures. Interventions were vertical and local health staff had little say in choosing sites for interventions. It was obvious that people had no alternatives to the river for water sources and so the goal of education strategies became reduced to making people seek treatment. This is in opposition to people's conviction that it is material conditions that prevent them from carrying out the preventive measures described in folders and flyers. The authors conclude that community mobilization is a discursive project in national documents that is far from the reality of local people's daily lives, and from the institutional culture of biomedicine, where mass treatment is a standard solution.

Ager A (1992). Perception of risk for malaria and schistosomiasis in rural Malawi. Tropical Medicine and Parasitology, *43(4):234-238*

Ager examined a group of rural Malawians' judgement of the risk of malaria and schistosomiasis along four dimensions to assess which dimension would most influence behaviour: the perceived level of risk, seriousness of risk, predictability of risk (these three parameters were measured on a scale between 1 and 100) and controllability of risk (open-ended question). Each individual was also interviewed about adherence to control and prevention measures. The hypothesis was that individuals who scored higher on the four dimensions would adhere more to prevention and control procedures.

The study showed that the link between individuals' perception of risk and their risk-related behaviour was complex. For malaria, there was no connection between adherence to preventive measures and any of the four dimensions of perceived risk, while there was some correlation between adherence to preventive measures and perceived risk of schistosomiasis.

The perceived likelihood of schistosomiasis among women in one study area correlated with the gendered differences in local water contact patterns. People who had been in education longer adhered more to prevention measures for schistosomiasis, while there was no correlation between length or level of education and adherence to malaria prevention measures. The study concludes by suggesting that compliance to control measures that are within the control of the individual (such as drug therapy) may be higher than measures that demand community-wide coordination and participation (such as environmental control).

The study does not consider the important differences between quantified interview responses and people's actual practices. Neither does it take into account that individuals' judgment of risk is situational and often depends on a compromise between several priorities, but it does show the complexity of studying perceptions of risk and actual behaviour.

Alves PC et al. (1998). A experiência da esquistossomose e os desafios da mobilização comunitária [Schistosomiasis and the challenge of community participation]. Cadernos de Saúde Pública, *14(Suppl. 2):79-90*

Socioanthropological analyses of health often operate with a distinction between biomedical and popular understanding of illness. The biomedical perspective regards disease as a context-free physical or mental dysfunction independent of the individual's experience of the illness. But popular understanding of illness emerges in interactive

processes between social actors and their practices within or outside institutions or specific groups. This is the reason why interpretations and representations of illness can vary considerably from one social context to another. The purpose of this study was to understand the processes whereby individuals construct meaning about schistosomiasis. It explores situations in which people develop knowledge about the infection and throws light on limitations and possibilities for community mobilization.

The authors describe four areas in Bahia, Brazil, where the *Programa de Controle das Doencas Endemicas do Nordeste* (North-east Endemic Disease Control Programme) was implemented: Laços, Santiago de Iguape, Barragem de Pedra and Cachoeirinha. The authors explain the presence of serious cases of schistosomiasis in Laços by the biosocioenvironmental factors present there: difficult access to medical treatment, and non-existence of information campaigns. Schistosomiasis is a concrete daily-life experience of people in the area. The biomedical image of the infection that is provided by health workers makes sense to people because they have empirical experience with symptoms. In this area, schistosomiasis is more than information from a health worker and the meaning of the infection is constructed with a basis in bodily experience, which is regarded as negative. In the other three areas, there are no severe cases, people have been targeted by campaigns and they have easier access to doctors. In these areas, the popular representation of schistosomiasis is not related to concrete experience with the infection. Schistosomiasis is not experienced in any physical way, but exists through a biomedical discourse, which is made concrete by programmes and campaigns regarding sanitation developed for the purpose of communication or education. In other words, schistosomiasis is not experienced, but only exists because health personnel speak about it and interventions relate to it.

The discourse of health personnel cannot always be incorporated into local systems of meaning regarding health. People will interpret messages from their own framework of understanding. Professional health discourses often build on the notion of "good" and "bad" as central themes or conceptual reference points. The bad is identified as the snails, as is the river, which is essential in people's daily lives. Even though people have piped water at home, they prefer to go to the river, where they can meet others. The public programmes often create distance between the programme and the people. It is assumed that people will listen gratefully, and there is no space for questions or comments. This discourse does not have any local basis and is not provided in a way that ascribes any social meaning to it.

An important aspect, which needs to be included into evaluation of control programmes, is the processes whereby individuals are led to understand the infection. This is particularly important for programmes with a political agenda to empower people so they will put forward their own demands. In Brazil, the *Programa de Controle das*

Doencas Endemicas do Nordeste aimed to stimulate a political culture that would enable participatory processes. The programme tried to create local organizations, both by establishing an ethical-political code in the organizations and by systematizing the accumulation of knowledge regarding health, which would be necessary when negotiating with the state. However, it suffered from a gradual weakening in the implementation of its ethical-political aims. The weakening, with its accompanying loss of people's control over their own situation, strengthened the centralized and bureaucratic practice of the state, since the possibility of creating a collective of interests and solidarity was lost.

Aryeetey ME et al. (1999). Health education and community participation in the control of urinary schistosomiasis in Ghana. East African Medical Journal*, 76(6):324-329*

This study documents the changes in knowledge and preventive behaviour taking place in three different villages in Ghana following different health education strategies. The study describes the wide range of coexisting interpretations of red urine in an insightful way and how this range of perceptions expands with health education. It is described how health education mobilized local communities to dig wells for safer water contacts, but also how the salty nature of the water, the drying up of the wells in the dry season and the lack of local funds for pumps inhibited change to safer water contacts. It is suggested that information about waterborne diseases be included in school curricula.

Asaolu SO, Ofoezie IE (2003). The role of health education and sanitation in the control of helminth infections. Acta Tropica*, 86(2-3):283-294*

This review discusses the role of health education, water supply and sanitation for control of ascariasis, trichuriasis, hookworm infection and schistosomiasis. It presents the variety of study designs used in evaluations and shows how few programmes actually evaluate the effects of these interventions systematically. Thus, the conclusion that water supply, sanitation and health education are necessary to sustain the results of chemotherapy is based on a relatively limited set of data. The review summarizes interesting discussions regarding the availability versus the sophistication of sanitation facilities and the relation between impact of sanitation and socioeconomic status of the community.

Barbosa CS (1998). Epidemiology and anthropology: an integrated approach dealing with bio-socio-cultural aspects as strategy for the control of endemic diseases. Memórias do Instituto Oswaldo Cruz, *93(Suppl. 1):59-62*

This paper does not report from a study as such, but discusses the methodological design of a doctoral thesis evaluating the epidemiological situation at local levels in a schistosomiasis-endemic area, which was published in Portuguese in the State of Pernambuco, Brazil. One of the basic assumptions in the thesis is that a great range of factors and processes (politically and culturally determined) are presented simply as a disease produced by a parasite transmitted by a snail, i.e. schistosomiasis. The point is that the presence of schistosomiasis is never just a result of biology, but of many other coinciding factors related to micro- and macro-level determinants in the endemization process.

In an attempt to comprehend the totality of the process of transmission and maintenance of schistosomiasis endemicity, an epidemiological cross-sectional study was combined with participant observation, interviews and group discussions. Barbosa presents the advantages of the combination of methods and how it has the potential to enrich the planning of future control programmes.

Barbosa FS (1995). Determination and control of schistosomiasis. Memórias do Instituto Oswaldo Cruz, *90(2):155-159*

This important paper presents many of the positions that are taken by proponents of a sociocultural approach to schistosomiasis as a public health problem. A central tenet is that the overall production of endemic areas can be explained with reference to social and cultural factors that should be the starting point for the planning of control efforts.

The organization of this book into presentations of micro- and macro-level factors in transmission is inspired by this paper.

Bian Y et al. (2004). Market reform: a challenge to public health--the case of schistosomiasis control in China. The International Journal of Health Planning and Management, *19(Suppl. 1):S79-S94*

This paper is one of the few to provide an in-depth analysis of the direct links between the institutional organization of schistosomiasis control and the development of endemicity. It illuminates the relationship between the level of budget support and

the balance between curative (focused on individuals for a fee – risking overtreatment) and prevention work (for the public good). The paper observes a change in values at control stations from "what good can you do?" to "how much profit can you make?". The findings reported in the paper are interesting in a health systems perspective and the paper closes with suggestions as to what could be done to absorb the successful control workers who are working themselves out of business. The paper closes by mentioning the lack of data regarding patient or community perspectives regarding user fees and prevention activities as a limitation of the study. Furthermore, the time span of the study does not permit the shifts in the emphasis of control efforts to be related to observations regarding changes in prevalence of schistosomiasis.

Brooker S et al. (2001). Community perception of school-based delivery of anthelmintics in Ghana and Tanzania. Tropical Medicine & International Health*, 6(12):1075-1083*

This study is one of the few to assess the opinions of teachers and parents involved in large-scale school-based schistosomiasis control programmes (assessing the opinions of children posed particular methodological challenges). The purpose of the assessment was to identify and address areas of concern for achieving long-term sustainability when scaling up control. Using a combination of methods for data collection, e.g. questionnaires, focus groups, interviews and meetings, the study assessed community perceptions of health problems, community awareness of the school health programme, perception of the teacher's role in the programme, perceptions of the side-effects of treatment, perceived benefits as well as willingness and ability to pay for treatment. The study notes that community acceptance is the bottom line for sustainability, but the support of relevant ministries and other key stakeholders is just as necessary for the adoption of programmes at a national level.

Chandiwana SK, Taylor P, Matanhire D (1991). Community control of schistosomiasis in Zimbabwe. The Central African Journal of Medicine*, 37(3):69-77*

This paper describes the implementation of a multipronged strategy for schistosomiasis control at community level, which included chemotherapy, the establishment of latrines and wells, health education and snail control. The paper presents useful considerations with regard to implementing as well as evaluating the effects of each component. A wide range of local actors, including the private sector, were mobilized in the implementation phase and several modes of health education were applied. The observations regarding health education are particularly interesting, since the increase in schoolchildren's and adults' knowledge was limited.

Regarding community involvement in this study, Cline & Hewlett (1996) have noted that the degree of local residents' influence on decisions was not clear. Nor were issues of sustainability addressed.

Cline BL, Hewlett BS (1996). Community-based approach to schistosomiasis control. Acta Tropica*, 61(2):107-119*

This paper describes a model for schistosomiasis control that has the potential to strengthen the primary health care system, and it discusses some lessons learnt for policy development in public health regarding the infection based on experience from a control project in Kaele subdivision, Extreme North Province in Cameroon. The focus of the paper is the issue of local capacity-building for effectively reducing morbidity and mortality related to schistosomiasis. The model had four components: health education, diagnosis and treatment, snail control and a cost recovery system, with health education as the centrepiece. Health education messages were developed on the basis of a thorough knowledge, attitudes and practices study and as many of the local institutions as possible were used for dissemination of the messages. Elementary school teachers and all health centre personnel were trained in the basics of the schistosome life-cycle, pathology, diagnosis and treatment as well as health education techniques. Diagnosis and treatment services were adapted to different local conditions depending on the distance to health centres. Snail control was carried out on a small scale in two villages, but this did not have an impact on prevalence and was not recommended for inclusion in the national schistosomiasis programme. Partial cost recovery for diagnosis and treatment was carried out successfully, and funds collected for snail control were returned after this component was taken out of the control programme. Lessons learnt are divided into general and specific issues and include unusually rich considerations for operations in similar settings.

For a paper focusing specifically on the anthropological contributions to the control programme, see Hewlett & Cline (1997).

Coura-Filho P (1996). Abordagens alternativas no controle da esquistossomose: buscando incluir o subjetivo na epidemiologia [Alternative approaches to the control of schistosomiasis: trying to include subjective elements in epidemiology]. Cadernos de Saúde Pública*, 12(1):95-101*

This critical study discusses the possibility of developing a model for the control of schistosomiasis that includes the perceptions and lifestyles of populations exposed to *S. mansoni*. The discussion springs from the negative experience of a schistosomiasis

control programme, *Programa Especial de Controle da Esquistossomose*, in north-east Brazil, which began in 1976 and which was intended to consist of treatment, vector control, improvement of sanitation and health education based on community participation. Instead, the community-level programme turned into a vertical programme where the community became an object for decisions made at a central level, and where the only remaining intervention – treatment – was carried out by non-locals. There was very little reduction in prevalence after interventions ended.

The author suggests that alternative approaches are necessary to remedy ineffective programmes. He suggests that the individuality of people must be embraced in programmes for them to have an effect, but that this is a double challenge. Firstly, there are very few intervention methods that transcend a focus on the biological aspects of transmission. Secondly, such intervention methods are not part of the biotechnological hegemony sustained by the interests of medical institutions, where doctors' medications legitimate the medicalization of the infection and the role of the state as the implementer.

The author proposes four alternative approaches to public health interventions and health education in general that can be applied to schistosomiasis control interventions. The four alternatives all regard individuals as parts of a whole and they embrace symbolic, cultural and historical aspects of individuals' lives as well as local ways of understanding health and illness. The author argues that these alternatives will contribute to an intervention practice in public health that will reduce the local production of illness. The first three alternatives are general models and the fourth is particularly inspired by anthropological perspectives.

- **Participatory investigation** is applied research where the focus is on basic necessities as defined by locals. Local people should participate in all levels of the research and in this way the local population participates in and shapes a social transformation.
- **Community epidemiology** is a way of conceptualizing and practising medicine so that everyday activities producing illness are transformed. The capacity of people to act on their own health is encouraged. Health is seen as an individual trait, but at the same time produced by global processes. It is fundamental to take a starting point in the myriad of situations, interventions and indicators of everyday life. Communities and health professionals should collaborate in diagnosis, elaboration of programmes, planning and evaluation.
- **Citizen education** is based on the presumption that access to health and education is a civil right. Public programmes have appealed for public participation, but at the same time addressed people as both victims and guilty of being illiterate, ill and poor. For this reason, it is necessary to educate people to become citizens and

to hold the state responsible for lack of information and education. People should demand that the state makes resources and facilities available and accessible.

- **Inclusion of subjective experience and knowledge** of infected people and those at risk of infection into control models is a way of adapting generalized models to local conditions and encouraging local engagement with control programmes.

As an opportunity for reflection on how subjective elements can be incorporated into epidemiology and how anthropological observations can be included in the design of control programmes, the author offers a few examples of how a fisherman and a woman washing dishes and her children in a stream were very well aware of the risk of getting schistosomiasis, how to treat it and how to avoid it, but that they had no real alternatives to their water contact activities. The woman responded that more people die from hunger than from schistosomiasis in the area, and that getting her work done was more important to her than the risk of being infected. The author continues with examples of informants' perceptions of the infection, which have consequences for the way people may or may not change behaviour and seek treatment (many people thought the infection was a worm eating them from their insides; a native chief assumed that the pills for treatment turned into worms inside his body, because worms came out when defecating; a wealthy and influential woman who became dizzy after taking the pills effectively warned everybody in her village against the pills; a young girl left the risk of getting infected in God's hands). By including these subjective, symbolic, irrational, theological and mythological experiences into the epidemiological description of the infection, it becomes easier to understand the complexity of the transmission cycle and its constantly changing image in communities.

The author interprets these representations of risk and of the infection as resistance to treatment and concludes that this resistance can easily be overcome by programmes that are based on community participation. People's constructions of health and illness are fragmented and have emerged from scientific information that has been adapted to subjective, cultural imagination and magical aspects. These aspects are real to those who experience them, and should be decoded by health workers, in order to find a shared language and establish contact. The federal government should provide the necessary material conditions for forming a citizenry with the collective will to control schistosomiasis.

The author suggests that epidemiology should transcend its traditional role of description only and also propose action that would change the biosocial reality of disease production. Anthropological approaches can contribute to schistosomiasis control by specifying the experience of individuals that can then be incorporated into control measures.

Coura-Filho P (1998). Participação popular no controle da esquistossomose através do Sistema Único de Saúde (SUS), em Taquaraçu de Minas, (Minas Gerais, Brasil), entre 1985-1995: contrução de um modelo alternativo [An alternative model for schistosomiasis control with active participation by the population through the Unified Health System (SUS) in Taquaracu de Minas (Minas Gerais, Brazil) from 1985 to 1995]. Cadernos de Saúde Pública*, 14(Suppl. 2):111-122*

This study reports experience from applying an alternative model for schistosomiasis control with active participation of the population through the Unified Health System (*Sistema Único de Saúde*) in Minas Gerais, Brazil. Experience has shown that treatment alone is not sufficient, but that popular participation and improvement in water supply and sanitation is also necessary. In the first phase of the programme, members of the local community, with the participation by professionals attached to the control programme, established a commission to develop the control programme. Volunteers were trained in registration of cases, collection of stool samples, booking for treatment at the health clinics and establishment of small ponds for keeping ducks and snail-eating fish. In the second phase, people were tested and treated if the test results were positive. Water supply was installed and information shared through videos and talks in formal and informal schools and associations. In the third phase, prevalence and intensity were measured and compared with pre-intervention levels. The study showed that installation of water supply and selective treatment of infected people, which were implemented with active participation of the local population, led to lasting reductions in the prevalence and intensity of infection.

The establishment of the commission, which united community representatives and the mayor with a researcher and a supervisor from the public health department, managed to develop an approach to schistosomiasis control that was well suited to local conditions. However, two considerations should be noted: (i) authorities and representatives of national offices at local level may not be prepared to collaborate with such new local commissions and (ii) local commissions risk abusing their power, by controlling instead of facilitating.

Dalton PR (1976). A socioecological approach to the control of Schistosoma mansoni *in St Lucia.* Bulletin of the World Health Organization*, 54(5):587-595*

This often cited paper was the first study to draw attention to the way the number and duration of daily contacts with water plays a role in determining the relative risk of infection. It points to the importance of breaking down exposure into different types of distinct and measurable domestic and economic activities and assessing their

relative importance when designing control programmes. A "socioecological approach" builds on the assumption that the ecosystem can be regarded as consisting of a number of interacting social and ecological subsystems, of which the human subsystem plays a special role. The task of control programmes is thus to select, measure and influence activities that are seen as key sociocultural variables, such as washing clothes or children's swimming, with the ultimate aim of breaking the transmission cycle – following MacDonald's hypothesis of a "threshold level of exposure" below which the transmission cycle can be broken (MacDonald, 1965).

Quantified observations of water contacts during 15 months, combined with anthropological methods for enquiry, was part of an assessment of a pilot scheme to control *S. mansoni* infections through the provision of domestic water supply. Three different interventions, located in separate, but otherwise similar valleys in Saint Lucia, were studied: (i) biological control (chemical control of the host snail), (ii) medical control (treatment of infected people) and (iii) socioecological control (provision of safe water supply and health education to reduce contact with contaminated water). The study showed patterns of water contacts throughout the day, week and month, and the typical activities of men and women of various ages and how they were linked to domestic and economic activities. The paper concludes that water contacts are complex and categories of contacts are often linked. The logical substitute for risky water contact would be the supply of water in households and communal laundry units, while also taking into consideration that rivers are also social meeting places.

Danso-Appiah A et al. (2004). Determinants of health-seeking behaviour for schistosomiasis-related symptoms in the context of integrating schistosomiasis control within the regular health services in Ghana. Tropical Medicine & International Health*, 9(7):784-794*

This study is one of the few investigating the factors involved when people actively seek treatment for symptoms that could be associated with schistosomiasis. It also studies knowledge and prescription and treatment practices of local health-care providers. Cases of blood in urine would usually receive a prescription of praziquantel, which might or might not be available in local drug shops. Cases of diarrhoea would receive oral rehydration salts and antibiotics. People treating themselves or consulting directly with drug shops would usually take metronidazole and other antibiotics. Very little herbal treatment was taken in this area. Self-treatment was very common and not related to insufficient supplies of praziquantel in health facilities. Instead, the overall quality of service delivery and the time needed to be attended to might be causes for high levels of self-treatment.

The implications for a control strategy based on passive case detection are discussed and the authors conclude that additional measures, such as health education, are needed. Attempts to integrate schistosomiasis control into the regular health-care delivery system should target both patients and health-care providers – particularly at peripheral levels – taking into consideration that *S. mansoni* is on the increase. Praziquantel should be made available and accessible at all levels of the health-care system.

Dias JC (1996). Tropical diseases and the gender approach. Bulletin of the Pan American Health Organization*, 30(3):242-260*

Mainly based on literature from South American settings, this paper provides an overview of the connections between aspects of tropical diseases, gender and health – of which inequality is central. Marginalized countries, provinces, villages and populations suffer and women are often among those who suffer most. Medical research has been confronted with the ethical issue of social responsibility and new attention has been given to the goal of enhancing human development and well-being. This development is supported by the increase of researchers native to endemic areas. The basis of gender bias in health research is questioned but the author does not completely break free of the same notions of women as intrinsically nurturing that the discussion aims to criticize.

Examples are given of the interaction between gender and health, and malaria, schistosomiasis and Chagas disease are analysed using a gender approach. For schistosomiasis, the author lists some – mainly biomedical – aspects of infection in women that deserve more attention. He notes how inexpensive and effective drugs have made treatment much simpler than prevention, and observes that women's role (as responsible for both care of the family and development of children's sanitation habits) in prevention of schistosomiasis has been rarely researched.

el Katsha S, Watts S (1994). A model for health education. World Health Forum*, 15(1):29-33*

The model presented in this paper is developed on the basis of cross-disciplinary research in Egypt and is aimed at planners and implementers of schistosomiasis control programmes. The model can be applied using local staff, expertise and finance and initiated by studies of local knowledge and practices related to health. Health education messages were developed with input from locals and educators were trained (nurses, primary school teachers, public service candidates and leaders of informal women's

groups). Training was adapted to the specific needs of each group of educators. It was often informal and consisted of group discussions and audiovisual aids. The specific target groups of the different educators were laid out.

The model does not rely on the establishment of new structures and therefore resource needs for implementing the model are limited. The paper notes that success depends on cooperation between various agencies and on their willingness to take a broad view of the process of health education at the community, district and governorate levels. It concludes by stating that a health education programme should not be perceived by locals as something coming from outside the community, but as something they have contributed in creating. See also other papers in this book by el Katsha & Watts regarding the same project setting.

el Katsha S, Watts S (1995). The public health implications of the increasing predominance of Schistosoma mansoni *in Egypt: a pilot study in the Nile delta.* The Journal of Tropical Medicine and Hygiene*, 98(2):136-140*

This study is part of three-year long project that combined epidemiological studies of infection, snail distribution and water quality with in-depth anthropological studies of human behaviour and the village context of schistosomiasis. This particular paper focuses on health services in Egypt and their need to change routines with the shift from *S. haematobium* to *S. mansoni* as the most dominant species behind infection. At the beginning of the study, local people were not aware of the two different species of schistosome. Health services and televised health information were geared towards signs and symptoms of *S. haematobium* infection. The recognition of *S. mansoni* as the more predominant species had consequences for diagnostic techniques and record keeping for individual follow-up (which is important in infections with *S. mansoni* due to lower cure-rates with single-dose praziquantel than for *S. haematobium* infections). Both local people and health personnel need to readjust routines to respond to the new situation. See also other papers in this book by el Katsha & Watts regarding the same project setting.

el Katsha S, Watts S (1997). Schistosomiasis in two Nile delta villages: an anthropological perspective. Tropical Medicine & International Health*; 2(9):846-854*

This study had an explicit aim to describe what happens in practice in two Egyptian villages in contrast to a unified model or a top-down view of what ought to happen. This was done through the application of both qualitative and quantitative research strategies over a period of five years. One of the few papers on local knowledge, this

paper included staff in local health centres in its analysis of behaviour related to transmission, knowledge and treatment. The authors found that health personnel still tested primarily for *S. haematobium* even though *S. mansoni* infection had become the most common form. Few people in the villages sought treatment from the health centres. They were not aware of the symptoms and they did not always feel that health centres were responsive to their needs. Parents depended on the school-based system for testing their children. An example of action research to mobilize local villagers and government staff in environmental schistosomiasis control in another Egyptian village is presented as an option for future activities. See also other papers in this book by el Katsha & Watts regarding the same project setting.

el Katsha S, Watts S (1998). Schistosomiasis screening and health education for children: action research in Nile delta villages. Tropical Medicine & International Health*, 3(8):654-660*

This study reports on the way national policies for schistosomiasis control had translated into practice in rural Egypt. The research led to a revised protocol for screening of schoolchildren for infections with both *S. haematobium* and *S. mansoni*. Working with all interested parties at the local level, the needs for improvements in service provision were identified at the point of health-care delivery. Among the initial findings were that only urine samples were collected, girls tended to be absent from school on the day of the screening, classes sent for screening were too big for technicians to examine and treat on one day, and school nurses did not inform the children in advance about the purpose and procedure of the screening. These and other issues were discussed by teachers, health unit staff and researchers and a revised protocol was developed and tested. The improved protocol may, however, require more technicians and improved management, training and supervision to work as intended. See also other papers in this book by el Katsha & Watts regarding the same project setting.

Espino F, Koops V, Manderson L (2004). Community participation and tropical disease control in resource-poor settings. *Geneva, World Health Organization, Special Programme for Research & Training in Tropical Diseases (Social, Economic and Behavioural Research. Special Topics No. 2)*

This commissioned paper critically discusses the concept of community participation in the control of tropical diseases. The main discussions revolve around the many meanings of "community" and "participation" as empowering (for social development in general) versus instrumental (for improved health status). It is suggested

that interventions aiming for community participation do not augment pre-existing communities, but create new ones (facilitatory communities) that include the external agencies coming to intervene. Viewing external agencies as de facto integral members of the created community has implications for the way sustainability is imagined. The paper points to the paradox that sustained and continuous involvement of external agencies is often needed for "local" communities to define their own priorities. Apart from a very illuminating general discussion, each of the 10 tropical diseases (in the current disease portfolio of the Special Programme for Research & Training in Tropical Diseases) is discussed in separate sections with examples of community participation in its control.

Feldmeier H, Krantz I (1993). A synoptic inventory of needs for research on women and tropical parasitic diseases. I. Application to urinary and intestinal schistosomiasis. Acta Tropica*, 55(3):117-138*

The research protocol suggested in this paper calls for methods and insights from many disciplines. Built on the chronology of the parasite life-cycle, it organizes topics for research in relation to common stages in the design and implementation of control measures. The paper mainly discusses gaps in knowledge of biomedical aspects of schistosomiasis in women, but also summarizes knowledge on women and water contact, attitudes of society towards people with the disease, factors in women's readiness to be treated and the role of women in transmission of schistosomiasis. Feldmeier & Krantz suggest that the application of their protocol would not only assist researchers in identifying gaps in knowledge about sex-related determinants of infection, but also illustrate how most issues would benefit from cross-disciplinary research and how new perspectives and approaches to studying these determinants are needed, which would benefit the study of tropical diseases in general.

Feldmeier H, Poggensee G, Krantz I (1993). A synoptic inventory of needs for research on women and tropical parasitic diseases. II. Gender-related biases in the diagnosis and morbidity assessment of schistosomiasis in women. Acta Tropica*, 55(3):139-169*

The inventory presents a comprehensive overview of biological and sociocultural issues related to the diagnosis of schistosomiasis in women. References span several disciplines and there is a large and rewarding amount of information obtained through personal communication with public health workers in the field. This approach is very suitable in an explorative inventory such as this.

Gazzinelli A et al. (1998). Sociocultural aspects of schistosomiasis mansoni in an endemic area in Minas Gerais, Brazil. Cadernos de Saúde Pública, *14(4):841-849*

This explorative, qualitative study among teachers and schoolchildren in the State of Minas Gerais, Brazil, was carried out to provide input to the design of a household-based knowledge, attitudes and practices study. The method of interviewing and analysis of the qualitative data is described in detail and the range of ideas regarding *xistose*,[26] its causes and symptoms are presented. People prefer the well-known biomedical treatment, but logistics and transport costs prevent people from seeking treatment for a disease that they do not consider to be too serious. Teachers' and children's extensive knowledge of the importance of the link between health and environmental conditions is documented. So is the paradox that teachers in particular expect the mayor to initiate the improvement of sanitation facilities, but at the same time most households have established latrines and other facilities themselves, which are, however, sadly insufficient. This could indicate community resources that are overlooked by teachers and programmers. The study acknowledges the political history of people used to subjection from authorities outside the community, which could foster a certain passivity with regard to their environment and the fact that agricultural water contacts cannot be changed with health education, but entail socioeconomic change.

Goncalves MM et al. (2005). Fatores sócio-culturais e éticos relationados com os processos de diagnóstico da esquistossomíase mansônica em área de baixa endemicidade [Socio-cultural and ethical factors involved in the diagnosis of schistosomiasis mansoni in an area of low endemicity]. Cadernos de Saúde Pública, *21(1):92-100*

This study documents a new approach to diagnosing schistosomiasis in populations in low prevalence areas in Brazil, which involves people in decisions regarding their own participation in a control programme. Many control efforts had taken place over many years in these rural areas, but in the early 1990s, people began complaining about symptoms that could be related to infection by *S. mansoni*. It was decided to introduce more sensitive diagnostics. After an explanation of the two methods and their differences, 518 people were given the opportunity to choose between stool analysis (three specimens over three days) or serological diagnosis, and they were recommended to take both tests. A total of 178 people were asked whether they preferred one or the other test and why. Of these, 99% took at least one of the tests, 56% took both, 23% chose the stool analysis only, while only 21% chose the

[26] A local term for symptoms that are more or less equivalent to the biomedical diagnosis of schistosomiasis.

serological test only. Those who chose both methods justified it by saying that it would be more accurate; 90% of those who chose stool analysis explained that they disliked having blood drawn. A total of 43% of those who had a blood test found it more effective than stool analysis ("I have already had stool samples analysed many times and they are always negative"). Of the people interviewed, 28% did not appear to have understood the purpose of testing at all.

The area where most people took both tests, and where participation was very high, had received the least attention during earlier control programmes. Only two people enquired about the quality of the blood test and whether the syringe was clean. As the testing involved a small community, where everybody knew each other, people were anxious about confidentiality of the results. Control programmes should consider that people who do not experience symptoms of infection may not be willing to go for diagnosis and treatment that they find uncomfortable.

Since it is impossible and unethical to force people into a particular course of action, this study raised the level of interest and participation by involving people in the decision about diagnostic technique. Furthermore, the study argued that people should look beyond their individual interests and concerns, because schistosomiasis is a collective problem. In this way, the study became an ethical "exercise". The study consciously made an effort not to impose information on people in order to facilitate access to specimens and subsequent interventions, but instead to create a two-way dialogue with people. This exchange implied that researchers took people's concerns about confidentiality seriously and also the fact that people had the right to refuse participating in the tests.

Herrin AN (1986). A social and economic analysis of schistosomiasis: a conceptual framework and a research strategy. The Southeast Asian Journal of Tropical Medicine and Public Health*, 17(3):413-420*

The basic interacting components of the conceptual framework in this study are: (i) a model of household decision-making, (ii) the physical, social and economic environment of the community, and (iii) changes in the environment arising from public policies and programmes as well as natural forces. A range of dimensions within each component are discussed and justified. A very comprehensive list of variables used in a schistosomiasis prevalence survey, a household socioeconomic survey, an individual survey, a school performance survey, a community survey, a water contact survey as well as a snail colonies survey are included.

Hewlett BS, Cline BL (1997). Anthropological contributions to a community-based schistosomiasis control project in northern Cameroun. Tropical Medicine & International Health*, 2(11):A25-A36*

This study is relatively unique in the field of schistosomiasis control for four main reasons: (i) people had to pay for diagnosis and treatment, (ii) the health education component was evaluated systematically, (iii) the project was not associated with a water resources development project and (iv) control biologists, epidemiologists and medical anthropologists actively participated in the activities of the other disciplines (i.e. community meetings, development of questionnaires and communication materials, collection and diagnosis of urine and stool samples and in monitoring of snail control efforts). Two orientations inspired the control programme: (i) strengthening schistosomiasis control locally was regarded an entry point to increasing the use of local primary health care in general and (ii) it built on existing beliefs and institutions and respected diversity between and within communities.

Anthropological contributions to the project included the elucidation of local community knowledge regarding schistosomiasis, which was then built upon, left alone or changed through health communication. Terms for the illness, the idea that haematuria and painful urination are symptoms of the illness and that it needs treatment, the connection with water and the greater risk for children were among the ideas that the project built upon. The project did not try to prevent children from swimming in streams or change practices of treating symptoms with herbs, but the lack of knowledge regarding the role of snails, the role of water contacts and the role of excretory behaviours in contaminating water sources, as well as the availability and inexpensive price of treatment in the local health centres were among the practices and knowledge that the project attempted to change.

Ethnographic insights were a useful input not only to health communication and to setting up the user-fee system that was an important part of the project, but also to snail control. Understanding people's concern about the quality of water after molluscicide made the project address this issue in a way that met the diversity of opinions between villages.

The impact of health communication was evaluated: schoolchildren in the intervention villages showed a much better understanding of the transmission of schistosomiasis than schoolchildren from the control village (a village in a subdivision outside the project area). Adults in the intervention villages also showed more knowledge of transmission even though they had not been targeted in the same way as schoolchildren. Use of health centres for treatment of schistosomiasis increased sixfold, but consultations for other conditions also rose. The paper closes with a discussion of community

participation and what it entails in terms of interaction and response to a diversity of political, social, cultural and economic factors and personalities.

For a paper focusing on the way this project involved the community and some wider lessons learnt for policy development, see Cline & Hewlett (1996).

Hielscher S, Sommerfeld J (1985). Concepts of illness and the utilization of health-care services in a rural Malian village. Social Science & Medicine*, 21(4):469-481*

This study from Mali is one of the few from Africa to provide more elaborate insight into the local actors' point of view. After presenting aspects of the three main sectors of a pluralistic medical system (popular, folk and professional), the study documents the way people interpret and group symptoms related to schistosomiasis and onchocerciasis, how biomedical knowledge and local knowledge is mixed and how people navigate between sectors when they try out different forms of treatment. It is underlined how the interpretation of specific cases depends on the development of symptoms as well as the social relations and personalities of the people infected and the treating specialist. It is argued that self-treatment and the folk medicine sectors satisfy needs that cosmopolitan medicine cannot meet, and that these should be recognized as autonomous parts of the health-care system.

Huang Y, Manderson L (1992). Schistosomiasis and the social patterning of infection. Acta Tropica*, 51(3-4):175-194*

This very important paper is the first attempt to review social issues related mainly to schistosomiasis transmission but also to control. Apart from providing a comprehensive overview of social themes, it also describes the way scientists have developed their approaches to studying these themes. The paper illustrates the broad variety of social factors that produce the different local "faces" and dynamics of the infection and it includes a section on socioeconomic consequences of schistosomiasis. Many of its observations and recommendations remain relevant today.

Huang YX, Manderson L (2005). The social and economic context and determinants of schistosomiasis japonica. Acta Tropica*, 96(2-3):223-231*

This important review fills in a gap in social science studies of schistosomiasis, which tend to focus on infections by *S. haematobium* and *S. mansoni*. The paper offers a useful conceptual framework for reviewing recent literature on the socioeconomic

context of schistosomiasis in China. This framework can also – with modifications relevant to the study area and perhaps with the addition of control programme policies and their implementation – be applied as a general framework in other parts of the world when embarking on analyses of the way social and economic factors at various levels relate to the distribution of schistosomiasis.

Hunter JM (2003). Inherited burden of disease: agricultural dams and the persistence of bloody urine (Schistosomiasis hematobium) in the Upper East Region of Ghana, 1959-1997. Social Science & Medicine*, 56(2):219-234*

This study is one of the few to return to a study area – in this case to investigate regional prevalence trends in an area where water resources development had changed the epidemiology of schistosomiasis many years earlier. Changes are interpreted in the context of observations regarding how dams were established and managed over the years, how they have or have not been maintained, and how rural-urban dynamics have influenced the prevalence of schistosomiasis.

The consequences of the study findings for policy formulation are discussed with reference to the role of rural health clinics and to the critical need for planning and coordination that is based on the wealth of existing knowledge regarding the links between disease and development.

Kamunvi F, Ferguson AG (1993). Knowledge, attitudes and practices (KAP) of human intestinal helminths (worms) in two rural communities in Nyanza Province, Western Kenya. East African Medical Journal*, 70(8):482-490*

This classic knowledge, attitudes and practices study includes an interesting methodological discussion about the differences in people's responses about symptoms of helminth infections when they are interviewed using a questionnaire as opposed to when they are shown actual samples of different vectors and parasites. An *Ascaris* sample in particular elicited different and less varied responses about symptoms, and a higher response rate, than the questionnaire. Apart from producing more nuanced data, the combination of methods also provided insight into the way knowledge in general depends on the way it is prompted.

Katsivo MN et al. (1993). Perception of a schistosomiasis control project in rural Kenya by the beneficiaries. East African Medical Journal*, 70(10):613-616*

This study reports from a survey of perceptions regarding a schistosomiasis control project in village situated in a rice irrigation scheme in Kenya. Randomly selected heads of households were interviewed using an open-ended interview schedule. Questions focused on the purpose of the programme, the need for it, people's level of involvement, and the management, benefits and sustainability of the project. People were asked to comment on the facilities established as part of the project (funded by local contributions) and they were also asked about the parasite life-cycle. The overall results showed positive attitudes to the project and also a reduction in schistosome egg counts. Among other issues, the closing discussion includes considerations related to latrine design and maintenance.

Kloos H, Desole G, Lemma A (1981). Intestinal parasitism in seminomadic pastoralists and subsistence farmers in and around irrigation schemes in the Awash Valley, Ethiopia, with special emphasis on ecological and cultural associations. Social Science & Medicine. Part B, Medical Anthropology*, 15(4):457-469*

The prevalence of intestinal parasitism in semi-nomadic pastoralists affected by river basin and irrigation development projects is studied in relation to cultural and ecological factors. Five ethnic groups in six cultural-ecological situations are studied in the Awash Valley of eastern Ethiopia. Sanitation level and other parasite transmission parameters in each of the six study populations are assessed using a simplified semiquantitative system of scoring for selected variables. Results are examined for two purposes: (i) to analyse the occurrence of infection in pastoralists largely continuing their traditional way of life and in tribesmen who settled in and around irrigation schemes and became farmers or farm labourers and (ii) to evaluate the effectiveness of disease control measures. Prevalence of infection in the indigenous peoples is compared with that in migrant farm labourers from the Ethiopian highlands, and the physical and cultural environment of the irrigation schemes and the Awash flood plains are examined to assess disease hazards created by the new farms and to make recommendations for parasitic disease control.

The study analyses the prevalence of a range of intestinal parasites in semi-nomadic pastoralists, subsistence farmers, indigenous farm labourers and settlers of different tribes indigenous to the Awash Valley. The analysis draws on insights into ecological and cultural changes during the previous 20 years. Since the 1950s, the area had undergone profound environmental and cultural change due to the construction of high dams and irrigated agriculture schemes occupying the best grazing lands. In

addition, there were serious droughts in the early 1970s. Loss of livestock and human lives caused survivors to move nearer to irrigation schemes and almost all five ethnic groups in the area had changed from exclusive semi-nomadic pastoralism to living from a mix of animal husbandry and farming. The extension of highland subsistence farming and charcoal production, the movement of other pastoral groups and the establishment of a national park drastically further reduced the grazing land available to the pastoralists. They had come to live in crowded settlements and in increasing contact with migrant labourers from the highlands. Competition for the remaining grazing land was intense between the groups.

The study describes the extensive efforts to mobilize a representative part of each study population to provide stool samples, which still resulted in an over-representation of children and older males. The parasitological study showed that pastoralists had a lower prevalence of most parasites and less than half as many multiple infections compared with subsistence farmers, indigenous farm labourers and migrant farm labourers. Hookworm and *S. mansoni* infections were the infections with the greatest variations between tribes, and between pastoralists and farm labourers. As women do not work in the irrigated fields, schistosomiasis prevalence was higher in men.

Findings were compared with semiquantitative scores for excreta and domestic refuse disposal, means of subsistence, mobility, village size and house type, water supply, duration of contact with irrigation schemes and environmental factors. Assuming an association between prevalence and intensity, the study suggests that disease surveillance and control programmes are more urgently needed for populations who mainly depend on farming than for people who, to a larger extent, maintain pastoralist mobility and settlement patterns.

The study points to the importance of screening and treating migrant farm labourers, equipping existing health facilities to screen and treat, and involving locals through the existing local farmers' associations, which have already developed other training programmes.

The paper supports a comprehensive approach to control that includes improvement of environmental sanitation, water supply and housing, control of vectors and change of disease-enhancing behaviour through health education and mobilization of resident populations. For the mobile populations, the paper suggests mobile health units that work together with clan chiefs. A prerequisite for the success of such an initiative, however, would be an improvement of working relations between the encroaching highland populations and the undercompensated pastoralists in the valley. Studies of the changing relationships between these groups of people in the irrigation schemes are needed for planning disease control programmes. The rapidly changing ecosystem

of the new farms also requires monitoring so that appropriate measures can be taken to prevent epidemics.

Kloos H et al. (1982). Disease concepts and treatment practices relating to schistosomiasis haematobium in Upper Egypt. The Journal of Tropical Medicine and Hygiene*, 85(3):99-107*

Based on a questionnaire with a mix of open and closed questions, and administered to a non-random sample of 386 men and boys, the study explores local illness concepts, treatment practices and sources of information regarding infection. The paper quantifies the questionnaire replies, but since the sample of informants is not randomly selected, the value of the study is rather its report on the range of different disease and transmission concepts that coexist and the observations about how men shift between and combine treatment regimens and doctors. It was observed that extensive use of traditional medicine was not correlated with level of education. The study also shows how people who live in an environment where schistosomiasis has existed for generations, and who are informed about the infection in various ways, have a fairly good idea of safe and unsafe waters.

Kloos H et al. (1987). Coping with intestinal illness among the Kamba in Machakos, Kenya, and aspects of schistosomiasis control. Social Science & Medicine*, 24(4):383-394*

Being part of a cross-disciplinary study, this sociological and behavioural study explored various resources and opportunities already present in a local community, which future control programmes could build upon. On the basis of interviews, mainly with wives of household heads, the authors identify preventive behaviour, previously unrelated to schistosomiasis, which can be highlighted by health educators. Similarly, the study proposes that women and mothers are previously untapped resources in prevention and control efforts, due to their role as caregivers and health promoters.

The study sought to illuminate some complexities of the motivational forces at play when people seek treatment and the various pathways of use in societies with pluralistic health-care systems. The objectives of the study were to identify behaviour compatible with or interfering with control programmes; evaluate patterns, opportunities and constraints in the use of local health resources; and evaluate perceived efficacy of treatment obtained from various medical services as well as from the schistosomiasis research project. After enquiring into the local categories of intestinal illnesses, their causes, symptoms and association with water contact, the researchers mapped the

forms of treatment that people had sought for intestinal illness over a period of 12 months, including herbal treatment and visits to herbalists and diviners/herbalists who were also skilled in handling witchcraft. More women than men applied herbal medicine prepared at home or visited herbalists. At the time of this study, and in this society, women were more often responsible for preparing herbal treatment in the home than men. Home-made herbal medicine was often considered most appropriate for new cases of stomach aches, diarrhoea and vomiting. If treatment failed or symptoms became chronic, people would seek assistance from specialists in the biomedical system or among the traditional healers. Considerations such as waiting time, transport fees and cost of treatment influenced the choice and sequence of treatment, but social pressure from relatives and neighbours also played a role. People registered a decline in symptoms of illness after treatment given by the project, but some experienced harmful side-effects of treatment with oxamniquine. This was handled with herbal medicines.

The study documents daily practices that unintentionally prevent transmission, such as lining cans for water with leaves that are lethal to snails and cercariae, using alkaline ashes to wash kitchen utensils as well as the use of alternative water sources established on people's own initiative.

Kloos H (1995). Human behavior, health education and schistosomiasis control: a review. Social Science & Medicine*, 40(11):1497-1511*

This comprehensive review provides a very good overview of approaches and lessons learnt with regard to health education in schistosomiasis control. It first points to the general conceptual and methodological gaps in previous approaches, such as blaming the individuals at risk of infection and the assumption that knowledge of risk will lead to behaviour change. The review continues with a critical discussion of studies that describe experience of implementing health education on schistosomiasis in a primary health care framework. The author presents some common reasons for failure of monitoring and evaluation of such interventions.

Following a presentation of common health education models and the conceptual framework behind them, the review presents a model for analysing schistosomiasis-related behaviour that is coupled with the PRECEDE model for planning, implementing and evaluating schistosomiasis control programmes that take individual behaviour in the context of community, regional and national factors as their starting point.

Lansdown R et al. (2002). Schistosomiasis, helminth infection and health education in Tanzania: achieving behaviour change in primary schools. Health Education Research*, 17(4):425-433*

This innovative study focused on the combination of health education and chemotherapy in Tanzanian primary schools. Teachers were trained to encourage children's awareness of personal hygiene with the aim of producing a low-cost, sustainable approach to health education that would bring about behaviour change. From the outset, the study was designed to include 50 schools, of which half became the control group (separated from the intervention group by a forest reserve). The paper presents the approach to informing community members and to training the teachers (two workshops run by Tanzanian staff). During the project, teachers' problems with teaching materials, time and parents' interest in the project were addressed locally. The three-pronged evaluation methods included: (i) a questionnaire for children administered twice; (ii) focus group discussions with children, parents, teachers and other community members; and (iii) continuous observation of practice in the school environment.

The project led to changes in littering, availability of drinking water, the use and cleanliness of school latrines and the provision of water and soap near the school latrines. Unfortunately, the study does not relate these changes to the prevalence of various parasitic infections.

Lucien KF, Nkwelang G, Ejezie GC (2003). Health education strategy in the control of urinary schistosomiasis. Clinical Laboratory Science*, 16(3):137-141*

This study is one of the few designed to systematically compare the impact of two different health education interventions on both perceptions and prevalence of schistosomiasis. Three rural villages around the Lagdo dam in north Cameroon were selected. A parasitological baseline survey was carried out and two different health education methods were applied in two villages. In one village, a new "active learning approach" was implemented, whereas standard teaching was implemented in the other. The paper does not mention whether treatment was part of the study design. Eight months later, another parasitological survey was carried out in the three villages. Children in the two villages where health education had taken place had a higher awareness of schistosomiasis, but available data do not supply information on the possible reasons why the village with active learning appeared to have a greater change in levels of awareness than the village where standard teaching had taken place. Furthermore, the finding that ignorance of schistosomiasis is strongly correlated with its prevalence is not followed up by other observations regarding changes in

daily practices. Nevertheless, the study offers an interesting approach to evaluating the impact of health communication.

Massara CL, Schall VT (2004). A Pedagogical approach of schistosomiasis – an experience in health education in Minas Gerais, Brazil. Memórias do Instituto Oswaldo Cruz*, 99(5 Suppl. 1):113-119*

Inspired by Paulo Freire, this paper describes experience with the implementation of a critical pedagogical approach to learning about schistosomiasis in four schools in Minas Gerais, Brazil. Critical pedagogy entails teaching students how to situate their everyday lives and culture in the social and political context where they live. In so doing, the approach aims to stimulate the generation of new knowledge, political reflection and ultimately a better quality of life. In phase one, parasitological surveys were carried out and teachers collaborated very well with the researchers. The fact that the researchers had moved into a house in the project area greatly facilitated the integration of project activities into the local community. In the second phase, teachers were enrolled in a course that aimed to stimulate reflections on the construction of knowledge, which was combined with practical classes on techniques related to schistosomiasis. A kit with teaching materials (including a video, snail shells, worm samples, tongs and gloves, as well as several publications) was given to each school. The paper describes school activities (including the dissection of mice) and gives examples of the way the approach has influenced teaching methods in general, teachers' attention to the local and structural processes that maintain the infection, their consciousness of other health issues, and confidence in their abilities to improve their own and their students' health.

Mata L (1982). Sociocultural factors in the control and prevention of parasitic diseases. Reviews of Infectious Diseases*, 4(4):871-879*

After describing a range of parasites common in humans and the complexity of their life-cycles, this paper suggests that the social determinants of disease are the most important factors to identify when planning intervention programmes for parasitic diseases. The complexity of determinants of parasitic infection requires interrelated measures at ground level. Acknowledging the close link between socioeconomic development and better health, and in line with the thinking of Alma-Ata, the paper suggests that a holistic approach to strengthening primary health care together with improvements in sanitation, housing and education is needed. The expenses attached to such efforts demand political decisions and support, which could be catalysed by the sustained efforts of an outspoken scientific community.

Mehanna S et al. (1994). Social and economic conditions in two newly reclaimed areas in Egypt: implications for schistosomiasis control strategies. The Journal of Tropical Medicine and Hygiene*, 97(5):286-297*

This study presents an approach to assessing how different social groups identify and prioritize community problems. In the initial free-listing of such problems, schistosomiasis was not mentioned by any of the informants. However, prompted by the subsequent paired comparison on the importance of different community-wide problems, where schistosomiasis was included, it received a relatively high score, particularly among the Bedouins, who had only recently been made aware of the infection.

Following a good discussion of the validity of data produced by the chosen methods, the paper discusses the role of chemotherapy, community-based health education and snail control in controlling schistosomiasis. The success of passive chemotherapy, which is the predominant strategy in Egypt, depends on whether people are informed about symptoms, whether they recognize them and seek treatment, and whether they have access to being tested and treated. These conditions cannot be assumed in more remote, reclaimed areas. The otherwise proven cost-effectiveness of chemotherapy alone will be challenged by the cost of establishing health services in these areas and making people attend. A combination of chemotherapy, community-based health education and snail control may be more cost effective. Community-based health education would be challenged by the fact that there is very little sense of community among the different social groupings in the settlements and by the high rates of migration. Access to water, however, seems to be a priority problem for most groups, which could form an entry point for community work. Selective and focal snail control might be valuable in the reclaimed area where the canal system is not yet very intricate. The paper concludes by suggesting that snail control combined with chemotherapy would be the most cost-effective measure for snail control in the reclaimed areas.

Mehanna S et al. (1997). Factors affecting knowledge of the symptoms of schistosomiasis in two rural areas near Ismailia, Egypt. Tropical Medicine & International Health*, 2(11):A36-A47*

This paper describes in detail a method to carry out structured data collection based on a step-wise progression from open-ended, semi-structured interviews and free-listing of illnesses to a large survey of people's association of various biomedically relevant symptoms with schistosomiasis. The approach is useful in documenting knowledge relevant to campaign efforts and for training health workers in responding to local idioms of complaints.

Michelson EH (1993). Adam's rib awry? Women and schistosomiasis. Social Science & Medicine*, 37(4):493-501*

This paper gives brief overviews of studies showing a large variation in men and women's water contacts; how gender roles may limit women's access to economic opportunities, education and health care; how gendered religious practices may influence exposure; the very mixed correlations between gender, education and infection; gendered knowledge of the use of plants that can also be used as molluscicides; women's responses in surveys of attitudes; and the fact that women may keep boys more well-fed than girls, who will then be more susceptible to the consequences of infection. Thus, this review supports the observation that men and women's exposure, prevention measures and access to treatment are very heterogeneous – not only between the genders, but also between endemic areas.

Mott KE et al. (1990). Parasitic diseases and urban development. Bulletin of the World Health Organization*, 68(6):691-698*

This often cited paper describes various scenarios of epidemiological determinants of parasitic diseases in urban areas and presents hypotheses about their impact on employment patterns, consequences for urban health services, and the ideal intersectoral and cross-disciplinary control measures needed. These include adequate public services such as water supply, sanitation and drainage; efficient health services including laboratories capable of diagnosis, drug supplies for correct treatment, surveillance and monitoring of data derived from inpatient and outpatient health services to determine the pattern and distribution of parasitic diseases; and appropriate and sustained vector control measures.

Mwanga JR et al. (2004). Schistosomiasis-related perceptions, attitudes and treatment-seeking practices in Magu district, Tanzania: public health implications. Journal of Biosocial Science*, 36(1):63-81*

This study takes as its starting point the acknowledgement that an understanding of local perspectives on the infection is needed for planning appropriate control programmes. Over a four-year period, qualitative methods were first applied to explore local perceptions and attitudes to symptoms associated with both *S. haematobium* and *S. mansoni* infections at various stages. Similarly, treatment-seeking practices were explored and core issues were then researched through a quantitative survey. A gender-balanced number of schoolchildren, health-care providers, patients from both public health-care clinics, traditional health-care providers and a group of villagers

were involved in the research. The time available for the study and the combination of methods allowed research questions to be formed on the basis of previously produced data from the same area. This enabled triangulation of findings to increase validity. The closing questionnaire-based survey was developed on the basis of accumulated knowledge of local categories of illness and priorities.

The discussion of recommendations to the District Health Management Team reflects the nuanced understanding of current barriers to control, including the lack of diagnostic equipment, lack of privacy during testing and drugs at the local government clinic, user fees as a prohibitive factor and people's generally positive attitude to public health facilities. The discussion also reflects on the need for health communication that responds to local concerns about shame, refers to local terminology regarding symptoms and encourages preventive measures, such as the construction of latrines.

Ndekha A et al. (2003). Community participation as an interactive learning process: experiences from a schistosomiasis control project in Zimbabwe. Acta Tropica*, 85(3):325-338*

This explorative study illustrates how qualitative methods can provide insight into some of the reasons behind the failure of programme components. It explores how the sociocultural context influenced local participation in a project that included the cultivation and application of a local plant as a molluscicide. Through the use of several qualitative methods, the following interrelated themes emerged: lack of plot care due to lack of time and labour, the cost of maintaining the plots, changing norms of traditional modes of communal work, negative experience with previous projects initiated from outside the community, and local power struggles between members of the village development committees.

The methods applied also allowed the identification of possible ways to improve participation. Local concepts of the value of farming and working together were voiced, and unplanned benefits of the project (fish intoxicated by the molluscicide were easy to catch, and the opportunity to grow vegetables on the plots) attracted positive attention. Local solutions to problems were also identified, such as the establishment of new plots in much smaller administrative units. Annual review meetings were also used to address other communal issues, such as water supply.

The study highlighted how the skills of local leaders are a key factor in successful community participation and how expectations of remuneration influenced participation over time. In spite of the very project-specific observations, this explorative study raises wider questions and generalizations regarding community participation.

Noronha CV et al. (1995). Uma Concepção Popular Sobre a Esquistossomose Mansônica: Os Modos de Transmissão e Prevenção na Perspectiva de Gênero [A popular concept of schistosomiasis mansoni: modes of transmission and prevention in the perspective of gender differences]. Cadernos de Saúde Pública*, 11(1):106-117*

This study from a small town in Bahia, Brazil, explores the dynamic intersection of young people's extensive knowledge of schistosomiasis transmission and prevention, which stems from health education, and their individual experience of risk and being infected. The study town was characterized by lack of sanitation and by open ditches and streams flowing through gardens and fields. A parasitological survey had shown that prevalence of schistosomiasis in both men and women who had recently immigrated to the town (less than 30 days previously) was 35%, which was clearly different from the prevalence in men and women who were native to the town (men 30%, women 18%). The authors suggest that the difference in living conditions of the two groups can explain this difference. Immigrants were typically poorer and lived in houses without piped water and without good sanitary infrastructure. They were illiterate and often unemployed, so they frequently travelled in endemic areas to look for work. Native men, however, worked as mechanics, salesmen, farmers and tradesmen. Native women were employed as cleaners, saleswomen, manicurists, etc. and were generally better educated than men, who had often had to leave school early to earn an income.

The analysis of the dynamics of knowledge was based on individual semi-structured interviews with a group of 29 young people (15-25 years old) consisting of both immigrants and natives to the town. When enquiring about perceptions of health and illness in general, women were thought to be more ill than men, due to an idea of women being physically weaker than men and often suffering from various symptoms related to menstruation and pregnancy. But parasitic infections in particular were associated with men and their freedom to move everywhere, including "dirty" places that are perceived as risky in terms of parasitic infections (forests, muddy places, streams and rivers). Indeed, informants pointed out that men were more unhygienic than women, and the fact that men and boys were freer to be dirty and had time to play in the river was associated with their greater risk of being infected.

Young men often spoke of alcohol in connection with parasitic infections. They explained that it would be more difficult for a person to have a healthy body if the person drinks, and that it would not be possible for a person to drink when taking the medicine. One young man said that he did not want to go through deworming because he preferred to drink beer. He had taken medicine for worms once, though, and afterwards cleaned his intestines by drinking lime juice.

When informants were asked questions about various symptoms and diseases, they often hesitated and responded that they did not really know about the disease. The authors interpreted this as an expression of medical doctors' monopoly of "correct" knowledge, which people reproduced in their responses.

People categorized parasites as more or less common or dangerous. Schistosomiasis was often classified as dangerous, but not life-threatening, and most people knew that the infection could be treated. They knew that worms can live for a very long time in a person's body and that they cannot live outside the body. They only referred to biomedical medicine as effective in treatment, although local herbal medicine was available too. Young people's accounts of the transmission cycle and risk factors were fairly close to the biomedical model and they reported that they had received their information from teachers and doctors. Regarding prevention measures, they emphasized that people should avoid the river, visit their doctor often and be tested at the laboratory, because people can be infected without having symptoms. The authors interpreted young people's firm statements in this regard as indications of a strong medicalization of health, which may be connected to the younger generations' faith in science, "progress" and technologies, including modern pharmaceuticals. The same trend characterized informants' management of their own symptoms. These had to be identified and legitimized by biomedical authorities and techniques that were given the monopoly of knowledge regarding health and illness.

The authors observed that even though young people were aware of risk factors and pointed to the importance of consulting their doctor, they did not translate their knowledge into practice. The enactment of local gender roles put men and women at different risk levels. Men's freedom and expectation to move was a threat to their health, because they spent their leisure time near or in the river. Young women, on the other hand, were not supposed to expose themselves to male eyes by bathing or swimming in streams and pools. Thus, women, who were expected to "be good", were also protected from parasite infection by this moral aspect of the feminine gender role. The authors suggest that moral values in the male and female gender roles should play a role in risk assessments.

Summarizing the study, it analysed how knowledge of transmission and prevention emerged between biomedical knowledge and popular knowledge. It also documented how knowledge was produced in a dynamic process where existing theoretical knowledge, individual experience and stories about other actors' experience was mixed in negotiations of meaning in social interaction. Furthermore, it illustrated how knowledge of risk and transmission was shaped in interaction with local understanding and enactments of men and women's typical behaviour. As a consequence of this insight, health education should incorporate sensitivity to the differences between medical

and popular knowledge. To understand behaviour, it is necessary to first understand how this behaviour makes sense to the person observed. Hygienic and preventive behaviours are connected to basic cultural ideas of what is "dirty" and what is "clean" and how men and women handle these differently. Education activities that directly implicate changes in habits and behaviour should incorporate knowledge, values and practices of the target groups.

Nwaorgu OC et al. (1998). A school-based schistosomiasis and intestinal helminthiasis control programme in Nigeria: acceptability to community members. Tropical Medicine & International Health*; 3(10):842-849*

This study assesses the opinions of pupils, teachers, parents and health workers regarding a planned school-based control programme of intestinal helminthiasis and schistosomiasis. The study is an example of the way quantitative and qualitative data can complement each other and enrich the interpretation of data. Focus group discussions were held with grade five and six pupils (primary school level), teachers and parents. In-depth interviews were held with headmasters, teachers and local health staff, as well as herbalists and medicine shopkeepers. Interviews dealt with local health problems, the role of schools in delivering health services, and willingness to accept and participate in a programme where teachers detected and treated infections. A questionnaire regarding knowledge, attitude, beliefs and practices in relation to schistosomiasis was administered to male and female heads of households. A parasitological survey was also carried out. Findings were used as a basis for decisions regarding control strategies involving schools in Nigeria.

Parker M (1992). Re-assessing disability: the impact of schistosomal infection on daily activities among women in Gezira Province, Sudan. Social Science & Medicine*, 35(7):877-890*

In contrast to clinical, physiological and epidemiological studies, this ethnographic case-control study takes women's daily experience of infection as a starting point and shows which of the women's functions were disabled and to what extent. Drawing out policy implications is complicated by the fact that the nature and extent of disability will vary between populations, because it is so influenced by local ecological, social, cultural and economic contexts. The data from this study do, however, underline the relevance of the question whether schistosomiasis should be accorded priority as a public health concern in Gezira Province.

Parker M (1993). Bilharzia and the boys: questioning common assumptions. Social Science & Medicine*, 37(4):481-492*

This well-substantiated paper provides a critical discussion of issues in relation to impact measurement and demonstrates in detail how qualitative, anthropological methods can supply essential insights into behaviour as one component of health. Literature on the biomedical, economic and social aspects is summarized.

Pathological and clinical studies point to the link between disease, worm burden and excretion of eggs, but this information does not illuminate how infection is related to disease or disability. Such studies have rarely included women, and when they have, the focus has been on their reproductive organs. Physiological studies have mainly examined the working capacity of infected men, but conclusions are often drawn without taking different intensity of infection, nutritional status, unfamiliar test apparatus and other factors into account.

Studies of economic aspects show conflicting results and generally apply inadequate methods and indicators to fully capture the complex coping strategies that women apply, for example, in agricultural work and in the domestic sphere. Based on an innovative and solid blend of quantitative and qualitative methods, this exploratory project shows that it is possible to integrate approaches for a fuller picture of the impact on schistosomiasis on behaviour. The author suggests that epidemiological, behavioural, social and economic aspects could be explored in an interdisciplinary way to provide more nuanced input to discussions of the relationship between infection and disability and the extent to which schistosomiasis presents a major public health problem.

Popkin BM (1982). A household framework for examining the social and economic consequences of tropical diseases. Social Science & Medicine*, 16(5):533-543*

The paper shows how social science methods used by economists can provide input to a household economics framework for the design of tropical disease impact research. It points to previous difficulties in measuring the complex social and economic impact of tropical diseases stemming from: (i) a narrow conceptualization of the economic and social factors representing consequences or outcomes; (ii) lack of consideration for the various steps of disease transmission, functional impact, variation in physical performance and the ultimate effects on production and income; and (iii) lack of consideration for differences in disease transmission, usage of health programmes, effects of disease, and the gross and net impact on both the sick individual and others in the household and community.

An alternative theory of the economics of households builds on the assumption that households (not individuals) form the indivisible locus of production, consumption and decision-making. The approach also assumes that measurements and modelling benefit from being built on insight into the total household dynamics, including market and home production, social interactions and the interchangeability of activities.

The selection of social and economic outcomes to measure is very important and an overview of possible dimensions is proposed, including usage of health services. Thus, the approach has the potential to capture more complex, but still mainly systematic, associations between infection and socioeconomic impact.

Rozemberg B (1994). Representação social de eventos somáticos ligados à esquistossomose [Social representation of organic processes related to schistosomiasis]. Cadernos de Saúde Pública*, 10(1):30-46*

This study highlights how local representations of schistosomiasis develop less as a result of the transfer of "knowledge" but rather as a consequence of the general activities of the national control programme in Brazil. The study takes its starting point in the assumption that it is just as important to focus on local representations of schistosomiasis as on the official biomedical understandings. Locals make an effort to understand the information they are given about schistosomiasis, and the authors hope that medical science will meet understandings created outside biomedicine with the same sincerity.

The study covered 579 households in an area that presented a schistosomiasis prevalence of 30%. Socioeconomic data were collected and 96 adults were interviewed, using a questionnaire, about their experienced signs of morbidity, with no references to schistosomiasis. In addition, 62 people were interviewed, using semi-structured interviews, about representations of schistosomiasis. The results of the 96 interviews showed that worms (unspecified) ranked fourth as a health problem in the area, following nervous problems, influenza and high blood pressure. Only three people explicitly mentioned schistosomiasis. When prompted, however, 74% reported ever having been infected; the diagnosis had been provided by the federal public health agency, *Superintendência de Campanhas de Saúde Pública Ministério da Saúde* (SUCAM).

On the basis of the 62 interviews, 22% reported that a person cannot know whether he or she is infected, but being presented with a positive result of a stool examination, 77% associated this with a series of symptoms and signs (mainly weakness, fatigue and not being able to work as hard as usual in daily routines). When answering questions about symptoms, 22% referred to serious cases even though prevalence had

only been medium in this area. A range of symptoms were mentioned and the type of diagnostic test influenced the representation of the parasite (e.g. if it had been diagnosed from blood samples, it was considered to live in blood vessels). Among the serious symptoms, *barriga d'água* ("water belly") had most impact on people's representations.

People were aware that worms can live for a long time in the body, and that the infection can become serious if it is not detected early enough. They were also aware that it can be treated to avoid the serious sequelae.

People's accounts showed a dynamic process of transformation between ignorance and access to information that derived from observations of control activities. The local term for the illness was *doença do caramujo* ("the snail disease"). Many people did not distinguish between the snail and the parasite, but based on the way they had understood SUCAM's information, 37% thought of the parasite as a mini-snail that enters the body and multiplies. Some 46% thought of the infection resulting from water snails entering the body, but at the same time they found this absurd, because the snail would be too big to enter the body.

A total of 71% found that their health improved after treatment with oxamniquine, but 7% found that the medicine was not strong enough, because treatment needed to be repeated regularly; while 15% had a perception of the infection as chronic because medication had to be repeated. Reinfection did not figure in their accounts. A total of 15% reported that they themselves had become ill from the treatment (due to the strength of the medicine) and the same proportion reported that someone they knew had become sick (because they had not avoided drinking alcohol or had eaten fatty foods). Some people found it difficult to choose between being ill from infection and being ill from its treatment.

The SUCAM control programme carried out health education sessions in the community, but the way people were cast as passive recipients made them think of the sessions as a kind of punishment after a hard working day. People received and remembered the information they heard, but this did not influence the way they acted. The biomedically "correct" information was actively interpreted with reference to people's earlier experience and these interpretations formed the basis of new interpretations.

Adults learn by integrating new elements of knowledge into existing areas of experience, and it is important to understand the individual and shared interpretations that emerge out of this process. The isolated scientific information about snails stemming from the biomedical body of knowledge (and actively interpreted as snail as entering people's bodies) was not related to any previous experience that people in the area

had, and the information remained rather abstract for them. At the same time, the information concerned something that potentially could take place in their own bodies. It was in this space between abstract concepts and bodily experience that people's own interpretations about transmission routes and symptoms developed.

When the illness had been diagnosed, there was only one solution: the designated "snail medicine". This medicine, which effectively materialized the power of science, was the only drug that could neutralize the snails in the body. People who took treatment even though they did not feel sick accepted the authority of the doctor/biomedicine. A total of 33% of people who took the medicine described negative experience with it – but not with the disease, which was seen as the cause of serious suffering, invalidity and even death.

There was a contradiction between faith in the medicine and people's experience of it. When people continued taking the medicine, they maintained the authority of doctors/biomedicine, but they also maintained the understanding of snails as entering the body, which appeared so illogical to them. The myth of the snail entering the body systematically removed attention from questions that would concern sanitation and the general living conditions that maintained the transmission of schistosomiasis. People were so occupied with medicine as the solution to the disease that they did not consider their general situation, which could be seen as the root cause of their health problems.

Ruyssenaars J, van Etten G, McCullough F (1973). Population movements in relation to the spread and control of schistosomiasis in Sukumaland, Tanzania. Tropical and Geographical Medicine*, 25(2):179-186*

This study is an example of a way to research mobility patterns, not only as an important input to the design of control programmes, but also as an entry point to better understanding the local distribution of *S. haematobium* infection. The study explores the reasons, geographical patterns and seasonality of mobility, both emigration and immigration, in an endemic rural area in the north-east of the United Republic of Tanzania. The data collection methods were observation and questionnaire-based interviews with heads of households (both to elicit information about all migration between 1968 and 1971 and the migration history of all household members over the age of 14 years). The main findings were that movement over relatively short distances was very common (75% of movements were within 100 km) and the amount of migration had increased during the previous 15 years. The main motives for migration for women were marriage and divorce. Death and disease, coupled with fear of witchcraft, were very common motivation factors, but the most frequent motivation

for both emigration and immigration was environmental factors, such as shortage of land, infertile soil and insufficient water supply. The increase of migration over the previous 15 years could possibly be explained by deteriorating economic conditions as well as political changes in the village communities after independence, which had weakened the traditional village organization.

The article discusses the role of emigration in the spread of schistosomiasis to previously underpopulated districts and the role of this mobility in the unusual non-focal distribution of the infection in the area. With regard to the design of control programmes in the area, the high mobility, high prevalence and non-focal transmission of *S. haematobium* sets certain conditions for the definition of the area size and intensity of activities of the programme.

Schall V, Diniz MC (2001). Information and education in schistosomiasis control: an analysis of the situation in the State of Minas Gerais, Brazil. Memórias do Instituto Oswaldo Cruz*, 96(Suppl.):35-43*

This paper reviews the quality of health education materials related to schistosomiasis in Minas Gerais, Brazil, and compares it with local men and women's experience with and understanding of the infection. The study shows how education materials have not had the expected effect, since many people have a poor understanding of the infection, its vector and the medicine for treating it. Nine lessons learnt regarding the effectiveness of materials and educational processes are presented as well as five recommendations specifically aimed at teachers' approach to health education.

Sleigh A et al. (1998). Eradication of schistosomiasis in Guangxi, China. Part 3. Community diagnosis of the worst-affected areas and maintenance strategies for the future. Bulletin of the World Health Organization*, 76(6):581-590*

This Chinese study uses qualitative methods to assess social dynamics in the communities as input into strategy development. Qualitative methods were unfamiliar to the research assistants and the local people involved, but people appreciated the approach. The combination of qualitative methods revealed how people in focus group discussions called for collective action, much in the style of former propaganda campaigns, while individual interviews indicated that people would be less willing to carry out preventive measures without incentives or payment. At the same time, many people expressed concern about the shift from collective attitudes towards the common good to individualistic outlooks. The observations of the study should be seen in the context of the profound social changes taking place in China between 1953 and 1992.

Sutherst RW (2004). Global change and human vulnerability to vector-borne diseases. Clinical Microbiology Reviews*, 17(1):136-173*

This multifactor risk assessment discusses a range of factors that may influence future vulnerability to vector-borne diseases. Specifically with regard to trends in socioeconomic development, the paper points to population growth, urbanization, land use, land cover and biodiversity, industrial and agricultural pollution with hormone-disrupting chemicals, trade and travel as factors that will impact the future distribution of infections. The paper refers to a study suggesting that the epidemic potential of schistosomiasis would decrease between 11% and 17% with global warming, due to higher mortality rates of miracidia, cercariae and the snail vector. Adaptation options discussed include legislative, engineering and behavioural measures.

A framework for assessing vulnerability is proposed and it is argued that the key to reducing societal vulnerability to the health impacts of climate change is to enhance existing public health infrastructure and intervention programmes. In the longer term, only improved living conditions will deliver a sustained reduction in vulnerability to environmental health hazards.

Talaat M et al. (2004). The social context of reproductive health in an Egyptian hamlet: a pilot study to identify female genital schistosomiasis. Social Science & Medicine*, 58(3):515-524*

This paper presents in detail some important practical and ethical considerations about the way women can be approached for studies of female genital schistosomiasis. Furthermore, it is one of the few studies to combine clinical examination with a concurrent study of the wider social context of reproductive health in the study area. The combination of epidemiological, clinical and social research enables an assessment of the surprising extent of the problem as well as the identification of strategies for treatment and health communication.

Similar to the study from Cameroon by Hewlett & Cline (1997), this study observes how the issue of infertility is of concern to both men and women and how the topic could be among the entry points for health communication on both schistosomiasis and reproductive health.

Tanner M (1989). Evaluation of public health impact of schistosomiasis. Tropical Medicine and Parasitology*, 40(2):143-148*

The paper points to important conceptual and methodological shortcomings of impact studies that could otherwise form important background information in the allocation of scarce resources for control programmes in rural communities. With this purpose in mind, the paper proposes that existing tools for assessing human activities, water quality and snail populations be combined with a method for ranking local perceptions of severity of infection, which would place the infection in the context of other health and development priorities of the community.

Tanner M (1989). From the bench to the field: control of parasitic infections within primary health care. Parasitology*, 99(Suppl.):S81-S92*

This paper takes a holistic view of parasite control efforts that entails a continuing interaction between laboratory scientists, field workers, primary health care cadres and community members. In line with the principles behind primary health care, the author argues that researchers, public health specialists and health planners should take community needs as the basis for priority setting.

The paper begins with a brief summary of reasons for previous failures in sustaining the levels of control that were envisioned at the beginning of programmes. The author then suggests how new technologies for control should be critically examined in terms of three levels: (i) efficacy (does it work?), (ii) effectiveness (how is it to be applied in practice?) and (iii) efficiency (how much does it cost compared with other tools?).

Through the detailed account of three case stories, the author argues that research and development priorities need to be developed in partnership with field needs. Citing the advice of David Werner, the author closes the article by saying that efforts should not be directed at inventing new wheels, but at getting the existing ones rolling.

Taylor M et al. (1999). Helminth control as an entry point for health-promoting schools in KwaZulu-Natal. South African Medical Journal*, 89(3):273-279*

This study differs from most studies of risk factors in four ways: (i) it is based on an explicit conceptual framework; (ii) the framework cuts across common divisions (e.g. knowledge, behaviour, environment, sanitation) and instead looks at predisposing, enabling and reinforcing elements of risk factors; (iii) it includes not only the main

target group (schoolchildren), but also those having power to influence the practices of the target group (parents, teachers, health workers); and (iv) it began with a qualitative explorative stage. Information from this part of the study was then used in a survey, where data were quantified.

Through this approach, the study created a sound basis for setting goals in the planned health promotion strategy aimed at pupils, teachers and parents, which would take place at the same time as a targeted treatment intervention in schools and a sanitation programme funded by the government.

Uchoa E et al. (2000). The control of schistosomiasis in Brazil: an ethnoepidemiological study of the effectiveness of a community mobilization program for health education. Social Science & Medicine*, 51(10):1529-1541*

The anthropological part of this cross-disciplinary study was initiated by an exploration of the semantic field associated with the local term *xistose*, which corresponded relatively well to the medical term schistosomiasis. The aim of the community mobilization component was to further increase awareness of schistosomiasis, increase prevention and change behaviour. The target populations were schoolchildren and the general community in two villages. Educators from the Ministry of Health assessed knowledge of basic hygiene and of schistosomiasis in one of the villages and discussed with teachers, children, and formal and informal community leaders how to approach the community. Then lectures followed for schoolchildren and the general population, training courses for teachers, schoolchildren wrote a booklet on prevention, and games and a public parade were held, with schistosomiasis as the theme.

However, biomedical knowledge conveyed through health education had been reinterpreted locally and was applied to classify symptoms (and not water contacts) in terms of risk. Furthermore, the study observed that health education had not contributed to a lowering of prevalence. The question remains, however, to what extent differences unrelated to project activities, such as the natural distribution of water sources between the two villages and some broken water pumps, contributed to this lack of effect on prevalence. The study concludes by recommending that specific local views of the disease and relevant behaviours should be incorporated into health communication efforts.

van der Werf MJ et al. (2004). Measuring schistosomiasis case management of the health services in Ghana and Mali. Tropical Medicine & International Health*, 9(1):149-157*

This study is an example of research focusing on case management with implications for the development of control strategies. It presents a quick method for assessing the case management of patients presenting blood in urine or stools in health facilities in two countries with distinctly different health systems, Ghana and Mali.

Health workers from various health facilities in high-prevalence areas were presented with four hypothetical clinical scenarios. After responses were coupled with a few other assumptions about the likelihood of getting positive diagnostic tests if infected and the availability of praziquantel in different health facilities, the researchers were able to quantify the likelihood of being treated with praziquantel, which they found to be low.

The study underlines that such results do not necessarily indicate low quality of case management, but may reflect the epidemiological situation and best clinical practice in an area where other infections with similar symptoms are prevalent. This observation is particularly relevant in the case of blood in stools. The study stops short of exploring the factors involved in patients' decision to actually procure praziquantel upon receiving a prescription, but the results of the study pose important questions for health systems' management of schistosomiasis.

Vlassoff C, Bonilla E (1994). Gender-related differences in the impact of tropical diseases on women: what do we know? Journal of Biosocial Science*, 26(1):37-53*

This review systematically presents the economic, social and personal determinants and consequences of malaria and schistosomiasis. First, the proposed gender framework is based on the assumption that women have needs and qualities that go beyond purely biological considerations in relation to their productive and reproductive capacities. Second, it places women's health within a broad sociocultural and economic context, which includes women's activities both inside and outside the home, their social roles and interactions, as well as personal attitudes, perceptions and needs. Finally, the framework acknowledges that both men and women in poor endemic communities live in poverty and unequal power relations that limit their access to resources.

Women are often particularly disadvantaged, because structural factors make them depend on men for social and economic security. Based on the proposed gender framework, existing evidence of sex and gender differences in the determinants and

consequences of malaria and schistosomiasis are reviewed; areas where new research is needed are pointed out; and areas where appropriate interventions can be carried out based on existing knowledge are proposed, including the incorporation of tropical disease education with maternal-child health services.

Vlassoff C, Manderson L (1998). Incorporating gender in the anthropology of infectious diseases. Tropical Medicine & International Health*, 3(12):1011-1019*

Many of the observations in this review article lead to similar points as in the more detailed paper by Vlassoff & Bonilla (1994) discussed above. However, the conceptual framework for analysing gender in tropical disease research is presented in a clear diagram and the implications of a gender-sensitive analysis for interventions and disease control strategies are elaborated.

The overall purpose of the paper is to illustrate how anthropological research with a gender-sensitive approach can complement insights from public health and epidemiology in the design of control strategies and interventions. The conceptual framework is applied to schistosomiasis to highlight the gendered pattern of exposure, knowledge and perceptions about the infection, its treatment and factors affecting treatment seeking, including access and ability to pay. Using a gender framework also raises the issue of underreporting and less visible manifestations of the infection, such as genital schistosomiasis in both men and women.

Watts S et al. (1998). The study of human behavior and schistosomiasis transmission in an irrigated area in Morocco. Social Science & Medicine*, 46(6):755-765*

The author presents a thorough, alternative approach to analysing water contacts and supports the approach with concise references to other social science studies of households, time geography and gendered space. The study observed how different sources of water are used for different purposes and tasks, which are also related to gender. Seasonal variation in water availability, farming activities and domestic chores influence who is at risk. To a certain extent, the task of fetching water follows a gendered hierarchy within the family, but also depends on who is at home at the time of day when tap water is available. Livestock in a household increases the need for water, but also the possibility to transport water from a source further away.

A factor contributing to the high quality of the study was the way the observers related to people in the villages. They lived in the villages for a while before the observations began and became familiar faces. This approach produces different results than when

outsiders come to ask questions regarding daily chores that people may not see the relevance of. Furthermore, it may be difficult to answer questions about daily chores and habits because they are often formed of non-verbalized and embodied knowledge rather than explicit knowledge or conscious choice.

Ximenes R et al. (2003). Socioeconomic determinants of schistosomiasis in an urban area in the Northeast of Brazil. Revista Panamericana de Salud Pública, *14(6):409-421*

This paper presents a detailed epidemiological analysis of socioeconomic determinants of schistosomiasis in the mainly urban area of São Lourenço da Mata, Pernambuco, Brazil. The analysis is based on the assumption that disease is not an individual biological phenomenon, but rather a social and biological phenomenon that occurs within a social setting. The study goes beyond univariate associations between single socioeconomic variables and schistosomiasis by analysing the risk of infection in relation to different sets of factors.

Furthermore, it was the intention that the analysis could provide the basis for estimating the probability of schistosomiasis when given a set of socioeconomic characteristics. The hypothesis was that the distribution of schistosomiasis in a population does not occur in a random manner, but that socioeconomic structures produce and condition the incidence. Data on sets of variables were analysed at family and individual levels and suggestions were made regarding differentiated target populations and frequency of treatment.

Apart from data on the theoretical reduction in the probability of infection if water supply and sanitation were improved, possible control efforts were discussed in relation to wider policy changes regarding the continuing decentralization of the health sector, community involvement, general socioeconomic development in the country, urban underemployment rates and access to land and education.

REFERENCES

Acioli MD, de Carvalho EF (1998). Discursos e práticas referentes ao processo de participação comunitária nas ações de educação em saúde: as ações de mobilizaçao comunitária do PCDEN/PE [Discourses and practices concerning the social participation process in health education activities: community mobilization in the PCDEN/PE. Programa de Controle das Doencas Endemicas do Nordeste/Pernambuco]. *Cadernos de Saúde Pública*, 14(Suppl. 2):59-68.

Ager A (1992). Perception of risk for malaria and schistosomiasis in rural Malawi. *Tropical Medicine and Parasitology*, 43(4):234-238.

Akogun OB (1991). Urinary schistosomiasis and the coming of age in Nigeria. *Parasitology Today*, 7(2):62.

Ali HF (2001). *Female genital schistosomiasis (FGS) in* S. haematobium *endemic areas in Egypt* [thesis]. Giza, Theodor Bilharz Institute.

Alves PC et al. (1998) A experiência da esquistossomose e os desafios da mobilização comunitária [Schistosomiasis and the challenge of community participation]. *Cadernos de Saúde Pública*, 14(Suppl. 2):79-90.

Amazigo UO, Anago-Amanze CI, Okeibunor JC (1997). Urinary schistosomiasis among school children in Nigeria: consequences of indigenous beliefs and water contact activities. *Journal of Biosocial Science*, 29(1):9-18.

Amorim MN et al. (1997). Epidemiological characteristics of *Schistosoma mansoni* infection in rural and urban endemic areas of Minas Gerais, Brazil. *Memórias do Instituto Oswaldo Cruz*, 92(5):577-580.

Ansell J et al. (2001). The effects of sex and age of responders on the reliability of self-diagnosed infection: a study of self-reported urinary schistosomiasis in Tanzanian school children. *Social Science & Medicine*, 53(7):957-967.

Arene FO, Ukpeibo ET, Nwanze EA (1989). Studies on schistosomiasis in the Niger Delta: *Schistosoma intercalatum* in the urban city of Port Harcourt, Nigeria. *Public Health*, 103(4):295-301.

Aryeetey ME et al. (1999). Health education and community participation in the control of urinary schistosomiasis in Ghana. *East African Medical Journal*, 76(6):324-329.

Asaolu SO, Ofoezie IE (2003). The role of health education and sanitation in the control of helminth infections. *Acta Tropica*, 86(2-3):283-294.

Assis AM et al. (2004). Childhood stunting in Northeast Brazil: the role of *Schistosoma mansoni* infection and inadequate dietary intake. *European Journal of Clinical Nutrition*, 58(7):1022-1029.

Ault SK (1994). Environmental management: a re-emerging vector control strategy. *The American Journal of Tropical Medicine and Hygiene*, 50(6 Suppl.):35-49.

Barbosa CS (1998). Epidemiology and anthropology: an integrated approach dealing with bio-socio-cultural aspects as strategy for the control of endemic diseases. *Memórias do Instituto Oswaldo Cruz*, 93(Suppl. 1):59-62.

Barbosa CS, da Silva CB, Barbosa FS (1996). Esquistossomose: reprodução e expansão da endemia no Estado de Pernambuco no Brasil [Schistosomiasis: reproduction and expansion of the endemia to the state of Pernambuco in Brazil]. *Revista de Saúde Pública*, 30(6):609-616.

Barbosa CS et al. (1998). Urban schistosomiasis in Itamaraca Island, Pernambuco, Brazil: epidemiological factors involved in the recent endemic process. *Memórias do Instituto Oswaldo Cruz*, 93(Suppl. 1):265-266.

Barbosa FS (1995). Determination and control of schistosomiasis. *Memórias do Instituto Oswaldo Cruz*, 90(2):155-159.

Barbosa FS, Coimbra Júnior CE (1992). Alternative approaches in schistosomiasis control. *Memórias do Instituto Oswaldo Cruz*, 87(Suppl. 4):215-220.

Barbosa FS, Pereira da Costa DP (1981). Incapacitating effects of schistosomiasis mansoni on the productivity of sugar-cane cutters in northeastern Brazil. *American Journal of Epidemiology*, 114(1):102-111.

Barbour AD (1985). The importance of age and water contact patterns in relation to *Schistosoma haematobium* infection. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 79(2):151-153.

Barreto ML (1991). Geographical and socioeconomic factors relating to the distribution of *Schistosoma mansoni* infection in an urban area of north-east Brazil. *Bulletin of the World Health Organization*, 69(1):93-102.

Barreto ML (1993). Use of risk factors obtained by questionnaires in the screening for *Schistosoma mansoni* infection. *The American Journal of Tropical Medicine and Hygiene*, 48(6):742-747.

Bello CS, Idiong DU (1982). Schistosoma urethritis: pseudo-gonorrhoeal disease in Northern Nigeria. *Tropical Doctor*, 12(3):141-142.

Bergquist NR (2002). Schistosomiasis: from risk assessment to control. *Trends in Parasitology*, 18(7):309-314.

Bethony J et al. (2001). Exposure to *Schistosoma mansoni* infection in a rural area in Brazil. II: household risk factors. *Tropical Medicine & International Health*, 6(2):136-145.

Bethony J et al. (2004). Exposure to *Schistosoma mansoni* infection in a rural area in Brazil. Part III: household aggregation of water-contact behaviour. *Tropical Medicine & International Health*, 9(3):381-389.

Bhargava A et al. (2005). Modeling the effects of health status and the educational infrastructure on the cognitive development of Tanzanian schoolchildren. *American Journal of Human Biology*, 17(3):280-292.

Bian Y et al. (2004). Market reform: a challenge to public health – the case of schistosomiasis control in China. *The International Journal of Health Planning and Management*, 19(Suppl. 1):S79-S94.

Biays S et al. (1999). Foyer de bilharziose à *Schistosoma mekongi* redécouvert au Nord du Cambodge: I. Perception culturelle de la maladie; description et suivi de 20 cas cliniques graves [A foci of Schistosomiasis mekongi rediscovered in Northeast Cambodia: cultural perception of the illness; description and clinical observation of 20 severe cases]. *Tropical Medicine & International Health*, 4(10):662-673.

Birley MH (1991). *Guidelines for forecasting the vector-borne disease implications of water resources development*, 2nd ed. Geneva, World Health Organization, Panel of Experts on Environmental Management for Vector Control (PEEM) secretariat (PEEM Guidelines Series, No. 2; WHO/CWS/91.3).

Birrie H, Medhin G, Redda A (1996). Schistosomiasis in Addis Ababa. *Ethiopian Medical Journal*, 34(2):117-121.

Blas BL et al. (1989). Epidemiology and control of schistosomiasis in the Philippines: progress report as of 1987. *Memórias do Instituto Oswaldo Cruz*, 84(Suppl. 1):105-116.

Blas BL et al. (2004). The schistosomiasis problem in the Philippines: a review. *Parasitology International*, 53(2):127-134.

Boelee E, Laamrani H (2004). Environmental control of schistosomiasis through community participation in a Moroccan oasis. *Tropical Medicine & International Health*, 9(9):997-1004.

Booth M et al. (1998). The use of morbidity questionnaires to identify communities with high prevalences of schistosome or geohelminth infections in Tanzania. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 92(5):484-490.

Booth M et al. (2004). Periportal fibrosis in human *Schistosoma mansoni* infection is associated with low IL-10, low IFN-gamma, high TNF-alpha, or low RANTES, depending on age and gender. *Journal of Immunology*, 172(2):1295-1303.

Bos R, Mills A (1987). Financial and economic aspects of environmental management for vector control. *Parasitology Today*, 3(5):160-163.

Bouchet F et al. (2002). First recovery of *Schistosoma mansoni* eggs from a latrine in Europe (15-16th centuries). *The Journal of Parasitology*, 88(2):404-405.

Bradley DJ (1968). Predicting the epidemiological consequences of changing water sources. II. A comparative approach to suburbanization. *East African Medical Journal*, 45(5):333-340.

Brooker S et al. (2001a). Community perception of school-based delivery of anthelmintics in Ghana and Tanzania. *Tropical Medicine & International Health*, 6(12):1075-1083.

Brooker S et al. (2001b). The potential of rapid screening methods for *Schistosoma mansoni* in western Kenya. *Annals of Tropical Medicine and Parasitology*, 95(4):343-351.

Butterworth AE et al. (1984). Immunity after treatment of human schistosomiasis mansoni. I. Study design, pretreatment observations and the results of treatment. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 78(1):108-123.

Cadot E et al. (1998) Approche géographique de la schistosomiase urinaire dans une ville moyenne africaine, Daloa (Côte d'Ivoire) [Geographic approach to urinary schistosomiasis in an average African town, Daloa (Ivory Coast)]. *Santé*, 8(6):447-453.

Campagne G et al. (1999). Evaluation preliminaire des indicateurs utilisables au cours d'un programme de lutte contre la bilharziose urinaire au Niger [Preliminary evaluation of usable indicators during a control program for urinary bilharziosis in Niger]. *Médecine Tropicale*, 59(3):243-248.

Carmo EH, Barreto ML (1994). Esquistossomose Mansônica no Estado da Bahia, Brasil: Tendências Históricas a Medidas de Controle [Schistosomiasis mansoni in Bahia, Brazil: historical trends and control measures]. *Cadernos de Saúde Pública*; 10(4):425-439.

Chandiwana SK (1987a). Seasonal patterns in water contact and the influence of water availability on contact activities in two schistosomiasis-endemic areas in Zimbabwe. *The Central African Journal of Medicine*, 33(1):8-15.

Chandiwana SK (1987b). Community water-contact patterns and the transmission of Schistosoma haematobium in the highveld region of Zimbabwe. *Social Science & Medicine*, 25(5):495-505.

Chandiwana SK, Taylor P (1990). The rational use of antischistosomal drugs in schistosomiasis control. *Social Science & Medicine*, 30(10):1131-1138.

Chandiwana SK, Taylor P, Matanhire D (1991). Community control of schistosomiasis in Zimbabwe. *The Central African Journal of Medicine*, 37(3):69-77.

Chandiwana SK, Woolhouse ME (1991). Heterogeneities in water contact patterns and the epidemiology of *Schistosoma haematobium*. *Parasitology*, 103(Pt 3):363-370.

Cheesmond AK, Fenwick A (1981). Human excretion behaviour in a schistosomiasis endemic area of the Geizira, Sudan. *The Journal of Tropical Medicine and Hygiene*, 84(3):101-107.

Cheng TH (1971). Shistosomiasis in mainland China. A review of research and control programs since 1949. *The American Journal of Tropical Medicine and Hygiene*, 20(1):26-53.

Chimbari M et al. (1992). Bilharzia in a small irrigation community: an assessment of water and toilet usage. *The Central African Journal of Medicine*, 38(12):451-458.

Chitsulo L, Lengeler C, Jenkins J (1995). *The schistosomiasis manual. A guide for the rapid identification of communities with a high prevalence of urinary schistosomiasis, for district health management teams, disease control programme managers and community health workers*. Geneva, World Health Organization, Special Programme for Research & Training in Tropical Diseases (Social and Economic Research. Methods for Social Research in Tropical Diseases, No. 3).

Chitsulo L et al. (2000).The global status of schistosomiasis and its control. *Acta Tropica*, 77(1):41-51.

Christensen NO, Simonsen PE, Furu P (1989). Training elements at different levels in the strategies for control of schistosomiasis. *Tropical Medicine and Parasitology*, 40(2):232-233.

Clark TE, Appleton CC, Kvalsvig JD (1997). Schistosomiasis and the use of indigenous plant molluscicides: a rural South African perspective. *Acta Tropica*, 66(2):93-107.

Clennon JA et al. (2004). Spatial patterns of urinary schistosomiasis infection in a highly endemic area of coastal Kenya. *The American Journal of Tropical Medicine and Hygiene*, 70(4):443-448.

Cline BL (1995). The slow fix: communities, research, and disease control. *The American Journal of Tropical Medicine and Hygiene*, 52(1):1-7.

Cline BL, Hewlett BS (1996). Community-based approach to schistosomiasis control. *Acta Tropica*, 61(2):107-119.

Coura-Filho P (1996). Abordagens alternativas no controle da esquistossomose: buscando incluir o subjetivo na epidemiologia [Alternative approaches to the control of schistosomiasis: trying to include subjective elements in epidemiology]. *Cadernos de Saúde Pública*, 12(1):95-101.

Coura-Filho P (1998). Participação popular no controle da esquistossomose através do Sistema Único de Saúde (SUS), em Taquaraçu de Minas, (Minas Gerais, Brasil), entre 1985-1995: contrução de um modelo alternativo [An alternative model for schistosomiasis control with active participation by the population through the Unified Health System (SUS) in Taquaraçu de Minas (Minas Gerais, Brazil) from 1985 to 1995]. *Cadernos de SaúdePública*, 14(Suppl. 2):111-122.

Coura JR (1995). Control of schistosomiasis in Brazil: perspectives and proposals. *Memórias do Instituto Oswaldo Cruz*, 90(2):257-260.

Cox FE (2002). History of human parasitology. *Clinical Microbiology Reviews*, 15(4):595-612.

Crawford R (1977). You are dangerous to your health: the ideology and politics of victim blaming. *International Journal of Health Services*, 7(4):663-680.

da Silva AA et al. (1997). Water-contact patterns and risk factors for *Schistosoma mansoni* infection in a rural village of northeast Brazil. *Revista do Instituto de Medicina Tropical de São Paulo*, 39(2):91-96.

da Silva LJ (1985). Crescimento urbano e doença a esquistossomose no município de São Paulo (Brasil) [Urban growth and disease: schistosomiasis in the municipality of São Paulo (Brazil)]. *Revista de Saúde Pública*, 19(1):1-7.

da Silva RA et al. (2002). Schistosomiasis mansoni in Bananal (State of São Paulo, Brazil): IV. Study on the public awareness of its risks in the Palha District. *Memórias do Instituto Oswaldo Cruz*, 97(Suppl. 1):15-18.

Dalton PR (1976). A socioecological approach to the control of *Schistosoma mansoni* in St Lucia. *Bulletin of the World Health Organization*, 54(5):587-595.

Dalton PR, Pole D (1978). Water-contact patterns in relation to *Schistosoma haematobium* infection. *Bulletin of the World Health Organization*, 56(3):417-426.

Danso-Appiah A et al. (2004). Determinants of health-seeking behaviour for schistosomiasis-related symptoms in the context of integrating schistosomiasis control within the regular health services in Ghana. *Tropical Medicine & International Health*, 9(7):784-794.

de Clercq D (1998). The relationship between *Schistosoma haematobium* infection and school performance and attendance in Bamako, Mali. *Annals of Tropical Medicine and Parasitology*, 92(8):851-858.

de Vlas SJ et al. (2004). Quantitative evaluation of integrated schistosomiasis control: the example of passive case finding in Ghana. *Tropical Medicine & International Health*, 9(6):A16-A21.

Dias JC (1996). Tropical diseases and the gender approach. *Bulletin of the Pan American Health Organization*, 30(3):242-260.

Dias JC (1998). Problemas e possibilidades de participação comunitária no controle das grandes endemias no Brasil [Community participation and control of endemic diseases in Brazil: problems and possibilities]. *Cadernos de Saúde Pública*, 14(Suppl. 2):19-37.

Disch J, et al. (2002). Factors associated with *Schistosoma mansoni* infection 5 years after selective treatment in a low endemic area in Brazil. *Acta Tropica*, 81(2):133-142.

Dunlop DW (1984). Theoretical and empirical issues in benefit identification, measurement and valuation related to parasitic disease control in poor countries. *Social Science & Medicine*, 19(10):1031-1037.

Dunn FL (1979). Behavioural aspects of the control of parasitic diseases. *Bulletin of the World Health Organization*, 57(4):499-512.

Ekeh HE, Adeniyi JD (1986). Targeting school children for tropical diseases control: preliminary findings from a socio-behaviour research in Nigeria. *The Journal of Tropical Medicine and Hygiene*, 89(1):1-6.

Ekeh HE, Adeniyi JD (1988). Health education strategies for tropical disease control in school children. *The Journal of Tropical Medicine and Hygiene*, 91(2):55-59.

el Katsha S, Watts S (1994). A model for health education. *World Health Forum*, 15(1):29-33.

el Katsha S, Watts S (1995a). The public health implications of the increasing predominance of *Schistosoma mansoni* in Egypt: a pilot study in the Nile delta. *The Journal of Tropical Medicine and Hygiene*, 98(2):136-140.

el Katsha S, Watts S (1995b). Schistosomiasis control through rural health units. *World Health Forum*, 16(3):252-254.

el Katsha S, Watts S (1997). Schistosomiasis in two Nile delta villages: an anthropological perspective. *Tropical Medicine & International Health*, 2(9):846-854.

el Katsha S, Watts S (1998). Schistosomiasis screening and health education for children: action research in Nile delta villages. *Tropical Medicine & International Health*, 3(8):654-660.

el Katsha S, Watts S (2002). *Gender, behavior and health: schistosomiasis transmission and control in rural Egypt*. Cairo and New York, NY, American University in Cairo Press.

el Kholy H et al. (1989). Effects of borehole wells on water utilization in *Schistosoma haematobium* endemic communities in Coast Province, Kenya. *The American Journal of Tropical Medicine and Hygiene*, 41(2):212-219.

el-Sahn F, Darwish O, Soliman N (1992). Socio-cultural and nutritional risk factors of adolescents and young pregnant women in an endemic area of schistosomiasis. *The Journal of the Egyptian Public Health Association*, 67(3-4):311-340.

Ellis MK et al. (2006). Familial aggregation of human infection with *Schistosoma japonicum* in the Poyang Lake region, China. *International Journal for Parasitology*, 36(1):71-77.

Engels D et al. (2002). The global epidemiological situation of schistosomiasis and new approaches to control and research. *Acta Tropica*, 82(2):139-146.

Enk MJ et al. (2004). Rural tourism as risk factor for the transmission of schistosomiasis in Minas Gerais, Brazil. *Memórias do Instituto Oswaldo Cruz*, 99(5 Suppl. 1):105-108.

Erko B et al. (2002). Control of *Schistosoma mansoni* by the soapberry Endod (*Phytolacca dodecandra*) in Wollo, northeastern Ethiopia: post-intervention prevalence. *East African Medical Journal*, 79(4):198-201.

Ernould JC et al. (2000). Recent urban growth and urinary schistosomiasis in Niamey, Niger. *Tropical Medicine & International Health*, 5(6):431-437.

Ernould JC, Labbo R, Chippaux JP (2003). Èvolution de la schistosomose urinaire à Niamey, Niger [Course of urinary schistosomiasis in Niamey, Niger]. *Bulletin de la Société de Pathologie Exotique*, 96(3):173-177.

Espino F, Koops V, Manderson L (2004). *Community participation and tropical disease control in resource-poor settings*. Geneva, UNICEF/UNDP/World Bank/WHO Special Programme for Research & Training in Tropical Diseases (Social, Economic and Behavioural Research. Special Topics No. 2; TDR/STR/SEB/ST/04.1).

Esser KB, Semagn K, Wolde-Yohannes L (2003). Medicinal use and social status of the soap berry endod (*Phytolacca dodecandra*) in Ethiopia. *Journal of Ethnopharmacology*, 85(2-3):269-277.

Etard JF, Borel E (1992). Contacts homme-eau et schistosomiase urinaire dans un village mauritanien [Man-water contacts and urinary schistosomiasis in a Mauritanian village]. *Revue d'Epidémiologie et de Santé Publique*, 40(4):268-275.

Farag MK et al. (1997). Prevalence and intensity of schistosomiasis haematobium among school children in respect of family social conditions in a village in Dakahlia Governorate, Egypt. *Journal of the Egyptian Society of Parasitology*, 27(1):101-111.

Farley J (1991). *Bilharzia. A history of imperial tropical medicine*. Cambridge, Cambridge University Press.

Farmer P (1999). *Infections and inequalities: the modern plagues*. Berkeley, CA, University of California Press.

Farooq M, Mallah MB (1966). The behavioural pattern of social and religious water-contact activities in the Egypt-49 bilharziasis project area. *Bulletin of the World Health Organization*, 35(3):377-387.

Farooq M et al. (1966a). The epidemiology of *Schistosoma haematobium* and *S. mansoni* infections in the Egypt-49 project area. 2. Prevalence of bilharziasis in relation to personal attributes and habits. *Bulletin of the World Health Organization*, 35(3):293-318.

Farooq M et al. (1966b). The epidemiology of *Schistosoma haematobium* and *S. mansoni* infections in the Egypt-49 project area. 3. Prevalence of bilharziasis in relation to certain environmental factors. *Bulletin of the World Health Organization*, 35(3):319-330.

Feldmeier H, Krantz I (1993). A synoptic inventory of needs for research on women and tropical parasitic diseases. I. Application to urinary and intestinal schistosomiasis. *Acta Tropica*, 55(3):117-138.

Feldmeier H, Poggensee G, Krantz I (1993). A synoptic inventory of needs for research on women and tropical parasitic diseases. II. Gender-related biases in the diagnosis and morbidity assessment of schistosomiasis in women. *Acta Tropica*, 55(3):139-169.

Feldmeier H et al. (1995). Female genital schistosomiasis. New challenges from a gender perspective. *Tropical and Geographical Medicine*, 47(2 Suppl.):S2-S15.

Fentiman A, Hall A, Bundy D (2001). Health and cultural factors associated with enrolment in basic education: a study in rural Ghana. *Social Science & Medicine*, 52(3):429-439.

Fenwick A, Cheesmond AK, Amin MA (1981). The role of field irrigation canals in the transmission of *Schistosoma mansoni* in the Gezira Scheme, Sudan. *Bulletin of the World Health Organization*, 59(5):777-786.

Fenwick A et al. (1982). Schistosomiasis among labouring communities in the Gezira irrigated area, Sudan. *The Journal of Tropical Medicine and Hygiene*, 85(1):3-11.

Firmo JO et al. (1996). Urban schistosomiasis: morbidity, sociodemographic characteristics and water contact patterns predictive of infection. *International Journal of Epidemiology*, 25(6):1292-1300.

Foster WD (1965). *A history of parasitology*. Edinburgh, Livingstone.

Fournet F, N'Guessan NA, Cadot E (2004). Gestion de l'espace et schistosomose urinaire à Daloa (Côte d'Ivoire) [Land-use and urinary schistosomiasis in Daloa (Côte d'Ivoire)]. *Bulletin de la Société de Pathologie Exotique*, 97(1):33-36.

Freire P (1970). *Pedagogy of the oppressed*. New York, NY, Seabury Press.

Fulford AJ et al. (1996). Water contact observations in Kenyan communities endemic for schistosomiasis: methodology and patterns of behaviour. *Parasitology*, 113(Pt 3):223-241.

Garba A et al. (2001). Impact de la sensibiliation des populations dans la lutte contre la bilharziose urinaire au Niger [Impact of health education programs on the control of urinary bilharziasis in Niger]. *Santé*, 11(1):35-42.

Gazzinelli A et al. (1998). Sociocultural aspects of schistosomiasis mansoni in an endemic area in Minas Gerais, Brazil. *Cadernos de Saúde Pública*, 14(4):841-849.

Gazzinelli MF et al. (2002). A interdição da doença: uma construção cultural da esquistossomose em área endêmica, Minas Gerais, Brasil [The interdiction of disease: a cultural construction of schistosomiasis in an endemic area in Minas Gerais, Brazil]. *Cadernos de Saúde Pública*, 18(6):1629-1638.

Giboda M, Bergquist NR (2000). Post-transmission schistosomiasis: a new agenda. *Acta Tropica*, 77(1):3-7.

Global Forum for Health Research (2005). *Health research for the Millennium Development Goals. A report on Forum 8, Mexico City, 16-20 November 2004*. Geneva, Global Forum for Health Research.

Goldstein BD (2001). The precautionary principle also applies to public health actions. *American Journal of Public Health*, 91(9):1358-1361.

Gonçalves MM et al. (2005). Fatores sócio-culturais e éticos relationados com os processos de diagnóstico da esquistossomíase mansônica em área de baixa endemicidade [Socio-cultural and ethical factors involved in the diagnosis of schistosomiasis mansoni in an area of low endemicity]. *Cadernos de Saúde Pública*, 21(1):92-100.

Goodwin L (1996). Schistosomiasis. In: Cox FE, ed. *The Wellcome Trust illustrated history of tropical diseases*. London, The Wellcome Trust:264-273.

Green LW et al. (1980). *Health education planning: a diagnostic approach*. Mountain View, CA, Mayfield.

Grove DI (1986). Who discovered that intestinal worm infections could be diagnosed by finding eggs in the faeces? *Journal of the Royal Society of Medicine*, 79(11):670-673.

Grove DI (1990). *A history of human helminthology*. Wallingford, CAB International.

Gryseels B (1989). The relevance of schistosomiasis for public health. *Tropical Medicine and Parasitology*, 40(2):134-142.

Guanghan H et al. (2000). The role of health education for schistosomiasis control in heavy endemic area of Poyang Lake region, People's Republic of China. *The Southeast Asian Journal of Tropical Medicine and Public Health*, 31(3):467-472.

Guiguemdé TR (1989). Education pour la santé, eau et assainissement dans la lutte contre les schistosomiases [Education concerning health, water and sanitation in the control of schistosomiasis]. *Tropical Medicine and Parasitology*, 40(2):223-225.

Guo JG et al. (2005). The role of 'passive chemotherapy' plus health education for schistosomiasis control in China during maintenance and consolidation phase. *Acta Tropica*, 96(2-3):177-183.

Guyatt H et al. (1994). Controlling schistosomiasis: the cost-effectiveness of alternative delivery strategies. *Health Policy and Planning*, 9(4):385-395.

Guyatt H (2003). The cost of delivering and sustaining a control programme for schistosomiasis and soil-transmitted helminthiasis. *Acta Tropica*, 86(2-3):267-274.

Guyatt HL, Tanner M (1996). Different approaches to modeling the cost-effectiveness of schistosomiasis control. *The American Journal of Tropical Medicine and Hygiene*, 55(5 Suppl.):159-164.

Gwatirisa PR, Ndamba J, Nyazema NZ (1999). The impact of health education on the knowledge, attitudes and practices of a rural community with regards to schistosomiasis control using a plant molluscicide, *Phytolacca dodecandra*. *The Central African Journal of Medicine*, 45(4):94-97.

Hailu M, Jemaneh L, Kebede D (1995). The use of questionnaires for the identification of communities at risk for intestinal schistosomiasis in western Gojam. *Ethiopian Medical Journal*, 33(2):103-113.

Handzel T et al. (2003). Geographic distribution of schistosomiasis and soil-transmitted helminths in Western Kenya: implications for anthelminthic mass treatment. *The American Journal of Tropical Medicine and Hygiene*, 69(3):318-323.

Hatz CFR (2001). The application of ultrasonography in schistosomiasis. In: Baker JR, Muller R, Rollinson D, eds. *Advances in parasitology*. San Diego, CA, and London, Academic Press:256-263.

Heggenhougen KH, Hackethal V, Vivek P (2003). *The behavioural and social aspects of malaria and its control. An introduction and annotated bibliography*. Geneva, World Health Organization, Special Programme for Research & Training in Tropical Diseases (TDR/STR/SEB/VOL/03.1).

Herrin AN (1986). A social and economic analysis of schistosomiasis: a conceptual framework and a research strategy. *The Southeast Asian Journal of Tropical Medicine and Public Health*, 17(3):413-420.

Hewlett BS, Cline BL (1997). Anthropological contributions to a community-based schistosomiasis control project in northern Cameroun. *Tropical Medicine & International Health*, 2(11):A25-A36.

Hielscher S, Sommerfeld J (1985). Concepts of illness and the utilization of health-care services in a rural Malian village. *Social Science & Medicine*, 21(4):469-481.

Hoeppli R (1973). Morphological changes in human schistosomiasis and certain analogies in ancient Egyptian sculpture. *Acta Tropica*, 30(1):1-11.

Hoffman DB, Warren KS (1978). *Schistosomiasis IV. Condensations of the selected literature, 1963-1975. Vols I/II*. Washington, DC, Hemisphere Publishing Corporation.

Hornstein L et al. (1990). Persistent *Schistosoma mansoni* infection in Yemeni immigrants to Israel. *Israel Journal of Medical Sciences*, 26(7):386-389.

Hu GH et al. (2005). The role of health education and health promotion in the control of schistosomiasis: experiences from a 12-year intervention study in the Poyang Lake area. *Acta Tropica*, 96(2-3):232-241.

Huang Y, Manderson L (1992). Schistosomiasis and the social patterning of infection. *Acta Tropica*, 51(3-4):175-194.

Huang YX, Manderson L (2005). The social and economic context and determinants of schistosomiasis japonica. *Acta Tropica*, 96(2-3):223-231.

Hunter JM et al. (1993). *Parasitic diseases in water resources development. The need for intersectoral negotiation*. Geneva, World Health Organization.

Hunter JM (2003). Inherited burden of disease: agricultural dams and the persistence of bloody urine (Schistosomiasis hematobium) in the Upper East Region of Ghana, 1959-1997. *Social Science & Medicine*, 56(2):219-234.

Hunter JM, Rey L, Scott D (1982). Man-made lakes and man-made diseases. Towards a policy resolution. *Social Science & Medicine*, 16(11):1127-1145.

Husein MH et al. (1996). Who misses out with school-based health programmes? a study of schistosomiasis control in Egypt. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 90(4):362-365.

Husting EL (1970). Sociological patterns and their influence on the transmission of Bilharziasis. *The Central African Journal of Medicine*, July(Suppl.):5-10.

Husting EL (1983). Human water contact activities related to the transmission of bilharziasis (schistosomiasis). *The Journal of Tropical Medicine and Hygiene*, 86(1):23-35.

Irwin A et al. (2006). The Commission on Social Determinants of Health: tackling the social roots of health inequities. *PLoS Medicine*, 3(6):e106.

Ishii A, Tsuji M, Tada I (2003). History of Katayama disease: schistosomiasis japonica in Katayama district, Hiroshima, Japan. *Parasitology International*, 52(4):313-319.

Jemaneh L, Shewakena F, Tedla S (1996). The use of questionnaires for the identification of high risk areas for urinary schistosomiasis: the Ethiopian experience. *Ethiopian Medical Journal*, 34(2):93-105.

Jiang Z et al. (1997). Analysis of social factors and human behavior attributed to family distribution of schistosomiasis japonica cases. *The Southeast Asian Journal of Tropical Medicine and Public Health*, 28(2):285-290.

Jordan P (2000). From Katayama to the Dakhla Oasis: the beginning of epidemiology and control of bilharzia. *Acta Tropica*, 77(1):9-40.

Jordan P, Rosenfield PL (1983). Schistosomiasis control: past, present, and future. *Annual Review of Public Health*, 4:311-334.

Jordan P et al. (1982). Value of individual household water supplies in the maintenance phase of a schistosomiasis control programme in Saint Lucia, after chemotherapy. *Bulletin of the World Health Organization*, 60(4):583-588.

Jukes MC et al. (2002). Heavy schistosomiasis associated with poor short-term memory and slower reaction times in Tanzanian schoolchildren. *Tropical Medicine & International Health*, 7(2):104-117.

Kamunvi F, Ferguson AG (1993). Knowledge, attitudes and practices (KAP) of human intestinal helminths (worms) in two rural communities in Nyanza Province, Western Kenya. *East African Medical Journal*, 70(8):482-490.

Katabarwa MN et al. (2005). Community-directed interventions strategy enhances efficient and effective integration of health care delivery and development activities in rural disadvantaged communities of Uganda. *Tropical Medicine & International Health*, 10(4):312-321.

Katsivo MN et al. (1993a). Perception of a schistosomiasis control project in rural Kenya by the beneficiaries. *East African Medical Journal*, 70(10):613-616.

Katsivo MN et al. (1993b). Involvement of a community in schistosomiasis control: a Kenyan experience. *East African Medical Journal*, 70(8):478-481.

Khairy AAM, Farag H (1995). Schistosomiasis reinfection and community compliance in a primary health care participatory research project in Menoufia, Egypt. *Eastern Mediterranean Health Journal*, 1(2):215-222.

King CH, Dickman K, Tisch DJ (2005). Reassessment of the cost of chronic helmintic infection: a meta-analysis of disability-related outcomes in endemic schistosomiasis. *Lancet*, 365(9470):1561-1569.

Kleinman A (1980). *Patients and healers in the context of culture: an exploration of the borderland between anthropology, medicine and psychiatry*. Berkeley, CA, University of California Press.

Kloos H et al. (1977). Haematobium schistosomiasis among seminomadic and agricultural Afar in Ethiopia. *Tropical and Geographical Medicine*, 29(4):399-406.

Kloos H et al. (1980). Intestinal parasitism in migrant farm labour populations in irrigation schemes in the Awash Valley, Ethiopia, and in major labour source areas. *Ethiopian Medical Journal*, 18(2):53-62.

Kloos H, Desole G, Lemma A (1981). Intestinal parasitism in seminomadic pastoralists and subsistence farmers in and around irrigation schemes in the Awash Valley, Ethiopia, with special emphasis on ecological and cultural associations. *Social Science & Medicine. Part B, Medical Anthropology*, 15(4):457-469.

Kloos H et al. (1982). Disease concepts and treatment practices relating to schistosomiasis haematobium in Upper Egypt. *The Journal of Tropical Medicine and Hygiene*, 85(3):99-107.

Kloos H et al. (1983). Water contact behavior and schistosomiasis in an upper Egyptian village. *Social Science & Medicine*, 17(9):545-562.

Kloos H (1985). Water resources development and schistosomiasis ecology in the Awash Valley, Ethiopia. *Social Science & Medicine*, 20(6):609-625.

Kloos H et al. (1987). Coping with intestinal illness among the Kamba in Machakos, Kenya, and aspects of schistosomiasis control. *Social Science & Medicine*, 24(4):383-394.

Kloos H et al. (1990). Water contact and *Schistosoma haematobium* infection: a case study from an upper Egyptian village. *International Journal of Epidemiology*, 19(3):749-758.

Kloos H (1995). Human behavior, health education and schistosomiasis control: a review. *Social Science & Medicine*, 40(11):1497-1511.

Kloos H et al. (1997). Spatial patterns of human water contact and *Schistosoma mansoni* transmission and infection in four rural areas in Machakos District, Kenya. *Social Science & Medicine*, 44(7):949-968.

Kloos H, Gazzinelli A, van Zuyle P (1998). Microgeographical patterns of schistosomiasis and water contact behavior; examples from Africa and Brazil. *Memórias do Instituto Oswaldo Cruz*, 93(Suppl. 1):37-50.

Kloos H et al. (2001). The distribution of *Biomphalaria* spp. in different habitats in relation to physical, biological, water contact and cognitive factors in a rural area in Minas Gerais, Brazil. *Memórias do Instituto Oswaldo Cruz*, 96(Suppl.):57-66.

Kloos H et al. (2006). Combined methods for the study of water contact behavior in a rural schistosomiasis-endemic area in Brazil. *Acta Tropica*, 97(1):31-41.

Klumpp RK, Webbe G (1987). Focal, seasonal and behavioural patterns of infection and transmission of *Schistosoma haematobium* in a farming village at the Volta Lake, Ghana. *The Journal of Tropical Medicine and Hygiene*, 90(5):265-281.

Kotb M et al. (1998). Evaluation of a school-based health education model in schistosomiasis: a randomized community trial. *Eastern Mediterranean Health Journal*, 4(2):265-275.

Kuntz RE (1952). *Schistosoma mansoni* and *S. haematobium* in the Yemen, Southwest Arabia; with a report of an unusual factor in the epidemiology of Schistosomiasis mansoni. *The Journal of Parasitology*, 38(1):24-28.

Kvale KM (1981). Schistosomiasis in Brazil: preliminary results from a case study of a new focus. *Social science & medicine. Part D, Medical geography*, 15(4):489-500.

Kvalsvig JD, Schutte CH (1986). The role of human water contact patterns in the transmission of schistosomiasis in an informal settlement near a major industrial area. *Annals of Tropical Medicine and Parasitology*, 80(1):13-26.

Kvalsvig JD, Becker PJ (1988). Selective exposure of active and sociable children to schistosomiasis. *Annals of Tropical Medicine and Parasitology*, 82(5):471-474.

Laamrani H et al. (2000a). New challenges in schistosomiasis control in Morocco. *Acta Tropica*, 77(1):61-67.

Laamrani H et al. (2000b). *Schistosoma haematobium* in Morocco: moving from control to elimination. *Parasitology Today*, 16(6):257-260.

Landouré A et al. (2003). Evaluation of case management in the integrated schistosomiasis-control programme in Mali. *Annals of Tropical Medicine and Parasitology*, 97(7):723-736.

Lansdown R et al. (2002). Schistosomiasis, helminth infection and health education in Tanzania: achieving behaviour change in primary schools. *Health Education Research*, 17(4):425-433.

Leenstra T et al. (2004). Prevalence and severity of anemia and iron deficiency: cross-sectional studies in adolescent schoolgirls in western Kenya. *European Journal of Clinical Nutrition*, 58(4):681-691.

Lengeler C et al. (1991a). Community-based questionnaires and health statistics as tools for the cost-efficient identification of communities at risk of urinary schistosomiasis. *International Journal of Epidemiology*, 20(3):796-807.

Lengeler C et al. (1991b). Rapid, low-cost, two-step method to screen for urinary schistosomiasis at the district level: the Kilosa experience. *Bulletin of the World Health Organization*, 69(2):179-189.

Lengeler C et al. (2000). Simple school questionnaires can map both *Schistosoma mansoni* and *Schistosoma haematobium* in the Democratic Republic of Congo. *Acta Tropica*, 74(1):77-87.

Lengeler C, Utzinger J, Tanner M (2002a). Screening for schistosomiasis with questionnaires. *Trends in Parasitology*, 18(9):375-377.

Lengeler C, Utzinger J, Tanner M (2002b). Questionnaires for rapid screening of schistosomiasis in sub-Saharan Africa. *Bulletin of the World Health Organization*, 80(3):235-242.

Leonardo LR et al. (2002). Difficulties and strategies in the control of schistosomiasis in the Philippines. *Acta Tropica*, 82(2):295-299.

Leutscher P et al. (1998). Clinical findings in female genital schistosomiasis in Madagascar. *Tropical Medicine & International Health*, 3(4):327-332.

Leutscher P et al. (2000). Community-based study of genital schistosomiasis in men from Madagascar. *Lancet*, 355(9198):117-118.

Leutscher PD et al. (2003). Sexual behavior and sexually transmitted infections in men living in rural Madagascar: implications for HIV transmission. *Sexually Transmitted Diseases*, 30(3):262-265.

Lewin PK (1977). Mummies that I have known. A pediatrician's venture in the field of paleopathology. *American Journal of Diseases of Children*, 131(3):349-350.

Li YS et al. (2000). Epidemiology of *Schistosoma japonicum* in China: morbidity and strategies for control in the Dongting Lake region. *International Journal for Parasitology*, 30(3):273-281.

Liese B (1986). The organization of schistosomiasis control programmes. *Parasitology Today*, 2(12):339-345.

Lima e Costa MF et al. (1987). Water-contact patterns and socioeconomic variables in the epidemiology of schistosomiasis mansoni in an endemic area in Brazil. *Bulletin of the World Health Organization*, 65(1):57-66.

Lima e Costa MF et al. (1991). A multivariate analysis of socio-demographic factors, water contact patterns and *Schistosoma mansoni* infection in an endemic area in Brazil. *Revista do Instituto de Medicina Tropical de São Paulo*, 33(1):58-63.

Lima e Costa MF et al. (1998). Questionnaires in the screening for *Schistosoma mansoni* infection: a study of socio demographic and water contact variables in four communities in Brazil. *Revista do Instituto de Medicina Tropical de São Paulo*, 40(2):93-99.

Locketz L (1976). Health education in rural Surinam: use of videotape in a national campaign against schistosomiasis. *Bulletin of the Pan American Health Organization*, 10(3):219-226.

Loroni-Lakwo T et al. (1994). Transmission of *Schistosoma mansoni* in Rhino Camp, Uganda. *East African Medical Journal*, 71(3):165-166.

Loureiro S (1989). A questão do social na epidemiologia e controle da esquistossomose mansonica [Social aspects of the epidemiology and control of schistosomiasis mansoni]. *Memórias do Instituto Oswaldo Cruz*, 84(Suppl. 1):124-133.

Lucien KF, Nkwelang G, Ejezie GC (2003). Health education strategy in the control of urinary schistosomiasis. *Clinical Laboratory Science*, 16(3):137-141.

Lwambo NJ et al. (1997). Control of *Schistosoma haematobium* morbidity on Pemba Island: validity and efficiency of indirect screening tests. *Bulletin of the World Health Organization*, 75(3):247-252.

Lwambo NJ et al. (1999). Patterns of concurrent hookworm infection and schistosomiasis in schoolchildren in Tanzania. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 93(5):497-502.

MacDonald G (1965). The dynamics of helminth infections, with special reference to schistosomes. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 59(5):489-506.

MacLachlan M, Namangale JJ (1997). Tropical illness profiles: the psychology of illness perception in Malawi. *Public Health*, 111(4):211-213.

Mafe MA et al. (2000). Control of urinary schistosomiasis: an investigation into the effective use of questionnaires to identify high-risk communities and individuals in Niger State, Nigeria. *Tropical Medicine & International Health*, 5(1):53-63.

Mafe MA et al. (2005). Effectiveness of different approaches to mass delivery of praziquantel among school-aged children in rural communities in Nigeria. *Acta Tropica*, 93(2):181-190.

Mafiana CF, Ekpo UF, Ojo DA (2003). Urinary schistosomiasis in preschool children in settlements around Oyan Reservoir in Ogun State, Nigeria: implications for control. *Tropical Medicine & International Health*, 8(1):78-82.

Magnussen P (2003). Treatment and re-treatment strategies for schistosomiasis control in different epidemiological settings: a review of 10 years' experiences. *Acta Tropica*, 86(2-3):243-254.

Magnussen P et al. (2001). The impact of a school health programme on the prevalence and morbidity of urinary schistosomiasis in Mwera Division, Pangani District, Tanzania. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 95(1):58-64.

Mahmoud AA (2004). Schistosomiasis (bilharziasis): from antiquity to the present. *Infectious Disease Clinics of North America*, 18(2):207-218.

Manderson L (1998). Applying medical anthropology in the control of infectious disease. *Tropical Medicine & International Health*, 3(12):1020-1027.

Manderson L, Huang Y (2005). Water, vectorborne disease and gender: schistosomiasis in rural China. In: Whiteford L,Whiteford S, eds. *Globalization, water and health – resource management in times of scarcity*. New Mexico, School of American Research Press:67-84.

Martins DF Jr, Barreto ML (2003). Aspectos macroepidemiológicos da esquistossomose mansônica: análise da relação da irrigação no perfil espacial da endemia no Estado da Bahia, Brasil [Macro-epidemiologic aspects of schistosomiasis mansoni: analysis of the impacts of irrigation systems on the spatial profile of the endemic in Bahia, Brazil]. *Cadernos de Saúde Pública*, 19(2):383-393.

Mascie-Taylor CG, Karim E (2003). The burden of chronic disease. *Science*, 302(5652):1921-1922.

Massara CL, Schall VT (2004). A pedagogical approach of schistosomiasis – an experience in health education in Minas Gerais, Brazil. *Memórias do Instituto Oswaldo Cruz*, 99(5 Suppl. 1):113-119.

Mata L (1982). Sociocultural factors in the control and prevention of parasitic diseases. *Reviews of Infectious Diseases*, 4(4):871-879.

Mehanna S et al. (1994). Social and economic conditions in two newly reclaimed areas in Egypt: implications for schistosomiasis control strategies. *The Journal of Tropical Medicine and Hygiene*, 97(5):286-297.

Mehanna S et al. (1997). Factors affecting knowledge of the symptoms of schistosomiasis in two rural areas near Ismailia, Egypt. *Tropical Medicine & International Health*, 2(11):A36-A47.

Michaud CM, Gordon WS, Reich MR (2004). *The global burden of disease due to schistosomiasis*. Boston, MA, Harvard Center for Population and Development Studies, Harvard School of Public Health (Schistosomiasis Research Program. Working Paper Series, Vol. 14, No. 1).

Michelson EH (1993). Adam's rib awry? Women and schistosomiasis. *Social Science & Medicine*, 37(4):493-501.

Miller RL et al. (1992). Palaeoepidemiology of Schistosoma infection in mummies. *BMJ*, 304(6826):555-556.

Minai M, Hosaka Y, Ohta N (2003). Historical view of schistosomiasis japonica in Japan: implementation and evaluation of disease-control strategies in Yamanashi Prefecture. *Parasitology International*, 52(4):321-326.

Montresor A et al. (2001). Extending anthelminthic coverage to non-enrolled school-age children using a simple and low-cost method. *Tropical Medicine & International Health*, 6(7):535-537.

Morrow RH Jr (1984). The application of a quantitative approach to the assessment of the relative importance of vector and soil transmitted diseases in Ghana. *Social Science & Medicine*, 19(10):1039-1049.

Mota E, Sleigh AC (1987). Water-contact patterns and *Schistosoma mansoni* infection in a rural community in northeast Brazil. *Revista do Instituto de Medicina Tropical de São Paulo*, 29(1):1-8.

Mott KE et al. (1990). Parasitic diseases and urban development. *Bulletin of the World Health Organization*, 68(6):691-698.

Mouchet J, Carnevale P (1997). Impact des transformations de l'environnement sur les maladies à transmission vectorielle [Impact of changes in the environment on vector-transmitted diseases]. *Santé*, 7(4):263-269.

Muela SH, Mushi AK, Ribera JM (2000). The paradox of the cost and affordability of traditional and government health services in Tanzania. *Health Policy and Planning*, 15(3):296-302.

Mwanga JR (2004). *Community-integrated and action-oriented health education intervention on schistosomiasis and other illnesses among children of primary school-going age in Magu District, Tanzania* [thesis]. Mwanza/Copenhagen/Charlottenlund, National Institute for Medical Research/Danish University of Education/Danish Bilharziasis Laboratory.

Mwanga JR et al. (2004). Schistosomiasis-related perceptions, attitudes and treatment-seeking practices in Magu district, Tanzania: public health implications. *Journal of Biosocial Science*, 36(1):63-81.

Ndamba J, Chandiwana SK, Makaza N (1989). Knowledge, attitudes and practices among rural communities in Zimbabwe in relation to *Phytolacca dodecandra* – a plant molluscicide. *Social Science & Medicine*, 28(12):1249-1253.

Ndamba J et al. (1994). Traditional herbal remedies used for the treatment of urinary schistosomiasis in Zimbabwe. *Journal of Ethnopharmacology*, 42(2):125-132.

Ndekha A (2001). *Strengthening community participation in schistosomiasis control: lessons from the Guruve District (Zimbabwe) schistosomiasis control programme using* Phytolacca dodecandra *(a plant molluscide)* [thesis]. Harare/Copenhagen/Charlottenlund, Blair Research Laboratory/Royal Danish School of Pharmacy/Danish Bilharziasis Laboratory.

Ndekha A et al. (2003). Community participation as an interactive learning process: experiences from a schistosomiasis control project in Zimbabwe. *Acta Tropica*, 85(3):325-338.

Ndyomugyenyi R, Kabatereine N (2003). Integrated community-directed treatment for the control of onchocerciasis, schistosomiasis and intestinal helminths infections in Uganda: advantages and disadvantages. *Tropical Medicine & International Health*, 8(11):997-1004.

N'goran EK et al. (1998). Identification rapide par questionnaire des principaux foyers de bilharziose urinaire au centre de la Cote d'Ivoire [Use of a questionnaire for quick identification of the principal foci of urinary bilharziasis in central Ivory Coast]. *Médecine Tropicale*, 58(3):253-260.

Noda S et al. (1997). Effect of piped water supply on human water contact patterns in a *Schistosoma haematobium*-endemic area in Coast Province, Kenya. *The American Journal of Tropical Medicine and Hygiene*, 56(2):118-126.

Nokes C et al. (1999). Evidence for an improvement in cognitive function following treatment of *Schistosoma japonicum* infection in Chinese primary schoolchildren. *The American Journal of Tropical Medicine and Hygiene*, 60(4):556-565.

Noronha CV et al. (1995). Uma concepção popular sobre a esquistossomose mansônica: os modos de transmissão e prevenção na perspectiva de gênero [A popular concept of schistosomiasis mansoni: modes of transmission and prevention in the perspective of gender differences]. *Cadernos de Saúde Pública*, 11(1):106-117.

Nozais JP (1987). Hypothéses sur le role du Sahara préhistorique dans la répartition de certaines affections parasitaires et hématologiques [Hypotheses on the role of the prehistoric Sahara in the spread of parasitic and hematologic diseases]. *Bulletin de la Société de Pathologie Exotique et de ses Filiales*, 80(1):121-131.

Nozais JP (2003). The origin and dispersion of human parasitic diseases in the old world (Africa, Europe and Madagascar). *Memórias do Instituto Oswaldo Cruz*, 98(Suppl. 1):13-19.

Nsowah-Nuamah NN et al. (2001). Urinary schistosomiasis in southern Ghana: a logistic regression approach to data from a community-based integrated control program. *The American Journal of Tropical Medicine and Hygiene*, 65(5):484-490.

Nwaorgu OC et al. (1998). A school-based schistosomiasis and intestinal helminthiasis control programme in Nigeria: acceptability to community members. *Tropical Medicine & International Health*, 3(10):842-849.

Odogwu SE et al. (2006). *Schistosoma mansoni* in infants (aged <3 years) along the Ugandan shoreline of Lake Victoria. *Annals of Tropical Medicine and Parasitology*, 100(4):315-326.

Ofoezie JE, Christensen NO, Madsen H (1998). Water contact patterns and behavioural knowledge of schistosomiasis in south-west Nigeria. *Journal of Biosocial Science*, 30(2):245-259.

Ohmae H et al. (2004). Schistosomiasis mekongi: from discovery to control. *Parasitology International*, 53(2):135-142.

Olds GR (2003). Administration of praziquantel to pregnant and lactating women. *Acta Tropica*, 86(2-3):185-195.

Ollivier G, Brutus L, Cot M (1999). La schistosomose intestinale à *Schistosoma mansoni* à Madagascar: extension et focalisation de l'endémie [Intestinal schistosomiasis from *Schistosoma mansoni* in Madagascar: extent and center of the endemic]. *Bulletin de la Société de Pathologie Exotique*, 92(2):99-103.

Olsen A (1998). The proportion of helminth infections in a community in western Kenya which would be treated by mass chemotherapy of schoolchildren. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 92(2):144-148.

Onayade AA, Abayomi IO, Fabiyi AK (1996). Urinary schistosomiasis: options for control within endemic rural communities: a case study in south-west Nigeria. *Public Health*, 110(4):221-227.

Ouma JH (1987). *Transmission of* Schistosoma mansoni *in an endemic area of Kenya with special reference to the role of human defaecation behaviour and sanitary practices* [thesis]. Liverpool, University of Liverpool.

Parent G et al. (1997). Grands barrages, santé et nutrition en Afrique: au-delá de la polémique ... [Large dams, health and nutrition in Africa: beyond the controversy]. *Santé*, 7(6):417-422.

Parker M (1992). Re-assessing disability: the impact of schistosomal infection on daily activities among women in Gezira Province, Sudan. *Social Science & Medicine*, 35(7):877-890.

Parker M (1993). Bilharzia and the boys: questioning common assumptions. *Social Science & Medicine*, 37(4):481-492.

Parraga IM et al. (1996). Gender differences in growth of school-aged children with schistosomiasis and geohelminth infection. *The American Journal of Tropical Medicine and Hygiene*, 55(2):150-156.

Pimentel D et al. (1961). Aspects of schistosomal endemicity in three Puerto Rican watersheds. *The American Journal of Tropical Medicine and Hygiene*, 10:523-529.

Poggensee G, Feldmeier H, Krantz I (1999). Schistosomiasis of the female genital tract: public health aspects. *Parasitology Today*, 15(9):378-381.

Poggensee G, Feldmeier H (2001). Female genital schistosomiasis: facts and hypotheses. *Acta Tropica*, 79(3):193-210.

Polderman AM (1995). Gender-specific schistosomiasis. Why? *Tropical and Geographical Medicine*, 47(2 Suppl.):S1.

Popkin BM (1982). A household framework for examining the social and economic consequences of tropical diseases. *Social Science & Medicine*, 16(5):533-543.

Porter J, Ogden J, Pronyk P (1999). Infectious disease policy: towards the production of health. *Health Policy and Planning*, 14(4):322-328.

Prescott NM (1979). Schistosomiasis and development. *World Development*, 7:1-14.

Prüss A et al. (2002). Estimating the burden of disease from water, sanitation, and hygiene at a global level. *Environmental Health Perspectives*, 110(5):537-542.

Qunhua L et al. (2000). Investigation of association between female genital tract diseases and Schistosomiasis japonica infection. *Acta Tropica*, 77(2):179-183.

Rabello A (1997). Diagnosing schistosomiasis. *Memórias do Instituto Oswaldo Cruz*, 92(5):669-676.

Randrianasolo BS et al. (2002). Validation de la méthode du questionnaire pour identifier les zones hyperendémique de la bilharziose à *Schistosoma haematobium* à Madagascar [Validation of questionnaire methods to identify *Schistosoma haematobium* bilharziasis hyperendemic zones in Madagascar]. *Archives de l'Institut Pasteur de Madagascar*, 68(1-2):59-62.

Raso G et al. (2004). Multiple parasite infections and their relationship to self-reported morbidity in a community of rural Côte d'Ivoire. *International Journal of Epidemiology*, 33(5):1092-1102.

Raso G et al. (2005). Disparities in parasitic infections, perceived ill health and access to health care among poorer and less poor schoolchildren of rural Côte d'Ivoire. *Tropical Medicine & International Health*, 10(1):42-57.

Red Urine Study Group (1995). *Identification of high-risk communities for schistosomiasis in Africa: a multicountry study*. Geneva, World Health Organization, Special Programme for Research & Training in Tropical Diseases (Social and Economic Research Projects Report, No. 15; TDR/SER/PRS/15).

Rée GH (1982). Schistosomiasis and human behaviour. *Ecology of Disease*, 1(2-3):131-133.

Reich MR (1988). Technical fixes and other problems in saving lives in the world's poorest countries. *Journal of Public Health Policy*, 9(1):92-103.

Reich MR, Govindaraj R (1998). Dilemmas in drug development for tropical diseases. Experiences with praziquantel. *Health Policy*, 44(1):1-18.

Reyman TA, Zimmerman MR, Lewin PK (1977). Autopsy of an Egyptian mummy. 5. Histopathologic investigation. *Canadian Medical Association Journal*, 117(5):470-472.

Ribeiro PJ et al. (2004). Educational program in schistosomiasis: a model for a methodological approach. *Revista de Saúde Pública*, 38(3):415-421.

Richens J (2004). Genital manifestations of tropical diseases. *Sexually Transmitted Infections*, 80(1):12-17.

Rigau-Pérez JG, Pereira Díaz LA (1996). Hay Bilharzia!, by Klock, Ildefonso, and Mateo-Serrano: medical images of poverty and development in Puerto Rico in the 1950s. *Puerto Rico Health Sciences Journal*, 15(1):33-44.

Ripert C (2003). Schistosomose due à *Schistosoma intercalatum* et urbanisation en Afrique centrale [Schistosomiasis due to *Schistosoma intercalatum* and urbanization in central Africa]. *Bulletin de la Société de Pathologie Exotique*, 96(3):183-186.

Robert CF, Bouvier S, Rougemont A (1989a). Epidemiology, anthropology and health education. *World Health Forum*, 10(3-4):355-364.

Robert CF, Bouvier S, Rougemont A (1989b). Epidemiology of schistosomiasis in the riverine population of Lagdo Lake, northern Cameroon: mixed infections and ethnic factors. *Tropical Medicine and Parasitology*, 40(2):153-158.

Rosenfield PL (1983). The need for social and economic research in tropical disease studies. *The Southeast Asian Journal of Tropical Medicine and Public Health*, 14(1):3-7.

Rosenfield PL, Golladay F, Davidson RK (1984). The economics of parasitic diseases: research priorities. *Social Science & Medicine*, 19(10):1117-1126.

Rosenfield PL (1986). Linking theory with action: the use of social and economic research to improve the control of tropical parasitic diseases. *The Southeast Asian Journal of Tropical Medicine and Public Health*, 17(3):323-332.

Rozemberg B (1994). Representação Social de Eventos Somáticos Ligados à Esquistossomose [Social representation of organic processes related to schistosomiasis]. *Cadernos de Saúde Pública*, 10(1):30-46.

Ruyssenaars J, van Etten G, McCullough F (1973). Population movements in relation to the spread and control of schistosomiasis in Sukumaland, Tanzania. *Tropical and Geographical Medicine*, 25(2):179-186.

Saker L et al. (2004). *Globalization and infectious diseases: a review of the linkages*. Geneva, World Health Organization, Special Programme for Research & Training in Tropical Diseases (TDR Steering Committee for Social, Economic and Behavioural Research. Special Topics, No. 3; TDR/STR/SEB/ST/04.2).

Sama MT, Ratard RC (1994). Water contact and schistosomiasis infection in Kumba, southwestern Cameroon. *Annals of Tropical Medicine and Parasitology*, 88(6):629-634.

Sandbach FR (1975). Preventing schistosomiasis: a critical assessment of present policy. *Social Science & Medicine*, 9(10):517-527.

Sandbach FR (1976). The history of schistosomiasis research and policy for its control. *Medical History*, 20(3):259-275.

Sangho H et al. (2002). Prévalence et perception de la schistosomose en milieu scolaire périurbain de Bamako au Mali [Prevalence and perception of schistosomiasis in a periurban school of Bamako in Mali]. *Bulletin de la Société de Pathologie Exotique*, 95(4):292-294.

Santana VS et al. (1997). Efetividade do programa de comunicação e educação em saúde no controle da infecção por *S. mansoni* em algumas áreas do Estado da Bahia [The effectiveness of the Program of Communication and Education in Health on the control of *S. mansoni* infection in some areas of the state of Bahia]. *Revista da Sociedade Brasileira de Medicina Tropical*, 30(6):447-456.

Sayed HA et al. (2000). Assessment of the diagnostic system of *Schistosoma* infection at rural health unit level, Egypt. *Journal of the Egyptian Society of Parasitology*, 30(2):487-503.

Schall V, Diniz MC (2001). Information and education in schistosomiasis control: an analysis of the situation in the State of Minas Gerais, Brazil. *Memórias do Instituto Oswaldo Cruz*, 96(Suppl.):35-43.

Schall VT et al. (1993). Educação em saúde em escolas públicas de 1˚ grau da periferia de Belo Horizonte, MG, Brasil. I – Avaliação de um programa relativo à esquistossomose [Health education in 1st grade public schools at the periphery of Belo Horizonte, MG, Brazil. I. Evaluation of the program relative to schistosomiasis]. *Revista do Instituto de Medicina Tropical de São Paulo*, 35(6):563-572.

Schall VT (1995). Health education, public information, and communication in schistosomiasis control in Brazil: a brief retrospective and perspectives. *Memórias do Instituto Oswaldo Cruz*, 90(2):229-234.

Schall VT (1998). An interactive perspective of health education for the tropical disease control: the schistosomiasis case. *Memórias do Instituto Oswaldo Cruz*, 93(Suppl. 1):51-58.

Shiffman J, Beer T, Wu Y (2002). The emergence of global disease control priorities. *Health Policy and Planning*, 17(3):225-234.

Simoonga C (2006). *The spatial epidemiology of schistosomiasis and soil-transmitted helminthiasis in Zambia* [thesis]. Kwazulu-Natal/Denmark/Lusaka, University of Kwazulu-Natal/DBL – Centre of Health Research and Development/University of Zambia.

Siziya S, Mushanga M (1996). Importance of schistosomiasis in the Isoka district of Zambia: a prerequisite for its control using community participation. *Social Science & Medicine*, 42(3):431-435.

Sleigh A et al. (1998a). Eradication of schistosomiasis in Guangxi, China. Part 1: Setting, strategies, operations, and outcomes, 1953-92. *Bulletin of the World Health Organization*, 76(4):361-372.

Sleigh A et al. (1998b). Eradication of schistosomiasis in Guangxi, China. Part 3. Community diagnosis of the worst-affected areas and maintenance strategies for the future. *Bulletin of the World Health Organization*, 76(6):581-590.

Soares MS et al. (1995). Schistosomiasis in a low prevalence area: incomplete urbanization increasing risk of infection in Paracambi, RJ, Brazil. *Memórias do Instituto Oswaldo Cruz*, 90(4):451-458.

Southgate BA (1970). Schistosomiasis: the last ten years. *The Journal of Tropical Medicine and Hygiene*, 73(9):235-236.

Sow S et al. (2003). Low awareness of intestinal schistosomiasis in northern Senegal after 7 years of health education as part of intense control and research activities. *Tropical Medicine & International Health*, 8(8):744-749.

Sow S et al. (2004). Pratiques hygiéniques et risques de contamination des eaux de surface par des œufs de schistosomes: le cas d'un village infesté le nord du Senegal [Hygiene practices and contamination risks of surface waters by schistosome eggs: the case of an infested village in Northern Senegal]. *Bulletin de la Société de Pathologie Exotique*, 97(1):12-14.

Steinmann P et al. (2006). Schistosomiasis and water resources development: systematic review, meta-analysis, and estimates of people at risk. *The Lancet Infectious Diseases*, 6(7):411-425.

Stephenson LS (2001). Optimising the benefits of anthelmintic treatment in children. *Paediatric Drugs*, 3(7):495-508.

Stoll NR (1999). This wormy world. 1947. *The Journal of Parasitology*, 85(3):392-396.

Stothard JR et al. (2002). Urinary schistosomiasis in schoolchildren on Zanzibar Island (Unguja), Tanzania: a parasitological survey supplemented with questionnaires. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 96(5):507-514.

Sturrock RF (2001). Schistosomiasis epidemiology and control: how did we get here and where should we go? *Memórias do Instituto Oswaldo Cruz*, 96(Suppl.):17-27.

Sutherst RW (2004). Global change and human vulnerability to vector-borne diseases. *Clinical Microbiology Reviews*, 17(1):136-173.

Talaat M, Omar M, Evans D (1999). Developing strategies to control schistosomiasis morbidity in nonenrolled school-age children: experience from Egypt. *Tropical Medicine & International Health*, 4(8):551-556.

Talaat M, Evans DB (2000). The costs and coverage of a strategy to control schistosomiasis morbidity in non-enrolled school-age children in Egypt. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 94(4):449-454.

Talaat M et al. (2004). The social context of reproductive health in an Egyptian hamlet: a pilot study to identify female genital schistosomiasis. *Social Science & Medicine*, 58(3):515-524.

Tan H et al. (2004). Rapid screening method for *Schistosoma japonicum* infection using questionnaires in flood area of the People's Republic of China. *Acta Tropica*, 90(1):1-9.

Tanaka H, Tsuji M (1997). From discovery to eradication of schistosomiasis in Japan: 1847-1996. *International Journal for Parasitology*, 27(12):1465-1480.

Tanner M, Degrémont A (1986). Monitoring and evaluating schistosomiasis control within a primary health care programme. *Tropical Medicine and Parasitology*, 37(2):220-222.

Tanner M et al. (1986). Community participation within a primary health care programme. *Tropical Medicine and Parasitology*, 37(2):164-167.

Tanner M (1989a). Evaluation of public health impact of schistosomiasis. *Tropical Medicine and Parasitology*, 40(2):143-148.

Tanner M (1989b). From the bench to the field: control of parasitic infections within primary health care. *Parasitology*, 99(Suppl.):S81-S92.

Tanner M, Lengeler C, Lorenz N (1993). Case studies from the biomedical and health systems research activities of the Swiss Tropical Institute in Africa. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 87(5):518-523.

Taylor M et al. (1999). Helminth control as an entry point for health-promoting schools in KwaZulu-Natal. *South African Medical Journal*, 89(3):273-279.

Taylor P et al. (1987). Knowledge attitudes and practices in relation to schistosomiasis in a rural community. *Social Science & Medicine*, 24(7):607-611.

Tayo MA, Pugh RN, Bradley AK (1980). Malumfashi Endemic Diseases Research Project, XI. Water-contact activities in the schistosomiasis study area. *Annals of Tropical Medicine and Parasitology*, 74(3):347-354.

Tiglao TV, Camacho AC (1983). Water contact behaviour among humans in Leyte, Philippines. *The Southeast Asian Journal of Tropical Medicine and Public Health*, 14(1):18-24.

Traoré M (1989). Schistosomiasis in the Selingue dam area: the integrated approach. *Tropical Medicine and Parasitology*, 40(2):228-231.

Traoré M (1995). Irrigation water and schistosomiasis in the Sahel. In: *Tropical diseases, society and the environment*. Proceedings from a research seminar jointly organized by the TDR programme and SAREC [Department for Research Cooperation] at Stenungsund, August 31-September 2, 1993. Stockholm, SAREC (Conference Reports: 2):91-95.

Uchoa E et al. (2000). The control of schistosomiasis in Brazil: an ethnoepidemiological study of the effectiveness of a community mobilization program for health education. *Social Science & Medicine*, 51(10):1529-1541.

Ukwandu NC, Nmorsi OP (2004). The perception, beliefs and practices toward genitourinary schistosomiasis by inhabitants of selected endemic areas (Edo/Delta States) in south-eastern Nigeria. *Revista do Instituto de Medicina Tropical de São Paulo*, 46(4):209-216.

Umeh JC, Amali O, Umeh EU (2004). The socio-economic effects of tropical diseases in Nigeria. *Economics and Human Biology*, 2(2):245-263.

Urbani C et al. (2002). Epidemiology and control of mekongi schistosomiasis. *Acta Tropica*, 82(2):157-168.

Useh MF, Ejezie GC (1999a). Modification of behaviour and attitude in the control of schistosomiasis. 1. Observations on water-contact patterns and perception of infection. *Annals of Tropical Medicine and Parasitology*, 93(7):711-720.

Useh MF, Ejezie GC (1999b). School-based schistosomiasis control programmes: a comparative study on the prevalence and intensity of urinary schistosomiasis among Nigerian school-age children in and out of school. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 93(4):387-391.

Utzinger J et al. (1998). *Schistosoma mansoni*, intestinal parasites and perceived morbidity indicators in schoolchildren in a rural endemic area of western Côte d'Ivoire. *Tropical Medicine & International Health*, 3(9):711-720.

Utzinger J et al. (2000a). Rapid screening for *Schistosoma mansoni* in western Côte d'Ivoire using a simple school questionnaire. *Bulletin of the World Health Organization*, 78(3):389-398.

Utzinger J et al. (2000b). Simple anamnestic questions and recalled water-contact patterns for self-diagnosis of *Schistosoma mansoni* infection among schoolchildren in western Côte d'Ivoire. *The American Journal of Tropical Medicine and Hygiene*, 62(5):649-655.

Utzinger J et al. (2004). Community health outreach program of the Chad-Cameroon petroleum development and pipeline project. *Clinics in Occupational and Environmental Medicine*, 4(1):9-26.

Utzinger J et al. (2005). Conquering schistosomiasis in China: the long march. *Acta Tropica*, 96(2-3):69-96.

van der Werf MJ et al. (2002). Evaluation of staff performance and material resources for integrated schistosomiasis control in northern Senegal. *Tropical Medicine & International Health*, 7(1):70-79.

van der Werf MJ, Borsboom GJ, de Vlas SJ (2003). No effect of recall period length on prevalence of self-reported haematuria in *Schistosoma haematobium*-endemic areas. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 97(4):373-374.

van der Werf MJ et al. (2004). Measuring schistosomiasis case management of the health services in Ghana and Mali. *Tropical Medicine & International Health*, 9(1):149-157.

Vlassoff C, Bonilla E (1994). Gender-related differences in the impact of tropical diseases on women: what do we know? *Journal of Biosocial Science*, 26(1):37-53.

Vlassoff C, Manderson L (1998). Incorporating gender in the anthropology of infectious diseases. *Tropical Medicine & International Health*, 3(12):1011-1019.

Waddy BB (1975). Research into the health problems of manmade lakes, with special reference to Africa. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 69(1):39-50.

Wagatsuma Y et al. (2003). Highly symptom-aware children were heavily infected with urinary schistosomiasis in southern Ghana. *The Central African Journal of Medicine*, 49(1-2):16-19.

Warren KS (1973). *Schistosomiasis – the evolution of a medical literature. Selected abstracts and citations 1852-1972*. Cambridge, MA, Massachusetts Institute of Technology Press.

Warren KS, Newill VA (1967). *Schistosomiasis: a bibliography of the world's literature from 1852 to 1962*. Cleveland, OH, Western Reserve University Press.

Watts S (2006). The social determinants of schistosomiasis. In: *Report of the Scientific Working Group meeting on schistosomiasis. Geneva, 14-16 November 2005*. Geneva, World Health Organization, UNICEF/UNDP/World Bank/WHO Special Programme for Research & Training in Tropical Diseases (TDR/SWG/07TDR):84-90.

Watts S, el Katsha S (1995). Changing environmental conditions in the Nile delta; health and policy implications with special reference to schistosomiasis. *International Journal of Environmental Health Research*, 5:197-212.

Watts S, el Katsha S (1997). Irrigation, farming and schistosomiasis: a case study in the Nile delta. *International Journal of Environmental Health Research*, 7(2):101-113.

Watts S et al. (1998). The study of human behavior and schistosomiasis transmission in an irrigated area in Morocco. *Social Science & Medicine*, 46(6):755-765.

WHO (1978). Declaration of Alma-Ata. *WHO Chronicle*, 32(11):428-430.

WHO (1985). *The control of schistosomiasis. Report of a WHO Expert Committee*. Geneva, World Health Organization (WHO Technical Report Series, No. 728).

WHO (1993). *The control of schistosomiasis. Second report of the WHO Expert Committee*. Geneva, World Health Organization (WHO Technical Report Series, No. 830).

WHO (2001). *International classification of functioning, disability and health*. Geneva, World Health Organization.

WHO (2002). *Prevention and control of schistosomiasis and soil-transmitted helminthiasis. Report of a WHO Expert Committee*. Geneva, World Health Organization (WHO Technical Report Series, No. 912).

WHO (2005). *Deworming for health and development. Report of the third global meeting of the partners for parasite control. Geneva, 29-30 November 2004*. Geneva, World Health Organization (WHO/CDS/CPE/PVC/2005.14).

WHO, UNICEF (2000). *Global water supply and sanitation assessment 2000 report*. Geneva and New York, NY, World Health Organization and United Nations Children's Fund.

Williams HA et al. (2002). The contribution of social science research to malaria prevention and control. *Bulletin of the World Health Organization*, 80(3):251-252.

Wu Z et al. (1993). Factors contributing to reinfection with schistosomiasis japonica after treatment in the lake region of China. *Acta Tropica*, 54(2):83-88.

Xiang H et al. (1998). Financing changes of schistosomiasis control programmes in China 1980-1995: a case study in Songzi county. *Tropical Medicine & International Health*, 3(6):454-461.

Ximenes R et al. (2003). Socioeconomic determinants of schistosomiasis in an urban area in the Northeast of Brazil. *Revista Panamericana de Salud Pública*, 14(6):409-421.

Ximenes RA et al. (2000). Migration and urban schistosomiasis. The case of São Lourenço da Mata, northeast of Brazil. *Revista do Instituto de Medicina Tropical de São Paulo*, 42(4):209-217.

Ximenes RA et al. (2001). Social environment, behavior, and schistosomiasis in an urban population in the Northeast of Brazil. *Revista Panamericana de Salud Pública*, 9(1):13-22.

Yoder PS (1997). Negotiating relevance: belief, knowledge, and practice in international health projects. *Medical Anthropology Quarterly*, 11(2):131-146.

Yu D et al. (2001). Is equity being sacrificed? Willingness and ability to pay for schistosomiasis control in China. *Health Policy and Planning*, 16(3):292-301.

Yuan L et al. (2000). The impact of educational videotapes on water contact behaviour of primary school students in the Dongting Lakes region, China. *Tropical Medicine & International Health*, 5(8):538-544.

Yuan LP et al. (2005). School-based interventions to enhance knowledge and improve case management of schistosomiasis: a case study from Hunan, China. *Acta Tropica*, 96(2-3):248-254.

Zhou H et al. (1998). Diagnosis of schistosomiasis japonica in Chinese schoolchildren by administration of a questionnaire. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 92(3):245-250.

ANNEX 1

LITERATURE SEARCH STRATEGIES AND SELECTION CRITERIA

Social science literature is relatively scarce compared with many other disciplines engaged in schistosomiasis research and many observations put forward in this book stem from articles in public health, epidemiology and other disciplines. A broad view, with visible overlaps with perspectives from other disciplines, has been prioritized over any rigid definition of social science in general and anthropology/sociology in particular.

The basis of the book has been limited to articles, but a few central books, chapters in books, dissertations as well as WHO reports and policy papers are also referred to. Articles have been culled from major medical, biological, and social science databases (see Table A1.1 for sources, search terms and results). No restrictions on period were applied. Additional studies were identified from the reference lists of studies located via databases. Relevant studies in Portuguese and French were included, but we had no access to a translation of Chinese and Japanese articles.

A few "grey" studies have been included as examples of innovative or otherwise illuminating studies, but it has been beyond the scope of this book to provide an exhaustive review of grey literature.

In order to better indicate how findings from the social sciences relate to studies of schistosomiasis from other disciplines, the book includes selected references to studies in epidemiology, public health and medicine. These references are often cited in boxes of selected references and text boxes, which are meant to give a quick overview of specific topics in schistosomiasis research.

A total of 913 articles and other items have been reviewed and 378 publications are referred to in the book.

A total of 67 social science studies have been selected for annotation, based on our assessment that they fulfil one or more of the following (non-quantified) criteria:

- rich contextualization of main findings
- well-founded generalizations in the discussion
- an explicit and well-founded theoretical basis
- critical and/or innovative use of methods.

Some studies with particularly interesting features, following the criteria above, are given more space. Since many good social science studies from Brazil are written in Portuguese – and thus inaccessible to many readers – they are presented in more detail.

Table A1.1 Description of sources, search terms and results

Source	Type	Description	Search terms	Details of results
PubMed	Database	PubMed (provided by the United States National Library of Medicine) includes over 15 million citations for biomedical articles from the 1950s onwards. These citations are from MEDLINE (also provided by the United States National Library of Medicine) and additional life science journals. PubMed includes links to many sites providing full-text articles and other related resources.	social science AND geohelminths	30 hits: 1 relevant and new
			schistosomiasis OR schisto* AND health policy	24 hits: 14 new, 1 of these relevant
			schistosomiasis [MeSH] AND social sciences [MeSH]	654 hits: 573 new, 86 of these relevant
			bilharz* NOT (schistosomiasis [MeSH] OR schisto*)	247 hits: 10 relevant, but not new
			red urine	39 hits: 1 relevant, but not new
Web of Science	Database	Web of Science is a part of the Internet portal ISI Web of Knowledge and includes three databases: • Science Citation Index Expanded • Social Sciences Citation Index • Arts & Humanities Citation Index. It provides access to multidisciplinary information from approximately 8700 research journals in the world. It also provides cited reference searching.	Searches were performed using the chosen search strings from the PubMed search	236 hits: 93 new, 21 of these relevant
			schistosomiasis OR schisto* AND ethics	None new
			schistosomiasis OR schisto* AND health policy	10 hits: 2 new, but not relevant

Source	Type	Description	Search terms	Details of results
POPLINE	Database	POPLINE (POPulation information onLINE) of the INFO (Information & Knowledge for Optimal Health) Project at the Johns Hopkins Bloomberg School of Public Health/Center for Communication Programs is the world's largest database on reproductive health. It provides more than 300 000 citations with abstracts to scientific articles, reports, books and unpublished reports in the field of population, family planning and related health issues.	schistosomiasis OR schisto*	603 hits: all were on either perception, control, treatment, prevention, knowledge, attitude, practice or behaviour
			schistosomiasis	171 hits: 17 new and relevant
Cochrane Database of Systematic Reviews	Database	Database of The Cochrane Library. It provides information on the effects of interventions in health care.	schisto*	10 hits: all new, 3 relevant
NHS Economic Evaluation Database	Database	Database of The Cochrane Library. It has been funded by the departments of health of England and Wales; it provides information about the costs as well as the effects of drugs, treatments and procedures.	schisto*	11 new. None selected because the economic focus of the articles lies outside the scope of this bibliography
Database of Abstracts of Reviews of Effects	Database	Database of The Cochrane Library. It provides assessments of systematic reviews from a variety of journals. It consists of structured abstracts of systematic reviews from all over the world, covering topics such as diagnosis, prevention, rehabilitation, screening and treatment.	schisto*	0 hits

Source	Type	Description	Search terms	Details of results
Social Science & Medicine	Journal	International and interdisciplinary forum for the dissemination of research findings, reviews and theory in all areas of common interest to social scientists, health practitioners and policy-makers	schistosomiasis	25 hits: 14 new, 11 of these relevant
Culture, Medicine and Psychiatry	Journal	An international journal of comparative cross-cultural research	schistosomiasis	0 hits
Health Policy and Planning	Journal	Published by Oxford University Press in association with the London School of Hygiene and Tropical Medicine	schistosomiasis	16 hits: 14 new, 7 of these relevant
Eastern Mediterranean Health Journal	Journal	Journal of the WHO Regional Office for the Eastern Mediterranean (online version searched)	schistosomiasis, bilharzia	46 hits: 3 relevant, but not new
25 years of social science research at TDR: a basic bibliography	Bibliography	CD-ROM produced in 2004 by the United Nations Children's Fund/ United Nations Development Programme/World Bank/ World Health Organization Special Programme for Research & Training in Tropical Diseases (TDR)	All 45 entries for schistosomiasis screened	37 relevant, but not new

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TDR/World Health Organization
20, Avenue Appia
1211 Geneva 27
Switzerland

Fax: (+41) 22 791-4854
tdr@who.int
www.who.int/tdr

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