



# Treating Bilharzia among High School Pupils

A study of opportunities and constraints for treating Bilharzia among high school pupils in Ugu district, South Africa.

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*This Master's Thesis is carried out as a part of the education at the University of Agder and is therefore approved as a part of this education. However, this does not imply that the University answers for the methods that are used or the conclusions that are drawn.*

University of Agder, June 2012

Faculty of Economics and Social Sciences

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By Andrea Lothe

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Faculty of Economics and Social Sciences  
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## Preface

In November 2011 travelled to South Africa to conduct fieldwork for data collection. These data form part of my final thesis of the master's degree Development Management at the University of Agder, Norway. In the thesis I will discuss and evaluate the various challenges in Bilharzia treatment in Ugu High Schools. The impediments are seen in light of existing theories and linked to research questions. Finally, suggestions are made as to how the identified challenges can be addressed.

I want to thank Professor Arne Olav Øyhus for his guidance throughout the process of finalizing this paper. I also want to thank Dr. Eyrun Kjetland, Dr. Myra Taylor and coworkers and staff at the local research project.

Andrea Lothe

Ålesund, June 2012

## Abstract

One of the many impediments of development is the poor state of health in developing countries. In order to cope with the challenges of poverty, there is a clear need to address the issue of poor health. WHO (World Health Organization) argues a need for further research and more attention on the group of neglected tropical diseases (NTD), one of which is Bilharzia. Bilharzia is a waterborne parasite that infests open fresh water sources such as rivers and dams. Research indicates that Bilharzia may increase susceptibility to HIV, a disease that was estimated to kill 1.8 million people worldwide in 2010. Ugu district is an area characterized by its many rivers, and is situated northeast in South Africa. As South Africa has the highest HIV prevalence in the world, one might easily argue that Bilharzia treatment should be prioritized.

This thesis explores variables that influence participation and non-participation in a mass treatment campaign (MTC) run by the South African Department of Health (DoH). By use of the Health Belief Model (HBM), the variables' effect on MTC participation rates is examined.

Through qualitative data collection using interviews and focus group discussions, local perceptions of Bilharzia as seen by pupils, teachers and selected community helpers are identified. Suggestions are made as to how the challenges of misconceptions and fear of barriers can be addressed in order to increase MTC participation rates, hence decrease Bilharzia prevalence in Ugu.

**Keywords:** Bilharzia, Ugu District, Schistosomiasis, South Africa, KwaZulu Natal



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*Thank you & Ngiyabonga ka khulu!*

## List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
DoE	Department of Education
DoH	Department of Health
FGD	Focus Group Discussion
FGS	Female Genital Schistosomiasis
GDP	Gross Domestic Product
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
IDI	In-Depth Interview
KZN	KwaZulu-Natal
LO	Life Orientation
MDG	Millennium Development Goals
MTC	Mass Treatment Campaign
PPP	Purchasing Power Parity
RQ	Research Question
WHO	World Health Organization

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## 1.0 Introduction

It can be argued that health is a human right, not only as a right in itself, but as essential to make use of the broader perspective of human rights. We may say that a disease hinders a person's ability to take full advantage of political and civil rights. (Austveg, 2006)

WHO defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948). The poor health of millions of people, especially in developing countries, constrains development. The importance of health as a development issue has also been recognized by the United Nations. Three of the United Nations Millennium Development Goals (MDGs) focus on improving the global health situation, mostly among middle- and low income countries. These aim to reduce child mortality, to improve maternal health and to combat HIV/AIDS, malaria and other diseases (UN, 2011).

When discussing development, several factors are involved. Human rights have to be considered, as well as peace and security, the environment and equitable capital (Goulet, 1997). It has been argued that the fundamental goal of development should be to create incentives so that every individual is able to realize their full potential and fulfill their capabilities of a good human life (Sen, 1997).

However, there has been a growing recognition that development is a contested concept since it reflects different social, political and economic values (Thomas, 2005), values that originated in the Western world (Goulet, 1997). As the notion that development is not value free has become more acknowledged, a need for more holistic approaches have been stressed within the development discourse (Goulet, 1997). Mchombu argues for a *people-centered development* where indicators including health, education, social rights and life-quality are more in focus than financial indicators (Mchombu and Evans, 2002). This is the definition that will be applied to the term development in this paper.

## 1.1 Background and Rationale

I have chosen to focus on Bilharzia. This disease is the second most devastating parasitic disease after malaria, and close to 800 million people are at risk of the infection (Steinmann et al., 2006). It is a waterborne disease that is believed to incapacitate the poor (Fenwick et al., 2005, Hotez and Kamath, 2009, Hotez et al., 2007, WHO, 2002). Several studies have indicated an association between Bilharzia and the increased susceptibility of acquiring HIV (Downs et al., 2011, Kjetland et al., 2006, Chenine et al., 2010, King and Dangerfield-Cha, 2008). Other deadly diseases have also been linked to Bilharzia (van der Werf et al., 2003)

King stresses that in the long haul, Bilharzia may lead to poverty through undernourishment and anemia (King, 2010). The “Poverty Trap” is of great relevance in a case like this. Sachs describes this as a vicious circle which impairs poor people’s opportunities to break out of poverty (Sachs and Bono, 2005). Bilharzia puts further constraints on the poor in terms of breaking this vicious circle of poverty (Prevention, 2011). Sala-i-Martin (Sala-i-Martin, 2005) links the poverty trap to health issues, particularly in African countries. He mentions some of the major causes of death in Africa, and continues to say:

Africa is also the poorest continent of the world. And this is not a coincidence: low income tends to cause poor health and poor health, in turn, tends to cause low income. This two-way circle of causation generates a trap that one well can call the health-poverty trap. A trap that has tragic consequences because poverty cannot be eradicated without dealing with the health issues of the poor, and these health problems, in turn, will not be fully solved until poverty is eradicated (Sala-i-Martin, 2005).

In an attempt to reveal the challenges of treating Bilharzia in rural and peri-urban districts of South Africa, this study aims to explore the causes of non-compliance, as seen by teenage pupils, their teachers and entrusted people in the selected communities. The study seeks to explore skepticism towards treatment and contextual perceptions of Bilharzia. Also, it aims at identifying other issues which may impede treatment coverage, in causing non-participation among pupils. The study will further explore pupils’

perceptions of the Bilharzia treatment, and whether they see any advantages by being treated. In conversation with the interviewees the study seeks to discover suggestions to facilitate an increase in compliance to the treatment campaign.

As a conceptual guide, the main section of the Health Belief Model (Rosenstock, 1974) is applied as a theoretical framework. It is applied due to the dimensions it includes, as they seem relevant to the main objective and research questions of this study.

## **1.2 Objectives**

The main objective of this study is to identify factors that may influence pupil's participation in the mass treatment campaign (MTC) for Bilharzia in Ugu district.

Pupils, teachers and community helpers are included in the study, to identify perceptions of main constraints and reasons for non-participation or participation in the MTC

### **1.2.1 Research questions**

1. How do pupils in Ugu District perceive Bilharzia?
2. How do pupils in Ugu District perceive Bilharzia treatment?
3. What can explain some pupils' hesitance to accept treatment during the MTC?
4. Who teaches young pupils about Bilharzia, and how?

The first research question is important to form a picture of the common knowledge and perception of Bilharzia in the schools and communities in which this study is done. Collected data will contribute to form an understanding of the perceptions of Bilharzia in the research area. The second and third questions are in the essence of the research, and the responses will account for a large part of the findings. Finally, answers to

research question number 4 will give an impression of the way in which pupils are informed, enabling a discussion of whether the given information is sufficient.

### **1.3 Methodology**

In order to acquire primary data to shed light on the set objectives, a fieldwork was conducted in Ugu district. The fieldwork was conducted from min-November 2011 to end of March 2012, during which the researcher gathered data. Six schools were included in the study, in addition to two communities surrounding the selected schools in Ugu district. The research was done in association with a local research project. Doctors and staff at the clinic were consulted throughout the fieldwork. The study applies a qualitative approach, but when analyzing the collected data, quantitative approaches were also applied, making this a study using mixed methods. During the fieldwork, semi structured interviews and gender based focus group discussions were conducted.

### **1.4 Outline of Thesis**

After the introduction, Chapter 2 presents the theoretical background for the topic of Bilharzia as well as for general health in South Africa. Health is not only important to an individual, but it further impacts families, communities, countries and development at large. Chapter 2 therefore introduces health in general and Bilharzia as a specific focus for this paper. As the fieldwork for this study was conducted in South Africa, local health issues are briefly addressed.

Chapter 3 presents the cultural, topical and geographical context of the study, and gives information about South Africa and specifically on Ugu district. Important statistical numbers and facts are given to better comprehend the context of this study. Furthermore, the Zulu culture and cosmology is explored, as well as the Zulu perception of health.

Chapter 4 constitutes a literary background of this study, by exploring health issues. Health's relevance to development will be presented, in addition to relevant theories of health within the field of development.

Chapter 5 explores the study's key model, and elaborates and argues its relevance to the research questions and the topology of this study.

Chapter 6 is a presentation of the methodological choices applied in this study. Advantages and disadvantages of the approaches applied are presented, as well as an ethical evaluation of the choices made. The methodological decisions are critically described and discussed.

Chapter 7 is the chapter in which empirical findings are presented. The various findings are categorized based on topic, such as stigma, sexual associations and lack of trust. Quotes and opinions from the interviews conducted are used to clarify the topics.

Chapter 8 discussed the empirical findings presented in chapter 7, and argues their relevance to the previously presented literature. In addition to linking findings with relevant theories, they are also linked to the research questions. Suggestions to improvements of the MTC are given, and potential opportunities are discussed.

Chapter 9 is the final chapter, and includes a summary of chapter 7 and 8 as well as concluding remarks.

## 2.0 Health and Development

The Millennium Development Goals, the United Nations (UN) human rights charter, the World Health Organization (WHO) and several development strategies argue that there is a need for improved global health. Illness among a population is plausible to limit the workforce of the affected community, as well as to devalue the sick's social capital. For this study, social capital is defined as the social networks of relationships between people who live in a particular society, enabling an efficient function of the society (Oxford, 2012). This implicates that illness does not only constrain the development of an individual, but also aggravates the chances for development of a community. More specifically, the so-called neglected tropical diseases (NTD) in which Bilharzia is included, are believed to further challenge the world's poorest (Prevention, 2011, Hotez et al., 2007).

### 2.1 Bilharzia

Bilharzia is medically known as *schistosomiasis*, and is considered to be the second most prevalent of the NTDs, surpassed only by hookworm (Hotez and Kamath, 2009). An estimation indicated that 25% of the population in Sub-Saharan Africa is infected with Bilharzia (Hotez and Kamath, 2009). The NTDs are known to particularly affect the poor in developing countries, especially in rural areas (Hotez et al., 2007, Prevention, 2011). Even though South Africa is not considered a developing country (Bank, 2012), Bilharzia is still very prevalent, including the province of KwaZulu Natal (KZN) (Group, 2010). Bilharzia is a chronic waterborne disease, and is the second most devastating parasitic disease after malaria (USAID, 2011, Center, 2012). Waterborne diseases exist all over the world, and constitute a hazard especially to people in developing countries. It is expected that the need for treatment of waterborne diseases will continue to increase (Pahle, 2008). Proper treatment and access to clean water is therefore essential. Former Secretary-General of the UN Kofi Annan, once said: "No single measure would do more to reduce disease and save lives in the developing world than bringing safe water and sanitation to all" (UNEP, 2007).

WHO defines Schistosomiasis as an “endemic, chronic and disabling disease”, which has been neglected up until recent years (WHO, 2009). Bilharzia may present itself as female genital disease, most commonly affecting the cervix (WHO, 2010), and may consequently increase the person’s susceptibility to HIV (Kjetland et al., 2006, Downs et al., 2011, Chenine et al., 2010). When in a larval form, the parasite penetrates human skin in fresh water, such as in rivers and dams. The female worm lays her eggs in the blood vessels, from where the eggs exit the human body via feces or urine (WHO, 2012b).

**Figure 2.1 Lifecycle of schistosomiasis**

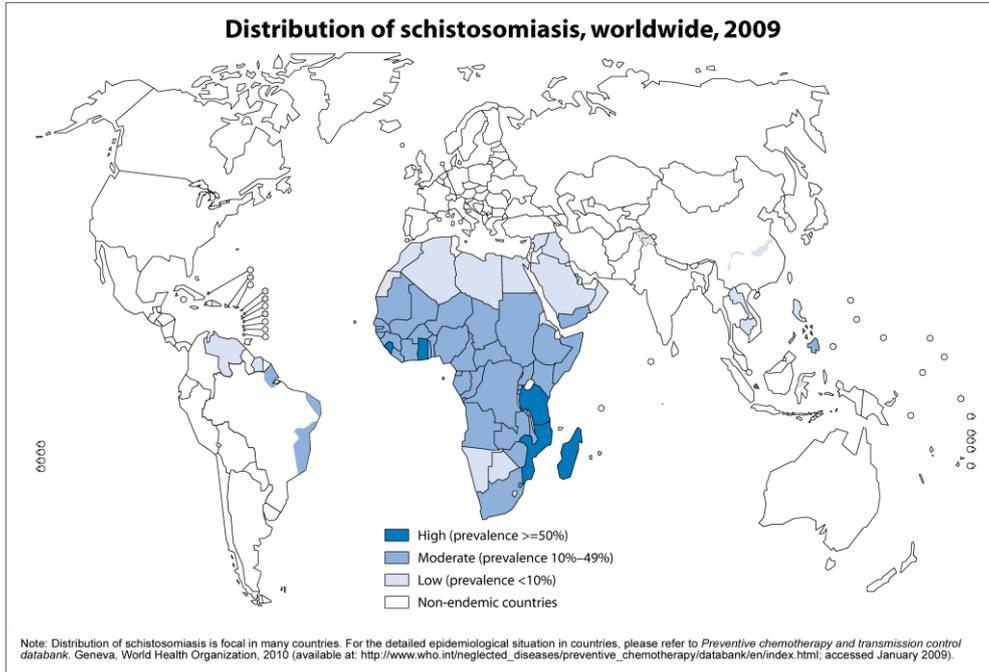


(WHO, 2012d)

The eggs laid by the female worms leave the (human) host by urine or feces. These eggs need to get to fresh water to hatch. After hatching, they are absorbed by a snail host. The parasite lives inside the snail for some weeks, to mature before being released into water again. These newborn parasites then again penetrate human skin, infecting them with Bilharzia (WHO, 2012d).

There are various species of the schistosoma parasite, the three most common being *Schistosoma haematobium*, *Schistosoma mansoni* and *Schistosoma japonicum* (USAID, 2011). The most common species in KZN, where this study is done, is *Schistosoma haematobium* (Group, 2010), and its distribution can be seen in figure 2.3. The exact focal distribution in KZN is not known.

Figure 2.2 Global Distribution of Schistosomiasis



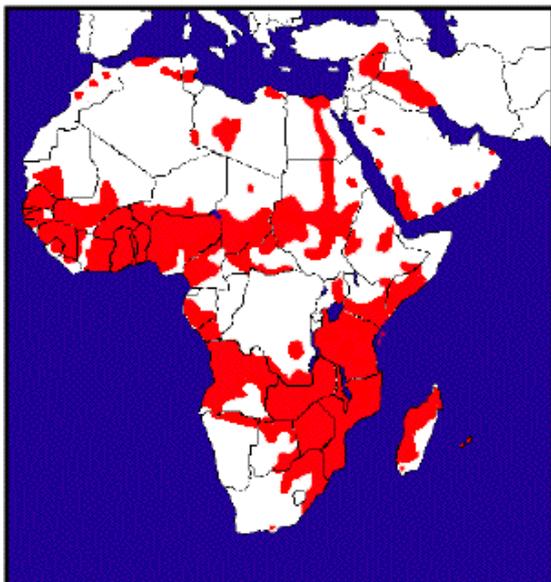
The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement. © WHO 2010. All rights reserved

Data Source: World Health Organization  
 Map Production: Control of Neglected Tropical Diseases (NTD)  
 World Health Organization



((GHO), 2010)

Figure 2.3 Distribution of *Schistosoma haematobium* in Africa



(Group, 2010)

### 2.1.1 Treating Bilharzia

The World Health Organization (WHO) has made a recommendation that school-aged children in high risk communities should receive treatment for Bilharzia annually, and school-age children in moderate risk communities should receive treatment once every two years (Crompton, 2006). Fenwick *et al* claim that a proper treatment strategy can eradicate disease transmission of parasitic and infectious diseases completely (Fenwick *et al.*, 2005). Hotez believes that increased treatment especially of young school-aged girls at risk of acquiring Female Genital Schistosomiasis (FGS), would not only prevent FGS, but also HIV (Hotez *et al.*, 2009). As South Africa has the largest prevalence of HIV in the world, such prevention is of great importance (HIV/AIDS., 2010).

The treatment of praziquantel was made available to a selection of primary schools and high schools in Ugu District. The student participation in the mass treatment campaign (MTC) varied from 20% to 95% in the schools (unpublished results). The reasons for non-participation are unexplored.

Praziquantel is the preferred drug of treatment (N'Goran *et al.*, 2003, Shekhar, 1991). It has been successfully used in MTCs in other countries endemic to Bilharzia (WHO, 2012e, King, 2009). Two of the advantages with praziquantel is the very rare occurrence of clinical resistance and no severe side effects (Prevention, 2010, Shekhar, 1991). WHO has set a strategy for how to address the tropical neglected diseases, including Bilharzia (Crompton, 2006, WHO, 1985). The strategy is to treat children with praziquantel at least three times during childhood, aiming at reducing the prevalence as well as Bilharzia related morbidity (WHO, 2012e, Crompton, 2006). Mass treatment is given as a single dose in one day. In 2001, WHO's overall aim in Bilharzia treatment was agreed upon, and the goal was set to treat at least 75% of all children at risk ((GHO), 2012, Southgate *et al.*, 2005).

One of the major challenges for treating Bilharzia in South Africa is the price of praziquantel. Twenty years back, praziquantel was expensive worldwide (Shekhar, 1991, Berge *et al.*, 2011b), but the cost of treatment should no longer be an issue as

donors have offered to donate enough tablets to all eligible areas in South Africa (WHO, 2012a). However, the tablets offered are not allowed in the South African market (Berge et al., 2011b), and the Medicines Control Council of South Africa does not allow for the cheapest brands of praziquantel to be sold in South Africa. The quality of the prohibited tablets are the same as those currently imported, also considering side effects (Appleton and Mbaye, 2001). This issue however is not within the topic of this study, and will therefore not be further addressed here. It is still of great importance to know that treatment for all has been offered, but not accepted by the government.

Mass treatment is considered crucial in order to reduce the prevalence of Bilharzia (Shekhar, 1991). But drug treatment alone may not be sufficient to tackle the problem. In areas where treatment by praziquantel is the only approach used to control Bilharzia, some have argued that treatment may have to be maintained indefinitely (Jia et al., 2007, King, 2009). In high-risk areas such as Ugu, it seems as though a combination of strategies will have to be applied to completely cope with the prevalence of Bilharzia. Such combination would include sewage management, drug treatment, water control, including recreational water contact and possibly snail control (King, 2009).

#### ***2.1.1.2 Side effects of treatment***

Praziquantel is considered to be a safe way of treating Bilharzia (Olds, 2003, Pearson and GUERRANT, 1983, Shekhar, 1991), as opposed to prior drug treatments (Shekhar, 1991, Berge et al., 2011a). The deworming drugs used in school health programs are effective, have an excellent safety record and are approved for use in school-age children, pregnant and lactating women, HIV positive and more (WHO, 2002, WHO, 2011b). Prior experience of deworming millions of children worldwide shows that these drugs cause only rare, mild and very temporary negative events or negative drug reactions (N'Goran et al., 2003). Those reactions are generally reactions to degenerations of the worms that have been killed. The majority of the side-effects observed in school programs, occur during the first rounds of implementation of the interventions; that is, at a time when children harbor more infections of high intensity (N'Goran et al., 2003, Olds et al., 1999). Mild abdominal pain, nausea, vomiting, diarrhea

and fatigue are the most frequently reported adverse effects and do not normally require medical treatment (Olds et al., 1999).

## 2.2 Health in South Africa

Though considered an upper middle-income country (Bank, 2012), South Africa is struggling with health-related challenges comparable to, and worse than those of low-income countries (Coovadia et al., 2009). South Africa's birth rate was similar to the world average, while largely because of AIDS, the country's death rate was about twice as high as the world average (2012). In addition to HIV/AIDS, South Africans are facing multiple health challenges. South Africa is i.e. one of the 12 countries in the world where child mortality rates have increased since the United Nations Millennium Summit in 2000 (Victora et al., 2007).

The Department of Health is responsible for all public health institutions such as public hospital and more local public clinics (Van Rensburg, 2004). A private health sector exists side by side with the public, and serves the people with private medical aid (Van Rensburg, 2004). Health care services in South Africa therefore vary greatly in terms of price and advancement. Basic primary health care is provided freely by the government, while advanced modern treatment is offered in the more expensive private health sector (Wilkinson et al., 2001, McIntyre et al., 2006, Leatt et al., 2006). A look at the allocation of health resources reveals that 80% of money spent on health care in South Africa is spent by 20 % of the South Africans, in the private sector. The remaining 80% of inhabitants in the country benefit from the remaining 20% of funds (Van Rensburg, 2004).

By referring to the South African constitution, their government is obliged to enable the people's fulfillment of the right to good health, yet the people of South Africa are facing four coinciding epidemics (Coovadia et al., 2009). Initiatives such as the Primary School Nutrition Program have failed to be efficient, as ownership and leadership has not been well defined or organized (Coovadia et al., 2009). Racial inequities in access to health care were evident during the apartheid regime, and continued to challenge South

African health care ever since the new government took over in 1994 (Coovadia et al., 2009, Benatar, 2004). Although a lot has been done to improve the living conditions for South Africans since 1994 (Benatar, 2004), South Africa has a long way to go to reach the health-related MDGs (Coovadia et al., 2009). Replacing the racial inequalities from the apartheid-era, there are now big differences in terms of health-care access based on financial status (Benatar, 2004). South Africa struggles to provide satisfying health care services for those without health insurance (Benatar, 2004).

There has been a slow change in allocation of health resources in an attempt to decrease inequalities in access to health care. Although relative population in wealthy provinces increased during the late 1990s, percentage of national health care budget allocated those provinces decreased (Benatar, 2004). Simultaneously, percentage of health care budget distributed to the historically “disadvantaged” provinces such as KZN increased (Benatar, 2004). Still it appears that the poor of South Africa cannot access health care as easily as the wealthier (Stuckler et al., 2011). According to the statistical findings of Stuckler *et al.*, the poor keep getting poorer, and “nobody is making the initial investment to build them a hospital where they can afford real health care” – he refers to this as the ‘infrastructure-inequality trap’ (Stuckler et al., 2011).

### Photo 2.1 Rural Ugu District



Photo: Andrea Lothe

### 3.0 Contextual background

#### 3.1 South Africa

Figure 1.1 Flag of South Africa



(2012)

South Africa is an upper middle income country (Bank, 2012), situated on the far south end of Africa. The country of South Africa can be said to be young, as the apartheid regime ended as recent as in 1994, considered by many as the re-birth of the South Africa. Racial discrimination is still an issue, and righting the wrongs from apartheid is a process that will probably take many years still (Agency, 2012).

Figure 1.2 Map of South Africa



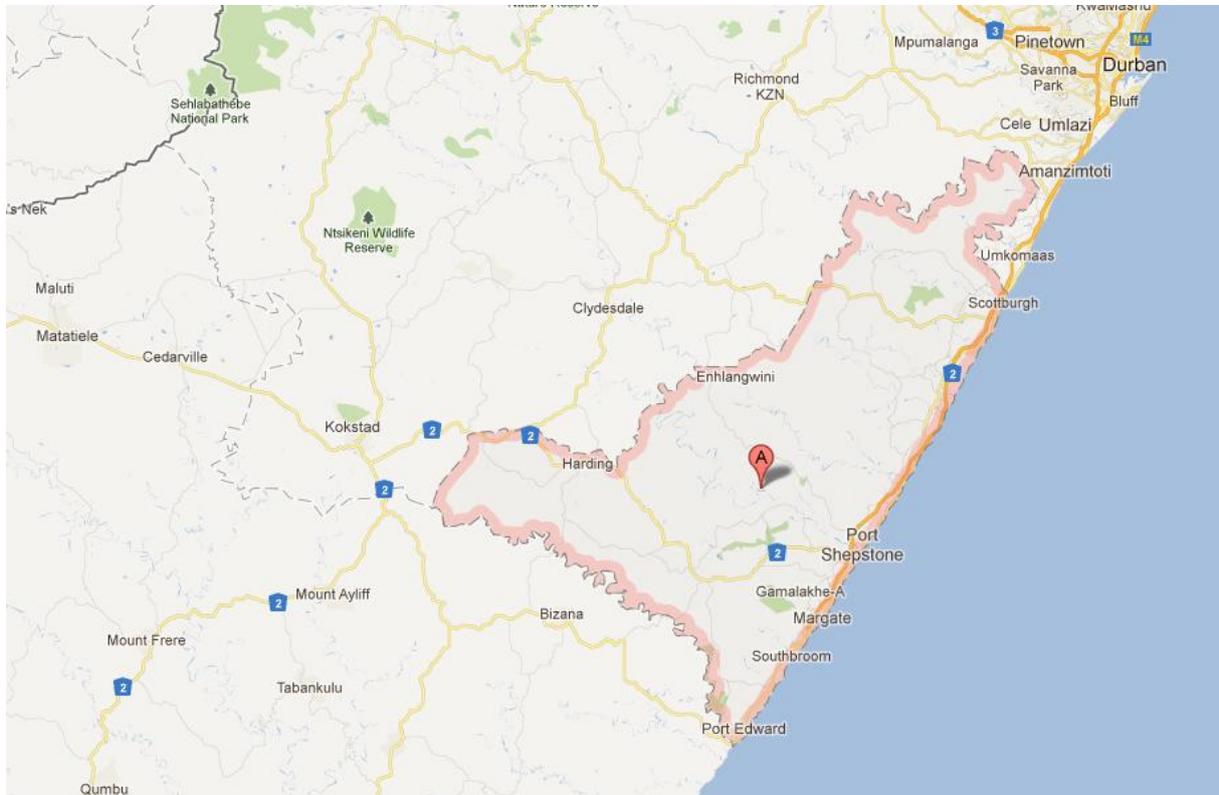
(2012)

**3.1.1 Facts about South Africa**

Form of government	Multiparty republic (President Jacob Zuma Head of State Since May 2009)
Life expectancy at birth in 1990 / 2000 / 2009	63 / 56 / 54 (WHO, 2011a)
Population Groups	Black 79.5%, Colored 9.0 %, Asian 2.5%, White 9.0% (SSA, 2011)
Official languages	Sepedi, Sesotho, Setswana, siSwati, Tshivenda, Xitsonga, Afrikaans, English, isiNdebele, isiXhosa and isiZulu. (Broeder et al., 2002)
GDP per capita (PPP)	\$10,960 (2004 est.) (WHO, 2006)
Population below poverty line	10.7 % (2000) (WHO, 2006)
Prevalence of HIV among adults aged 15-49 in 2009	17.8 (WHO, 2011a)
Annual national deaths caused by AIDS (%)	43.6% (SSA, 2011)
South Africans at risk of Bilharzia	25.7 million (Berge et al., 2011a)
Access to improved water resources	73% in rural areas, 98 % in urban areas (85.5 % at average) (WHO, 2006)

### 3.2 Ugu District

Figure 3.1 Map of Ugu District



Source: (AfriGIS (Pty) Ltd, 2012)

The Ugu district, in which this study was conducted, is one of the ten district municipalities of the KwaZulu-Natal (KZN) province on the East coast of South Africa (UDM, 2009). KZN is a province with 10 819 130 inhabitants (SSA, 2011), and 738 504 live in Ugu District (UDM, 2008).

In 2001, 97.9% of the people in Ugu District lived in rural areas, and 88% of them spoke isiZulu whilst 7% spoke Xhosa. Among all households in Ugu, 64% had a lower annual household income than R (Rands) 9600 (USD 1320.5)<sup>1</sup>, and 79% of all households had an annual income below R19200 (USD 2641.2) (DPLG, 2007). Besides the financial status, education is one of the greatest challenges in Ugu, as one in four inhabitants above the age of 20 had no formal education whatsoever, whilst one in four above the

<sup>1</sup> Numbers taken from bar chart in reference DPLG 2007. Nodal Economic Profiling Project: Ugu: KwaZulu Natal. In: GOVERNMENT, P. A. L. (ed.). South Africa: DPLG and Business Trust.

age of 20 had some primary school education (DPLG, 2007). In other words, more than half the inhabitants of Ugu District had either no education, or had some primary school education. However, among those aged 5-24 years in Ugu District, 71% attended school, a number that exceeds the South African average (DPLG, 2007). In 2005, the total number of schools in Ugu was 624, out of which 426 were primary schools, 154 secondary (high) schools, and the rest were post primary-, combination- and tertiary schools (DPLG, 2007).

According to statistics from 2001, Ugu District comes out worse than the national average in several measurements. The Ugu employment rate was 21%, compared to 33.7% nationally. In Ugu, 79% of households live below household subsistence level, compared to 65.3% nationally. Also, 67% of the Ugu population lacked basic access to water according to government set policies. There was also a lower percent of educated adults in Ugu than the national average. (DPLG, 2007)

All of these factors may contribute to the prevalence of Bilharzia in Ugu (King, 2010). Although it is not so easily seen on the map above, the Ugu district is characterized by rivers that make their way through the rural areas on their way to the ocean. In total there are approximately 70 rivers in the district, in addition to several dams (UDM, 2009). These rivers constitute an additional risk factor to the inhabitants of Ugu, as they often have to cross the rivers, and they have long-lived traditions of using the rivers for daily chores and hygiene purposes.

### **3.3 Zulu Cosmology**

In order to fully understand the context in which this study is done, one has to look at the cosmology of the Zulu people of the province KwaZulu Natal, as they form the majority of the people in Ugu district. Cosmology is a term that refers to the way a people perceives the universe, and how they consider the universe to be organized (Washington, 2010).

### 3.3.1 Zulu Health

In a Zulu tradition, one may divide between different types of illnesses, categorized by the cause of illness. Roughly, the two major groups are *ukufa kwabantu and umkhuhlane*, where the first category consists of illnesses specific to the African people, and hence needs African treatment (Crawford and Lipsedge, 2004). The latter however, *umkhuhlane* consists of diseases that simply occur, in all societies, and that can, if treatable, be treated by modern medicine (Ngubane 1977 in (Crawford and Lipsedge, 2004):133).

#### 3.3.1.1 Traditional healers

One of the Zulu traditions is to consult traditional healers in times of trouble. These healers recognize both external and internal factors as influential to a person's wellbeing (Washington, 2010), also in illness. However, depending on the issue, the Zulu's may also consult doctors who practice Western medicine instead of, or in addition to a traditional healer (Crawford and Lipsedge, 2004).

Traditional healers have been categorized into three different types by Edwards (1987 in (Washington, 2010)); all three types are represented in this paper, as healers from all categories have been interviewed. The first is the *iSangoma* (the diviner), who communicates with ancestors either directly or through traditional rituals (Crawford and Lipsedge, 2004). The *iSangoma* is consulted to diagnose the ill or troubled and to determine the reason for illness or trouble. In many cases, the *iSangoma* therefore functions as a counselor (Washington, 2010). After having diagnosed the patient, the *iSangoma* can then refer them to another traditional healer, like an *inyanga* (Washington, 2010). The *inyanga* is an herbalist, using herbs to cure people from sickness, either mental or physical. In some cases, a person is trained and has been an apprentice in both disciplines, making them able to both diagnose *and* cure.

The third type of traditional healer relevant for this study is the *umthanzi*, who uses prayer to heal people. It has been argued that the *umthanzi* is the newest category to be integrated into the group of traditional healers, as a mix of Christian belief and

traditional African religion (Washington, 2010). Through prayer, God helps the umthanzi diagnose patients, sometimes with help from ancestors, and divine powers also help the umthanzi give the right treatment. However, the *umthanzi* can in addition to prayer and holy symbols also give herbal medicine. (Crawford and Lipsedge, 2004)

### **3.3.1.2 Muti**

The word *muti* is isiZulu, and can be translated to medicine (Labuschagne, 2004, Stewart et al., 1999). Muti is traditionally used to treat people for medical needs, both mental and physical, but may also be used to do harm. The most damaging side of muti is the ways in which some of the “ingredients” are gathered – by murder. Such murders are often referred to as muti murders, and are characterized by the death of a person whom has died after dismemberment of body parts (Labuschagne, 2004). The use of traditional muti in Ugu is of great interest to this study. However the process of making it is not relevant, and will therefore not be further assessed.

## **3.4 The research organization**

University of KwaZulu-Natal (UKZN) has conducted Bilharzia research in KZN from the 1970s. A parasite control program which included mass treatment for Bilharzia was implemented 1998-2001 (Appleton and Mbaye, 2001, Appleton and Kvalsvig, 2006). The initiative has since died out. Although there is a national policy to treat the disease, no funding has been provided (Berge et al., 2011b). Several publications since year 2000 have shown a Bilharzia prevalence warranting mass treatment ((GHO), 2010, WHO, 2012d). Furthermore, in the wake of findings in other countries, UKZN entered into collaborations with the Department of Health and other institutions. The research aims to explore the association of Bilharzia with HIV transmission and susceptibility to other diseases.

## **4.0 Literary background**

### **4.1 Health in Development**

At the United Nations Millennium Summit in September 2000, 189 world leaders committed to ending poverty by the year of 2015, creating the millennium declaration. In making this promise, they also agreed to meet the United Nations' (UN) eight Millennium Goals based on the millennium declaration. Among those eight goals, three of them focus on improving the health situation in the world, mostly among middle- and low-income countries. The MDGs considering health are; No.4: Reduce child mortality and No.5: Improve maternal health and No.6 combat HIV/AIDS, malaria and other diseases. As more than 200 million people worldwide are affected by Bilharzia (King, 2009), and its consequences are considered to be underestimated (Nour, 2010), one might easily argue that preventing and treating Bilharzia is indeed of great importance.

Maslow's pyramid presents medical needs in the base of the pyramid, as a necessity to fulfill safety needs, social needs, esteem needs and self-actualization. This is in accordance with Austveg (Austveg, 2006), who also argues health as a criterion to fully exploit ones potential. The limitations that follow poor health will not only have consequences on an individual level, but also for society at large (Prevention, 2011).

Development is halted by the poor health of millions of people, especially in developing countries (Prevention, 2011). The findings of this study will be reported to staff of the DoH and UKZN through the local research project. It may therefore contribute to improve the MTC, hence increase local knowledge about Bilharzia. A qualitative fieldwork such as this does not have very strong external validity; however, findings will show a tendency that may be valid also in other contexts.

### **4.2 Genital Schistosomiasis**

WHO's report on urogenital schistosomiasis from 2009, played an important part as informative literature to this research (WHO, 2010). Also, the UKZN has conducted

research on the subject, some of which will be used also in this research. These articles will form part of the secondary analysis in the methodological approach. Most of those infected by Bilharzia have acquired the parasite during childhood. It is estimated that in Africa alone, 120 million people are carriers of *Schistosoma haematobium*, while it is estimated that 200 million are carrier's worldwide (Kjetland et al., 2006). During adolescence, it seems that the vulva and the vagina are the organs most commonly affected for women. These damages have been hypothesized to impair the women's protective barriers to secondary infections, and they may therefore be at greater risk of both receiving and spreading sexually transmitted infections (STIs) (WHO, 2012b). The treatment for genital schistosomiasis is praziquantel. However, the efficacy effects of such treatment are poor in regards to clearing of lesions (Kjetland et al., 2006). It has not yet been determined how treatment affects the patient's susceptibility to STIs including HIV (Kjetland et al., 2006).

WHO has made a recommendation that school-age children in high risk communities should receive treatment for Bilharzia annually (Crompton, 2006). School-age children in moderate risk communities should be treated once every two years (Crompton, 2006). Fenwick *et al* claim that a proper treatment strategy can eradicate disease transmission of parasitic and infectious diseases completely (Fenwick et al., 2005). Several studies have indicated an association between Bilharzia and the susceptibility of acquiring HIV (Kjetland et al., 2006, Downs et al., 2011, Chenine et al., 2010). Also other deadly diseases are linked to Bilharzia (van der Werf et al., 2003). Hotez believes that increased treatment especially of young school-age girls at risk of acquiring Female Genital Schistosomiasis (FGS), could not only prevent FGS, but also HIV (Hotez et al., 2009). An important factor in this equation is that South Africa has the largest prevalence of HIV in the world (HIV/AIDS., 2010). Hence, it is evident that preventing and treating Bilharzia is of great importance. The treatment of praziquantel is given in a selection of primary schools and high schools in Ugu District. As previously mentioned, student participation in MTC varied from 20% to 95% in the schools (unpublished results). The reasons for non-participation are unexplored.

Previous studies have suggested an association between FGS and infertility, though it has not been sufficiently investigated (King and Dangerfield-Cha, 2008, Swai et al., 2006, Kjetland et al., 2010). The assumption is that women with FGS have a higher risk of becoming infertile, but there is a great need for more research on this association (Poggensee et al., 1999b).

**Photo 4.1 One of the many rivers in Ugu**



Photo: Andrea Lothe

## 5.0 Conceptual Framework

As a guide for this study, I have prepared a conceptual framework, based on existing theories and a particular model called the Health Belief Model (HMB). This framework impacts and helps shape the study design as well as the methodological approaches. The dimensions of the model used in this framework, are considered relevant to both the main objective and the research questions of this study.

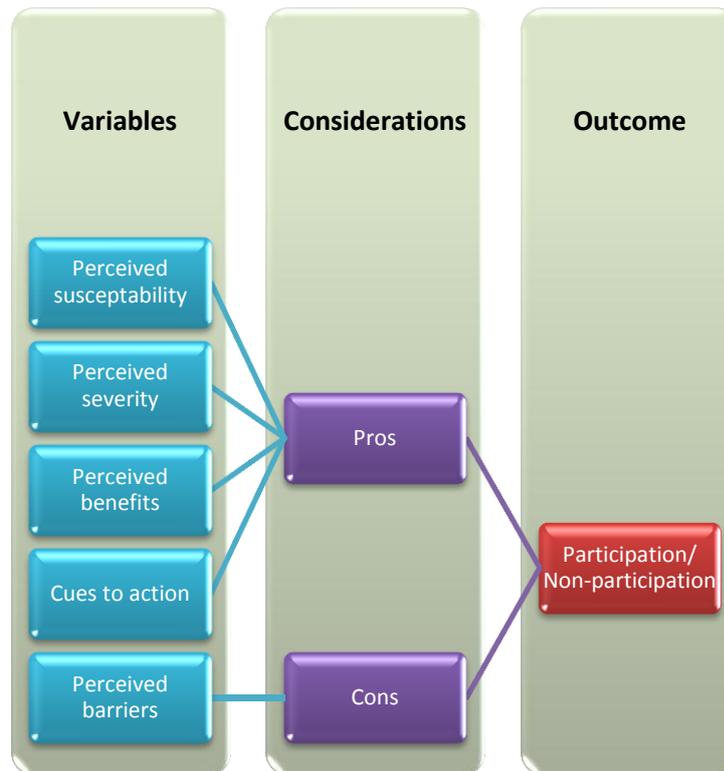
As this study aims at exploring the participation in the MTC against Bilharzia, it seems suitable to apply the “Health Belief Model” (HBM) for the conceptual framework (Rosenstock, 1974). The HBM originated in the USA during the 1950s, when the Public Health Service failed to reach a satisfying level of participation in health-related programs intending to treat or prevent disease (Champion and Skinner, 2008, Rosenstock, 1974). The model was designed to help explain and explore reasons for non-participation in these screening programs (Rosenstock, 1974). However, it has been extended since the 1950s to also include patient’s responses to symptoms and diagnosis (Becker, 1974). It has later been frequently used in various studies of health behavior (Poss, 2001). Participation and non-participation in the MTC may be identified as health behavior, as the action can have consequences on the pupils’ medical condition. For this study, it will therefore be used to explore decisive factors to participation. Prior to any MTC there is a screening process. This was done in the primary schools two years prior to the MTC. As the MTC in high schools primarily covers treatment, treatment will be identified as the final goal when further explaining the model.

The HBM model is based on an assumption that recipients will decide whether or not to accept treatment based on a calculation of pros and cons. The first criterion and key element of the HBM is that the recipient has to believe that s/he is susceptible to the disease, *perceived susceptibility*. If they consider their own risk of infection as high, themselves to be susceptible disease, chances of participation increase. Furthermore, the severity of the disease is taken into the equation, and the recipient evaluates if treatment is necessary. This dimension is called *perceived severity*. The recipient’s perception of possible consequences of the disease will also determine their willingness

to participate, *perceived benefits*. In order to take action, in this case participate in the MTC, cues for action are needed (Poss, 2001). Finally, the *perceived barriers* and costs of treatment will be considered against the potential benefits. If all of these factors lean towards a positive total, chances of participation are expected to be high. (Rosenstock, 1974)

Other dimensions, such as *self-efficacy* and variables such as sociopsychology and demography, may also be included in the model (Rosenstock, 1974). They will be excluded from this study as the timeframe does not allow for the inclusion of all variables. The ones selected are considered more relevant. The *self-efficacy* dimension is included for cases where one is not looking at actions of “one-shot nature”, such as screening or accepting treatment (Rosenstock, 1974). As this study focuses on the acceptance of treatment during the MTC, an action of “one-shot nature”, *the self-efficacy* dimension is also excluded. Figure 5.1 shows how the model looks after having been adjusted.

The HBM model is considered suitable for this study because the dimensions of the model are closely intertwined with the previously presented research questions (RQs). The two first dimensions, perceived susceptibility and perceived severity dimension are relevant to the first RQ, which asks for the general pupil perception of Bilharzia. The third RQ concerning pupil hesitance to MTC participation might be explained by a lack of motivational triggers, or *cues to action*. The latter two dimensions of perceived benefits and perceived barriers are both relevant to the second RQ about perceptions of Bilharzia treatment among pupils in Ugu.

**Figure 5.1 Adjusted Health Belief Model**

Model made by author, adjusted from Rosenstock (Rosenstock, 1974)

If the four variables on the “pros” side are strong while the opposing variable is weak, the pros outweigh the cons, and participation can be expected. However, if the pros are weak and the cons are strong, non-participation is likely.

In order to reach the WHO set aim, at least 75% of children in Bilharzia endemic areas need to be treated (Southgate et al., 2005, (GHO), 2012). When the goal of the MTC is to treat a pupil, the pupil’s perceived susceptibility is of relevance, according to the HBM. The pupil needs to believe s/he might have Bilharzia. Also, the pupil needs to consider Bilharzia as a disease severe enough to require treatment. If both perception of susceptibility and perception of severity are high, the pupil also needs to believe that there are benefits of treating Bilharzia. If there are no perceived benefits of treatment, it is likely that the pupil will lack motivation for MTC participation. To actually take action by accepting treatment however, motivational factors must trigger action. Such triggers can be recognized symptoms (the pupil has noticed blood in his/her urine) or it can be given information of treatment prior to the MTC (Poss, 2001). Finally, the barriers or

costs of accepting treatment need to be considered few or minor. As the offered praziquantel is free of charge for the pupils during the MTC, there is no financial cost. However, there might be social or cultural barriers of accepting treatment, issues that will be addressed later on.

Criticism of the HBM has mainly been based on its lack of uniformity, as its variables have been interpreted and used in various different ways (Poss, 2001). As the dimensions and variables have not been standardized, researchers may apply them as wanted, as done in this study by identifying treatment as the final goal. Also, its lack of standardization lets researchers exclude and include variables to adjust the model for the intended use (Poss, 2001). This has also been done for this study, by excluding *self-efficacy* as a variable from the extended version of the original model. By identifying specific variables, others have automatically been excluded from the HBM, and one can therefore not expect that a full understanding of health seeking behavior is given. This however, is a criticism that could probably be directed to most model in social science as well as psychosocial models (Poss, 2001).

## 6.0 Methodology

It is common to divide research strategies into two, separating qualitative research from quantitative. Some studies, such as this one, utilize mixed methods, integrating both qualitative and quantitative approaches. It has been argued that these two strategies are not compatible (Bryman, 2008). However, in many cases the two overlap, and a combination is plausible to benefit from the advantages of both (Bryman, 2008). A cross-sectional descriptive study has been chosen as the study design for this research in Ugu district, with the Bilharzia mass treatment campaign as main topic. Furthermore, this study is influenced by the researcher's ontological perspective, constructionism, (anti-objectivism) (Bryman, 2008). The researcher believes that social actors in any given community and context contribute to the shaping of that community. A social context is in continuous evolvement, characterized by its participants. The epistemological view of the researcher is one of interpretivism, an anti-positivist view with a belief in causal explanation (Bryman, 2008). In accordance with interpretivism, the researcher believes it is essential to contextualize in order to understand the given setting and issue in question, in this case Bilharzia.

Method triangulation is used, and may be described as a combination of various approaches to data collection (Bryman, 2008). Such triangulation, if used correctly, may provide a validity check, and also to give "added depth to the description of the social meaning involved in a setting" (Hammersley and Atkinson, 2007). A combination of in-depth semi-structured interviews, focus group discussions and statistics will be used to achieve a deeper perspective of the issues related to Bilharzia. As qualitative methods are often about comparison within or between limited individual communities, qualitative methods were applied in this study, to compare genders and schools (Repstad, 2007). Quantitative methods are known to employ measurements of larger samples (Bryman, 2008), and give a wider understanding, as opposed to qualitative data which often give a deeper understanding. As a total of 97 people were interviewed, quantitative approaches were also considered suitable.

**Table 6.1 Overview of informants divided by category and gender**

	Female	Male	Total
Teachers	2	4	6
Pupils	44	43	87
Community helpers	2	2	4
Total	48	49	97

## 6.1 Fieldwork Context

The researcher needed to conduct fieldwork to gather primary data as very little had been published in South Africa on the constraints of conducting mass treatment against Bilharzia (Appleton and Kvalsvig, 2006). This way, the study does not solely depend on secondary data. Prior to starting the fieldwork, contact was made with a local research project in Ugu district and a literature search was done.

### 6.1.1 Primary Data Collection

#### 6.1.1.1 In-depth semi structured interviews

Qualitative in-depth interviews were used to explore the interviewees' personal experiences of Bilharzia treatment, and to develop an understanding of attitude towards it. They were conducted as semi-structured interviews, to allow some digressions and follow-up questions.

The qualitative research-interview is known as a way to get access to the interviewee's own description of their situation (Dalland, 2006). The personal contact between researcher and interviewees has been criticized. This criticism is based on an perception that in-depth interviews are too idealistic and individualistic (Bryman, 2008). The interviews are intended not only to explore the situation of one individual, but to potentially explore the general teenage attitude towards Bilharzia and treatment of Bilharzia. Such generalization is difficult to reach, but if the same questions are posed to many interviewees, the findings may still be valid to the majority of a group, which in this case will be teenagers in the Ugu District (Dalland, 2006).

Six schools were selected in rural areas, and pupils were approached during school hours. As approved by teachers, interviews were conducted during lunch breaks. All interviews were conducted in rooms where fellow students and teachers were not able to hear what was said. This was important to ensure the confidentiality of the interviewee.

### ***6.1.1.2 Focus group discussion***

A focus group may be defined as “a group that is given a specific theme for discussion” (Halvorsen, 2008), and it functions more or less as an interview, only with several interviewees (Bryman, 2008). Focus group discussions (FGD) were conducted in selected schools in Ugu District. The FGDs provided insight in how teenagers communicate the topic of Bilharzia amongst one another, and towards others (Bryman, 2008). One of the main characteristics of the FGD is how people interact and discuss as members of a group, not solely as individuals. As in a semi-structured or open interview, the FGD allows for digression. In a focus group the participants are presented with a topic to discuss, whereas an interviewee in an in-depth interview (IDI) is asked a question. It may therefore be expected that there will be more diversions in a FGD than in an IDI. One of the FGDs great advantages is that the participants often probe and challenge each other (Bryman, 2008). A topic is presented to the group, in this case Bilharzia, and the group shares thoughts and discusses the topic, with some guidance from the moderator. A typical size of a focus group is 5-10 participants (Bryman, 2008). The focus groups of this study consisted of seven participants, well within the typical size. An isiZulu speaking moderator runs the FGD and guides the session, by use an interview schedule. The researcher is also present at all times, observing and taking notes. One of the great challenges in FGDs is the transcription process, which is considerably more complicated than in individual interviews, as participants often talk simultaneously, making it difficult to distinguish the interviewees from each other (Bryman, 2008). The moderator of the focus groups was also the one transcribing and translating them - utilizing a voice recorder and notes made by the researcher.

As in the in-depth interviews, the focus groups were organized in rooms where fellow students or teachers were not able to hear what is said to ensure confidentiality. The students were divided according to gender, and focus groups were formed based on gender.

### **6.1.2 Secondary Data Collection**

Secondary data, such as previous research findings from the area, played an important part in the initial phase of the research. These data provided a lot of both general and specific information about Bilharzia. Articles were read that contain information on the prevalence of the disease, water contact, risk behavior and psychological issues in patients living in Bilharzia endemic areas. Local staff from a research station in the area provided professional and cultural advice and also background information. (Bryman, 2008)

#### **6.1.2.1 Statistics**

Excel is used to analyze quantitative data in this study. These data were extracted from the conducted interviews and focus groups, with an emphasis on the FGDs. Several multiple choice questions were posed to all participants in the focus groups and responses were noted. The data have then been inserted into spread sheets, and further made into bar charts.

## **6.2 Study population and sampling**

All interviewees are inhabitants of the Ugu District. There were three main groups of interviewees, (1) teenage students in grades 8 – 11 in high schools that had participated in at least one round of the MTC organized by the Ugu District Department of Health, (2) teachers for grades 8 – 11 in the selected high schools and (3) community helpers – entrusted people in the study areas.

Purposive sampling is used for both focus group discussions and in-depth interviews. The Department of Health had already been in contact with the selected schools through the MTC. The selection criteria are: all interviewees are inhabitants of Ugu District, all pupils are in grade ten to twelve in schools that had been visited by the MTC, and they are divided by gender. Purposive sampling was done to ensure a wide range of participation rates for the prior MTC. Among the six selected schools, three had low participation rates; two of them had 10% and one of them 20%. The remaining three schools had the highest participation rates of the district, 50, 60 and 70%. Also, the selected schools were situated in different zones, and different kinds of settlement; some in rural areas, and some in peri-urban areas (unpublished data, Myra Taylor).

The sampling is done through a theoretical approach, where the goal was to reach theoretical saturation. Theoretical saturation is reached when a pattern can be seen in the given responses, and it becomes somewhat predictable. When no new information emerges, one has reached theoretical saturation (Bryman, 2008). Also, the theoretical saturation is needed to be able to quantify some of the findings in the study (Bryman, 2008). A high number of interviewees was also beneficial when the study takes aim at comparing boys and girls, and also schools with low participation rates with schools of high participation rates (Bryman, 2008).

Two FGDs with seven participants in each were arranged in each school, divided by gender. One female and one male pupil were interviewed individually, as well as a teacher from each school. In the final phase of the fieldwork, community helpers were interviewed from two of the school areas. These community helpers were identified by people living in the given communities as people that were trusted to be able to help others from the community with health issues. Hence, the community helpers were chosen through convenience sampling. Some pupils withdrew from the study, so the number of interviewees was slightly reduced. In total, 44 female pupils, 43 male pupils, six teachers and four community helpers participated in the study, adding up to 97 participants.

## 6.3 Challenges in use of methodological approach

### 6.3.1 Language

The language of an area is a tool of great importance, as it is through this that we ask questions, and answers are given (Bryman, 2008). Languages are not merely words, but also speak of our culture and our cosmology. Our language also reveals what is of importance to us (Patton, 2002). In languages that are very different from English, such as isiZulu, one simply cannot directly translate all words into English (Kapborg and Berterö, 2002). The word might either lose its original meaning, or may be taboo in one of the languages. An example of language taboos from the study area can be given: In teaching pupils about common water-borne diseases and worms, it was discovered that the isiZulu word for worm, “iskelemu”, is of an embarrassing character. It is associated with malnutrition and is considered a baby’s disease. Therefore, it is considered humiliating for a young adult to have worms. Such examples show that it is of great importance that the researcher spends some time to get to know the culture, the contents of terms in the given context and words relevant to Bilharzia.

One of the major challenges in this research is the fact that several languages are involved. My native language is Norwegian, but I speak English quite fluently. But as the research is conducted in an area where the majority speaks isiZulu, and some very few speak Xhosa (DPLG, 2007), four languages are involved. The Xhosa interviewees of the study were fluent in isiZulu, and went to isiZulu speaking schools. And as the researcher also speaks English, the main challenge exists in the translation English-isiZulu. An interpreter conducted the vast majority of the interviews in isiZulu, whilst the researcher conducted some teacher interviews with teacher whom spoke well English.

All interview guides were initially written in English, and then translated to isiZulu by the interpreter. In these translations, the researcher had no competence to know whether the questions were modified or directly translated. The translations were therefore double checked by two other isiZulu-speakers at the local research project to ensure the accuracy of the translation. Also, as an interpreter conducted the entire interviews in isiZulu, and later translated them into written English, she did not have to

rush the translation. To be able to do this properly, a tape recorder was used, and the challenges of this will be discussed in a later chapter.

### **6.3.2 Taboo**

A taboo may be defined as “a social or religious custom prohibiting or forbidding discussion of a particular practice or forbidding association with a particular person, place, or thing” (Press, 2012). Studies on Bilharzia in other countries than South Africa portray communities where the disease is considered taboo (Ukwandu and Nmorsi, 2004, Kvalsvig et al., 1991). Worm diseases among children are considered normal and can easily be spoken about amongst friends. However, as a child reaches adolescence, worms and similar diseases are perceived as embarrassing, and are not talked about, not by mothers or by the infected adolescent. In South Africa, some children experience such taboo related to Bilharzia already before adolescence and puberty.

This taboo constitutes an additional challenge in conducting research on Bilharzia among teenagers. The researcher therefore strived to create an atmosphere during the interviews where Bilharzia was not embarrassing, and aimed to keep the conversation as casual as possible. It may be expected that by increasing the local knowledge on the causes of Bilharzia, the taboo will decrease (Hivos, 2011).

### **6.3.3 Use of interpreter**

Due to the language barriers, it was necessary to use an interpreter in conducting the data collection. The interpreter is a female Zulu master’s student born and raised in KZN. She has studied development studies and communication, making her suitable for this type of study. She is brought up in a Zulu home, but has studied in English-teaching schools, and is therefore fluent in English as well. The researcher and the interpreter spent a month together at the local research project prior to conducting the fieldwork, getting to know each other and preparing the data collection. Some guidelines were agreed upon, such as dividing of responsibility in the field. It was agreed that all

interviews in isiZulu were to be conducted by the interpreter, following an interview guide adapted to the local decorum in collaboration with local research staff. The interpreter was told which questions might need probing, and knew the purpose of the study very well. She was therefore given a large amount of trust to help gather the necessary data.

In some occasions the interviewee's reaction to a question triggered the researcher's interest. For instance, they might start laughing during a more serious section, look down a lot or shake their heads vigorously. The researcher would then ask which question was asked, and the interpreter would explain. At the end of all individual interviews and FGDs, the researcher would ask the group or interviewees whether s/he or they had any questions or comments to the interview. Some then talked to the interpreter, who translated to the researcher, and some talked directly to me in English.

The role of an interpreter is of great importance to data collection, as their interpretations greatly contribute in shaping the findings (Freed, 1988). The words and phrases used in a question will partly determine whether or not the interviewee is comfortable answering honestly (Bryman, 2008). In order to get the interviewees to trust us and be comfortable enough to speak freely, it was of great importance for the researcher that all interviewees felt comfortable during the interviews. The interpreter played an essential part in achieving that.

The same interpreter was used in all interviews, contributing to continuity and consistency in the research. There are risks to using the same interpreter for such a long period, as the interpreter might feel saturation is reached earlier than the researcher, or might even get bored. There was also a risk of lacking motivation, as the interpreter was not given any monetary payment. However, as this research will be attempted to be published, the interpreter and the researcher have agreed to write an article together, with the interpreter as a second author. Furthermore, the interpreter thought this study might help her decide how she will conduct the study for her own master's thesis. As she by time knew this study very well and was trustworthy, it is considered an advantage for this study to use the same interpreter throughout the whole process of data collection.

#### 6.3.4 Use of tape recorder

There are both advantages and disadvantages of using a tape recorder while conducting interviews. Patton perceives tape recorders as essential instruments while conducting qualitative interviews, and argues one cannot do without them (Patton, 2002). When a tape recorder is used, it gives the researcher and interpreter the opportunity to focus on the interview. Full attention may be given to the interviewee(s) by nodding, smiling or responding in other ways. Without the tape recorder, one might be too busy taking notes to be able to give undivided attention to the actual situation. However, some stress that tape recorders should not be used unless absolutely needed (Lincoln and Guba, 1985). One of the strongest arguments for not using a tape recorder is the intrusiveness it may cause. When doing research in rural or peri-urban areas such as in this study, many of the interviewees have never before seen a tape recorder, and most had certainly never been recorded before. However, all interviewees were informed through an informed consent form that there would be a tape recorder, and the absolute majority seemed comfortable with it. Some female pupils whom participated in FGDs tended to be shy about it, and would speak very quietly at the beginning of the interview. They would warm up and speak louder as the discussion progressed though. There were only two cases where the tape recorder was given a lot of attention, and both were with male interviewees. Firstly, a male pupil in a FGD tended to lean forward and speak directly into the tape recorder to make sure he was properly recorded. He did not seem uncomfortable and spoke very freely. It was, however, clear that he was very conscious about the presence of the tape recorder. The second case was when interviewing a male teacher. He was somewhat hesitant to sign the consent form because of the tape recorder. When it was properly explained that the tapes were kept safe until transcribed and deleted however, he gave his consent. There are still some considerations one has to take when using a tape recorder.

First of all, if one chooses to use a tape recorder, interviewees need to be made aware of it. For this study, the written informed consent form contained information on usage of tape recorder. Also, interviewees were informed that all tapes would be deleted after

having been transcribed and checked, so they should not worry about their tapes being “leaked”. Before hitting the “record” button, the interpreter and the researcher introduced themselves, and served the interviewees their food. Their age and grade was noted, and once again the voice recorder was introduced. So when the “record” button was pushed, no more names were mentioned.

To supplement the transcription, the researcher took notes of body language during the interviews, noting the time. If for example the interpreter/moderator asked the focus group whether they had ever talked to their boy/girlfriends about Bilharzia and they all started giggling or hiding their faces, the researcher would note the time, and the action (i.e.: 10:34, Pear [code name] giggling). The researcher would also note it if participants responded by nodding or shaking their heads, responses that would not be recorded by the tape recorder.

All isiZulu interviews were transcribed into English by the interpreter, and most of them were quality checked by two other English-speaking Zulus. When quality checking, they listened to the tapes while reading what was transcribed, one by one. The English interviews were transcribed in English by the researcher, and all of them were quality checked by two English-speaking Zulus, one by one. As soon as they were quality checked, the tapes were erased.

### **6.3.5 Use of statistics**

Most of the statistics used in this paper are provided by “Statistics South Africa” (SSA). Such state-run statistics might be misleading, as they are based on cases that have been reported to public offices, missing all other cases. However, using official statistics was considered to be the best option for this study, as private actors might also have misleading numbers, and seemed less comprehensive. (Bryman, 2008)

Official statistics were first used in the initial phase of planning the fieldwork, to achieve general knowledge about South Africa. Further on, statistics concerning health-issues were looked into, to better understand the topical context. During the fieldwork,

unpublished data were also used to more fully comprehend the issues or limitations of the MTC. These data showed participation rates in different schools as well as indications to Bilharzia prevalence in the area.

#### **6.4 Research Ethics**

As a researcher in a foreign country and culture a lot of ethical considerations had to be made continuously, before, during and after the fieldwork. For instance, rooms in which the data were collected were situated so that fellow students or others could not hear what was said during FGD or individual interviews. This was a measure to ensure confidentiality in the participation of the study. Furthermore, when doing social research in South Africa, research permission is needed. Four ethics' committees have granted permission to conduct the research: the Biomedical Research Ethics Administration, University of KwaZulu-Natal KZN on February 20<sup>th</sup> 2011 (Ref BF029/07), the Department of Health, Pietermaritzburg, KZN, February 3<sup>rd</sup> 2009 (Ref HRKM010-08), the Norwegian ethics committee, Regional Etisk Komité Øst-Norge (REK-Øst), gave ethical clearance in September 17<sup>th</sup> 2007 (Ref 469-07066a1.2007.535) and The European Group on Ethics in Science and New Technologies in 2011 (Ref IRSES-2010:269245). The Department of Health and Education in Ugu district, KwaZulu-Natal has also given permissions. The local research project has been granted such a research permission to study Bilharzia and associated diseases, a permission that also covered this study.

Diener and Crandall (Diener and Crandall, 1978) mention four main principals in research ethics, all of which were applied in this study. The first principle states that research should not cause harm or damage to the participants. The second principle puts emphasis on informed consent. Thirdly, privacy should be protected for participants, and finally the researcher is responsible for avoiding deception.

#### **6.4.1 Harm to participants**

The first, and maybe most important ethical principle, states that social research should not cause harm to the participant. In many cases, the researcher may cause such harm unintentionally, as s/he does not fully understand the consequences of participation in the research (Bryman, 2008).

As a precaution to the primary data collection, local research staff was consulted in order to avoid harmful questions and approaches. When entering a classroom, the interpreter explained that this was a study where pupils would be randomly selected and that it was voluntary. Pupils were then asked if they would want to participate. In that manner, other students did not suspect that the chosen participants were picked due to any particular reason, for example that they were all affected by Bilharzia. Also, the participants were at no point asked if they themselves had ever been infected by Bilharzia neither in individual interviews nor in FGDs. All information on the participants is safely stored, only by use of ID numbers, excluding names.

#### **6.4.2 Informed consent form**

An important ethical principle is that of informed consent. As the British Sociological Association states, the researcher has a responsibility to thoroughly explain the study to the participants, so that they can give informed consent to be a part of it (Bryman, 2008). This may be given either orally or in written form. For this study, the researcher chose to make written informed consent forms for participants, both in English and in isiZulu. Firstly, a phone-call was made to the school in question, and a meeting with the principal was arranged. At the meeting, the study was presented to the principal or in one case to a teacher chosen by the principal and oral permission was given to randomly choose participants.

All participants were given time to properly read the forms, and sign them before data collections were conducted. The large majority of interviewees in this study were pupils in high school, and the consent form was written so that the interviewees had to be 16

years of age to sign them. If they were younger than 16, they needed parents/caretakers consent and a signature from a parent or caretaker. The consent forms were therefore handed out to the chosen participants at least 24 hours before the day of the interview. In most cases, the pupils had approximately a week between being asked to participate, and to the actual interview.

The consent forms informed the participants of the objectives and purpose of the study as well as the background of the researcher. Furthermore, it explained that the participants were free to withdraw from the interview or FGD, and that they had the right not to answer any given question. Participants were informed that all sensitive information containing identification of the interviewee would only be read or heard by the researcher and the moderator/interpreter. The form also contained information saying that parts of the interview might be used in the final thesis and/or publication, with no identification to track back to the interviewee. The participants were thereby informed that participation was voluntary, and were finally asked to sign the form if agreed. Most consent forms were written in isiZulu, and some in English, if preferred. In some cases where the level of literacy was low, or in visual impairment, the interpreter/moderator read the consent forms out loud to ensure that the participants fully understood its contents.

Even though several measures were taken so that the participants were well informed, one has to question whether the youngest participants fully understood the concept of research (David et al., 2001). The youngest ones to be interviewed were 15 years of age, and had never before participated in a study. However, considering that consent forms were handed out in due time before the interviews, it was considered acceptable to include all agreeing participants.

The participant was still free to withdraw after having signed the informed consent form and the researcher in cooperation with the moderator/interpreter continuously evaluated the comfort of the participant and did not probe if the participant seemed too uncomfortable.

### 6.4.3 Confidentiality and right to privacy

Although interviewees sign an informed consent form, they have the right to withhold information they do not wish to share (Bryman, 2008). Even though it is the participants' right to say no, the researcher should not ask questions that s/he feels breach a privacy limit.

When meeting the principal and/or contact teacher, the researcher always asked them for help to arrange for a venue. These were venues where interviews and FGDs for pupils could be conducted as privately as possible. Most schools had an available room for such purposes. If not, the principal's office, the staff room or simply the researcher's car was used as a venue. In all cases, fellow-pupils would be curious as to what was going on and what was said. However, FGDs were conducted during lunch hours, so the level of noise from the outside was usually so loud that passing fellow-pupils would not be able to hear what was said inside. Also windows were kept shut and the participants were placed on the opposite side of the room from the windows. A tape recorder was always used during the FGDs to transcribe at a later stage. Before the tape recorder was started, all interviewees were asked to choose a code name. In the male focus groups, participants were asked to choose a car they thought was cool, whilst girls chose either a fruit or a celebrity. This way, none of the tapes contained any sensitive information on the participants' identities. Records of the participant's names were never stored digitally, but only on a paper sheet safely stored with the researcher. That piece of paper was destroyed before returning home from the field.

Most teacher's interviews were conducted in a school office, whilst the interviews of community people were all done in their homes. In all these "adult" interviews, the tape recorder was only started after the interviewee had stated his/her name.

The researcher had no knowledge of whether or not interviewees had ever been ill with Bilharzia, and also did not ask about it. However, some interviewees willingly told the other FGD participants that they had previously had Bilharzia. In such cases, they were usually met with interest and questions from fellow-pupils. As I will come back to later,

having Bilharzia does not seem to cause any trauma or stigma to the patient in Ugu district. Still, the researcher had to consider the pupils ability to protect their own privacy, by not sharing information that might later harm them, or that they might regret sharing. In retrospect, it is believed that no such information was shared, also because the topic was not of a harmful character.

#### **6.4.4 Deception**

Deception occurs when a researcher presents the study in a false way or misleads participants when explaining the purpose and aims of the study. In this study, the researcher has done everything possible to avoid deceiving research participants. As mentioned above, one of the means used to properly inform the interviewees were the informed consent forms. Deception does sometimes occur in social research, where the researcher does not desire to give a complete description of the study to the interviewees (Bryman, 2008). However, this study has no hidden agenda or aspect to it that would shame the participants. There was therefore never a need or wish to keep information about the study secret from the participants, their schools, the DoH or the politicians. Hence, there is no deception.

#### **6.4.5 The researcher's role**

A researcher undoubtedly affects the findings and results of a research. As a female researcher with a European cultural background, I started my fieldwork with a full set of preconceptions and values. These factors determined my field of interest, affected my research questions and generally influenced the entire study. It is largely recognized that such sets of values cannot be zeroed out during a fieldwork such as this (Bryman, 2008). However, as an interpretive study, the researcher strived to consider the local context and the Zulu culture when analyzing data.

As a foreign researcher, my presence in the interviews and focus groups clearly affected the participants. In agreement with the moderator, we decided to be aware of our own

body-language during the FGDs and IDIs to attempt to create a relaxed environment. Therefore, the way of interacting was informal and the researcher and moderator sat either on desks or with one foot on the edge of the chair. Such body language may affect the participants and their perception of what this would be like (Legard et al., 2003).

To compensate for taking their lunch break, food and drink was provided for all participants. The served lunch was kept simple, usually a chicken burger, an apple and a box of juice. When the interviewees had agreed to participate, they were informed of this, so that they would come straight to the interview venue instead of eating lunch first. Some schools were “feeding scheme schools”, where pupils are given free lunch. In a couple of instances, the pupils in those schools were a bit late to the FGD as they had first collected their lunch. Interviewees were allowed and encouraged to eat during the interview, as we used their lunch-break, and also to keep it informal. In all interviews the moderator and the researcher also ate with them.

As a strategy in all interviews, neither the interpreter nor I corrected the participants if they had misconceptions about the topic. As such misconceptions were also of great interest to the study, we simply let them continue the discussion or interview without corrections. However, after every interview we asked if the participant(s) had any comments or questions, which they usually did. We then responded to their questions, some of whom queried facts about discussed topics. The researcher finally asked the participants what they felt about the session. The majority said it was fun, and some even asked if we could repeat it sometime in the future. Some said they learned a lot by discussing with their peers, and now knew much more about Bilharzia than before, only through dialogue with fellow pupils.

The researcher receives more from the participant than what is given back. However, some studies might also have benefits for the participants. The informed consent form stated that the benefits of participation in this study, is their contribution in enhancing local knowledge on Bilharzia. This is an indirect benefit however, as it will not constitute a practical change in their lives. On the other hand, their contribution is plausible to help improve the MTC lead by the South African DoH. They may benefit from such

improvements, as a more efficient MTC might decrease the prevalence of Bilharzia in Ugu.

## 6.5 Validity and Reliability

When making an assessment of the quality of a social research, it is common to use the terms validity and reliability. The two terms represent different criteria to assure good quality of a study. Validity refers to “the integrity of the conclusions that are generated from a piece of research” whilst reliability is “the degree to which a measure of a concept is stable”. Originally *validity* and *reliability* were concepts applied to explore the quality of quantitative research. It has therefore been discussed whether the terms are applicable to qualitative research. Yet, the terms are widely used in both approaches, and many also argue that the terms may be made valid for qualitative research, basing them on internal and external validity, and internal and external reliability (LeCompte and Goetz, 1982). These terms have therefore been taken into account in this study. (Bryman, 2008)

*Internal validity* is reached if the observations of the researcher match his/hers theoretical ideas (Bryman, 2008), in other words when the researcher can demonstrate that there is evidence for the statements and descriptions made (Kapborg and Berterö, 2002). As this study is based on fieldwork, it might have the advantage of contextual understanding (LeCompte and Goetz, 1982) and is believed to meet the aim of internal validity. However, being a case study is not an advantage when it comes to *external validity*, as the findings from this study cannot be generalized to be valid for larger populations or to other areas. Qualitative research often does not aim at being generalizable, especially case studies. On the contrary, a case study focuses on a limited geographical area, hindering external validity. If one uses the alternative term *transferability* however, the findings from this study may be used as a database when addressing another context. (Bryman, 2008)

External reliability depends on the “degree to which a study can be replicated” (Bryman, 2008):376. If a researcher was to replicate this exact research, s/he might possibly reach

the same findings as presented in this paper. However, as social settings are in continuous change, it very much depends on the time passed since this research. This is what constitutes the challenge for qualitative research, and therefore inhibits *external reliability*. The use of method triangulation can balance out the disadvantages of qualitative methods in relation to validity and reliability. As for *internal reliability*, it is considered less relevant in this study, as there was only one researcher. During the fieldwork however, an interpreter/moderator participated in all interviews, and agrees with the understanding of observations made. She fulfilled the same role throughout the study. (Bryman, 2008)

## 7.0 Empirical findings

Throughout the fieldwork, empirical data was collected, most of which are presented in this chapter. As a manner of organizing them, the findings are presented by categories, based on common characteristics. The findings are based on the perceptions of interviewees; pupils, teachers and community helpers, and are sometimes linked to theories on similar data. The researcher's analysis of the findings and their relevance to the MTC are not presented in this chapter, but will be further discussed in chapter 8. Chapter 7 intends only to present the findings.

### 7.1 Bilharzia as a disease with low grade of severity

The majority of interviewees explained Bilharzia as a minor problem, with few or no serious consequences. When asked about what Bilharzia does, the majority responded only by mentioning symptoms such as blood in urine, discomfort when passing urine and urinating often. Also, some adult interviewees claimed Bilharzia was a big problem some twenty years back, but that it is not a current problem in Ugu. One teacher even said that Bilharzia was eradicated in Ugu.

Approximately a third of the informants were under the impression that Bilharzia is a disease that may heal on its own, some thought that it usually does, and a few thought that it always did. They explained that it might sting when you urinate, and that you might find there is blood in your urine. These were clear symptoms that you had Bilharzia. But after a while (might be a week, might be some years), all the symptoms would disappear, and your body had healed. A teacher said he had been ill through Bilharzia when he was a young boy. He said there had been no need to treat it however, as it had disappeared on its own after some months. He did not know how it healed, but was happy it did.

In the cases where it does not seem to disappear on its own, or for the people that think it should be treated, traditional medicine is available, in addition to modern medicine.

Pupils reported that they had been referred to iSangomas and inyangas by parents or elderly relatives for treatment of Bilharzia. According to the pupils, one has to go to such traditional healers if an elderly tells you to. Most pupils said that they would have gone straight to a clinic of modern medicine if they had not been told to first seek traditional help.

Though it seemed like the majority of interviewees did not consider bilharzia as chronic or severe, some had heard about the risk of infertility. A female pupil said that the fear of infertility should be a great motivational factor for participation in the MTC. As symptoms do not always manifest themselves (Harries et al., 1986) though you have Bilharzia, she argued that you should treat it while you are young – as a precaution. The interviewee said that you might not know you have Bilharzia until you are married and discover you cannot give your husband babies.

## **7.2 Bilharzia as a stigma**

Stigma related to a health issue or disease may be defined as “social disqualification of individuals and populations who are identified with particular health problems” (Weiss et al., 2006). More specifically, a person who is a victim of health-related stigma experience exclusion, judgment and rejection based on the health situation. The stigma cannot be justified based on medical grounds, but is more of a cultural phenomenon (Weiss and Ramakrishna, 2006). Such exclusion will further affect a person’s social life, challenging and reducing their ability to prosper (Sen et al., 2000). Historically, the term stigma was used to describe someone who had been branded or was scarred (Weiss et al., 2006). A brand or scar does not simply disappear, and one might therefore say that stigma was something permanent.

A person’s access to health care appears to decline if s/he is a target of stigmatization (Ribera et al., 2009, Weiss et al., 2006).

Prior to the fieldwork, the researcher discussed stigma with staff at a local research clinic, and was under the impression that Bilharzia might be stigmatized in KZN. Stigma

has been described as a social consequence of Bilharzia in Southern Africa before (Ahlberg et al., 2004), especially urinary bilharzia (Hotez et al., 2006). A male teacher mentioned stigma in relation to Bilharzia, and claimed it is similar to the stigma of having AIDS. As the following chapter will present, pupils are often teased about having Bilharzia. The teasing seems to cease however, when the disease is cured. As reported by an interviewee, one student was teased for having Bilharzia, but as soon as she was well, she participated in the teasing of others with Bilharzia. If the teasing ceases as soon as a person is no longer infected with Bilharzia, it may not be correct to use the term stigma, as it implies a more long-term condition. In some cases, as will be presented later, people relate Bilharzia to sexual behavior. In those cases there might be stigma, but this study has not looked further into such cases.

However, there are physical consequences from Bilharzia that may cause stigma, such as infertility (King and Dangerfield-Cha, 2008). Such cases will be further discussed in chapter 8.2.

### **7.3 Bilharzia as an embarrassment**

In many discussions and interviews Bilharzia was mentioned as an embarrassment in different ways and for different reasons. Such embarrassment may adversely influence MTC participation rates in schools. When asked if they would prefer to take the treatment in private, unattended by peer students, approximately half of the interviewees said yes. The others said they would prefer to take it in the classroom, with peers present. The pupils were also asked who they would be comfortable confiding in if they found that they had Bilharzia. Categories of people they could potentially inform were presented, and the interviewees then discussed amongst themselves whether or not they would tell these people. After some discussion, the number of interviewees who *would* tell the presented category was asked to raise their hand, and numbers were noted.

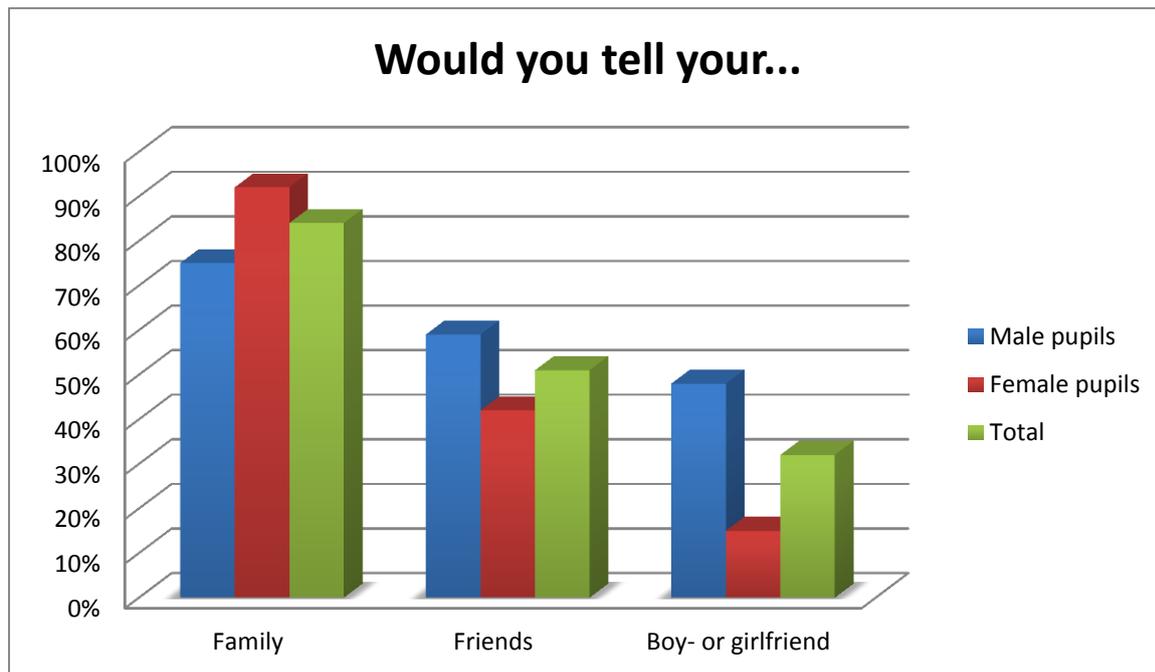
**Figure 7.1: “Who would you tell” bar chart**

Figure: Andrea Lothe

All interviewees were asked the same questions, but not all responded. In the family category, 41 pupils responded from each gender, comprising 82 respondents in total. For the friend category, 31 female and 39 male pupils responded, adding up to 70 in total. In the question if they would tell their boy- or girlfriend, 41 male pupils and 40 female pupils answered.

As shown in the bar chart above, the vast majority of female pupils would tell a family member if they had Bilharzia, whilst they would prefer not to tell friends or boyfriends. This may be explained by a lack of trust, an issue that will be further discussed later on. The male learners on the other hand, were a bit more reluctant in telling a family member if they had Bilharzia, but the majority of them tell a friend about it.

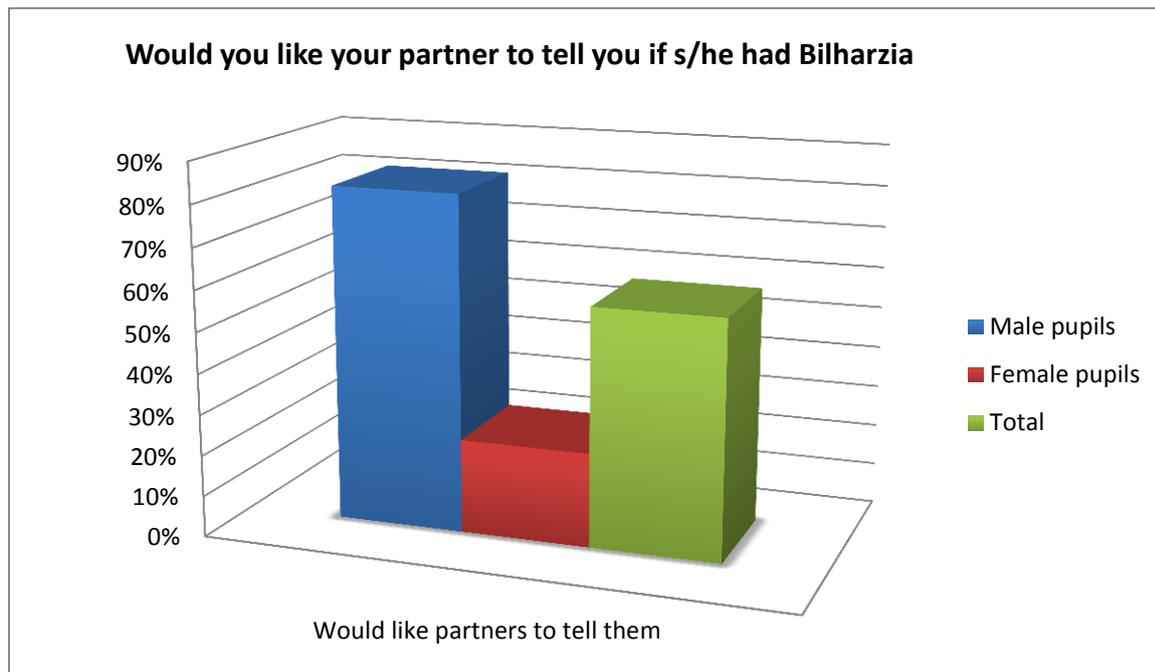
**Figure 7.2** “Would you like to know” bar chart

Figure: Andrea Lothe

Finally, pupils were asked whether they would want to know if their partners had bilharzia. 29 male pupils and 21 female pupils responded to the question. Amongst them, less than one in four female pupils would like to know if their partners had Bilharzia. However, the vast majority of male pupils would like their girlfriends to confide in them if they had Bilharzia.

### 7.3.1 Use of the river

Traditionally, laundry, bathing and swimming were all activities that took place in rivers, lakes and dams. As late as in 2001, 33% of the inhabitants of Ugu did not have basic access<sup>2</sup> to piped water (UDM, 2009). As access to clean water has increased (Bank, 2012), many households now have the facilities to do laundry and bathing at home. Thus, going to the river for laundry, is perceived as dirty and a sign of poverty (lack of access to clean water). One of the pupils said that even though most houses have tapped

<sup>2</sup> Defined as not having piped water within a distance of 200m of dwelling (South African government policy on minimum basic human need)

water now, some parents were very careful with how they use it. Bathing in tap water may be considered as a “waste of water” whereas the river has unlimited amounts of it. Another girl confirmed that the rivers are still very much used in daily life and said: “We collect water from them, drink from them - everything we do from them”.

It seemed as though all interviewees knew that rivers and dams were places where one might get Bilharzia. Some even said that parents had been very strict and forbade swimming and playing in the rivers. Surprisingly though, some mentioned parents whom encouraged their children to play in the rivers. A male focus group interviewee said this about some parents:

They say “go and swim and be happy with your friends. It’s your right”. It’s their right they say, and this causes Bilharzia to spread. They end up say never mind this Bilharzia because the older generation has this habit of taking things lightly     -*Informant 96*

An adolescent pupil said that having Bilharzia might be perceived as a very rural, thus embarrassing thing.

It’s just that people are becoming more township. You see if you talk about Bilharzia they just say you are from the farms. They just criticize you. They criticize you with everything they can     - *Informant 24*

When the interviewee uses the term “township”, she is referring to the township culture as opposed to the rural culture. But rivers flow through all parts of Ugu, also the peri-urban areas, and many pupils have to cross these rivers on their way to school. When driving out in the peri-urban and rural areas of Ugu, it is easy to see that many of the bridges will be flooded by water when there is heavy rainfall. So even if the pupils do not take shortcuts through the river purposively, they might sometimes have to be in contact with water in order to get to school.

### 7.3.2 Sexual association

In every age group, interviewees believed that Bilharzia can be sexually transmitted. A 17 year old girl said:

Okay, I think that you can get Bilharzia sexually because it is something inside you. It's the blood that is dirty inside you right? So when you have intercourse so definitely you will get it because the dirt will come inside you      *-Informant 70*

A male interviewee did not perceive Bilharzia as a sexually transmitted disease, but was worried his mother did. He would therefore be very hesitant telling his mother if he had Bilharzia, out of fear of a misunderstanding. "I will not say: mom I have Bilharzia because mom won't fully trust me. She would think a lot she won't tell herself that I was swimming she will associate it with sex so I will hide it from her." However, according to one of the interviewed iSangomas, it is quite common to differentiate between age groups when considering the sexual aspect of Bilharzia. Both iSangomas claimed that it is more common to suspect sexual transmission with adults than with children. Generally, Bilharzia is perceived as a disease that mainly infects children, as they go swimming in lakes and rivers on warm summer days. However, if an adult woman claims she has Bilharzia, some believe that she is using Bilharzia as a cover for hiding that she has a STI. One may also suspect that a teenage girl has been infected through sexual relations if she is of the promiscuous kind.

Among some pupils, Bilharzia is believed to be sexually transmitted, making it hard to be open about the disease. An adolescent girl said that even some nurses imply that it might be related to sexual behavior.

And many don't think that you get it by dirty water only, they will say that you, you are sexually active. That's why many people don't want to come out that they have Bilharzia or even treat it. Because also the nurses at the clinic - they will first ask you why you have Bilharzia. They ask you things that are none of their businesses      *-Informant 72*

### 7.3.3 Mistreatment in school

Among the interviewed pupils, many claimed that being infected by Bilharzia is embarrassing. Some claimed that Bilharzia is rarely or never discussed amongst pupils. Interviewees tended to laugh when asked if they ever talked about Bilharzia in the schoolyard or among friends.

When discussing the MTC, pupils were asked about reactions or sanctions from peer pupils when receiving treatment. Pupils said that if another pupil accepts treatment, chances are s/he will be teased by fellow-pupils. Focus group participants usually did not know why, but said it was fairly common. After some discussion they often came to the conclusion that if a pupil takes the tablet, s/he sends a signal that they suspect they have Bilharzia. Some pupils reported that the praziquantel tablets were occasionally called "dog pills" among pupils, referring to the size of the pill. The term was used to make fun of pupils who had taken them. A 15 year old male interviewee spoke of his own experiences from the MTC:

[...] people said many things, that people are making us eat [pills] that are for dogs because they are big. They said they are tablets to treat dogs that we are going to eat. But because I had Bilharzia, I liked to get help so I took them. *- Informant 63*

During the interview the pupil was asked whether those who chose to take the tablets were laughed at by peer-pupil, he confirmed: "Yes they laugh, they say... Maybe at the time you are taking the tablets they peak through the windows and say you are getting treated for HIV/AIDS". The same boy further reported that his relationship to his peer pupils had changed since he took the Bilharzia treatment. He no longer talked as much with his peers as before and said that he now preferred to play with and speak to pupils in primary school.

A female interviewee said that she herself had participated in the MTC, accepting the treatment. She had found it hard to take the tablet, as there was a lot of teasing and threatening from fellow classmates.

I was one of them that drank the tablets. They said we just go drinking and that the government wants to decrease the people in this world. So I was like “whatever” and they kept on asking why we doing this and the boys in my class just talked a lot.

*-Informant 69*

Adding to the burden of barriers for treatment and the causes for teasing are the previously mentioned challenges. The perception that using the rivers for practical reasons is considered dirty and as a sign of poverty and the misconception of sexual association contribute to the roots of bantering.

#### **7.4 Bilharzia as gender-specific**

When speaking to the pupils, it was evident that some think Bilharzia is more common or more damaging to one of the genders. All focus groups were asked whether they saw a difference in boys and girls in terms of accepting treatment during the MTC. In some of the focus groups pupils had not really noticed any difference, while other claimed there were big differences. A male learner said that there was a higher participation rate amongst boys than girls: “because Bilharzia is more common in boys that is why they drink the tablets. And the girls they don't often get Bilharzia”. Another boy confirmed the perception that girls do not need treatment by saying that girls also have their period. “I think that is the same thing”. However, he was corrected by another boy saying boys and girls are basically built in the same way, and that girls could therefore probably also get Bilharzia.

An argument that seemed thought-through was presented by a 20 year old pupil during a FGD. He said that girls could also get Bilharzia, but that they rarely did.

There are those that you find have it, but there are not many. This is caused by the fact that us boys love to go and swim there yet they don't swim. They plan their stuff but we are unable to do so. We don't pay attention to many things. So that does have a contribution. But there are a few

*-Informant 41*

A 16 year old girl said that in her school, many pupils had the opposite idea: “Many learners here at school say that Bilharzia is in girls and that boys don’t have it and I don’t see that being true”.

Pupils indicated that there were differences between the genders in terms of participation in the MTC. The Department of Health has not yet reviewed numbers of participation based on gender, so these findings cannot be verified. According to some of the female interviewees however, there were fewer boys accepting treatment in their school, than girls. They discussed this in the focus group, and came to an agreement that it is more difficult for boys because of peer pressure. Interviewees said that Bilharzia had a bad reputation rumor in their school; hence it would be bad to be associated with it. As mentioned in the previous chapter, taking the tablet to treat Bilharzia sends a signal that you suspect you might be infected. The female focus group in this particular school agreed that boys would make more fun of each other than girls, and therefore feared participation more. The interviewees in this female focus group were worried about the boys, and wondered if boys might end up not getting the help they need, just because they are showing off for their friends.

A male interviewee confirmed that male pupils put a lot of pressure on each other, and further claimed that they do not see the gravity of Bilharzia. He considered girls to be more far-sighted, and therefore more able to make health related decisions. His conclusion was still that both male and female pupils should accept taking praziquantel.

One of the perceptions concerning Bilharzia and gender is related to the physical differences between boys and girls. As girls’ genitals are on their inside, and boys’ genitals are external, some pupils considers Bilharzia to be more serious for girls, as the disease is then internal. The logic behind this is that genital Bilharzia in boys will only affect their genitals, whilst genital Bilharzia in girls is plausible to affect other parts of their body; it spreads more easily.

## 7.5 Alternative and traditional treatment

When the MTC visits the various schools in Ugu, they treat pupils with praziquantel, the only Bilharzia treatment accredited by the South African Medicine Control Council. African health culture however, has a history of using alternative and traditional medicine, also for treating Bilharzia (Kvalsvig et al., 1991). Both individual interviews and FGD therefore contained questions about such alternative medicine. Initially, the interviewee(s) were asked whether or not Bilharzia should be treated, and if so, how it should be treated. Everyone knew of the tablets provided through the MTC and also said that some clinics had the same tablets to offer. But interestingly, other options for Bilharzia treatment were also available, especially in the rural areas.

### 7.5.1 Jik (chlorine) and/or boiling water to treat Bilharzia

In two separate male FGDs in two separate schools, pupils mentioned that “Jik” is used to treat Bilharzia. Jik is a bleaching product, used to bleach clothes, disinfect and clean floors, plastic hardware and more, according to their own website (2011). The first time it was mentioned, the FGD participant was responding to the questions “How do we treat Bilharzia?”

They use Jik, but there is a limit on how many spoons you use and you also add salt then you drink it. You measure how much you drink. That’s what they used to do I don’t know if they still do it. But the right way is to go to the clinic

*-Informant 39*

When saying “they” he refers to people in the community. But as mentioned at the end of the quote, the participant considered praziquantel to be the proper treatment. Others also reported to have heard of the Jik treatment, and mentioned that the water should be boiled. A couple of the pupils had also heard of the treatment, but believed it was intended to treat cholera, not schistosomiasis.

The first interviewed community helper was an elderly woman whom had treated Bilharzia several times.

If a child has Bilharzia, I boil water and make the child drink it while it's very hot. That usually makes the blood in the urine disappear, and if it doesn't, the children go to the doctor

*- Informant 114*

According to informant 114 it was "common knowledge" that hot boiled water cleans your kidneys. But several others also mentioned boiled water, sometimes in combination with other ingredients.

There is carbonate and they take it and put it in water or use vinegar, sugar and salt and add it to water. They say when you drink this it, it causes the blood clots in your womb to be loose and then they come out. Then you won't have it [Bilharzia] any more.

*-Informant 72*

After having conducted this study, it seems as though many believe that as long as the symptoms are gone, so is the disease. Thus, if there is no more blood in the urine, there cannot be any more Bilharzia. A 17 year old girl said that when the MTC came to her school with treatment, her first thought was "oh please, where would I get Bilharzia from? - I have never urinated blood and therefore I don't have Bilharzia".

### **7.5.2 Herbal muti (medicine)**

The Zulus have a long tradition of using traditional medicine to prevent, treat and cure different health issues, both physical and mental. During interviews, pupils were asked who they would talk to if they found out they had Bilharzia. Although many of the interviewees did not have any grandparents left, they said that they would have preferred to talk to a grandmother about their health issues. One pupil said that he would have preferred to talk to a grandmother because she knows which muti is needed. If he told his mother that he had Bilharzia, she would just tell him to go to the clinic.

## 7.6 Fear of side effects and lack of trust

The participants of the focus groups were asked to discuss their opinions on why so many students did not want Bilharzia treatment. One of the answers that were heard in all schools, repeatedly, was the fear of side effects. The interviewees had not necessarily experienced it, and in most cases did even know anyone whom had experienced it. However, informants said that pupils will know of the reported side effects in a nearby school. A learner said: “So now they think that they will get too sick and even die because they are going to check for Bilharzia”. When the MTC then comes to the next schools, pupils fear the treatment, and the participation is low. In an individual interview, a girl told us she had refused to take the treatment out of fear. When asked what she was afraid of, she said “I was scared because other children had taken them and they said these tablets treated them badly in their stomachs”. These pupils, she said, were from other schools in the area.

As previously mentioned, a girl got worried when fellow pupils said that the pills were a measure taken by the government to decrease the population in the area. She did not believe them, and had still taken the tablet. However, they had made her insecure about the outcomes and consequences of accepting treatment.

### 7.6.1 Lack of trust

Lack of trust in friends, family, romantic partners and also the authorities are recurring concerns throughout the pupil interviews. The pupils did not mention this as a reason for non-participation, but as a reason for not talking openly about Bilharzia, whether infected or not. Even though 69 of 82 pupils (84%) said that they would tell a member of their family if they had Bilharzia, several pupils raised concern of trust. Some said they would rather tell a brother or sister than a parent, while others would have preferred to tell a grandmother if she was still alive. Most pupils would still prefer to tell their mother, especially the female interviewees.

It's very hard to tell your parents that why I said that I would tell a friend because parents most of the time don't feel comfortable talking about things that concern your private parts. When you bring it up they just say you are naughty now. So now, if I have Bilharzia and I am old, then it's just an embarrassment and parents like talking - they would just tell the entire family

*-Informant 72*

Other interviewees told of mothers who had hit the child when they found out that their child had Bilharzia. A 21 year old male pupil had been beaten by his mother in order to learn not to go swimming in the river again, and another pupil said he was beaten for being naughty.

Also friends were given a limited amount of trust, as many pupils said that you never know who your friends might talk to, or what they might tell. It was said that even if you consider someone your best friend, you cannot be sure that you are *their* only best friend. As in most high schools, rumors travel fast, and they have to start somewhere. The pupils said that in some cases a fellow pupil had only told one friend, yet a short period of time later, the whole school seemed to know about the infected pupil. Sometimes rumors might even start with your boyfriend or girlfriend. When a female focus group was asked whether they would be comfortable telling their boyfriends that they had Bilharzia, one of the participants replied that she would never tell him. "I cannot trust people even if we have been in a relationship for seven years, I don't think I can. Maybe if we are married. If it's a boyfriend "no, because when we fight they can bring it up". So never!" As shown in figure 7.1, only 30% of interviewees whom responded would want to tell their boy- or girlfriend if they had Bilharzia.

A few pupils also stressed a lack of trust in doctors and nurses. A female interviewee said she feared to go to the local clinic to get treated for Bilharzia, because the nurses would make fun of her. Several others reiterated that statement, saying nurses are not sensitive enough with their patients, and that they sometimes openly make fun of their patients. An 18 year old male interviewee said that he had tried not to get too involved with the MTC because "many of the people, like the doctors that come here to school - some come to be naughty with the children and others come to do the right thing. So basically I would not know."

## 7.7 Need for more information

Several of the adult (teachers and community participants) interviewees agreed that the transfer of knowledge between parents and their children was more common 40 years ago than in the current generation. When asked why, they argued that the general communication between parents and their children had changed for several reasons. The first one is that many children do not live with their parents. They might live with a caretaker within the family or a more distant relative; some children live in child-headed households<sup>3</sup>. The mode of health communication may therefore be interrupted and guardians may not feel the same obligation to educate a child as a parent. Other interviewees had observed that children no longer talk to their parents about their everyday challenges. According to these interviewees, you would only communicate with your parents when being reprimanded. This may not be an accurate description of all households, but many pupils confirmed that they do not speak to neither of their parents about everyday challenges. According to the adult interviewees, it was much more common to talk to parents about health issues before. Also, parents used to teach their children about common health conditions, challenges and changes. In some families, it was considered the elder's responsibility to educate the grandchildren. However, most interviewees did not have grandparents, as they had passed away.

People in the community have that thing that you get Bilharzia if you want to go and swim. They shout at children when they are young that they should not go and swim since they will have Bilharzia. They have never just sat down and talk to us and told us that this is Bilharzia and this is what it causes. They have never - you grow up and find it out yourself - *Informant 70*

This 17 year old girl presents a situation and communication that will leave very little knowledge in a child or teenagers mind. Simply being told that one should not swim due to Bilharzia might in many cases not be sufficient information.

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<sup>3</sup> A child-headed household is a household in which a child is in charge, often living only with siblings and/or other children. RICHTER, L. M. & DESMOND, C. 2008. Targeting AIDS orphans and child-headed households? A perspective from national surveys in South Africa, 1995–2005. *AIDS care*, 20, 1019-1028.

According to the informants Bilharzia had not been addressed in any of the school subjects. In one occasion, a female focus group participant said she believed some highlights were mentioned in the subject “Life Orientation” (LO). Interviewed teachers said that it could be incorporated in LO, but felt that subjects are already cluttered with topics and the compulsory curriculum. One teacher said that Bilharzia should absolutely be included in their teaching material. When he was asked to explain why, he responded: “It should be there, why, you see, these things we are talking about – people’s health. We’re talking about people’s futures. They should be empowered, they should know” – *Informant 29*.

A female learner was concerned that a lot of people in the community did not even know of Bilharzia. She said the main concern where she lived was cholera, and that as long as you do not drink the water in the rivers, they believe you are safe when you just swim. Hence, she is concerned that fear of cholera puts Bilharzia in “the shadow”, underestimating its hazards.

### 7.7.1 Misconceptions

There are various symptoms that may point towards Bilharzia, and the multiple damages Bilharzia may cause even without recognizable symptoms. However, Bilharzia is only transmitted in infested fresh water. A female focus group discussed freely the differences between boys and girls, when one of the girls expressed frustration in boys’ little knowledge of Bilharzia. She said that many of the boys in their school believed Bilharzia infects mainly by an insect that comes with the wind. However, the insect has to “leave” Bilharzia on the female genitals somehow. So the theory is that when a girl has done her laundry, she will hang the underwear outside to dry. An insect then sits on her panties and “leaves Bilharzia on it”. When the girl then puts the underwear on, she is infected. But as previously mentioned one of the misconceptions is the one of sexual association. The argument that says Bilharzia infects through panties is also used in a sexual argument. According to some girls in a female focus group, some boys believe girls are responsible for spreading Bilharzia. One of the girls said that

[..] there are these things on your panty liners that cause dirt in your sexual organs. So when you have sex you [the boys] get Bilharzia. So they say you get Bilharzia because the female has given it to you. Her panties, panty liners or tissues she uses are dangerous

*-Informant 72*

Another misconception is one presented by pupils as well as teachers – believing Bilharzia is not a current problem. A female interviewee said this:

People from here, what I can say it's - they just don't have information about Bilharzia. They tell themselves that it is a disease that passed long time ago. Also even if they hear about it they take it lightly because they have not heard that anyone died of Bilharzia

*-Informant 69*

Mortality rates for Bilharzia have probably been underestimated, and it is believed that 200 000 people die every year in Sub-Saharan Africa due to Bilharzia (WHO, 2012d). Firstly however, the inhabitants of Ugu must be made aware that Bilharzia is a serious problem in their district. As long as some do not believe Bilharzia is a current problem, and that it may do much harm, little can be done to lower prevalence. Basic knowledge about Bilharzia must be provided before further measures in fighting the disease can be made (King, 2009). There is no use in treating the people if they do not take precautions not to get re-infected.

Some informants also thought that if infected by Bilharzia, a child might not reach puberty, never grow a moustache and a boy's voice may never break. These consequences however, are not known to be caused by Bilharzia.

## 8.0 Analysis and Discussion

All main findings of the data collection have now been introduced in the previous chapter, addressed by category. This chapter will apply the same categories, analyzing and discussing the findings, seen in light of the RQs and the health belief model.

As three of the six schools included in this study had a participation rate of 10%, it is evident that the MTC did not succeed as intended. In order to reach the aim of WHO's strategy in Bilharzia prevalence reduction, 75% of children in exposed areas need treatment by praziquantel ((GHO), 2012). The findings presented above are considered major contributors in the MTC coverage. The findings will therefore be discussed and analyzed one by one in order to identify how they affect the MTC participation rate.

### 8.1 Bilharzia as a disease with low grade of severity

When pupils reported the consequences of having Bilharzia, most interviewees merely mentioned symptoms. The most common symptoms of Bilharzia are blood in urine, a burning sensation when urinating and the need to pass urine more often than usual (Danso-Appiah et al., 2004). All of these symptoms may be categorized as minor problems. The fact that pupils only present these minor problems when explaining Bilharzia, points directly to research question number one; "How do pupils in Ugu District perceive Bilharzia?" Given the data collected from interviews, it seems as though pupils generally perceive Bilharzia as a disease of low severity, while it is in fact considered to be the second most devastating parasitic disease after malaria (USAID, 2011, Center, 2012). Its mortality rates are also believed to be underestimated Bilharzia (WHO, 2012d), especially if HIV association is tangible. A cluster of the findings related to the severity of Bilharzia as mentioned by interviewees, may look like this:

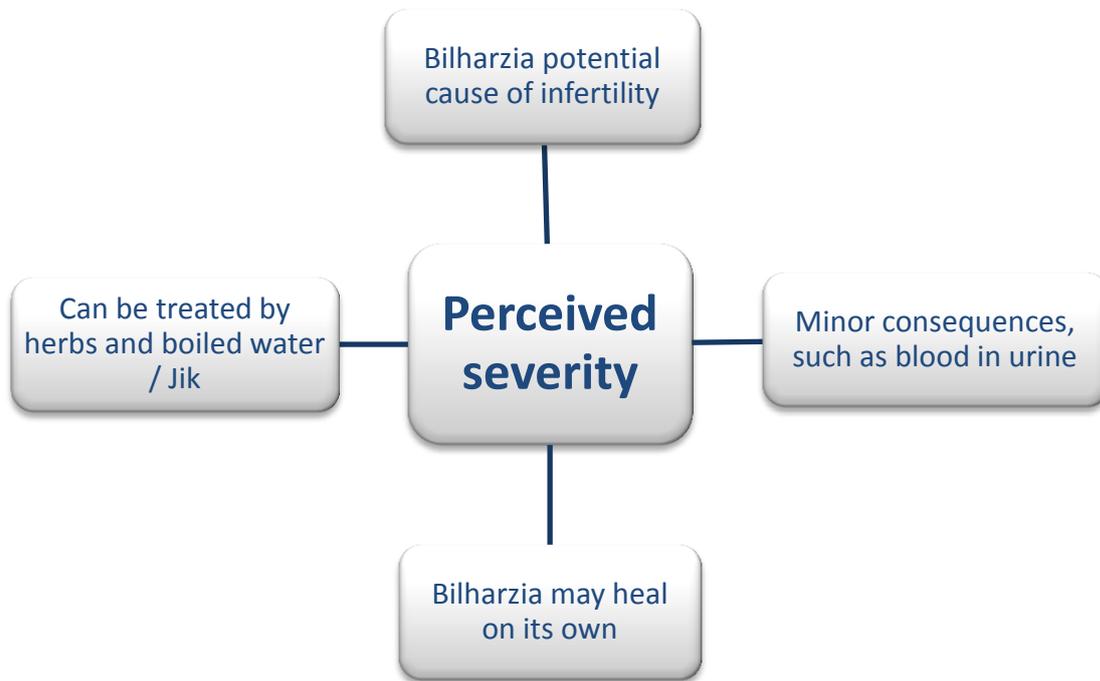
**Figure 8.1 Cluster presentation of perceived severity**

Figure: Andrea Lothe

As adults in Ugu perceive Bilharzia as an outdated problem that is no longer current in Ugu, this opinion might be transferred to the children of Ugu. If parents are well informed about the symptoms and consequences of Bilharzia, chances of efficient education about Bilharzia in school increases (Berger, 1995). Teachers report that Bilharzia is not part of compulsory school curriculum. The information given in schools, it given by DoH visitors prior to the MTC. The understanding among pupils that Bilharzia may heal without treatment or intervention has also been confirmed by adults. As long as there are adults in the communities that say Bilharzia does not require treatment, pupils may believe they do not need the praziquantel offered during the MTC.

Infertility was occasionally mentioned by interviewees as a possible outcome of having Bilharzia. Traditionally, fertility has been important in Zulu culture, and a woman's value has been measured in her ability to produce babies for her man (Craig and Richter-Strydom, 1983). If further research on Bilharzia-related infertility proves a strong association, it might be a motivational factor for female pupils to accept treatment. As one interviewee said, the fear of infertility was considered a motivation for her to accept treatment, a *cue for action* by the terms of the HBM. It may be argued to be unethical to

increase participation rates by means of fear. Yet, I believe it is of great importance that pupils understand potential consequences of Bilharzia in order to decrease prevalence as well as increase participation rates for the MTC.

However, most pupils merely mentioned symptoms such as discomfort when urinating and blood in urine as consequences of Bilharzia. Approximately a third of the interviewees believe that Bilharzia may indeed pass on its own, without PZQ, sometimes by traditional medicine. These impacts can be classified as minor, hence decreasing the perceived severity of Bilharzia. According to the HBM model, perceptions of low severity might to a large extent influence the chance of participation. To increase those chances, it is therefore of great importance that measures are taken to increase the high school pupil's knowledge on potential Bilharzia-related damages. In the long run, the knowledge acquired by pupils now will benefit their children in the future (Berger, 1995), hopefully resulting in a much lower Bilharzia-prevalence in Ugu.

## **8.2 Bilharzia as a stigma**

Bilharzia has previously been suggested to carry with it a social burden of stigma (Takougang et al., 2005). However, caution should be applied when using a strong term such as stigma. It is believed that it may undermine other coexisting factors and consequences (Ribera et al., 2009), such as socioeconomics, demography and political limitations.

Despite a range of negative findings reported by pupils, Bilharzia-related stigma as defined by long-term or detrimental consequences was not mentioned. But this finding is only valid when looking at Bilharzia as an isolated condition. When or if combined with other diseases or health conditions such as HIV or infertility, stigma might apply. Generally speaking, infertility may be the cause of great social stigma (King and Dangerfield-Cha, 2008). Also, as previously mentioned, reproductive abilities and reproductive health is considered very important in Zulu culture (Craig and Richter-Strydom, 1983). Hence, one might conclude that indirectly, Bilharzia may be cause of stigma if it is discovered to be critical to fertility.

Furthermore, several interviewees raise a concern for sexual transmission of Bilharzia, a variable that is likely to influence the probability of stigma (O'Farrell, 2002). There is only one efficient way of coping with such misconceptions, namely by enhancing the general knowledge about Bilharzia in the various communities in Ugu. This will be discussed more comprehensively in chapter 8.6.

In relation to the RQs, the issue of stigma would have been suited under RQ three, concerning pupils' hesitance to participation in the MTC, as participation signals a suspicion of infection. On the other hand, the fear of stigmatization by Bilharzia-related consequences (such as infertility) could also be a motivational factor for treatment, a cue for action. But as initially stated long-term stigma related to Bilharzia does not seem prevalent in light of this study. Stigma can therefore not be identified as a reason for non-participation.

Pupils broke and sometimes lost contact with friends as a consequence of getting Bilharzia. Others also reported that nurses would make fun of them if they visited the local health clinic, intending to test for Bilharzia. These two situations carry with them an association to stigma as defined by "social disqualification of individuals and populations who are identified with particular health problems" (Weiss et al., 2006). However, as the fieldwork progressed and more interviews were conducted, the researcher found no reason to conclude that there is a stigmatization of people infected with Bilharzia. The reason for this is that the teasing and isolation seems to be temporary, and totally ceases as soon as the person has been healed.

### **8.3 Bilharzia as an embarrassment**

The subchapters "sexual association" and "teasing in school" are both of great relevance to the second RQ "How do pupils in Ugu District perceive Bilharzia treatment?" RQ number three "What can explain some pupils' hesitance to accept treatment during the MTC?" may also be partly answered in this chapter.

Quite early in the process of collecting data, the researcher got an impression that Bilharzia was considered to be an embarrassing disease. Pupils then told that accepting treatment during the MTC sent signals to peers that “I think I might have Bilharzia”. A question of public versus private consumption of PZQ then arose, and pupils were asked about it. The two options presented were to either take the treatment in the classrooms (in front of peers and teachers) or in private rooms. No difference was found between the two options, as approximately half of the pupils were okay with taking PZQ in front of their peer pupils. Still, it is apparent that accepting treatment causes challenges for the pupils. First of all, admitting to the use of the rivers might be hard if the reason is daily chores such as laundry. Furthermore, the pupil might be accused of having dirty habits or being sexually active, all factors constituting potential causes for teasing.

### **8.3.1 Use of the river**

As chapter 7.3.1 presents, using the river for cleaning and laundry purposes, may be perceived as a sign of poverty. Such implications will contribute to the notion of embarrassment connected to Bilharzia. Pupils said that some parents will go to the rivers to do laundry even though they have tapped water by their own house. The perception that those who do laundry in the river are poor might therefore be unsubstantiated. Doing laundry in the river might also have a social aspect, providing a break or small excursion from the household. It is likely to think that the people of rural areas use the rivers more than those living in urban or peri-urban areas. But to be affiliated with the rural areas may also be a challenge for some. As said by one of the pupils, people from townships may make fun of you and say you are a farmer if you have Bilharzia.

As with children in the rest of the world, the children in Ugu enjoy swimming in the rivers and dams, especially on hot days. After having finished an interview, pupils were always given the opportunity to ask questions or give comments. In some few occasions, pupils asked if it was safe to swim in the river, believing one would have to drink the infested water to get ill with Bilharzia. Others told stories of being beaten by parents who have found their children swimming in the river. Surprisingly though, some

mentioned parents whom encouraged their children to play in the rivers. It is therefore clear that there is not enough information about the risk of infection circulating in Ugu.

Although more information about the risks may contribute to a decrease of Bilharzia prevalence, some risks are more difficult to avoid. A lot of pupils pass rivers on their way to school. Shortcuts may lead the children to rivers where they skip on rocks to cross. Other rivers have proper bridges that safely lead the children across without being in contact with the water. However, during seasons of heavy rainfall (typically in November) many of the rivers flood, leaving the bridges below water surface. In order to address this problem, infrastructure needs to be improved. As long as the bridges are built in places where they might be flooded, or too low, pupils will have no other option than to wade across them. This concern could be raised to the appropriate authorities.

### 8.3.2 Sexual association

The mode of transmission for Bilharzia compared to sexually transmitted diseases is completely different (Poggensee et al., 1999a, Kjetland et al., 2008). However, genital bilharzia has been found to cause symptoms that are also typical for sexually transmitted diseases. The similarity in symptoms may be why interviewees from all age groups claimed that Bilharzia may be sexually transmitted. A 20 year old male pupil claimed that only girls perceive Bilharzia as sex-related, whereas boys do not. Some pupils believed that say that the sexual perception of Bilharzia is gender specific. A peer agreed and said that boys would not mind having sex with a girl even though one of them had Bilharzia. But according to him, a girl would not allow it: "Girls exaggerate when it comes to Bilharzia - like having sex. Some people would mind to have sex with you if you have Bilharzia. So if I tell her then I'm locked outside". By "locked outside" he means the girl would not agree to have sex with him.

There is little doubt that if rumors say Bilharzia is sexually transmitted, and that the misconception is believed to be true, it constitutes a major problem. First of all, it will contribute to the embarrassment of having the parasite, but might also in the long run develop into a stigmatization of those infected. Also, it is Zulu custom to pay *lobola*

(pride price) for a bride, usually by cows or by converting the value of a cow into monetary payment. Traditionally, two extra cows are paid if the girl is a virgin. Hence, the family of a girl will lose parts of the lobola if their daughter is accused of having been sexually active.

According to adult interviewees, a promiscuous adolescent girl may not be trusted if she claims to have Bilharzia. For some reason, adult women and promiscuous girls are believed to lie about Bilharzia to keep a sexually transmitted infection secret. Interestingly, men and promiscuous boys were not mentioned, giving the impression that it may be gender based in favor of men. This study did not further investigate these perceptions, but one may assume that some of these promiscuous women and teenagers may actually be infected with Bilharzia. Whether they have an STI or Bilharzia can easily be determined by simple tests at a health clinic. However, not all find it easy to seek treatment in their local community as even health workers may question your character. Some refer to nurses as people that ask questions that are none of their business, others say they have been made fun of and called dirty.

Pupils explain that rumors spread very quickly in many of these communities, and tell stories of broken promises of confidentiality. When ill, many therefore prefer to consult doctors or nurses at clinics further away from their own homes. When pupils repeatedly hear of breached confidentiality by health personnel, it also influences their trust to DoH nurses. This will be further discussed in chapter 8.6.1.

### **8.3.3 Mistreatment in school**

By reviewing the findings of this study, it appears evident that pupils do experience teasing in school related to Bilharzia. As described by interviewees, accepting treatment sends a signal to peers that you think you might have Bilharzia. Hence, by accepting treatment, pupils make themselves vulnerable to all potential social reactions related to having Bilharzia. In light of this, most pupils claim that the main reason for non-participation probably is the fear of being teased by peers. Research question 3 “What

can explain some pupils' hesitance to accept treatment during the MTC?" can therefore be partly answered by this finding.

Root causes for teasing vary in severity and character, from accusations of taking "dog tablets" to being treated for HIV. As previously discussed, sexual associations, poverty, being "too rural" and being dirty are also arguments that may lead to teasing related to Bilharzia. Regardless of the level of information given, children will probably always make fun of each other for some reason. But the perceptions of sexual transmittance, poverty and being dirty are notions that may cause serious social damage to a pupil, as it may lead to stigma (O'Farrell, 2002). These arguments can be disarmed by more information and increased knowledge about transmittance, symptoms and treatment of Bilharzia.

Some of the reported attempts to ridicule pupils whom accept treatment are considerably graver than merely calling the tablets "dog tablets". As one girl said, pupils had claimed that the PZQ was a measure taken by government to kill people, in order to decrease population. Luckily, in the reported case, the interviewee had not believed the argument, and still accepted treatment.

According to interviewees, the risk of teasing greatly adds to the dimension of "perceived barriers" as presented in the HBM. It is therefore of great importance in order to increase participation rates for the MTC that measures are taken to reduce the level of bullying. Roots of mistreatment can be included into a cluster of perceived barriers, constituting most of the barriers.

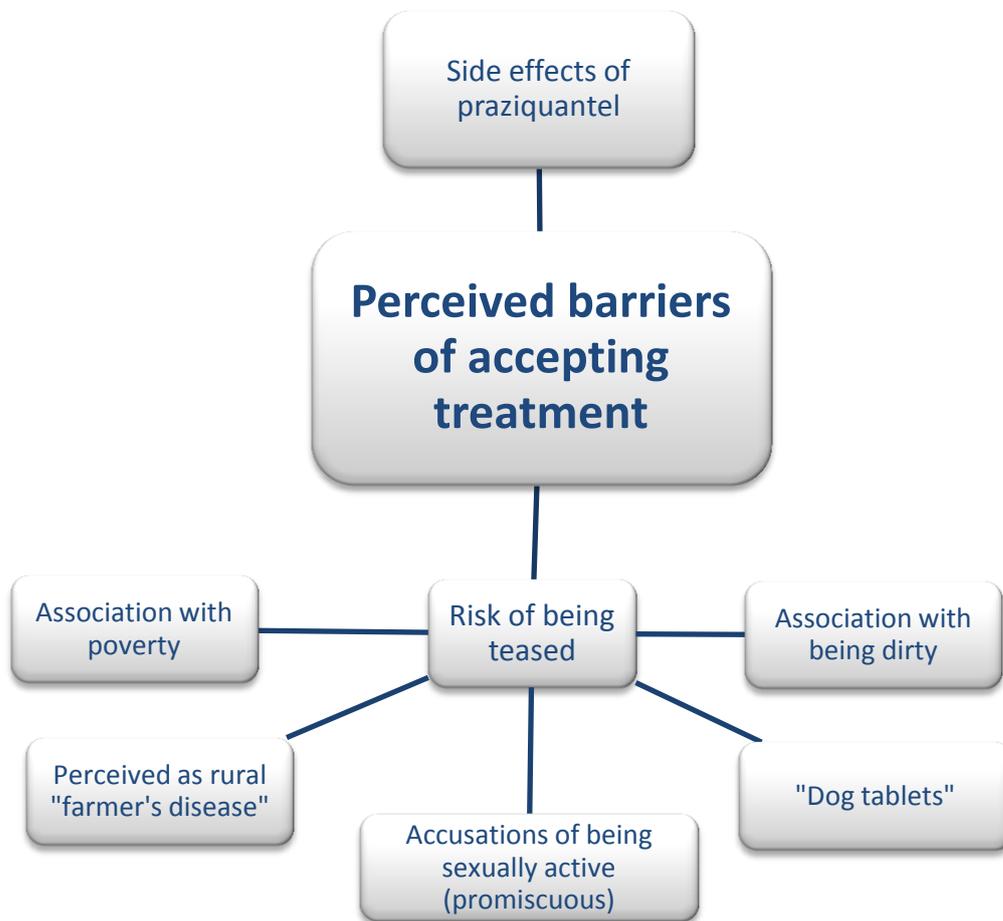
**Figure 8.2 Cluster presentation of perceived barriers for treatment**

Figure: Andrea Lothe

#### 8.4 Bilharzia as gender specific

Of the 87 pupils that were interviewed for this study, only one claimed that Bilharzia could only affect one of the genders. However, several of the interviewees knew of peer pupils whom argued that Bilharzia only manifests itself in either only boys or only girls. Consistently through the data collection period though, pupils believed that Bilharzia is more common for one of the genders, or that the consequences are graver for one of the genders. Most common was the perception that Bilharzia is more common in boys than in girls. One of the pupils argued that this can be explained by boys' higher level of risk-taking than girls'. Strangely enough, most pupils still argued that during the MTC, there

were more girls than boys whom accepted treatment. This observation was made logical by several pupils claiming that girls are more far-sighted, and take their health condition much more seriously than boys. Others (mostly boys) said that it is more difficult for boys to participate in the MTC, as the pressure amongst friends of being “cool” is much higher for boys than girls.

Finally, one of the pupils concluded, in agreement with others, that once infected with Bilharzia, the consequences are more severe in girls. The reason for this was that girls’ genitals (where symptoms first occur) are on the inside of their body, whilst boys’ genitals are external. In summary, it is considered that boys are infected more often, but that it is more severe for girls, and amongst MC participants, the majority are female pupils. As mentioned, all of these findings are observations made by pupils, and have not been confirmed by reported data from the DoH.

From the findings in this category, there are no urgent concerns that the perception of Bilharzia as gender specific largely influences neither prevalence in Ugu nor participation rates in MTC. Because, correctly, the vast majority of the pupil acknowledge that both genders are susceptible to Bilharzia, and that it therefore threatens both boys and girls. This means that the dimension of “perceived susceptibility” is not affected by gender-related misconceptions. Also, these findings contribute to an impression of pupils’ general view on Bilharzia, hence it points back to the first RQ.

## **8.5 Alternative and traditional treatment**

It was of great importance during the fieldwork that the role of traditional medicine in the Zulu culture and in the communities was not underestimated or undermined. It was especially important that pupils did not feel ridiculed by the interpreter, me or others in the focus groups when speaking about usage of traditional or alternative medicine. In several occasions it seemed as though pupils were somewhat reluctant to talk about it. The researcher then mentioned that in Norway, grandmothers sometimes have some

“muti”, or old women’s remedy’s that may treat various health conditions. It was explained that these remedies often involve herbs and other natural ingredients.

As presented in figure 8.1, the notion that Bilharzia may be cured by traditional medicine may contribute to the perception of Bilharzia as a disease of low severity. As reported by a combined iSangoma and inyanga, the patient has to drink a prepared herbal mixture for a week or two, or until symptoms diminish. There are however no known side effects of such traditional medicine, as presented by interviewees. Treatment by praziquantel on the contrary, is of a one-shot nature, but side effects do occur (N'Goran et al., 2003).

#### **8.5.1 Jik (chlorine) and/or boiling water to treat Bilharzia**

Drinking boiled hot water will not cure Bilharzia, but neither will it do much damage, besides maybe burning the patient’s mouth a little. Adding a bit of salt, vinegar, sugar or other cooking-ingredients is also considered quite harmless. However, the problem occurs when a patients of Bilharzia does not seek other treatments in addition to the water-based one. Many of the interviewed pupils say that their parents or elders in the communities often send their children to a community helper, an iSangoma or an inyanga for treatment. If the treatment given there does not seem to work properly, a medical doctor at a health clinic will be consulted. Some pupils also reported that they would go to both traditional and modern doctors, regardless of the effects – just in case. As long as the patient and/or parents await and see the effects of traditional healing, and then accept treatment by PZQ, the biggest problem is that the parasite has more time in the body to do damage. But according to the iSangoma and inyanga interviewees, traditional Bilharzia treatment should take effect after 1-2 weeks.

When it comes to treatment by Jik, it is of great importance that the inhabitants of Ugu are informed that drinking Jik is very dangerous, and may lead to sodium hypochlorite poisoning (ADAM, 2009). Such poisoning might lead to vomiting, blistering of the skin, burns on the esophagus, and dramatically, also coma (ADAM, 2009). However, serious and permanent damages are extremely rare (Racioppi et al., 1994). It is the amount of

bleach per kilo of body mass that seems to determine the damages done (Jakobsson et al., 1991). Drinking large amounts will damage even an adult person (Jakobsson et al., 1991).

Treatments by Jik or boiled water seem to be initiated by parents or guardians, not by the pupils. Regarding the Jik treatment, it seems as though the Ugu inhabitants might have confused the treatment of Bilharzia with a method of purifying water. The use of Jik has namely been recommended in South Africa as a way to purify water from open sources such as rivers (Hemson and Dube, 2004). It has no reported effect on Bilharzia ones it has infected someone however.

### **8.5.2 Herbal Muti (medicine)**

Less dangerous and more common than treatment by Jik is the use of herbal muti. The interviewed community helpers had never heard that Jik could be used to treat Bilharzia, but they knew of a more common treatment, typically used to treat several health conditions. According to them, the combination of African potato and Aloe Vera could do wonders. One of them said: "You mash it, mix it with water and then drink one liter of it". These mixtures are known to treat and cure people and can either be made at home or even bought at chemists. Although some herbs might be poisonous, the iSangomas and inyangas have been trained for a long time to know the function of the various herbs. Cases of malpractice or poisoning were never mentioned during the data collection. As with boiled water-based treatments, it is essential that patients consult a health clinic to get PZQ if the traditional medicine does not seem to cure the patient from Bilharzia.

The problem here is the previously mentioned observation that a lot of the interviewees seem to believe that as long as you do not see the symptoms any more, you are healed. All interviewed community helpers (including iSangomas and inyangas) and several pupils told of healing traditional medicine. The patient had been drinking the mixture for almost a week when there was no more blood in the urine, whereby the treatment ends and the patient is considered to be healed. However PZQ is the only reported

efficient cure for Bilharzia (N'Goran et al., 2003, Shekhar, 1991). Traditional mixtures of herbs which occasionally result in the fading of symptoms may impede further treatment, as patients believe they are cured.

One of the interviewed inyangas said that he could in fact treat cancer and HIV in addition to a wide range of other diseases, but explained that he is not allowed by South African government to say so. All of the pupils interviewed for this study indicate that they go to traditional healers only if told by parents or elderly, but claim to prefer modern health clinics. One may therefore speculate in whether the use and roles of traditional healers might dramatically change as the pupil generation grows up.

Meanwhile, an intervention with Ugu-based traditional healers could be arranged, explaining the parasitology and needs for PZQ. The iSangomas and inyangas will probably continue their practice as usual, but more information may encourage them refer patients to health clinics if traditional medicine does not work as intended.

## **8.6 Fear of side effects and lack of trust**

As chapter 2.1.1.2 reported, side effects may occur with praziquantel (N'Goran et al., 2003). However, opposed to what some interviewees fear, the tablets are not a means to decrease population, nor are they “dog tablets”. Generally speaking, praziquantel is considered a safe drug (Olds, 2003, Pearson and GUERRANT, 1983, Shekhar, 1991) and the most common side effects are temporary (Olds et al., 1999). The fear of side effects should therefore not have a large effect on participation rates, based on scientific reasoning. Still, it is not so strange that pupils fear side effects. If they have heard of, or seen pupils get sick after treatment by PZQ, it is only natural that they link the side effects to the pill. One girl said: “With my thinking, I think it is the tablets that made them sick, because they were not sick when they did not have the tablets”. Most reported cases of side effects that the pupils knew of, were cases from neighboring schools. It therefore seems as though such news are sufficiently scary for pupils to refuse treatment when the MTC visits their own school.

Usually, an information visit is done to the schools by the DoH prior to the actual day of treatment. Consent forms and information about Bilharzia, information about treatment and presentation of potential outcomes of treatment are given. However, when the DoH comes to inform pupils of a school, the pupils have already heard of side effects in other schools. It seems as though the fear of similar events of side effects may distract the pupils from the information given about benefits of treatment. In an attempt to inform pupils before rumors of side effects spread, it might be beneficial for participation rates that information is given to several neighboring schools before offering treatment in any of them. That way, when pupils hear of side effects that have occurred in closely located schools, they have already been told about the importance of treatment, and benefits of such. Pupils need to understand the positive effects of treatment, as a counterpoint to the risk of side effects. If they understand the benefits of treatment and a cure for Bilharzia, they may endure the risk of side effects. As reported by this study, there are only two major benefits of treatment, as perceived by interviewees.

**Figure 8.3 Cluster presentation of perceived benefits of treatment**

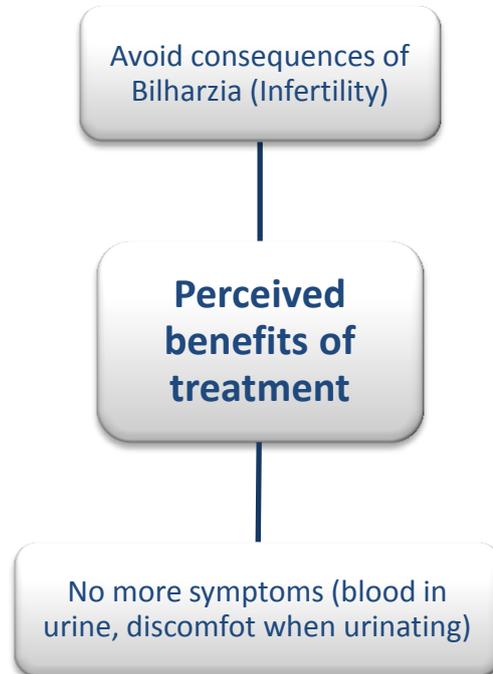


Figure: Andrea Lothe

In addition to the risk of being teased, the fear of side effect will add on to the list of “perceived barriers” in the HBM, constituting a cofactor no non-compliance of the MTC

(See figure 8.2). It is therefore evident that by curbing the fear of side effects, participation rates may increase.

### 8.6.1 Lack of trust

Almost one in five pupils would not be comfortable telling a family member if they had Bilharzia. Some worried that parents would sanction them with physical punishment if they found out their child had Bilharzia. Even though Bilharzia is considered embarrassing, the majority of the pupils whom would not tell a parent were hesitant out of fear that the family member might spread the word by telling others. The risk of having rumors about you seems to be the most common cause for the hesitance in telling others that you have Bilharzia. A peer, a close friend, a mother, a boyfriend or even a nurse may be the root of those rumors. Lack of trust in health personnel in local clinics is plausible to also affect the trust towards DoH nurses whom come to the schools during the MTC. If the general perception of health workers is that they cannot always be trusted, it may contribute to the general insecurity concerning the MTC. Hence, it also affects RQ number two “What can explain some pupils’ hesitance to accept treatment during the MTC?”

Cues for action are decisive factors in the pupil’s decision of participation in the MTC. However, it cannot be expected that friends or family members whom do not know of a pupil’s Bilharzia infection will encourage treatment. Thus, if a pupil tells someone about their disease, additional cues for action might apply.

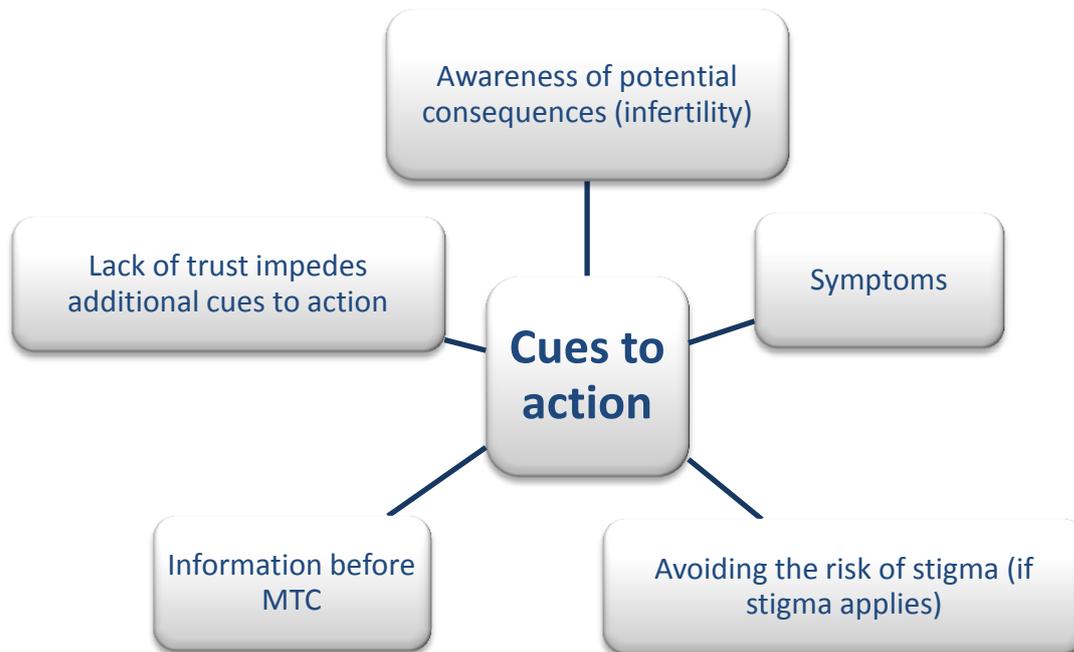
**Figure 8.4 Cluster presentation of cues to action**

Figure: Andrea Lothe

There are no obvious measures that can be taken by the DoH in order to address the lack of trust. To avoid the spread of rumors, treatment could be offered in private rooms, where all pupils had to pass through whether they wanted the treatment or not. The potential outcome of that however, is that the notion of Bilharzia as an embarrassment is further underlined by the secrecy. It may therefore increase participation rates at first, but might result in an increased degree of shyness and embarrassment related to the disease.

### 8.7 Need for more information

Previous research shows that MTCs are not successful unless transmission is reduced (King, 2009). In order to achieve the necessary reduction of prevalence, knowledge must be increased in Ugu, enabling the Ugu population to take necessary precautions to avoid re-infection. The vast majority of the interviewees said that their knowledge about Bilharzia had been acquired during the MTC. Some teachers said that information of Bilharzia could be incorporated into the subject "Life Orientation". One school did actually teach their pupils about Bilharzia, though only briefly, emphasizing some

highlights of the disease. A pupil also said that, family members, guardians and authorities rarely take their time to properly inform children about bilharzia, but might rather use violence or power. I believe that in order to make a child fully understand the consequences of Bilharzia and the potential dangers of water-related risk behavior, one should explain Bilharzia is and what damage it might do. If parents, caretakers or neighbors are not able to do this properly, one should consider incorporating Bilharzia in the school curriculum. These findings are relevant to research question number four; “Who teach young pupils about Bilharzia, and how?”

A common thread throughout chapter eight is the need for better information and more knowledge concerning Bilharzia. By increased knowledge, pupils in Ugu high schools will know that Bilharzia *is* a serious disease, and that it *cannot* be healed by Jik or herbs. By breaking the association between Bilharzia and promiscuous behavior or sexual habits, the grounds for teasing will also be reduced. If the benefits and reliefs provided by treatment are understood, it might finally overshadow the fear of side effects. All of this knowledge combined with an offer of free treatment through the MTC may be sufficient cues for action. All dimensions of the HBM will be affected, and the sum will probably point towards participation.

All in all, a well-planned and structured information campaign in several neighboring schools prior to offering the treatment may lead to an increase in the MTC participation rates.

### 8.7.1 Misconceptions

It seems as though one of the consequences of insufficient knowledge of poor information about Bilharzia is that it enables a breeding-ground for misconceptions. These misconceptions largely contribute to form pupil’s perception of Bilharzia in general (RQ 1). Also, the misconceptions indirectly influence MTC participation and hesitance toward it by adding to the root of teasing.

One of the mentioned misconceptions was that of underwear-transmittance. By wearing dirty underwear and then having sex, girls are the cause of transmission. However, this notion was only mentioned in one school and some of the focus group participants in that same school had never heard of such transmission before. If it were a common perception however, it could have big consequences for women in Ugu.

Beyond the sexually related misconceptions were those of “dog pills”, public population-decrease campaign, and also that Bilharzia is not a current problem. As mentioned above, by empowering pupils with more knowledge, the number of misconceptions may drastically be reduced.

## 9.0 Conclusion

A strategy for development as defined by Mchombu, needs to emphasize more on variables such as health and social rights than mere financial indicators (Mchombu and Evans, 2002). Ill health may impede people's chances of breaking out of poverty, and taking full dividend of their human rights (Austveg, 2006, Sachs and Bono, 2005). One can therefore conclude that health issues urgently need to be addressed, also in order to reach the MDGs (UN, 2011). The fact that Bilharzia is categorized as a neglected tropical disease increases the importance of reducing prevalence in order to reach the MDGs (Hotez and Kamath, 2009). By the argument that Bilharzia possibly increases a person's susceptibility to HIV, treating Bilharzia is plausible to save the lives of thousands of people (WHO, 2012c).

This thesis has examined Bilharzia as perceived by pupils, teachers and community helpers (RQ1). Pupils' perceptions of Bilharzia treatment have also been investigated (RQ2), identifying constraints and opportunities to improve the MTC. To understand their view on whether or treatment is necessary, their perceptions of susceptibility and severity related to Bilharzia has been explored. In accordance with the HBM, these perceptions have further been argued to impact participation. By the aim of exploring pros and cons of treatment as perceived by pupils, their sense of barriers and benefits of accepting treatment are included in the analysis.

It is indicated through the findings of this study, that the influential factors for participation in the MTC are many. Regardless, it can be expected that there are several more than those identified in this thesis. The high schools with the three highest participation rates for the Ugu MTC in 2011 had coverage rates of 50, 60 and 70%. The lowest three all had coverage rates of 10%. As the WHO goal is to treat a minimum of 75% of children in these areas, a lot needs to be done ((GHO), 2012). But in order to increase participation rates, several challenges have to be addressed and dealt with.

The study was conducted by the use of mixed method, combining qualitative and quantitative strategies. Data collection was comprised by focus groups for pupils as well

as individual in-depth interviews with male and female pupils, teachers and community helpers. In analyzing data, some quantifiable data were analyzed as statistics, and converted into bar charts. Internal validity has been promoted by the case study, as the theories and conceptual framework are well applicable to the findings. The contextual understanding provided through the four months of fieldwork is also believed to strengthen internal validity.

### **9.1 Decreasing the prevalence of Bilharzia among pupils**

Findings include perceptions of low severity, misconceptions such as sexual association and Bilharzia as an embarrassment and thus a subject for mocking. In line with the HBM, all of these perceptions need to be averted and disproved to increase participation rates for the MTC. If not, participation rates may never reach the needed 75%, as insisted by WHO ((GHO), 2012, Southgate et al., 2005).

Misconceptions of Bilharzia as seen in the light of the HBM, contribute to suppress the MTC participation rates. Obtained data imply that a wide range of misconceptions concerning Bilharzia are evident in Ugu, whereby the perception of sexual association may be the most common one. This perception can also be severely damaging, as it may lead to false accusations such as assuming virgins are sexually active. It is also plausible to reduce lobola and might influence a pupil's future sexual or romantic relations. Interestingly, if an adult woman or a promiscuous teenager claims to have Bilharzia, she might be accused of covering up for an STI. Men on the other hand, seem to be believed if they claim they have Bilharzia, as this argument only was connected to female patients by both male and female interviewees. This finding might therefore be of interest to further research. If only girls and women are victims of such indictments, it further adds to the perception that Bilharzia is gender based.

Figure 8.2 shows the main barriers for treatment as perceived by interviewees. Most barriers are used as causes for mocking patients of Bilharzia. When a pupil accepts treatment, peers assume it means the treatment recipient is infected with Bilharzia.

Accepting treatment therefore makes the recipients vulnerable to mocking and misconceptions.

Further research on the perceptions of Bilharzia among adults is needed, as this study mainly sheds light on pupils' perceptions. The opinions and perceptions of parents and guardians are influential to pupils' decision-making. Thus, their perceptions should be further investigated. Seemingly, grandparents and other elderly also largely contribute to a pupil's choice of action in terms of health care. To achieve a more comprehensive understanding of Ugu perceptions, both adults and elderly should therefore be included as interviewees in future studies. The sum of the studies may then give a substantial set of data that can be applied to reduce Bilharzia prevalence in Ugu. It may also indicate barriers of treatment for KZN at large.

## 9.2 Need for increased knowledge

Only one of the schools included in this study taught the pupils about Bilharzia, and then only briefly. As findings indicate that misconceptions of Bilharzia are common among all age groups, measures should be taken to increase the knowledge of Bilharzia in Ugu district in general. One of the teachers said it in very clear words: "We're talking about people's futures. They should be empowered, they should know."

As the intended deadline for reaching the MDGs is creeping in, efficient measures to address health issues are urgently needed (UN, 2011). Categorized as a neglected tropical disease, Bilharzia has been listed as one of the diseases in the world that need to be given critical attention (Prevention, 2011, Hotez et al., 2007). Considered the second most devastating parasitic disease in the globally (Steinmann et al., 2006), Bilharzia causes additional challenges in poor people's fight to break out of poverty (Fenwick et al., 2005, Hotez and Kamath, 2009, Hotez et al., 2007, WHO, 2002, Prevention, 2011). These facts leave little doubt that decreasing the prevalence of Bilharzia in Ugu should be prioritized. In order to do this however, the inhabitants of Ugu need to be made aware of the urgency of actions. As long as Bilharzia is considered harmless, eradicated or of low severity, there will be a lack of motivation for actions to reduce prevalence.

### 9.3 The way forward: improving the MTC – decreasing Bilharzia prevalence

Increased knowledge of Bilharzia among Ugu pupils is essential in the road forward. By empowering them with such knowledge, the HBM indicates that participation rates for the MTC may increase (Rosenstock, 1974). thus contributing to a decrease of Bilharzia prevalence in Ugu.

It has been estimated that a fourth of the entire sub-Saharan population is infected by Bilharzia (Hotez and Kamath, 2009). The prevalence of Bilharzia in KZN, the province in which Ugu district is situated, is also considered to be high (Group, 2010). In an attempt to decrease this prevalence, the South African department of health (DoH) has organized and implemented an annual MTC in Ugu district. This MTC, nonetheless, has not been successful in terms of coverage. With an aim of treating at least 75% of children ((GHO), 2012, Southgate et al., 2005), even the school with highest coverage (70%) fails to meet the WHO aim.

The only people that are in a position to ultimately increase participation rates for the MTC are the pupils themselves. However, by the information given through interviews, it seems as though the elderly's opinion of treatment is greatly valued and considered by the pupils. If a grandmother tells you to consult an iSangoma, you do so. It might therefore benefit the MTC participation rates to also give information about Bilharzia in the communities. If adults and elderly understand the need for treatment by praziquantel, they might be more supportive of the MTC, and encourage children to participate. Meetings in community halls could be arranged, inviting all age groups, including traditional healers, local health workers, parents and children. Such forum could also be used to let the participants discuss the topic of Bilharzia, in order to share knowledge, and teach each other.

Concluding, it is important to fight the perception of Bilharzia as an embarrassment. It impedes treatment rates, causes insecurity in pupils and suppresses other important factors and consequences of Bilharzia. Anyone in contact with open source fresh water is susceptible to Bilharzia. Infection does not necessarily say anything about sexual habits, economic situation or standard of living. This information needs to get out there, to all inhabitants of Ugu. As said by one of the teachers:

**“We’re talking about people’s futures. They should be empowered, they should know”**

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## Appendices

### Appendix 1: Interview guide for teachers

1. Indawo (*Schoolcode*)
2. Usuku |\_\_|\_\_| 2012 | ( | DD | MM | YYYY | ) (*Date*)
3. Education
4. Isikhundla (*Position*)
5. Isikhathi esingakanani usebenza (*How long in this job*)
6. Ngiyazi ukuthi lesikhole sasiyinxenye MTC we. *What do you think of that campaign?*
7. Usakhula oluphi ulwazi owawunalo ngesikhathi nisakhula oluphi ulwazi nani nalo ngesi scenene? (*When you were young, what did the youngsters know about bilharzia?*)
8. Ubani owanifundisa lolu lwazi? (*Who taught you these things?*)
9. Njengoba sowkhulile lukhona ulwazi olusha osowunalo ngesicene? (*Have you learnt anything new about bilharzia after becoming an adult?*)
  - a. Luthini? (*What?*)
  - b. Ulifundephi lolulwazi? (*Who taught you these things?*)
10. Uyacabanga ukuthi abafundi bakulesisikole bazi ulwazi oluningi ngeischenene kunawe ngesikhathi ungangabo (*Do you think pupils in your school know more about bilharzia than you did at their age?*)
  - a. If yes, why/how?

11. Ngabe ulwazi nefundo lwesicene kumele libe inxenye yohlelo lokufunda ezikholeni? *(Should information and education about Bilharzia be a part of school curriculum?)*
- a. Why/ why not?

### **Motivational factors**

12. Abanye abafundi kulesisikole abafuni ukwelashelwa isicene. Yini indaba ucabanga ukuthi abafuni ukulashwa? *(Some of the student in this school did not want to receive treatment for Bilharzia. Why do you think they did not want it?)*
13. Ukhona umehluko phakathi kwabafana nama ntombazane ekwamukeleneni noma ekungakwamkelekini ukulashwa? *(Are there differences between boy and girls in accepting the treatment or not?)*
- a. Uma ukona yini umehluko? *(If yes, what is the difference?)*
14. Ukuphawula *(Comments or questions)*

## Appendix 2: Interview guide for learners in English

### English interview guide for learners

1. School code:
2. Date |\_\_|\_\_|2012| (|DD|MM|YYYY|)
3. I know that this school participated in the mass treatment campaign for bilharzia. What do you think of that campaign?
4. What do you know about bilharzia?
  - a. What of this knowledge is from home?
  - b. Who taught you these things?
5. What do you know about bilharzia treatment?
7. What did you think when were asked to swallow the offered tablets?
8. What did your friends think about taking the tablets?
9. Are there differences between boys and girls in accepting or not accepting treatment?
10. How did your parents/caretaker react when you brought the consent form home, and what did they say?
11. Do you ever talk about bilharzia with someone? (Friends, family etc)
  - a. What do you talk about?
12. What do you think your community feels about bilharzia?

**Appendix 3: Focus group discussion topics**

13. What is bilharzia
  - What does it do
  - How does it infect
14. Should bilharzia be treated?
  - Why/ why not
  - How?
    - Other ways than tablets?
  - Many learners don't want treatment (in MTC), why do you think that is?
    - Would you take them if they were given in a private room?
15. Word in school about bilharzia
  - Teachers
  - Learners (boys, girls)
16. Word in community about bilharzia
17. Word at home about bilharzia
18. Word among friends about bilharzia
19. Do boys see bilharzia differently from girls?
20. If you had bilharzia, would you tell
  - Your family?
  - Your friends?
  - Your girlfriend/ boyfriend?
21. If you boyfriend/girlfriend has bilharzia, would you want him/her to tell you?
22. Have you ever seen learners being teased for having bilharzia?
  - In school
  - In community

**Appendix 4: Topics for talks with community helpers**

- Why did some of the learners withdraw?
- Why is bilharzia an embarrassing disease?
  - Why are some people teased if they have bilharzia?
- How widespread is the “Jik” treatment?
- How many think bilharzia is sexually transmitted?
- In the community’s perception, who gets bilharzia?
- Stigma is a strong word, is it suitable for bilharzia in South Africa?
- How common are traditional medicines in the treatment of bilharzia?

## **Appendix 5: Personal informed consent form in English**

### **Bilharzia treatment among teenagers in Ugu district**

As a part of a Master's thesis at the University of Agder in Norway, and the University of KwaZulu Natal, we, Andrea Lothe and Nqobile Dlomo are doing our research here in Ugu district. We want to find out about people's thoughts about the mass treatment campaign of bilharzia.

#### **Why you are being asked to participate**

The participation in some schools in Ugu is very good, but in other schools very few want treatment. I want to find out why some teenagers do not want the treatment, and since you are in one of the schools where the mass treatment campaign has been I ask you.

#### **Your decision**

You can choose if you want to be a part of this study or not. If you choose to be a part of it, you can still regret and withdraw whenever you want, and you do not have to give a reason for withdrawing. If you have any questions about the study, you can ask us at any time, and we will do our best to answer. Approximately 100 people will be interviewed for this study, from six different schools.

#### **Consequences for you**

Participating in this study will mean that you will be asked some questions or will be given some topics that we want you to talk about (either alone with us, or together with others in a group). We will write your name and your information down on a piece of paper, but your name will never be mentioned in the final thesis (paper). So nobody will know what you say to us, besides us in this room.

#### **Risks**

People at your school might see that you are talking to us.

**Benefits**

We know that it is very important to be treated for bilharzia if you have the disease. And we want as many people as possible to take part in that treatment. So we want to find out why some people do not want to participate, so that we can help improve the mass treatment campaign.

**How your data are taken care of**

The information we collect will provide new information about the treatment of Bilharzia in South Africa, and this information will be shared with health workers who may need it, and will maybe also be published. However, no one will ever know your personal information. All the information you give us will be stored **without** your name on it. Anything with your name will be stored in a different place. All of this information will be safely stored. The researcher of this study is formally responsible for the security.

**Economy**

The study has received some student grants, and the rest is covered by the researcher.

**Contact information**

If you want to contact us with questions or comments, you can reach Andrea by her e-mail address or phone (English):

andrealothe@gmail.com or tel: 072 089 7532

or you can contact Nqobile through her e-mail address or phone (Zulu)

nqobile.ntoko@gmail.com or tel: 084 752 7506

**Your rights**

If you agree to participate in this study, you have the right to access all personal information we have registered about you. You can also withdraw at any given time in the interview without giving us any reasons. Your participation or non-participation in this study will not affect your access to health treatment later. If you decide to withdraw, you have the right to request that your data will be deleted.

A voice-recorder will be used during the interviews and the focus group discussions. The tapes from these interviews will not be heard by anyone else but the two researchers, and tapes will be deleted immediately after use.

**Consent to participate in the research project**

You have been informed about the study by \_\_\_\_\_

*Participation in the study is based on voluntary, informed consent. You are free to ask for any additional information. If you, after having received all the information you find necessary, wish to participate in the study, you must sign this consent form*

*I, \_\_\_\_\_(name in capital letters), confirm that I have received written information about the study and have had the opportunity to ask for additional information, and that I will participate in the project.*

*Signature*\_\_\_\_\_ *Date*\_\_\_\_\_

*(Signed by the project participant)*

*(Dated by the project participant)*

*Participation in other project, which, what happens there?*\_\_\_\_\_

\_\_\_\_\_ *Year:*\_\_\_\_\_

*If we have further questions concerning the study, how would you like to be contacted?*

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