# “YOU SEE IT, YOU KNOW IT, BUT YOU DON’T SAY IT”

Community based perception of HIV and AIDS
Testing, counseling and ARV treatment
Shiselweni region, Swaziland

Patient on ARV and TB treatment
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MEDECINS SANS FRONTIERES

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## Executive Summary

The executive summary presents an overview of the most important findings of and comments on the study's topic in general and provides answers to specific points discussed with Roger Teck and Cell 1 in Geneva, the Head of Mission and Medical coordinator in Mbabane and the Field coordinator and the Field Team in Nhlangano in May 2011. This summary covers the whole report; a complete description of the findings and recommendations can be studied in detail.

### Knowledge of HIV and AIDS

Generally speaking and in contrast to what some medical personnel say, people have quite good knowledge – or how I perceived it – enough knowledge about HIV and AIDS. Even though many mix HIV and AIDS and do not differentiate between the infection and the disease. Local terms are used to express HIV, which for the people means AIDS. The scientific terms HIV and AIDS are rarely used and if only by medical professionals or trained MSF staff.
People know how you can get it, how you can prevent it; they were able to enumerate signs and symptoms, were informed of where you can go for a test and that treatment is available. But all the knowledge and awareness is of less importance when people live in a non-supportive environment and are still afraid of stigma – to be suspected of being HIV positive when seen by others going for a test or to be known as HIV positive person.

### Origins of HIV and AIDS

Where is HIV and AIDS coming from and what or who is responsible for the disease?
Ideas about the origin of HIV and AIDS were very much homogenous in almost all the interviews with all different target groups. It was clearly stated that it comes from outside or that it was brought to Swaziland. On some occasions it was related to construction and street workers who came from abroad to work in Swaziland and who were pointed at as the ones who brought the disease. In other encounters respondents blamed the "white people" who brought it to South Africa and Swaziland to reduce the black population.

### Attitudes and Perception of HIV and AIDS

It is a new disease because at the beginning of the epidemic people related it to sexually transmitted illnesses that traditional healer were able to cure. Different healers stated that they could successfully treat STI and STD but now recognize that they fail to treat HIV. All people I interviewed answered the questions "what do you know or what do you think about HIV and AIDS?" "it is killer disease" or "it kills".

### Signs and Symptoms

In general it can be said that people perceive an HIV positive person as a person suffering from AIDS as they interpret it according to the signs and symptoms they have observed. This means that a healthy, good-looking person cannot be infected. In most cases it was mentioned that the person has diarrhea, is losing weight, has light hair like a perm; the person's complexion becomes darker and sores appear on the body. Community members also said that the body becomes dry and stiff.

### Transmission and Prevention

All respondents knew that you could get it through sexual intercourse – and they specified – with an infected person. The second major cause mentioned by most of the participants referred to persons that care for a sick person

Others mentioned mother to child transmission, sharing razor blades, by injections, not wearing gloves when a person has an accident and is bleeding or you have an injury.

**Causes of HIV and AIDS**

Who blames whom in causing the epidemic? We can refer causes to the social world, where a third person is held responsible for the harm like witchcraft and sorcery-conspiracy theories. Another interpretation is a moralistic understanding that blames others for prostitution and that uncontrolled sex had caused the epidemic.
But in general answers referred to sexual behavior as the major cause of HIV and AIDS. Some talked about alcohol to be an additional factor for high-risk behaviors.
Mobility and labor migration were also brought up as important factors contributing to the high prevalence of HIV in the country.

**Risk Perception**

All people expressed in one way or another that they feel at risk: women – older and younger – because they cannot protect themselves, men because they want to engage in multiple partnerships and youth since they are sexually active.
In all the answers youth were clearly defined as the group that was most at risk. Reasons for that ranged from sexual activity (not protecting themselves) to not taking care of themselves, to drinking alcohol and engaging in risky behavior.
Older women expressed concern about being at risk because they care for AIDS patients, and some who are still sexually active feel at risk of getting infected by their husbands because, as they said, they don't know if he has other women and refuses to use condoms. Younger women engaged in stable relationships whether living together or not and with or without kids felt very much at risk when they were not infected yet.
Young males and females believed that they were at risk because they engage in sexual relations and do not negotiate or always use condoms. Young boys asserted that if they are circumcised they are less at risk. Young males in or out of school could not really explain why they feel at risk, saying only that they fear going for a test so much and being told they are HIV positive.

**Male Circumcision (MC)**

Perceptions of male circumcision were very mixed, from very positive to negative with fear and misunderstandings. It was clearly noticeable that boys from secondary schools were well informed about male circumcision and knew what it means in terms of prevention and reduced risk of infection. Ideas grew more vague when out-of-school boys discussed it. Some thought that circumcision protects them from getting infected or that they are protected when the sexual intercourse is over quickly. It was also mentioned that boys become more sexually "strong" and active and that "they are good in bed".
Others said that male circumcision is promoted by the whites that male youth in Southern Africa derive less pleasure from sex thus reducing the chances of infection. One man said that boys think circumcision makes the penis inactive. The fact that male circumcision goes with an HIV test hinders those who would be reluctant to go for a test anyway from going.

**Condom perception and Condom Use**

Condoms are free and available almost everywhere. The only concern for young people is getting them in a discrete setting, either in clinics or other places offering them for free or buy them in the shops.
Condoms are perceived still as an uncomfortable but necessary means to protect against HIV infection, which does not necessarily mean that they are used. Female condoms are known to be difficult to use and uncomfortable to wear. Several respondents, both male and female, asserted that they make noise and that the woman has to hold it so that it does not slip out of place.
Youths complain about the free condoms. They say that they smell bad and are of bad quality compared to the ones (Trust condoms) they buy in the shops. Color, shape and the design of the package are important for its use.

**Women/men relationship and Sexual Behaviour**

As in many other countries in southern Africa, men are the decision-makers and have all the power in the family. Women traditionally move into the husband's home after marriage. If the

husband away for work, it is the father- or mother-in-law who make any decision concerning the daughter-in-law. Men are always the strong ones and have the say in the family. This male power influences all levels of male/female relationships whether it be to negotiate condom use or to go for an HIV test.
Male respondents attributed great importance to the meaning of sexuality. It is said that a man has sexual desire all the time and it is his nature.

In Swaziland dry sex is traditionally practiced. It is sudden penetration where women have no time to get sexually aroused. It is a painful and often disappointing experience for women and above all could harm them and put them at greater risk of HIV infection.

**Pregnancy and PMTCT**

Traditionally women during pregnancy and breastfeeding had to follow many rules and regulations. All women know about these conventions but younger ones do not follow them anymore. Most say they know but don't believe in them anymore; others say it is too difficult to accept all the rules. Traditionally it is the grandmother's task to teach young girls about these regulations, but in some households there is nobody anymore who can fulfill this long-established oral practice. Some mothers-in-law also encourage their daughters-in-law to take herbs so that the delivery is not painful.
PMTCT services are well accepted by young women. A pregnant mother is in an extraordinary position. While the baby is still in her womb she has power over it, and she wants to protect the child. Once the baby is born, it belongs to the family. Because of pregnancy and the woman's increased sensitivity she needs longer counseling according to the experience of some MSF staff. But in general pregnant women are very receptive during this stage and even try to talk to their families about HIV and AIDS. According to an MSF staff member, pregnant women comply with the ARV drugs.
Most of the young women give birth in hospital. Under some circumstances when they are far away or labor starts unexpectedly, it may require a home birth. There is no such thing as a TBA, as it is known in other countries.

**Stigma and Discrimination**

All respondents stressed the fact that stigma has been reduced. Above all PLWHA who have known their status for some years spoke about their experience when they revealed their condition to the community. In most cases they were treated badly, rejected and shunned. But these same persons tell us that they have seen the communities' attitudes changing. In the past people had many misconceptions about HIV transmission and were afraid of sharing plates and spoons, sitting near someone or touching an HIV positive person.
To be HIV positive differs very much if the person is married or not and if it is a woman or a man. When a woman is married and tests positive, it is mostly said that she got if form her husband; she is less stigmatized (women say so) in contrast to the mother-in-law who would still insist that she had brought the disease into the household. When an young unmarried woman is HIV positive, she is seen as a prostitute or as someone who has had many partners in her life.

**Perception of HIV Testing and Counselling**

As mentioned above testing is very much related to stigma. Testing itself would not be such a problem for some of the target groups, but most fear testing because they don't want to be discovered by their peers. Going for an HIV test equals the suspicion being HIV positive. In terms of Swazi perception this is the same as being sick and having HIV which means AIDS and as a consequence, HAVING to die.
When people were not tested or tested negative, they felt very much at risk and were afraid of an HIV infection and AIDS.
The willingness to go for a test increases with the person's state of health. Another of the study's findings is that people only go for a test when they feel critically ill or when they show severe signs and symptoms.
The group most reluctant to go for a test is youths. Middle-aged men are also very reluctant to go for an HIV test. Most respondents are women.

When it came to questions about where people would like to go for an HIV test or where they would 'rather' accept to go, answers were also quite uniform. In the first place the Gogo centers and NCP were mentioned. For youths, testing should take place at school. Mobile clinics were also often mentioned. Testing at work was also recommended by the respondents.

Door-to-door rapid blood testing for HIV was very much welcomed and seen as the best solution when discussed in the interviews.

Another outcome of perception of testing and counseling was that the testing should be done by someone from 'outside' in order to respect confidentiality.

**Perception of AIDS treatment**

Everyone knows that treatment is available; only a few respondents ignored the fact that it would really help them. These same respondents were also the ones that refused or were reluctant to go for an HIV test.
The difficulties arising in taking ARV treatment were that it is lifelong and that some people, even when they take treatment, still die.
In contrast answers to the perception of TB treatment differed very much. TB treatment is much more accepted simply because TB is curable and there is the prospect of the treatment's ending one day. In this respect it was also mentioned that TB is better because HIV is contracted through sex.
The drugs themselves were accused of making people fat.

**Labour Migration**

Limited job opportunities in Shiselweni region force people to search for employment outside the country. Labour migration is an important factor contributing to high risk behaviour and also to loss to follow up for ART. Once people are working far away from home they tend to have other sexual partners and thus putting themselves and others at risk of getting infected with the virus.

**Community Dynamics**

A close collaboration with the communities is one of the prerequisites for an appropriate and accepted community based-approach and this collaboration needs to be strengthened. Within the communities a traditional and political structure has to be considered for any collaboration. The right person to talk to is the *Indvuna* (chief/headman) together with the Inner Council.

## Abbreviations

| | |
|---|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| ARV | AntiretroViral |
| ART | AntiRetroViral Therapy |
| CCE | Community Capacity Enhancement |
| CCSO | Community Care and Support Officer |
| CHW | Community Health Worker |
| CSO | Central Statistical Office |
| CSS | Community System Strengthening |
| DHS | Demographic and Health Surveys |
| DR | Drug Resistant |
| FGD | Focus Group Discussion |
| HBC | Home Based Care |
| HIV | Human Immunodeficiency Virus |
| HP | Health Promotion |
| HTC | HIV Testing and Counseling |
| IEC | Information Education Communication |
| LDP | Leadership Development Program |
| MCP | Multiple and Concurrent sexual Partners |
| MDR TB | Multi Drug Resistant Tuberculosis |
| MoU | Memorandum of Understanding |
| MSF | Médecins Sans Frontières |
| NCP | Neighborhood Care Point |
| PLWHA | People living with HIV and AIDS |
| RHM | Rural Health Motivators |
| STD | Sexually Transmitted Disease |
| STI | Sexually Transmitted Infection |
| TB | Tuberculosis |
| TMG | Therapeutic Management Group |
| VCT | Voluntary Counseling and Testing |
| WHO | World Health Organization |
| ZCC | Zion Christian Church |

As a presupposition for a cultural-sensitive community approach I would like to cite Edward C. Green who proposed to “arrive with a sense of humility and willingness to learn from our hosts, rather than simply with determination to teach them, show them the errors of their ways, and transfer technology.”[1]

## 1. Introduction

This report has been carried out in order to analyze the findings based on field research with qualitative interviews and observations in the Shiselweni region between 30th April and 20th May 2011. In-depth document review before and after the fieldwork and productive discussions with MSF teams in Swaziland and Geneva Headquarters are included in the analysis. Different internal MSF reports and comprehensive discussions with Roger Teck, Medical Coordinator, Head of Mission, Field Coordinator, and the psychosocial team in Nhlangano have been taken into account for defining the recommendations.

The report makes no claim to be exhaustive. It gives an insight into the perspective of the people we are working for and will serve to help us to better understand them. In this regard we especially focus on the voices of people living in the communities, in particular patients, their families and caregivers, expert clients and traditional and political authorities. What is their daily reality in relation to HIV and AIDS? What do they think about it and how do they deal with it? What is their risk perception; how do they try to prevent transmission, and what influences their decision to make use of health services (MSF, other NGOs or governmental institutions) for testing or/and treatment? These questions are made more specific in the general and specific questions to which this report will try to give adequate answers leading to adapting our operational approach and strategies to the local cultural particularities. Furthermore this analysis has to be seen in addition and comparison to the findings of my previous study on “Traditional Concepts and Perceptions of TB and DR TB and the Possibility of HBC”. Finally this qualitative research should give us a profound understanding of the functioning of the communities enabling them to become active stakeholders in the response to HIV and AIDS.

The document is divided into three parts: part one is an introduction, which consists of background information of the MSF OCG HIV/AIDS project in Shiselweni region and its prospective Treatment-as-Prevention strategy, the study's objectives, and the methodologies used. Part two highlights all relevant findings according to the terms of reference (TOR). And part three focuses on recommendations. A glossary on some important siSwati terms can be consulted in the appendix, as well as a detailed bibliography with a list of external and internal documents. The anthropologist's working plan is shown in order to give a better idea of the target groups and working procedures. There are also some maps of the study area.

### 1.1. General Objective

The main objective of the report is to develop a comprehensive analytical document that gives an insight into the local perception of HIV testing and AIDS treatment in the Shiselweni region and how to involve the communities for becoming active stakeholders in a “Treatment-as-Prevention approach”.

### 1.2. Specific Objectives

- Outline the **functioning of the communities**; hierarchy, roles of their representatives, social and cultural activities

- Assess the **extent of labor migration** as an important factor contributing to high-risk behavior but also to loss to follow-up for ART

[1] Edward C. Green 2003:330

- Document **the most common beliefs about health and health care**

- Clarify the importance and role of **traditional healers** in responding to health-care needs.

- Refer to community-based initiatives for **health promotion**.

- Explore the **perception** of:

    - **HIV infection** and **AIDS disease**
    - **HIV testing & counseling**; in particular the investigation of barriers to HTC among youth and male adults
    - **Prevention of mother to child transmission services** as included in antenatal care services, especially among male adults
    - **ARV treatment;** as life-saving treatment but also as potentially causing life-threatening side effects and requiring life-long treatment adherence compliance
    - **The main prevention strategies of sexual transmission:** behavior change, condom use and male circumcision

- Assess the **readiness of communities to engage directly** in the fight against HIV/AIDS by organizing community-based access to HIV testing and counseling and community-based support for people on ARV treatment

- Provide **recommendations** on how to **improve the interaction with the communities** through consultation and initiatives, enabling them to become active stakeholders in the response to the HIV/AIDS epidemic in their respective communities.

### 1.3. Background

Since its start at the end of 2007, the MSF OCG TB/HIV project in the Shiselweni Region has made significant progress in scaling up, in collaboration with the MoH, access to diagnosis, care and treatment for people with HIV infection or co-infected with HIV and TB, including MDR TB. But incidence levels of HIV infection and TB remain high in the whole of Swaziland, including the Shiselweni Region.

In line with the new MSF Strategic Framework for HIV/AIDS and TB (The Paris Statement of May 2010) which formally leaves space for new innovative pilot projects aiming at "reversing" the epidemic (or "bending the curve"), this MSF mission has decided to look at piloting the integration of a "Treatment as Prevention" project in addition to the ongoing TB/HIV project.[2]

A few retrospective studies and publications based on mathematical modeling present the perspective of "Treatment-as-Prevention" strategies with the potential to significantly contribute to reduction of HIV transmission and new infections in addition to the reduction of HIV-related morbidity and mortality. Through the combination of expanded access to HIV testing & counseling linked to the early initiation of life-long ARV treatment, transmission of the virus could be significantly reduced resulting in a reduction of new HIV infections with the potential to bend the HIV epidemic curve and reduce TB incidence. The notion of threshold for beginning ARV treatment is under discussion, whether for pregnant HIV+ women in PMTCT services or for the general HIV+ population.

Whereas MSF's HIV strategy has focused till now on treating people with advanced HIV/AIDS disease, there is an opportunity to push for a change of paradigms: treating HIV+ people for their own benefit well before they develop advanced HIV/AIDS but also for a community (public health) benefit by contributing to the reduction of new HIV infections in their respective communities. Yet this requires much greater community involvement for organizing community-based HIV testing and counseling, for supporting HIV+ people for their ART compliance, for organizing adapted ART re-filling activities and all this supported by much more decentralized diagnostic services in health facilities enabling the monitoring of treatment compliance and response. There is also an

[2] Roger Teck preliminary findings March 16th, 2011.

opportunity to demonstrate the long term financial benefits for health care systems by treating HIV patients earlier.[3]

## 2. Methodologies

### 2.1. Research Methods

The whole investigation is based on qualitative methods. The research team consisted of a driver, an interpreter, a research assistant and myself as co-ordinator. Since time was limited we hired a research assistant who was Swazi himself and did not need a translator. Drawing from the specific objectives we apportioned the work according to the topics. The assistant was working on community dynamics and labor migration and myself on all questions related to medical issues. Following briefings in Mbabane and Nhlangano we started working right away in the three different health zones in the Shiselweni region, Matsanjeni, Nhlangano, and Hlatikulu. The idea was to cover the catchment area where MSF is working and to spend equal time in each of the three health zones. Purposive sampling was applied, a technique employed in qualitative investigation, which means the number of people interviewed is less important than the criteria used to select them. The characteristics of individuals are used as the basis of selection, most often chosen to reflect the diversity and breadth of the sample population.

Subsequent to identifying the different target groups we wanted to meet and support from the psychosocial coordinator and the community facilitators we set out to the field. The research team was independent in its course and could organize the fieldwork autonomously. Identified target groups were patients, caregivers, expert clients, support group members, RHM, women and men of different ages, youths[4], traditional healers, traditional and political authorities, religious leaders and health facilities staff (MSF or other). 92 Interviews were conducted and around 150 persons participated during a stay of 3 weeks in the field[5] .

One to one, in-depth semi-structured interviews and narrative interviews were conducted in the participant s' first language siSwati. Some additional FGD were organized. Serving as an outline for the interviews, a questionnaire was compiled prior to the field study. The questionnaire was never directly used during the interviews. Flexibility is a key in qualitative research. I had to listen carefully, ask questions appropriate to the respondent's narrative and adjust to every particular interviewee.
In the course of the field research some of the questions were changed to adapt to the local characteristics and to the different target groups.
A translator was needed since most of the population did not speak English. Some interviews were conducted without translator whereas in one case the respondent insisted on speaking English but his/her vocabulary was limited. In that particular situation I was worried about missing important details. Either notes were taken during the interviews or FGD or the interviews were digitally recorded, transcribed and translated into English.
A system of manual coding was used to identify the central concepts that emerged, making it possible to describe categories, themes and patterns related to the research question.

Validation of data will be achieved through triangulation, seeking evidence from a wide range of different sources (interviews, observations, document review, etc.) and comparing the findings (Brikci and Green 2007).

### 2.2. Applied medical anthropology

The study is part of the field of applied medical anthropology, which looks at the applied aspects of health care and preventive care. Questions such as "how do people deal with HIV and AIDS", "what do people do when they feel sick", "where do they go and who takes the decision where and how a sick person has to be treated" were asked in the interviews. In practice interview

[3] Roger Teck TOR Qualitative Research March 24th 2011.
[4] One important perception must be mentioned in the perception of the people we talked to that "youth" was always attached to individuals ranging form 18-35 in age.
[5] Please also refer to the work program in the appendix to see all the interviews, discussions and observations done.

begins by trying to understand what health problems are common in a particular community and what causes these health problems. This particular study focuses on HIV and AIDS and how the community perceives it. It helps us to recognize how patients, care givers, families and significant others conceptualize health problems and respond to proposed care. Understanding a patient's personal and social life in relationship to the treatment helps ensure effective communication, appropriate resource utilization, and the success of treatments (Winkelman 2009:11).
The spread of HIV is strongly related to behavior, mainly through sexual intercourse. In this respect patterns of sexual behavior are profound elements that must be understood. Knowing and comprehending these patterns will help us to create an appropriate response to the needs of the communities. Cultural attitudes play a significant role in influencing the experiences of illness of those with diagnosed HIV and AIDS. Stigmatization is only one of these attitudes that shapes an individual's conduct in HIV testing. In regard to the general objective of this study we will try to enlighten cultural aspects that may have an important bearing on the future strategy of a "Treatment-as-Prevention" approach.

Another important aspect is how far we try to understand and accept the health-seeking behavior of our patients without judging them for their conduct in a non-ethnocentric way. How do we welcome our patients when they come to the health facility? How do we act in response to non-compliance/non-adherence to the ARV treatment offered, and how do we react if expected results do not appear?

### 2.3. Limitations

One major limitation to this study was the selection of the persons to be interviewed. As the time was limited and we had to start quickly with the interviews, we needed support from the community facilitators to get in touch with the communities. In Swaziland it is not possible to just enter any household without having informed the chief beforehand about the study or any activity that will take place in his area of responsibility. In view of the fact that MSF has been working in Swaziland for some years now, the organization is well known to the chiefs and most of the communities. The closest link we have to these communities is assured through our expert clients who were of great help in identifying people to talk to. At the same time it has to be acknowledged that the choice of these individuals may have an influence on the results of the study. On some occasions it was possible to randomly go to a household or to talk to persons that were not directly linked to the MSF community contacts.

Another requirement imposed on the study was to spend equal time in each of the three health zones since every health zone has its particularities. At the end of the field stay it turned out that we spent slightly more time in Matsanjeni health zone than in Nhlangano and Hlatikulu. Matsanjeni is specific for its proximity to the South African border; Hlatikulu and Nhlangano have many remote communities in mountainous areas where people live far from the health centers and have difficulties with means of transport.
An additional constraint I consider of importance is that I did only very few interviews with medical staff (MSF or other) from the clinics to crosscheck information gathered in the communities.

The focus on rural areas was directly related to the time constraint faced during this study. It would have also been interesting to work in urban communities as they may have different perceptions and dynamics of the subjects asked.

My intention is always to have the interviews in the place where people live to accomplish participant observation. It makes it possible to witness in what circumstances people reside, what their living conditions are, how the compound is organized and what are their daily activities: who is at home, who is at work or at school etc. Additional to the interviews, it gives an insight into what role is played by the context in influencing people's coping mechanism in terms of HIV and AIDS. When this is not possible for a majority of interviews carried out, I see it as a limitation. In this present study I was able to see many homes.
In some other situations respondents preferred not to be interviewed in their compound because of confidentiality and a desire to feel free to express their opinions (e.g. women out of earshot of their mothers-in-law).

All interviews with traditional healers were done in their living situations. I always asked to see the place where they work as healers (a separate house or room) to assess if the person was still active as a healer or not.

### 2.4. Ethical considerations

The research team explained the purpose of the study to participants prior to any interview or discussion. The team offered information about the study, its purpose and its aim. No information was collected from the participants without prior consent. The respondents were assured that all data would be handled with confidentiality. Participants enrolled in the study had the right to withdraw at any time during the discussion. Moreover, permission to take written notes or tape-recording the interviews was obtained before the start of the interview, discussions or focus groups.

## 3. Major Findings

In this chapter we will focus on the major findings that will help us to understand what it means to live in a country that has the world's highest HIV prevalence rate – 26.1 percent of people aged 15-49 are living with the virus, which has reduced average life expectancy to 39 years[6] . What do the people think about HIV and AIDS, how do they name it, how do they perceive it and most important how do they deal with it?

### 3.1. Background of HIV and AIDS

No other health issue has attracted as much attention and controversy as HIV and AIDS. For a long time it has been the deadliest disease of the modern age, but with access to treatment, even though limited in many parts of the world, AIDS has become a chronic disease. However only wealthy people can afford drugs, yet they still have to make difficult decisions about whether and when to spend their household resources on drugs. In poor parts of the world, most people are treated in health facilities and treatment is funded by international donors (Whiteside 2008:34). In Swaziland so far access to treatment is still not a problem in terms of availability of drugs and financial resources to provide these. But it is not only the question of free drugs that creates problems of access. Many people may not be able to afford transport to the clinic, and since drugs should be taken with food, numerous comments were raised in the interviews that people have access to drugs but not food.

> "You find sick persons, no water, no food, no shelter, sometimes muddy water to drink, to swallow the drugs.[7]
> "Some stop treatment when they feel better, but there are different reasons: the major reason is poverty, transport problems, food, they need to eat first before swallowing the drugs in some homes there is nothing to eat[8]."

In this regard poverty affects the access, compliance and success of treatment. Nevertheless it may also be important that the socio-cultural factors influence individual access and health-seeking behavior, as we will see later in the report. The discussions about HIV and AIDS have to take place within a specific socio-cultural, economical and historical context. The people's situation and their coping mechanism with the HIV and AIDS problem are understandable only from this perspective and need a holistic approach.

AIDS is not only unique from a biological point of view. Because its spread is linked to certain patterns of human behavior, especially sexual behavior, it is both a biological and socio-cultural phenomenon. As such any attempt to control its spread cannot focus only on the search for a biomedical solution. It must also take into account the complex social, cultural and economic environments in which the disease is embedded, and which may either help or hinder its spread (Helman 2000:235). HIV and AIDS cannot be seen as a personal affair, the epidemic touches the society as a whole. It affects people in urban and rural areas, rich and poor, young and old, educated and uneducated. It is part of everyday life, changes lives and influences people's actions.

In this respect we may ask ourselves how can we as a medical organization with the objective of reducing mortality and morbidity "by seeking innovative operational strategies aimed at reversing the epidemic curve while impacting mortality and morbidity at the community level"[9] best respond to HIV and AIDS. The "Treatment-as-Prevention" is a preventive approach but is also a high cost and high tech intervention. Whereas Green & Ruark emphasize that prevention is the mainstay of any response to AIDS, they call attention to a non-drug and technology-based solution:

[6] IRIN, Manzini, 14 June 2011,
[7] Interview 2, male Expert Client,
[8] Interview 18, Community head man
[9] Stated in the new MSF HIV Strategic Framework for HIV And TB/HIV co-infection, HIV Strategic Meeting, Paris April 2010)

"Successful responses to HIV and AIDS have often been community based, low cost, low tech, and culturally grounded" (Green & Ruark 2011:11).

HIV is transmitted by behavior that is deeply rooted in human cultures, so solutions will also be fundamentally cultural. In the local context of Swaziland understanding factors that contribute to multiple and concurrent sexual partners (MCP) could add new insights about how this behavior might be influenced.[10]

### 3.2. Knowledge of HIV and AIDS

Before starting to describe knowledge, attitudes and perceptions of HIV and AIDS I would like to begin with a surprising fact I became aware off only after I had carried out some interviews. According to my previous experience in the field of HIV and AIDS, I realized that most of the persons interviewed did not name the infection or disease but spoke about "the disease" (Burtscher 2004:9). This time in Swaziland almost all people I talked to used HIV when they meant either HIV or AIDS, but in most cases they referred to AIDS.

Generally speaking and in contrast to what some medical personnel say, people have quite good knowledge–or how I perceived it–enough knowledge at least about HIV and AIDS, even though many mixed up HIV and AIDS and did not differentiate between the infection and the disease. And as I said before local terms were used to express HIV, which for the people meant AIDS. The scientific terms HIV and AIDS were rarely used and only by medical professionals or trained MSF staff.
People know how you can get it, how you can prevent it, they were able to enumerate signs and symptoms, were informed of where you can go for a test and that treatment is available. But all the knowledge and awareness are of less importance when people live in a non-supportive environment and are still afraid of stigma – to be suspected of HIV positive when seen by others to be going for a test or to be known as an HIV positive person.

#### 3.2.1. Names for HIV and AIDS

Asking about expressions in the local language gives insight to some extent into perceptions as well. Some speak of the "Zed Three" which I was told is a fast car like a Ferrari, it means that HIV (AIDS) is fast. In an article on Women's perceptions and experiences of HIV prevention in South Africa, "HIV/AIDS was referred to by anything but by name. For example, HIV was the "Z3" a BMW sports care because HIV has three letters, invoking AIDS as a metaphor for dangerous and *luxury* consumptions" (Stadler et al. 2008:193). Other names for HIV were "The three names", "The three letters", "The three characters", "The number", "The number 8", or people said you have "The A". It was also found to be named as *Inala*, which I was told is a common cheap soup and it means that HIV is cheap (easy) to get. Another term used was *Silwane*, which is the name for a big animal or a beast. Further explanations showed that a big animal or beast is frightening as is AIDS. *Umbulalave* was also widespread and often used which gave a clear sense on what people think about HIV and AIDS. *Umbulalave* translated into English means "killer disease" or "world killer". In some other cases it was named simply "The disease".
One person with an important position in the community said it is the disease you don't express, you don't say.

> "HIV is an unmentioned disease – people don't say it. The unsaid disease, you don't say the name, you don't say it, you don't pronounce it, you see it, you know it, but you don't say it. Some say they are bewitched, they say they have *sidliso*. Some are in denial, they are hiding it.
> "Do they really believe in *sidliso* or do they know deep-down inside themselves?
> "Even the ones that can see you are HIV+, they are in denial. They just don't want to accept it. *Akushiwo* – you don't say it[11]."

[10] It was only later in the course of my fieldwork that I tried to work more on sexual behavior and the meaning of sexuality. It would need a more in-depth study to understand the whole range of patterns that influence sexual behavior.
[11] Interview 29, chief's mother

It is taboo to speak about it as Rödlach explains in his book *Witches, Westerners and HIV* "… speaking about HIVAIDS is a taboo theme in the same way as sexual behavior, promiscuity, and prostitution are. These are not only taboo-themes because of their private or shameful nature. It is taboo to speak about these issues because of the cultural concept of "respect" … which regulates much of social behavior, including who speaks in what manner about what topic with whom" (Rödlach 2006:21). In Swaziland it was argued not only that it was not so related to respect but as a stigma, as explained by one of the expert clients:

> "Did they blame you for the death of your husband?"
> "They never blamed me, but they made some signs like the three alphabets, they came for mourning and they give finger signs, they scratch on their hair in a way that you understand what they mean. It means that he was dying of HIV. At that time it was a disgrace to talk about it. The stigma was too high. He was working in the mines in South Africa[12]."

### 3.2.2. Origins of HIV and AIDS

Where is HIV and AIDS coming from and what or who is responsible for the disease?
Ideas about the origins of HIV and AIDS were very similar in almost all the interviews with all target groups. It was clearly stated that it comes from outside or that it was brought to Swaziland. On some occasions it was related to construction and street workers who came from abroad to work in Swaziland and who were fingered as the ones who brought the disease. In other encounters respondents blamed the "white people" who brought it to South Africa and Swaziland to reduce the black population. Conspiracy theories involving Westerners, as Rödlach described for Zimbabwe that blamed white people – mostly Americans – who triggered the epidemic (Rödlach 2006:141) are also widespread in Swaziland.

> "You might never know, maybe the white nation has done something to decrease the black population. Maybe it is away of decreasing the number."
> "Why then should they come to help?"
> "It is just from way back; we never trusted white people so if they come now with the treatment we don't trust them[13]."

> "They don't know, they say it came from abroad, from the whites, from the mines. It came when they are very sick[14]."

> "Here in this area there was road construction, and foreigners were here to work, from SA. They came with HIV and the white people, from other countries, from SA and from overseas, people at the border they come and go[15]."

> "They used to say it comes from white men, from all over the world; they want to kill us in Swaziland[16]."

> "I heard that rich people have slept with animals, people from other countries that is why we got HIV[17]."

Another common answer was related to a religious interpretation of "the end of the world". It was said that HIV and AIDS are the "revelation of the bible". In this respect it looks as if people accepted it in a fatalistic way that if it comes from God, there is nothing to do.

> "It is a revelation of the bible that in times of the last days there will be incurable diseases and this is the time now[18]."

> "I really cannot say, I sometimes mix with the holy bible, who says there will be diseases that will never be cured. There are many stories about HIV[19]."

[12] Interview 32, female expert client
[13] Interview 50, female *sangoma*/prophet
[14] Interview 6, support group secretary
[15] Interview 9, HBC giver
[16] Interview 32, female expert client
[17] Interview 52, woman at traditional beer drinking place
[18] Interview 9, HBC giver

### 3.2.3. Attitudes and Perception of HIV and AIDS

All people I interviewed answered the question "what do you know or what do you think about HIV and AIDS." “it is killer disease” or “it kills”.

> "I fear HIV. I heard it is a killer disease, looking at my relatives way back; they still would be alive if they knew earlier about it.[20]

It is a new disease because in the beginnings of the epidemic people related it to sexually transmitted illnesses that traditional healers were able to cure. Different healers claimed they could successfully treat STI and STD (such as *Ligola* and *Gcunsula*) but now admit that they fail to treat HIV. Another woman pointed out:

> "It is a new disease because it came after we have conceived and our kids have grown old[21]."

*Ligola,* a traditional Swazi disease concept, was long used to interpret and understand the cause of HIV and AIDS. *Ligola* is a disease one gets when one breaks a taboo, like having sex with a woman right after menstruation, with a woman that just gave birth, a woman who had an abortion or a miscarriage or having sex with a widow during the mourning period.

> "HIV is a killer disease. I can compare it with *ligola*, the symptoms are the same: it makes you thin, you have herpes zoster, some cough, some have ulcers in the intestines, sores in the buttock, in the private parts, deep sores. As a woman you menstruate, if you have just finished it is not good (to have sexual intercourse), you have *ligola*; after birth if you have too early sexual intercourse it causes *ligola*. You have to wait 2 days. Nowadays people don’t wait which is why HIV and AIDS spread. Young people don't respect tradition, for older people the chances to get HIV are less[22]."

> "Long time ago if a man get intercourse with a widow its where he got the *ligola*; he got it from the widow. The widow uses a medicine to protect her not to be touched by the man. When you are a widow you do not have sexual intercourse for two years. The woman receives a medicine to wear around the neck to protect her, made of two small sticks with a small cord around the neck. A man gets *ligola* when he has sex with a widow during the mourning time[23]."

*Ligola* is an STI a traditional healer could heal successfully. It is treated with enemas to cleanse the body. Enemas in general are used widely among the Swazi for diarrhea and other stomach centered illness (for prevention as well as for treatment), including ridding the body of “bile”; for sexually transmitted illness such as *gcunsula* (probably syphilis), … *ligola* …[24]

Reactions on the epidemic have varied since its emergence and range from rational (prevention campaigns and care facilities) to irrational (blame and denial) (Meursing 1997:21). In Swaziland responses to HIV and AIDS are still related to witchcraft like *sidliso* or the breaking of traditional laws or taboos like *liogla*. *Sidlliso* is the common name for a variety of poisons, which are put either into food or drink and taken by the unaware victim. Individuals who are in denial insist that it is caused by witchcraft. In these cases a *sangoma* is consulted to understand why it happened to them and why not to others. These individuals still have difficulties accepting an HIV+ status because of the fear of stigma.

> "Some know that it is a serious disease but some believe in witchcraft. Some believe it is a disease for adults. When I talk to them they say that you get it only through sex, so since they don’t have intercourse they think they cannot get it. Those who see the signs and symptoms like herpes zoster say it is witchcraft; some who grow thin think people are jealous because they have a job; when they get confused they think they are bewitched.

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[19] Interview 21, male *inyanga*

[20] Interview 30, FGD 21y old boy out of school

[21] Interview 10, female RHM

[22] Interview 11, female *sangoma*

[23] Interview 12, female *sangoma* (Swaziland 2008)

[24] Compare with Green 2003:102

> Some with blisters and sores on the face call it *sicitfo sinyama*[25]. If you have that people don't like you[26]."

Both types–the belief in sorcery and taboos–trigger fear in the minds of people, which serves to control their sexual behavior, and to a larger extent it is a form of social control. *Ligola,* for example, should discourage men from having sexual relations with married women as it's a serious life-threatening disease and a consequence of this "forbidden pleasure". As Rödlach concluded in his research on sorcery in Zimbabwe, "… sorcery suspicions are sometimes just a cover-up hiding a shameful and stigmatized disease" (Rödlach 2006:103).

However respondents asserted that profound believes in witchcraft as a cause of HIV and AIDS are rare nowadays, as this respondent put it:

"I don't know, they must believe in witchcraft, but even though people believe in witchcraft, a lot of them believe in the treatment, and we have seen many in the community[27]."

### 3.2.4. Signs and Symptoms

Signs and symptoms did not differ much from earlier field research (Burtscher 2004, 2008). In general it can be said that people perceive an HIV positive person as someone suffering from AIDS because they interpret it according to the signs and symptoms they have observed. This means that a healthy, good-looking person cannot be infected. One expert client emphasized this fact by saying that she experiences these notions because people do not believe she is HIV positive because they say "she is too beautiful."

In most cases it was mentioned that the person with diarrhea is losing weight, has light hair like a perm; the person's complexion becomes darker, and sores appear on the body. Community members also said that the body becomes dry and stiff.

> "Coughing, vomiting, mouth ulcers, loss of appetite, body sores, never ending dandruff in the hair. Ringworms are all over the body and a herpes zoster on one eye. When you have a herpes zoster, you are so positive the hair becomes light like a perm; the complexion becomes darker, the nails become black and the lips get red. I use gloves to treat patients and refer them to the hospital. Mostly female youths who have AIDS don't have the monthly menstruation, but when they bleed, they bleed a lot. Young boys are not so active in bed; they don't erect, and they have sores on their foreskin. When the eyes are yellow, I know there is a liver problem[28]."

> "The eyes go sunken, deep; the hair is like permed hair, loss of weight, the cheekbones stick out, the shoulder bones stick out[29]."

But some clearly stated that you couldn't say if someone has the virus unless the person is tested.

### 3.2.5. Transmission and Prevention

Compared to a study I did in a rural area in Zimbabwe in 2004, awareness and knowledge of transmission and prevention have increased tremendously in Swaziland.

All respondents knew that you could get it through sexual intercourse – and they were specific – with an infected person. "I don't really know, HIV enters the blood and fights the soldiers, and it can intimidate the soldiers."[30]
The second major cause mentioned by most of the participants referred to persons that care for a sick person.

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[25] *sicitfo sinyama* sores and blisters on the face that are associated with witchcraft, thus having bad luck.
[26] Interview 17, female community expert client
[27] Interview 31, female Sangoma
[28] Interview 11, female Sangoma
[29] Interview 20, 25 y-old boy out of school
[30] Interview 10, female RHM

> "We were taught that you get it through sex from someone who has it (HIV), if you take care of a person and the person has an injury and you touch this injury[31]."

Others mentioned mother to child transmission, sharing razor blades, with injections, not wearing gloves when a person has an accident and is bleeding and you have an wound. People very often started the response by saying "we were taught…", which means they say what they were taught so they're aware of it, but that does not mean they behave according to this knowledge.

Concerns were often expressed about using gloves inside the family when taking care of an AIDS patient. It was clearly stated that it is uncomfortable or stigmatizing to use gloves with a relative.

> "With the gloves we do not have a problem. Some hate it when we wear gloves, they feel they are being stigmatized; most are women who have not revealed their status[32].

> "The older folks (40-60), especially women, are also at risk. Because in most cases they are left behind with the kids, because the parents have gone for jobs, especially ladies. This person only comes home on Fridays or once a month; because sometimes young ladies in Mbabane might be infected there, getting sick, coming home, not saying or not knowing that they are positive, and the *Gogo* (grandmother) takes care of her. The older people are told to protect themselves with gloves, but it is not easy to use them with your child[33]."

From this observation people drew the conclusion that caregivers are especially at risk of infection. One of my analyses of this information was that maybe it is easier to accept being HIV+ and concluding that one was infected because she was taking care of a sick person rather than thinking she had got it through sexual intercourse.

However in general transmission is linked to behavior, sexual behavior. It was said that you get it when you have multiple concurrent partners, which applies for many Swazis. Associated to having multiple concurrent partners was the never satisfied desire for sexual intercourse, which was mentioned more by males. People expressed it as “something that is natural and innate in the person; men and women want to have different partners as much as possible”.

> "Some are attracted by a lust like eating a lot, tasting different ladies; it is not helping them in any way.
> "Why do people here have so many partners at the same time?
> "I believe it is not having enough, and the person is not satisfied e.g. polygamous men, even for women, if they don’t have many at the same time, they have many partners in their lives[34]."

It is also mentioned (generally by women) that predominantly husbands brought HIV to the marital relationship. Polygamy[35] has always been present in Swaziland. In the past polygyny was well organized and meant that men had several wives, sometimes up to 15 but did not have extramarital relationships in addition to their wives. And these women were faithful to their husband. Nowadays polygyny is still practiced but has almost been replaced by polygamy. Polygamy means that not only men engage in multiply relationships with women but also women have multiple partners both inside and outside marriage.
Here it it must be mentioned that, relating to these multiple partner relationships, most of the younger generation do not marry anymore. Some marry in the traditional way, others not. First I thought it was maybe related to financial reasons, not being able to afford the *lobola,* the dowry; however this assumption proved to be wrong. I realized that the younger people do not want to engage in marriage. Women traditionally have to move to the husband’s family home, and once there are held responsible for everything. She has to do all the work and is far from her family. The only emotional support may be her husband, and if there are any problems, the family-in-law will blame her. Therefore women prefer to stay within their families even when they have already

[31] Interview 30, FGD 40y old woman
[32] Interview 14, FGD women NCP
[33] Interview 18, community head man
[34] Interview 25, male inyanga
[35] Polygamy is the term used to describe a marriage which includes more than two partners. When a man is married to more than two wives it is called polygyny. When a woman is married to more than one man it would be called polyandry.

had one or two children. For men it is more not to commit to marriage and remain free to go whenever they want. Green supports this conclusion as well in his book *AIDS, Behavior and Culture*: “Unmarried sexual partnerships, whether cohabiting or not, have now become the norm in certain countries of southern Africa. In the last DHS, the figure was 23% among Swazi men and 32% among Swazi women (CSO, Swaziland and Macro International 2008). It is striking that the country with the world’s highest HIV prevalence has what may be the continent’s lowest rates of marriage." (Green 2011:205)

### 3.2.6. Causation of HIV and AIDS

The question of the causes of HIV and AIDS was already touched upon in the chapter on attitudes and perception as these two subjects are strongly interrelated. Here we will try to explore a bit more whom is blaming who in the cause of the epidemic. We can refer causes to the social world[36], where a third person is held responsible for the harm as we have explored for witchcraft and sorcery conspiracy theories. Another interpretation is a moralistic understanding that blames others with prostitution and uncontrolled sex having caused the epidemic.

> "They still have that mentality that for a woman to have been a prostitute it is both sides. For the men we are in a polygamous country. If he has H/A, people don’t look at it like negative. For a woman who is not yet married people would think that she had many partners. When she is married they think it is the man who came with it[37]."

Female respondents insisted on the fact that prostitution was only meant for women, since is somehow accepted that men can have multiple concurrent partners since polygyny has always been practiced in Swaziland.
But in general, answers referred to sexual behavior as the major cause of HIV and AIDS. Some talked about alcohol as an additional factor for high-risk behavior.

Mobility and labor migration were also brought up as important factors contributing to the high prevalence of HIV in the country[38]."

## 3.3. Risk Perception

We can take it as a positive characteristic that all people expressed in one way or another that they feel at risk; women – older and younger – because they cannot protect themselves; men because they want to engage in multiple partnerships, and youth since they are sexually active. We will explore sexual behavior in Swaziland further in an extra chapter.

Questions relating to risk perception were sometimes put at odds because many people I interviewed had either tested HIV+ or were already on ARV treatment. This was not always clear from the beginning of the interview, but in the course of the conversation I realized it when I asked if they feel at risk and the answer was "no". With further questioning the respondents specified that “their blood had been checked and was dirty”. Some responded directly and said that they are on treatment.

In all the answers young people were clearly pointed to as the group that is most at risk. Reasons for that ranged from sexual activity, not protecting themselves, to not taking care of themselves, to drinking alcohol and engaging in risky behavior.

> "Young ones from 17-35 are getting more infected. Those are the victims because of their age they turn a lot to alcohol. If they have started the medication they go for alcohol because they feel better and then they go back to drink more alcohol. The alcohol causes that. Some stop treatment when they feel better, but there are different reasons: the major one is

[36] Please refer to Helman (2000:91) who speaks about the cause of illness and relates it to the individual, natural, social and supernatural world.
[37] Interview 9, HBC giver
[38] For more information please refer to the report on labor migration.

> poverty, transport problems, food. They need to eat first before swallowing the drugs, but in some homes there is nothing to eat[39]."
>
> "The sexually active ones are most at risk. HIV was put on the wrong part (i.e. the sexual organ); everyone wants to pass there. They say they should have put it on the mouth[40]."
>
> "Because most of the guys (youths) don't want love just sex, they are highly sexually active[41]."
>
> "The young ones, we have lost many of them. In the homes you find old people like me who take care of our grandchildren. They will look for money to buy fancy things; they go about and will go with older men or boys to buy them cell phones[42]."

Older women raised their concern of being at risk because they care for AIDS patients, and some who are still sexually active feel at risk of getting infected by their husbands because, as they specified, they don't know if he has other women and refuses to use condoms. Younger women engaged in stable relationships, cohabiting or not, with or without kids, felt very much at risk when they were not infected yet.

> "I am scared; I didn't go for a test and the husband refuses condoms. I live in uncertainty[43]."

Young males and females believed that they are at risk because they engage in sexual relations and do not always negotiate or use condoms. Young men asserted that if they are circumcised they are less at risk. Male youths in or out of school could not really explain why they feel at risk. They only said that they are very fearful about going for a test only to be told they are HIV positive, as this young school boy expresses is:

> "I talk about H/A with my girlfriend; she proposed we go for a test but I refused. I am so afraid. I cannot stand the idea of being told that I am HIV+. I think I am going to die. People are dying, also people who take the ARVs. Sometimes people forget to take the pills. Better would be an injection for 1 month instead of taking pills[44]."

Another way of creating a feeling of safety was by denying the seriousness of the situation or even the existence of the disease. I was also told that men engage in risky sexual behavior even when they know the partner they are having sex with is HIV positive. It is either because they do not want to use a condom or they do not want to face reality, denying that it is really true or that they do not care at all because they don't believe it or because treatment is available.

### 3.4. Male Circumcision (MC)

Perceptions of male circumcision were very mixed, from very positive to negative, with fear and misunderstandings. It was clearly noticeable that boys from secondary schools were well informed about male circumcision and knew what it means in terms of prevention and reduced risk of infection. Ideas grew more vague when it was discussed with boys out of school. Some thought that it protects them from getting infected or that they are protected when the sexual intercourse is short in time. It was also mentioned that boys become more sexually "strong" and active and that "they are good in bed". Others said that male circumcision is promoted (by the whites), that male youth in South Africa derive less pleasure from sex, thus reducing the chances of infection. One man said that boys think it makes the penis inactive. The fact that male circumcision goes with an HIV test stops those from going who are afraid of a test in any case. Some stated that they were misled because they did not understand that it reduces only the infection but thought it would protect them fully from HIV. Some simply said that it is not in Swazi culture to circumcise and therefore believe it should not be practiced.

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[39] Interview 18, community head man
[40] Interview 1, female community expert client
[41] Interview 8, youth out of school
[42] Interview 21, male *inyanga*
[43] Interview 9 young woman, HBC giver
[44] Interview 7, secondary school youth

In general it was observed in the course of the interviews that many rumors circulate in the communities. One that was prevalent was the idea that circumcised boys cannot last long in sexual intercourse because their sexual strength is reduced, which again contradicts the perception mentioned earlier that circumcised boys are sexually potent. Fears of MC ranged from losing sexual strength to the pain of the operation, having problems with the healing of the wound and getting infected from the operation. One of the ideas was also that one could die after the operation. The worst rumor people revealed was that they make Benny stoke out of the foreskin (Benny stoke being a common condiment used in Swaziland).

One older man who worked many years in the mines in South Africa said the following:

"This white people are so clever, first they say you get it through sexual intercourse but now it is in the sperm. For me it is confusing how you get it, they told me you get it through sex and I don't believe it any more. We Swazis are now making mistakes. I stayed in SA with the Xhosas. All are circumcised and they also die there even though they promote circumcision. I think the only option is wearing condoms[45]."

### 3.5. Condom Perception and Condom Use

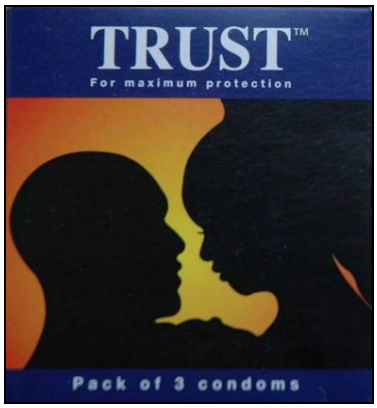
Condoms are free and available almost everywhere. The only concern is for young people to be able to get them in a discrete environment either in clinics or other places for free or to buy them in the shops. One boy said he does not buy the condoms in the shop in his community because his aunt works there. Another young girl in a very remote area said that condoms are not available in the community but only at the clinic that is 13 km away.

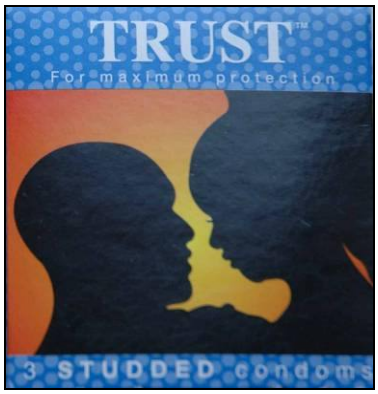
Condom names range from "the boat", "the son in law's coat," "the women's traditional dress" to the abbreviation CD. These codes are used to avoid naming them directly, and to talk about condoms in a discrete manner.

Condoms are still perceived as an uncomfortable but necessary means to protect against HIV infection, which does not mean that they are necessarily used. Female condoms are known to be difficult to use and uncomfortable to wear. Several respondents, male and female, asserted that they make noise and that the woman needs to hold it so it does not slip out of place.

> "The problem with the female (condom) we have to hold it so how can we romance. It is a risk because we may stop holding the condom and romance the man[46]."

Young people complain about the free condoms. They say that they have a bad smell and are of bad quality compared to the ones (Trust condoms) they buy in the shops. Color, shape and the design of the package are important for its use.




> "I prefer the ones from the shop, they have different flavor, they smell nice; it has a color even if the condoms are a bit rough, the ladies say they are nice; she has more feelings[47]."

[45] Interview 43, elderly HIV+ man, on ARVs
[46] Interview 42, female MDRTB support group member

"The TRUST condom can really protect. The ones from the clinic are not good quality; all condoms for free are not good quality."
"Where can you get the condoms?"
"We can get them in the shops and in the clinic."
"When you compare them, they are not the same as the TRUST; the TRUST is thicker than the free ones; we feel free to get the condoms. We want to have a lot of TRUST condoms[48]."

"What could increase condom use?"
"Maybe if they are made attractive, if they had a heart on the package or if the package was in a heart form; the package should maybe be changed not to look like a condom."
"What color is the condom?"
"This color disturbs us; it is transparent like the skin. Some say it takes long to put it on, and the penis is not stiff anymore. They have problems with the erection. People with diabetes say the penis quickly goes down[49]."

In some ways it was difficult to assess condom use directly in the interviews. We have to keep in mind that as the interviewed persons knew we work with MSF and MSF is a medical organization, answers could be shaped in the sense that people wanted to give the "right" answer. So we tried to assess this question in a more indirect way and asked respondents to tell us about condom use in general in the community according to their experience but not personal experience.
One positive remark was an observation made by a bar keeper in a place bordering South Africa. He confirmed that condom use from the bar is high as he had to fill up the free condom box twice a week. He asserted as well that even the condoms they have to buy are finished after a short time.


One of the conclusions is that condom use is still not fully accepted by most of the respondents, and condom use depends very much on the kind and perception of the relationship. In stable relationships non-use of condoms is a sign of faithfulness and fidelity.
It is obvious that a married woman faithful to her husband is more at risk than a woman who lives independently from a man and is able to negotiate condom use. Many emphasized that in marriage they do not use condoms. Since most of the people in Swaziland engage in multiple concurrent partnerships, risks of infection increases with the number of partners. Some of these concurrent relationships, initially short-termed, become stable, thus the use of condoms is often discontinued. "… such concurrent partnerships are often long term and are viewed not as casual sex but as regular and trusted relationships. Within such trusted relationships, condom use tends to be low. It is perhaps ironic that a relationship based on a degree of commitment and responsibility may be considered more dangerous than casual, commercial or one-night-stand sex, liaisons that typically do not involving commitment or responsibility (but are more likely to involve condom use) (Green 2011:135).

[47] Interview 7, male youth
[48] Interview 37, FGD high school boys
[49] Interview 6, female support group secretary

All women said that men do not like the condoms and want to have flesh-to-flesh intercourse because they "cannot eat a sweet in its plastic wrapper".

> "It is a belief that since it is not flesh-to-flesh it is not good."
> "How can a woman negotiate condom use?"
> "Through negotiation but even then if they (men) agree one day, the next day it is a different story. Men are resistant to trying; men say they are uncomfortable with the condoms[50]."

It was also said that in a situation where women were successful in negotiating the use of a condom the man may accept to use it for the "first round but will not use it when he goes for the second round"[51]. In many circumstances condom negotiation is unsuccessful because men cannot be persuaded to use them arguing that "condoms prevent the real taste of sex" (Winsell et. al. 2011:953).

Campbell in her book *Letting Them Die* on the question why HIV/AIDS programs fail exposed a very interesting supposition on the importance of flesh-to-flesh sex for male mine workers in South Africa. First it is a sense of masculine identity for men who assist other men in their day-to-day coping but also puts them at high risk, and secondly it often comes to symbolize a form of emotional intimacy that is lacking in other areas of their lives (Campbell 2003:32).

Others distance themselves from using condoms by stressing the fact that they are not 100% reliable since they could burst. There are also rumors that condoms contain the virus.

> "They say the white people brought HIV with the condoms. The condoms have small worms that are inside, so by using the condoms the disease spreads[52]."

For young people condom use is difficult. In several conversations it was confirmed that young people do not feel confident using them, for one, because they had never been shown how to put them on. A study on Swazi youth perception of pregnancy and contraception states that adolescents are excluded from contraceptive information. Male condoms look simple but are not always easy to use. The man must have an erection to put it on and he must withdraw his penis immediately after ejaculation so that semen does not leak. Young man in particular feel embarrassed and out of control when they first try male condoms, finding them difficult to use. A bad experience such as losing their erection and not being able to complete sex may make them reluctant to try again.
For female youth it turned out that they are not familiar with the female condoms; some elder ladies even said that they are not for the young ones.

### 3.6. Female/Male Relationships and Sexual Behavior

As in many other countries in southern Africa men are the decision makers and have all the power in the family. Women traditionally move to the husband's home after marriage. If the husband is away for work it is the father- or mother-in-law who make any decision concerning the daughter-in-law. Men are always the strong ones and have the say in the family. This male power influences all levels of male/female relationships whether it is to negotiate condom use or go for an HIV test. Women asserted that they are not allowed to ask or propose anything and as I have concluded already for my study in Zimbabwe in 2004 lover relationships give women room for freedom to express their wishes and to feel more respected by men. Motivations such as lust, love and passion and revenge are mentioned to justify extramarital relationships. Dissatisfaction, sexual or otherwise, with a spouse was a prime reason for seeking an extramarital partner, and women also had affairs out of revenge when their husbands were unfaithful (Green 2011:195). One of the answers to the question why many individuals want to have different partners was that one partner could be in a bad mood or not being or talking nicely to them, or disappointing them so they go to the other one to comfort themselves.

[50] Interview 6, support group secretary
[51] Interview 1, expert client
[52] Interview 3, treatment supporter

> "Sometimes you have arguments with the stable girlfriend when she is angry, and I go to someone else. I think the women are the same. Sometimes it is the way she holds me, or how she talks to me that counts[53]."

A clear distinction was also made between the relationship with a boyfriend or a husband.

> "How do you enjoy sex?"
> "It is a problem, there's a lack of communication, We cannot introduce new positions because he would say that I had practiced it before. Or if I would like to have sex or have the orgasm I cannot say it. With a boyfriend you can be more free than at home[54]."

Additional to the male power and its interpretation of masculinity we have to discuss sexual behavior related to it sexual strength. Respondents reported a clear notion of masculinity that requires men to be and act in control, to be strong and healthy and to be highly sexually active (Morten et al. 2011). In Swaziland men traditionally take herbs for sexual strength. It can be a kind of herbal drink – *imbita* – that men take for sexual potency or they use enema. It is less important how sexual intercourse is performed as how many times a man is able to ejaculate and have an orgasm.
Male respondents attributed great importance to the meaning of sexuality. It is said that a man has sexual desire all the time and it is his nature. In Tanzania it was described that "a healthy body was always sexually demanding" (Ezekiel et al. 2009:261). A sexually active man needs to have multiple partners; he is considered to be a 'rich', wealthy, respected and powerful man. This fact makes clear that being HIV+ is a painful reality and difficult to accept for men. In contrast is the perception of a traditional Tanzanian healer who said that strong blood usually relates to someone who may be infected with HIV but has not come down with symptoms (Green 1999:169).

At some periods of a women's life, such as during menstruation, from the 6$^{th}$ month of pregnancy onwards and during breastfeeding, it is considered taboo for men to have sex with their wives because it would cause *ligola*. If the husband continues to have sex with his pregnant wife he will "dirty" the child, and both could fall ill. At such times many men do not abstain or seek alternative means of pleasure, such as non-penetrative sex, but seek other women for sex . Men say they need to have different women during their life to be strong. From several respondents it was confirmed that most men and women do not respect these taboos anymore.

In Swaziland traditionally dry sex is practiced. Compared to Zimbabwe where women insert plant powders to the vagina to keep it dry, Swazi women explain dry sex with sudden penetration where they have no time to get sexually aroused. It is a painful and often disappointing experience for women and above all can harm them and put them at greater risk for HIV infection. Men often do not know that women naturally produce fluids in their vagina as a sign of pleasure when they are sexually aroused. Men insist on dry sex because it gives them the feeling "having sex with a virgin". Sex has to be hot, tied and dry (Burtscher 2004:17). When a woman is wet in the vagina men perceive it negatively and blame the women for having had sex with another man. Another assertion says that it comes from contraceptives and men force women to stop using them.

> "When you are wet in the vagina they (men) say you had another man. They say the liquid is sperm[55]."

> "The men tell us you are wet you should wipe, they don't like a wet vagina, they want us to be dry. You wipe out with a towel[56]."

> "No foreplay, immediate sex like a cucaracha in our Swazi culture our forefathers did sex without foreplay and the women still will pretend that she enjoys[57]."

[53] Interview 8, male youth
[54] Interview 9, HBC giver
[55] Interview 1, female expert client
[56] Interview 35, female expert client
[57] Interview 2, male expert client

> "It is sudden penetration, no preparation by the time you feel it he is over. It is without romance. When you do feel it yourself you cannot make any noise; you are not allowed. He would call you a prostitute; you were taught you have a private man. Some say if you take the contraceptives you become wet, or they say you slept with somebody else. The old people want dry sex[58]."

Women said that for men sexual intercourse means to be superior and having power over them and to release the sperm. As I have heard in other African countries (Senegal, Zimbabwe, Kenya) men emphasize that they 'need' to discharge their sperm on a regular basis because if it stayed too long in their 'stomach' it would cause abdominal pain. Body liquids such as blood and sperm are loaded with great symbolism. In Malawi, for example, semen is believed to be healthy when rubbed on the skin (van den Borne 2005). In that respect condom use may be considered a hindrance to 'deliver' the sperm.

### 3.7. Pregnancy and PMTCT

Traditionally women during pregnancy and breastfeeding had to follow many rules and regulations. All women know about these conventions but younger ones do not follow them anymore. Most say they know but don't believe in them anymore; others say it is too difficult to accept all the rules. Traditionally it is the grandmother's task to teach the young girls on these regulations but in some households there is nobody anymore who can fulfill this long-established oral practice. Some mothers-in-law also encourage their daughters-in-law to take herbs so that the delivery not be painful.

Some of the rules during pregnancy:

- Do not go up and down in a doorway because birth will be difficult, the child will get stuck
- Do not climb a tree, the baby will not turn
- Do not wear a belt during pregnancy otherwise the child will have the umbilical cord around the neck
- Do not look into a mirror, the baby will be crossed eyed
- Do not take pictures the baby will be an albino
- Do not eat the head of a cow, otherwise the baby will come out without hair
- Do not eat mangos the baby will be sweet stuffed and have a lot of saliva
- Do not eat honey, or the child will be blind

These moral precepts imposed on women and men are not just funny or strange patterns of behavior but denote deep-running social norms that regulate societies and, more to the point of this study, sexual behavior, e.g. to abstain from sexual intercourse after childbirth, miscarriage and during menstruation and breastfeeding. In former times the older men took young men to the bush to educate them about proper behavior, this included instruction in 'thigh sex' – *ukusoma, ukufema* – where there is no penetration (Green 1995:507).

PMTCT services are well accepted by young women. A pregnant mother is in an extraordinary condition. While the baby is still in her womb she has power over it, and she wants to protect the child. Once the baby is born it belongs to the family. Because of pregnancy and an the woman's increased sensitivity, she needs more extensive counseling according to the experience of some MSF staff. But in general pregnant women are very receptive during this stage and try even to talk to their families about HIV and AIDS back home. According to an MSF staff pregnant women comply with taking ARV drugs.

The problem of PMTCT may be that in most of the cases women get tested before their husbands or the father of the child and in consequence they are blamed for having brought the infection to the couple. Women also feel guilty to infect their babies then and are eager to protect it but at the same time fear also to harm the baby in the womb with the drugs. In discussions with elder women there was always a negative tone when they spoke about their daughters in law and HIV infected children. They call them careless and selfish.
But there are also numerous young women who are afraid to get pregnant when they are HIV positive because they fear to have an HIV positive child then.

[58] Interview 6, support group secretary

Most of the young women deliver at the hospital. Under some circumstances when they are far away or the labor starts unexpectedly it may come to a home delivery. There is no such kind of TBA, as it is known from other countries. Some elder women said that they delivered alone and only the mother in law came to help them or they delivered at their parent's home with the help of their mother. There is a kind of delivery assistant – *babelekisi* in siSwati who assist the women for delivery. They were chosen in the community but are not very active according to some support group members since they were not trained. It is more the health motivators that assist women at home when help is needed.
The position to deliver traditionally is that the woman kneels down and holds a rope, the delivery assistant is in front of her. But as said before, nowadays most deliver at the hospital and there it is on the chair with open stretched legs. Some respondents also said that young women fear to go to the hospital because elder nurses treat them in a rude way and sometimes even beat them.

Breastfeeding the baby is mentioned by all the women to be important, first for the health of the baby and secondly not to be exposed to rumors. All respondents affirmed that there is now less stigma, but when asked what people would say about a woman who did not breastfeed her child, the answer was "they would gossip about her".

### 3.8. Stigma and Discrimination

All informants stressed the fact that stigma has been reduced. Above all PLWHA who have known their status some years spoke about their experience when they disclosed it to the community. In most cases they were treated badly, rejected and avoided. But these same persons tell us now that they have seen the communities' attitudes changing. In the past people had many misconceptions about HIV transmission and were afraid of sharing plates and spoons, sitting near someone or touching an HIV positive person. To some extent stigma may have a positive side as mentioned by Green, "fear of stigma can keep people form engaging in risky sexual behavior, to their own benefit, if by that we mean decreased morbidity and mortality" (Green 2011:182).

To be HIV positive differs very much if married or not and if the person is a woman or a man. When a woman is married and gets tested it is mostly said that she got if form her husband, and she is less stigmatized (women say so) as opposed to the mother-in-law who would still say that she has brought the disease with her. When an unmarried young woman is HIV+ she is seen as a prostitute or as someone who has had many partners in her life.
For us this is an important fact in the sense of how to convince unmarried women to test! Could it be that married and pregnant women agree to be tested more readily because marriage makes it easier? And when a woman is not married she hides the results from others for fear of being abandoned.
Older women who test HIV positive say they got the virus from an AIDS patient they cared for. Accepting a positive test result is easier when the person thinks they got it by care giving rather than by sexual intercourse. Which again would be considered to be 'bad behavior' with a moral connotation (see also chapter 3.2. Knowledge on HIV and AIDS). It creates a psychological distance between an individual and the problem.

It emerged from many interviews that people say that at home they swallow TB drugs when they are already taking ARV treatment to avoid being discriminated against. Many say–and it was confirmed in a MDRTB support group meeting–that people suffering from TB are also stigmatized. Nevertheless the problem with stigma towards HIV positive individuals is that it carries moral judgment, meaning that they were "careless in their lives and had many different partners. This attitude is even more marked towards young unmarried women because they are seen as prostitutes.

> "They still have that mentality about a woman that you have been a prostitute; it is both sides. For the men we are in a polygamous country. if he has H/A people don't look at it as negative. For a woman who is not yet married people would think that she had many partners. When she is married they think it is the man who came with it [HIV][59].

[59] Interview 9, HBC giver

Fear of stigma increases if it comes to going for an HIV test. Let us explore this subject in the next chapter.

### 3.9. Perception of HIV Testing and Counseling

As we mentioned before testing is very much related to stigma. Testing itself would not be such a problem for some of the target groups, but most fear the testing because they don't want to be seen by people they know. Going for an HIV test is equal to the suspicion being HIV positive. In terms of Swazi perception this is equal to being sick and having HIV which means AIDS and in consequence HAVING to die.

When people have not been tested or have tested negative, they felt very much at risk and were afraid of HIV infection and AIDS. Green contrasts this result by saying that negative tested individuals tend to engage in riskier behavior because they feel safe. "There is even some evidence that testing negative may lead to *riskier* sexual behavior, a phenomenon known as risk compensation or behavioral disinhibition." He mentions a study done by Corbett et al. in Zimbabwe that "high risk behavior after VCT was common and that behavior after VCT was not significantly different than that before VCT" Green 2011:139).

The willingness to go for a test increases with the person's state of health. Another result of the study concludes that people only go for a test when they feel critically ill or when they show severe signs and symptoms. This explains why Swazis mix HIV infection with AIDS because many go only when they feel sick. In addition a positive result of an HIV test is frequently known when an individual suffers form TB.

The group most reluctant to go for a test are the young people. This hypothesis was confirmed by all the informants. And as we mentioned earlier in the chapter on risk perception, a young boy expressed his fear of going for an HIV test because he was so afraid of a positive result. Because of these findings young people have to be especially targeted and in a very sensitive way. In one of the discussions a young man talked about the Swazi people's mentality of fear.

> "What kills people is not the Aids but the fear. As an organization, deal with the stress of the people and not with the disease itself. First change the mentality to better understand the disease and then come with the treatment. E.g. diabetes is much more dangerous than HIV and AIDS but people live longer with it because they understand it[60]."

Middle-aged men also are very reluctant to go for an HIV test. Most respondents are women. But during antenatal care when young women should be tested they often cannot agree to take the test on the spot because they have to ask their husbands or in-laws (especially the mother-in-law) which sometimes results in not testing. It was also reported that husbands sometimes do not allow their wives to be tested of fear of having to go themselves.

One respondent spoke of her concern to get the husbands or partners tested. It was reported that men often assume that they have the same HIV status as their tested wives or girlfriends. So when she tests negative they assume that they are negative too, and the same applies if she is tested positive. One possible solution to this problem is that when the woman testes positive, she would return home but not reveal the result and to try to come back with her husband or boyfriend and to take the HIV test again together simultaneously and then receive partner counseling.
If the woman is put on ARV treatment, their partners who refuse to go for a test sometimes force their wives or girlfriends to share the ARV drugs with them.

When it came to the question where people wanted to go for an HIV test or where they would 'rather' accept to go, answers were also quite unified. In the first place the Gogo centers and NCP were mentioned. For the young testing should take place at school.[61] Mobile clinics were also often mentioned, which is kind of surprising because a mobile clinic is easily identified and people

[60] Interview 30, secretary assistant at the Free Evangelical Assembly School

[61] Testing at schools for youth was proposed by community members, like middle aged women, men, *indvuna*, support group member etc. but the young people themselves did not precise where they would go for a test as they all said they are too much afraid.

are highly visible when going there for a test. Testing at work places was also recommended by the respondents.

As I said earlier, testing itself is not the problem, but a person testing positive by a rapid blood test would then need to go for a $CD_4$ count, and people would then know that this person is HIV positive. To avoid indiscretion in general in testing facilities we have to find constructive solutions that ensure anonymity. In a discussion with the program manager of another NGO based in Nhlangano what was proposed was to make it appear like a general check up and not to call it a $CD_4$ count.

A door-to-door rapid blood testing for HIV was very much welcomed and seen as the best solution when discussed in the interviews. In practice problems might arise when family members agree to test but then want a discrete setting to receive the results. The greatest challenge are the mothers-in-law who again put pressure on their daughters in law. A study in Malawi on door-to-door testing showed that rural Malawians were very responsive to door-to-door testing because it is convenient, confidential and the rapid blood test is credible. In their conclusions the authors explain that it is convenient because distance and transport problems and costs are prohibitive factors [for the patients]. Confidentiality is important because health personnel were reported to be rude and did not keep one's affairs secret. Most of the health facilities have an extra wing for VCT so individuals are exposed to others. And it is credible because the testing technology was plausible. The rapid test ensured that test results were not tampered with and/or confused with someone else's (see Angotti et al. 2009). These persuasive results could work also for Swaziland because transport and distance were often mentioned as hindrances for accessing health care. Confidentiality was also mentioned as an obstacle to agreeing to a test.

Another outcome of the perception of testing and counseling was that the testing should be done by someone from 'outside' concerning confidentiality. Respondents stressed the fact that they were happy with all the expert clients and that they have nothing against them, but they would prefer someone not known in the community.

> "When you do home visits, if the patriarch is against no one will accept; it is only possible if it is done by an expert client. People will know the expert client, so it should be someone from another zone. The testing in the clinic is not optimal. We don't get a lot of men to test in the clinics. Only women and children come. Especially here in Nhlangano we could find them [men] in factories. If we could make it part of the work place, it could work. We need to educate the men and it should be done by men. When a father is convinced he comes with his kids[62]."

Confidentiality is still a big issue for the community members. When this issue was addressed in the interviews respondents expressed their concerns about stigmatization; and as we have seen earlier in this report, it may hinder individuals from going for an HIV test.

### 3.10. Perception of AIDS Treatment

Everyone knows that treatment is available; only some few respondents ignored the fact that it would really help them. These same respondents are also the ones that refuse or are reluctant to go for an HIV test.

> "What makes people hesitant to go (for an HIV test)?"
> "They are afraid, once you are pronounced (tested positive of HIV) you are going to die. They don't want to know that they are going to die; they can say they kill themselves."
> "But there is medicine."
> There are those who say it is a waste of time because you go to die. To swallow tablets every day if they don't exist anymore we are going to die[63]."

> "What is the difficulty of taking ARVs?"
> "The problem is to take them for the rest of the life, so we feel they harm us when we don't have food; once you default, you die[64] ."

[62] Interview 4, Medical Doctor
[63] Interview 21, male traditional healer, *inyanga*

In most situations community members did not name the ARVs as such but used different expressions from their daily lives to express when taking the tablets. To talk about ARV treatment in a discrete manner it is said that “someone eats the spices” or “someone it’s the mealie mill”, or “we eat our allowance” or “we receive our bonus”. Some say, “I am putting my airtime”.

Clear results could also be drawn from people’s perception of ARV treatment. One of the immediate answers to the questions about what the difficulties in taking ARV treatment was that it is problematic because it is lifelong and that some people even when they take treatment still die.

> "Why did you call it killer disease, there is treatment available?"
> "This thing is not curable you can take treatment but it will conquer you. You cannot take these tablets all the time. In the clinic once there was no supply[65]."

In contrast answers to the perception of TB treatment differed very much. TB treatment is much more accepted simply because TB is curable and there is the outlook exists that one day it will be over. In this respect it was also mentioned that TB is better because HIV was caught by having sex. Some respondents said that at in their family home they say they are take TB treatment when in fact they take on ARV treatment, this only to avoid stigmatization from their family members and the community.

But in some very few cases people who were already on ARV treatment said that they are happy because they feel much healthier than before.

About the drugs themselves it was said that they make you fat. There was even the rumor that chicken breeders use the ARVs to feed their chickens because they were so fat. Some say that with ARVs you get muscles. In Zambia dressers[66] feel that ARVs are very strong and that this strength is appropriate, for it is equivalent to the strength of the disease (Schumaker & Bond 2008:2126).
In a study on youth perception of ARVs in Tanzania participants described an HIV positive person as always sick, appearing weak, eventually dying. On the contrary, ART made infected people experience brief recovery from illness and look fat/healthy (Ezekiel et al. 2009:957).

To remember taking the ARV drugs many patients use the radio. They swallow the drugs when they hear the 7am and 7pm news. Or they use an alarm clock or their mobile phone or when they have disclosed their condition to their family, they ask the family to remind them when it is time. Sometimes these families are children or grandchildren. Understanding why an HIV positive person should take the treatment and what could motivate this person together with a supportive environment helps very much to adhere to ARV treatment. Respondents who reported that they have disclosed to their families and community appeared more self confident with their HIV-positive status. Accepting their status helped them to reach this attitude[67]. A bar owner observed that around 8pm many patients in his bar ask for a glass of water to take their ARV treatment[68].

Compliance with antiretroviral therapy in Swaziland is relatively high according to the 2010 MSF annual report for Swaziland. Understanding what motivates patients to comply with therapy helps us to address it in health-promotion messages and in counseling sessions for patients who have difficulties sticking to treatment or perceive it as damaging to their health. In a study on compliance with antiretroviral therapy in a Tanzanian setting the authors identified five factors that explain excellent compliance. First, respondents experienced substantial improvement in their health after starting ARTs; second their perceived need to be able to meet their family responsibilities motivated respondents to stay healthy. Third respondents developed specific strategies to remember to take pills, linking it to daily activities or events. Fourth, material and emotional support received from others facilitated adherence, and finally respondents trusted the

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[64] Interview 26, female HIV+ person on ARV

[65] Interview 28, bottle store owner

[66] A category of Classified Daily Employees (CDEs) – medical auxiliaries subordinate to nurses, mainly found in rural areas with staff shortages.

[67] Compare also with Nam et al. 2008.

[68] Interview 28, bar owner

advice and instructions of their health care providers who regularly emphasized compliance (Watt et al. 2009:1793).

One misconception reported by an MSF doctor applied to the mixing of Cotrimoxazol with ARV treatment. According to this respondent, patients who were taking Cotrimoxazol perceived it as a booster for their body, which brought their $CD_4$ count up, which consequently meant for some that they were taking the ARVs.

A Black market for ARV drugs could develop through individuals who do not want to go for a test but think that they are positive because their (mostly female) partner has tested positive (as we mentioned in the previous chapter). These men may force their partner either to share the drugs with them or to test again (at another health facility) and get a double dose of drugs so her husband can be treated too. Another respondent mentioned the traditional healer who would like to get the drugs to mix them into their herbal medication and expressed concern about an overdose.

"I have heard that witch doctors mix their *muti* with ARVs. When I go to the witch doctor I am on ARTs myself so if I take *muti* I will overdose myself. It is the *inyanga* or *sangoma*[69]."

### 3.11. Health seeking behaviour and traditional healer

Similar to what I analyzed 2008 in my report on traditional concepts and perception of TB and DR TB in Swaziland, most community members profoundly trust the traditional health care system and the professionals working in this sector (Burtscher 2008:17).

The general term for traditional healer is *inyanga* that can be used for all three types of traditional healers in Swaziland. However *inyanga* is often used when community members talk about the herbalists.

- The *Sangoma* are mostly consulted to find out what are the causes of the ill health. *Tangoma* (pl. of *Sangoma*) are usually called upon by their ancestors to become a traditional healer; refusal may end up in ongoing mental and physical ill health. *Tangoma* work with their ancestors whom they ask to help them in their work. It is the ancestors who they talk through the *Sangoma* to the patient.

- The *lugedla* or *inyanga yemitsi* works with herbal medication to treat their patients. *Inyanga* is a Zulu word and literally means "the man of the trees". In most cases *inyanga* treat patients after they have consulted a *Sangoma* and have received their diagnosis. The *inyanga* gets his knowledge through inheritance form his father or grandfather.[70]

- The prophets *umprofeti* are religious or faith healers but sometimes are a mix between *Sangoma* and prophet. They use the Holy Spirit to treat their patients and operate with prayers and water.

In most cases community members first try the traditional health care system and then go to a western health facility, or the try both at the same time. In some cases the western health facility may be the first step but then the traditional healer will be consulted additionally later or after dissatisfaction with western treatment. In any case traditional treatment is an important factor for the wellbeing of patients. "Traditional healers treat the whole person; they do not simply give medication for particular symptoms. They know how to calm a patient's fears, explain how and why they became ill, and perhaps even make sense of their problems with neighbors and family" (Green 1984:1074). Green explains in his article on healer collaboration in South Africa: "Part of the moral/ethical code of *sangomas* is that they are forbidden by their ancestor spirits to reject patients "(Green 1995:512).

Many different factors influence individual health seeking behavior; these factors may refer to social and cultural aspects of how patients and others around them perceive the problem; refer to practical aspects if medical care is available; to economical and financial factors whether patients can and want to afford it; to empirical factors which determine the failure or success of treatment

[69] Interview 35, female expert client

[70] See also Green 1984.

within the popular or fold sector[71] and to qualitative aspects which explain if the quality of care is adequate and appropriate to the patient's perception[72].

One female patient who is now on ARV treatment but has lost three children at a young age before going for an HIV test narrates her anamnesis. In her case she did not go to a western health facility because as she expresses it, "I come from a traditional family, my father is an *inyanga* and my brothers are also *tinyanga*"[73]. She further explained that it was her father who decided that she should go to see a traditional healer to treat her sick children. From this healer she got the diagnosis that the children were bewitched in the compound where she is living. Even though she tells us that she did not believe it, she had no other choice since she could not decide on her own to go for an HIV test. Only when her husband was very sick and the traditional treatment failed again did he finally accept to go to the hospital and be tested together with his wife.

Almost all of the interviewed healers admitted that AIDS is incurable and they themselves have failed to treat it. Many said that they first send the patient for an HIV test to the hospital or health clinic and tell them to then come back and be treated for opportunistic infections. One *Sangoma* explained that patients get angry when she tells them to go for an HIV test at the hospital.

> "People don't like it when I tell them to go to the hospital."
> "What do they say?"
> "They get angry, they say, "I will never come back again", and you find them positive in the hospital[74]."

Another healer, a male *inyanga,* described how he can see if a patient should go to the hospital or clinic when he suspects the person to be HIV positive:

> "I understand with my patients which symptoms are for me and which ones are for the western system[75]."

Only one older female sangoma stressed the fact that her medication is the same as the ARV, because as she puts it, the ARVs are also made of herbs[76]. However in this interview she did not claim that she treats AIDS patients.

One big concern related to ARV treatment are the churches which – in several cases reported by expert clients – tell its members who are already on ARV treatment that there is no need for medication because only Jesus is capable of curing them. These individuals are told to bring their ARV drugs to the church where the prophet prays over them, and then the patient should throw them away because "In the name of Jesus she or he is saved"[77]

In general we can assume that the traditional health care sector plays an important part in the health seeking behavior of our target population.

### 3.12. Labour Migration[78]

Limited job opportunities in the Shiselweni region force people to search for employment outside the country. Most of them are young male adults between 20-40 years old who work in the mines in Johannesburg, in the sugar cane fields and in the forestry industries. Few women work as

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[71] Kleinman speaks of three sectors that influence the Health Seeking Behavior:
*Popular* sector: lay, non-professional, non-specialist domain of society. Where ill health is first recognized and defined and health care activities are initiated. The main area is the family where ill health is recognized and treated firstly.
*Folk* sector: healers, TBAs that are not part of the official medical system, but have networks like healer associations. The WHO stated in 1978 that traditional medicine should be promoted, developed and integrated.
*Professional* sector: modern western scientific medicine (Kleinman 1981).

[72] For more details please refer to my Swaziland report from 2008 p. 17ff.

[73] Interview 45, female HIV+ patient on ARV

[74] Interview 11, female *Sangoma*

[75] Interview 21, male *inyanga*.

[76] Interview 22, female sangoma

[77] Interview 32, FGD expert clients, male and female

[78] We will mention here only the main results, the whole report can be seen in the Annex.

maids. These young men and women cross the border unlawfully. Only truck drivers and those working in the mines have fixed jobs. Home visits are mostly during Easter and Christmas holidays for those who work far away. Some come home once a week or once a month depending on the distance. Some cross the border on a daily basis.

Labor migration is an important factor contributing to high risk behavior and also to loss-to-follow-up for ARTs. Once people are working far away from home they tend to have other sexual partners, thus putting themselves and others at risk of getting infected with the virus. When people fall ill, they come back home to start treatment but then go back to work outside the country. Sometimes it is their relatives back home who get the refill for these patients and then send it to them.

### 3.13. Community Dynamics[79]

Within the communities we are confronted by a traditional and political structure.

#### The traditional structure

The communities are organized in chiefdoms with a chief who looks after the king's land. One chief is responsible for several chiefdoms; he reports directly to the king. The chief's assistant is the *Indvuna Yemcuba*. He is the "prime minister" the "senior headman" who replaces the chief in his absence. He reports directly to the chief and is the contact person for any activity together with the Inner Council.
Next to the chief and the chief headman is the chief's advisory committee *Emalangeni* or *Bandtwabenkhosi* which is comprised of the chief's uncles.
Next to the chief's advisory committee are the community headmen *Indvuna Yemphakatsi* or *Indvuna Yemmango*. Their role is to deal with cases on the community level together with the inner council. They have to maintain peace and stability in the chiefdom.
The Inner Council works directly together with the community headmen. This committee is composed of men and women who are chosen by the community. The *Indvuna* chief's assistant and the Inner Council are the **entry point** for any intervention in the communities.

#### Personalities of the Inner Council

The *Umgijimi* are the messenger boys of the *Indvuna* and the Inner Council. These men are chosen during community meetings by the community. In case of a conflict in the community the *Indvuna* first sends the messenger to talk to the parties involved.
The *Umsumpe* are part of the Inner Council and are persons well versed in the area. They intervene when the chief asks them to allocate land to someone.
The *Bucopho* is the link between the political and the traditional structure. This person is part of the Inner Council and delivers messages from *Indvuna* to *Indvuna*.
The *Bosigodzi* is again chosen by the community and a member of the Inner Council. They are responsible for sub-chiefdoms within the chiefdom. They are also called the chief's runners as they are seen as the chief's helpers to reach the whole area.

#### Community policemen

These are men and women who are responsible for police work within the chiefdom. They provide the police with information relating to crimes committed in their area. The chief's runner is their direct supervisor.

#### Lihlombe lekukhalela (shoulder to cry on)

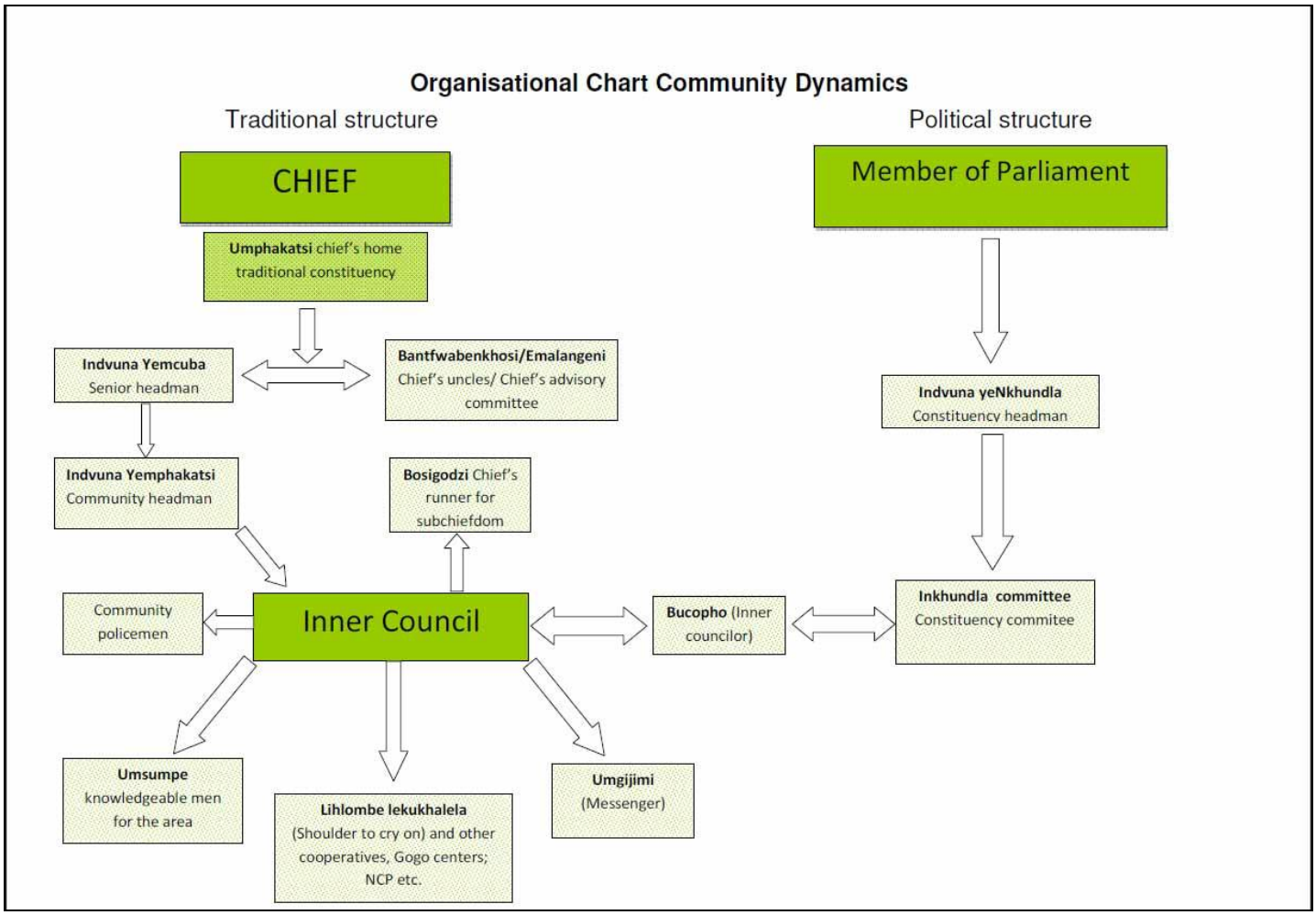
Under the inner council there are many organizations and co-operatives. The *Lihlombe Lekukhalela* is a committee of women responsible for orphans, the vulnerable and abused children.
Under these cooperatives we have the community members.

[79] The following are the main findings; the full report can be found in the Annex.

**The political structure**

The leader is the Member of Parliament (MP) who is elected in national elections held every 5 years. The MP makes policies, mobilises resources and advocates for development in his constituency. He is elected for 5 years and is paid a salary.

The *Indvuna YeNkhundla* is the leader of the constituency and is also elected for 5 years and is paid. His role is to welcome development projects and to coordinate them. He works together with the *Inkhundla* committee (constituency committee) and the *Bucopho*. The *Inkhundla* (constituency) reports to the Ministry of *Tinkhundla* (pl. of *Inkhundla*) through the Regional Administrator (RA).



# 4. Recommendations

Cultural knowledge and intercultural perspectives help facilitate relations among provider cultures (MSF), community, patient/patient cultures (PLWHA) and institutional cultures (MoH). The cultural perspectives analyzed above inform us about how individuals, HIV positive or negative, PLWHA, care givers, families, and significant others conceptualize health problems and respond to proposed care. Understanding a patient's (caregiver's) personal and social life in relationship to the treatment helps ensure effective communication, appropriate resource utilization and the success of treatments. Culturally-sensitive approaches also help patients by helping MSF accommodate itself to patients' concerns about alienation, powerlessness, distress and despair (Winkelman 2009:11).

The following recommendations have to be seen in terms of the already mentioned paradigm. They are drawn from analysis of the field research, exchanges with national and international MSF staff working in the Shiselweni Region, conversations with the coordinator of the Treatment as Prevention strategy, discussions with the MSF coordination team in Mbabane and with different medical anthropologists specializing in HIV and AIDS and in Southern Africa. Finally my own field experience with MSF leaves its mark on data analysis and recommendations and especially my previous research done in 2008 in the Shiselweni region on TB perception.

Relating to the TOR mentioned in the Introduction of this report the following recommendations are in line with the expected outcomes of this study.

Provide **recommendations** on how to **improve the interaction of the health care teams with the communities** enabling the communities to become active stakeholders in the response to the HIV/AIDS epidemic in their respective communities.

## 4.1. Community-based approach and community involvement

"Community approach" or "community involvement" in terms of MSF policies means working closely with the communities of concern in recognizing that the community approach means something different for every local context (Islamic countries, armed conflicts, natural disasters, etc.) and countries (Africa, Asia, Latin-America, etc.) and for every program (violence, mental health, nutrition, HIV/AIDS) we are working in.

Community-based approaches play a critical role in responding to HIV and AIDS. A "community-based approach" is a way of working in partnership with persons of concern during all stages of a program cycle. It demands that we understand and consider the political context, the host population, gender roles, community dynamics, and protection risks, concerns and priorities. A community-based approach can help communities work to prevent social problems and to deal directly with those that do arise instead of having external actors step in and assume these responsibilities. It reinforces the dignity and self-esteem of people of concern and empowers all the actors to work together to support the different members of the community in exercising and enjoying their human rights (UNHCR 2008).

If communities can be seen as the heart of an AIDS-competent society, it is the individual members of communities that allow it to function. One definition of a community is a group of individuals who are bound together by common interests. But, whilst the community might be a harmonious entity with a set of shared ideas and principles, it can also embody the desires and rights of the powerful, reinforced by local traditions and laws. Thus, to avoid the domination of a powerful minority, the full and active participation of all members of communities, including the most marginalized, is critical. This is not simply because it is everyone's right to be involved in decisions and actions that impact on their lives: it is because ignoring the rights and needs of vulnerable or marginalized people is likely to undermine the relevance and sustainability of such

change processes. Thus, to bring about AIDS competence, PLWHA, young people, mobile populations, poorer people and women need to be actively encouraged to participate in community-led change (Acord 2003).

In relation to our treatment as prevention approach we have to distinguish between the different target groups within the communities in the Shiselweni region. When approaching community members we may approach young people and youths in different way than we work with pregnant women or again, with men.

Therefore I want to propose having two main targeted interventions: the first deals with young people while the second with adult middle-aged men and women. Within the latter we can distinguish pregnant women and their partners, women and men in the community and individuals living with HIV and AIDS.

### 4.2. Community Involvement – Community Capacity Enhancement CCE

To attain the above suggestion, I would like to suggest a Community Capacity Enhancement approach. The focus of the community capacity enhancement approach is people centered. It takes into consideration their interactions, strengths, resources and their collective dealing with their concerns. The program recognizes the capacity and knowledge of communities and appreciates that they possess the strength to build on these and put them through a process of validation as a group.

The chapter is divided into three sub-sections. The first sub-section gives an overview of how a given society is formed with its individual and collective structures and culture. Three tables will show the way a given society develops a response to HIV/AIDS. The four different sectors that exist in every society will be presented by means of the Four Quadrant Framework, adapted from Ken Wilber. The first table shows how a society is built in theory. The second table shows an analysis of the specific society the program is working with, i.e. the communities in the three regions. The third table gives an idea of expected results after an evaluation of this long-term intervention.
The second sub-section explains the so-called methodologies for transformation in general and why they are proposed.
The third sub-section describes the selected methodologies for transformation that should be implemented to attain the overall objectives.

#### 4.2.1. The society

One of the specific objectives of the IEC program at present is to raise awareness on HIV and AIDS. Beyond raising awareness we will also focus on changing sexual behavior – for youths it means delaying their sexual debut, and for adults it means a primary behavior change: encouraging not only risk reduction but risk avoidance (Green 2011:163). Discussions about programs and strategies that are focused on behavioral change came to the conclusion that IEC strategies focus too much on imparting knowledge and not on bringing about behavior changes. Even if the focus is put on behavioral change, responses to HIV and AIDS mostly focus on the achievement of “objective, exterior, visible and measurable” results (refer to Table 1 below). Priority is given to increasing people’s knowledge about HIV/AIDS, to make them change their behavior and to practice safe sex. This kind of intervention is an essential and important part of the response to HIV/AIDS. But what has become clear is that these interventions alone are not sufficient. Results achieved are often only temporary and not sustainable because they are not built on a foundation of attitudes, norms, values and beliefs to support them. That means, for example, if we want to change people's behavior towards PLWHA it is not enough to target only a behavioral change if their attitude towards PLWHA remains the same.

By means of the Four-Quadrant Framework it will be shown how the four sectors are interrelated in a given society if the program is based on a behavioral change intervention.

The first sector shows the individual in the society, his attitudes, beliefs, ways of thinking, (lack of) commitment or motivation, and perceptions that lead to behavior that could contribute to the spread of the epidemic. This sector is invisible and immeasurable. The second sector focuses on

a person's behavior and action, which is visible and measurable. The third sector explains the collective norms and traditions, culture and language of a given society, and the fourth sector is the response to HIV/AIDS on the system level.

**The Four Quadrant Framework adapted from Ken Wilber**

**Table 1:**

| | Subjectivity<br>Interior, Invisible, Unmeasurable | Objectivity<br>Exterior, Visible, Measurable |
|---|---|---|
| Individual | Attitude<br>- Belief<br>- Perception<br>- Ways of thinking<br>- Enthusiasm<br>- Feelings<br>- Motivation/Commitment<br>- Integrity<br>- Skills | Behavior<br>- Action<br>- Performance |
| Collective | Culture<br>- Norms<br>- Shared values<br>- Morals/ethics<br>- Shared assumptions<br>- Language<br>- Traditions | Systems, Structures<br>- Processes<br>- Work-plans<br>- Policies<br>- Technology<br>- Equipment<br>- Resources<br>- Spoken language |

What is suggested here is that any (objective, exterior, visible, measurable) action taken, in order to be sustainable and to achieve long-lasting results, needs to be supported by a transformation of those individual and collective attitudes and values (subjective, interior, invisible).

The second table shows how the given society is analyzed together with the communities that the psychosocial team is working with. How does the individual behave, what is his/her attitude; what is the collective culture? What are the norms? And which systems and structures support society?

**Table 2:**

| | Subjectivity<br>Interior, Invisible, Unmeasurable | Objectivity<br>Exterior, Visible, Measurable |
|---|---|---|
| Individual | My attitude<br>lack of commitment<br>rejection/refusal<br>denial<br>judgmental<br>'I don't care'<br>self esteem/confidence<br>indecision | My behavior<br>unprotected sex<br>incorrect use of condoms<br>unprotected sex with multiple sexual partners |
| Collective | Our culture/norms<br>women considered less important<br>multiple partner sex considered a sign of wealth<br>insecurity<br>taboos<br>shyness in the family<br>power relations<br>attitude of religious organizations towards the use of condoms etc. | Our System, Structure<br>IEC<br>VCT<br>ARV<br>HBC<br>systems in place (National Coordinating Structures)<br>AIDS education syllabus for schools<br>National AIDS curriculum<br>early marriage<br>traditional cultural practices<br>lack of sex education<br>religious practice against condoms |

With an intervention by the means of transformational methodologies the given objectives could be attained and sustainable results achieved. The following table demonstrates the expected results.

**Table 3:**

| | SUBJECTIVITY<br>Interior, Invisible, Unmeasurable | OBJECTIVITY<br>Exterior, Visible, Measurable |
|---|---|---|
| Individual | - Attitudinal change towards PLWHA.<br>- Feeling of empowerment<br>- Reflection on underlying causes of HIV/AIDS<br>- Enthusiasm and commitment to change<br>- Complex understanding of HIV/AIDS<br>- Clarifications of misconceptions | - Individual behavior change for safer sex<br>- Delay in sexual debut<br>- Risk avoidance<br>- Individual action<br>- Leadership skills<br>- Action taken<br>- Advocacy |
| Collective | - Reflection on cultural values, the role of women and stigma and discrimination<br>- Commitment to cooperate and change<br>- Shared understanding of the complex phenomenon of HIV/AIDS<br>- Clarifications of misconceptions | - New partnerships<br>- Dialogue<br>- Joint activities<br>- Mobilization of resources<br>- Advocacy |

### 4.2.2. Methodologies for Transformation

Methodologies of transformation try to work in-depth with the communities and find solutions together with the community. They empower individuals as well as groups, communities and organizations to take responsibility and action and to break the silence around HIV/AIDS. They contribute to the creation of a social movement that is carried by individual responses built on insights of individuals and on individual commitment and responsibility. They contribute to the creation of networks, linkages and group dynamics among responsible and committed individuals who have decided to work individually AND collectively to combat HIV/AIDS.

**Methodologies for Transformation contribute to the Response to HIV/AIDS by**

- addressing the underlying causes of the epidemic
  The major non-medical factors that fuel the spread of the epidemic are stigma, taboo, denial, the suppression of women, and some of the sexual practices, like multiple concurrent partnerships. The approaches lead people to a complex understanding of HIV/AIDS, and strengthen their capacity to look deeper and to change structures/systems/power relations/social contracts that contribute to the spread of HIV.

- leading people to behavior change that builds on individual and collective leadership
  Transformation methodologies go beyond many of the approaches usually used to deal with HIV/AIDS. They are not “training programs“ as such, but help to set free people’s intrinsic wisdom, creativity, intuition and power. They build on people’s strengths, on existing social capital and on the human potential for transformation. They allow people to become leaders in the combat against HIV/AIDS.

- contributing to the creation of a social movement built on individual responsibilities and responses → ‘response-abilities’

### 4.2.3. Specific Transformational Methodologies

The following selected transformational methodologies will be recommended and should be used as strategies for the Community involvement intervention.

• Leadership Development Program Methodology (LDP)
• Community Capacity Enhancement (CCE)

• **Leadership Development Program Methodology LDP**
Key to the program is the empowerment of individuals and groups, the development of a complex understanding of the nature of the HIV/AIDS epidemic, the creation of insights and the shift of perspectives that lead to action, the unleashing and strengthening of existing leadership qualities, and the understanding that addressing HIV/AIDS is everybody's individual responsibility.

- Strengthening of Personal Leadership and Commitment
- Strengthened Civil Society Leadership, in equal numbers of women and men, to support the response to HIV/AIDS at the local level

- **Community Capacity Enhancement CCE**

The Community Capacity Enhancement approach is based on the vision and recognition that communities have capacities to care, change and sustain positive thinking. Local responses to HIV/AIDS need to be based on the reality of existing social dynamics and relationships and on the concerns of local communities. The creation of 'spaces' of trust and mutual respect is critical. Genuine interaction can stimulate sustainable changes from within the community that are relevant to HIV/AIDS prevention and care and to reduce the impact of the epidemic. In a Community Capacity Enhancement process this is accompanied and accelerated by a facilitation team approach that works in respect and inclusion of all actors.

A community capacity enhancement approach starts from where people are, their perspectives of the situation and their interest in change. Through these processes of inclusive interaction, collective or social learning occurs, power relations shift, changes are initiated and ownership and responsibility for change is strengthened, and local capacities and resources are mobilized. The latter include material resources, social systems, time, social capital, skills, knowledge, values, tradition, etc.

**Objectives of the CCE Approach**
- Reinforce the capacity in individuals and within communities to better understand HIV/AIDS
- Reflect, initiate and sustain changes for an effective multidimensional response to HIV/AIDS
- Facilitate social mobilization and strengthen the capacity of communities with the view to ensuring community participation in the development of action plans and their implementation
- Support the development of self-esteem, self-confidence, tolerance, trust, accountability, introspection and the ability to see that one's attitudes have impact on other people's lives

**Overall Strategic Objectives**
- To create a supportive environment that nurtures and sustains individual behavior change.
- To shift the national discourse on HIV/AIDS from one, which is primarily focusing on death, sickness and fear – "it is a killer disease" – to one that provides hope and societal transformation by promoting positive role-models and the language of change.

### 4.3. Translated into Practice

One of the main concerns in discussions with MSF staff from the psychosocial team was that our intervention is influenced by a western-driven approach with its western shaped values and attitudes. With the above mentioned approach we listen to what community members propose and think should be changed. As for a less western intervention I stress the behavior-change approach.

Start a process called 'Community Conversations'[80]. These facilitated dialogues stand in contrast to conventional approaches in which people are brought together for awareness-raising lectures, accompanied by the distribution of pamphlets. Community conversations proved to be a platform for people to think through the ways their individual values and behavior, and that of their family and neighbors, affect people's lives. Community conversations create a space for mutual learning and result in new perspectives. They raise the awareness of communities to attitudes and values that encourage risky sexual behavior like multiple concurrent partnerships.
Community conversations should be done with all different target groups and will be started with the traditional and political hierarchy (see the report on community dynamics from Dlamini) in collaboration with health personnel. These dialogues should be done as well with the other target groups and will ideally result in behavior change avoiding risky behaviors.

As a result of these community conversations link the program with the communities through the following:

- Traditional and political structures (chiefs, *indvuna, inkhundla*)
- Traditional healers
- Traditional women's organizations like the one for married women (*Lutsango Lwa boMkae*) and the one where people are trained to protect children and support those abused ("a shoulder to cry on")
- Community Expert clients
- Community Support Groups
- RHM
- Youth groups (listening centers)
- Women Communicators
- Male Communicators

**Target groups**
The traditional and political levels need to be involved in the planning and implementation of community approaches where we listen to their proposals. The practical facilitation will take place through the different groups mentioned above.

- **Men**

In the Swazi society the voices of men have more legitimacy than those of women. As we have seen throughout this report men play the decisive role in the relationships. If we want to reach women we have to reach men first.

Have a network of male communicators in the communities that act as peer educators to sensitize other men on risky behavior, VCT, ART with a positive message to protect their wives and children and finally themselves. Men assume their responsibility. Being responsible will be associated with power and strength. A strong and powerful responsible man cares for his family. Men should talk to men because they prefer listening to a male person.

- **Women**

For women to encourage and empower themselves, have female communicators in the communities; these could also be the community expert clients, to discuss condom negotiation, VCT and PMTCT. As we have seen women are not difficult to reach; they are already very active in the communities (NCP, Gogo centers etc.).

Convince parents to test and get ARV treatment for the sake of their children. Tell the parents what you hear from their kids in schools, about their fears and worries (children say they are afraid that when their parents cough they have HIV). Children are stressed that their parents might be sick, might be HIV positive or might die.

- **In-laws**

The program should have a strong focus on parents-in-law, especially mothers-in-law since they are the decision-makers if their sons live outside the family or country. In some areas in the

[80] For facilitation use the handbook from UNDP *Community Capacity Enhancement*.

Shiselweni region many women stay alone with their parents- mothers-in-law. Men practice "informal polygyny", which means that a man who has a wife in their rural area has another wife at his work place. All the adults in our target groups are also parents-in-law. In the course of our awareness and sensitization programs we should not forget addressing them as parents-in-law as well especially to support their daughters-in-law that will be part of the PMTCT program. Mothers-in-law always blame their daughters-in-law, therefore through community conversations we could tackle these attitudes and behavior in order to create a supportive environment for young married women.

- **Youth**

Create listening centers or a youth corner for young people, because they are afraid of going with their concerns to clinics, to their parents or to teachers.
These listening centers will work separately from health facilities for counseling purposes for young people where they can come and ask questions. A core point is that the personnel working there should be highly motivated and professional. They should know how to deal with youth and with their health problems and concerns. Ideally a younger social worker or two, a female and a male, could be the contact person. These centers should also offer VCT for young people because they need another approach. Young people mentioned their desire to have a person with the expertise to teach them.

- Internalize knowledge about HIV/AIDS, MC, testing and treatment. Misconceptions about transmission, difference between HIV and AIDS and the incubation period should be tackled
- Awareness education in a culturally appropriate setting: for example, in discussion groups or after they have met at the football or netball clubs, but also through attractive means such as video shows (cinema)[81]
- To work with youth in order to let them empower themselves in an appropriate local way to prevent HIV infection in a setting in which many factors (poverty, gender inequality, peer pressure) put them at risk of infection
- To sensitize boys and girls about decision-making and negotiation with respect to relationships and condom use in a way that connects with daily reality
- Teach about condoms and to tackle misinformation and myths about condoms, in order to make condoms more socially acceptable also for girls and link them strongly to the concept of protection. To teach youth about condom use, the problems that could arise, how to deal with them and to give demonstrations of condom use. Boys should be encouraged to practice condom use by masturbating with one on so that they feel comfortable with them during sex.
- To teach youth about reproduction (the menstrual cycle and pregnancy)

Make sure that in the meetings there is no person the young people do not trust. Show films on how to use condoms and engage in condom negotiation. And young people wish to have the meetings with someone from outside, because as they say, "We take this person more serious"[82].

You people also need psychosocial support for they can feel ashamed when their parents are sick or suffering from AIDS or have even died, they are traumatized and need comfort.

- **Kids**

Target kids to reduce trauma and stigma. Have activities with children aged from 8-12 to create drawings and discuss these drawings together. Use the article on children's stigmatization in Zimbabwe through drawings as an example and inspiration (Campbell 2010:975).
Prepare children how to deal with sick parents, listen to their fears and worries and work with them to reduce these fears.

- **RHM, support groups**

Have community conversations with RHM and support groups on the subject of testing and treatment motivation. Pass the message that with treatment you don't show symptoms, so you are not seen to be HIV-positive in addition to other messages.

[81] The community awareness advisor team has already started with video discussions with young people.
[82] Interview 8, young boy out of school.

- **Religious leaders**

Churches have a major influence in communicating with communities. Some churches create misconceptions about condom use and ARV treatment. We should work with religious leaders in order to influence them for creating a moral-free message and to assess attitudes towards condoms and ARV treatment. To inform them about the MSF programs and to create messages together that can be transmitted in the churches.
The church plays a major role in creating linkages with other institutions in the community. This is clearly demonstrated by the recognition that apart from providing spiritual nourishment, the church is as well involved in the provision of health, education and community projects. For example the ZCC church treats sick people spiritually and harms patients on ART by telling them that only Jesus can help them.

- **Traditional healers**

Traditional healers assume an important role in the community. They have high credibility and deep respect among the population they serve. They are knowledgeable about local treatment options as well as the physical, emotional and spiritual lives of the people, and are able to influence their behavior. Therefore I want to emphasize the [importance of] collaboration with traditional healers.

They should become one of our main target groups to work with. People have a lot of trust in all kinds of traditional healer, and what they say has weight.

Train them as educators in general because people listen to them.
Train them as RHM and HBC givers as it is their role to care for the sick.
Train them for condom demonstration and provide healers with a wooden penis. Green describes that these new skills along with accompanying ADIS/STD knowledge has increased healers' status ... Medical personnel have begun to refer HIV-positive patients for condom demonstration and HIV counseling (see Green's article from 1995:508).
Collaborate with them for psychosocial support to comfort youths and children (female *sangoma*).
Train them for VCT encouragement (*sangoma* traditionally are the ones who find out the cause of the disease).
Train them for ART encouragement with a positive message.
Collaborate with them as educators and counselors on alternative sexual behavior for non-penetrative sex as described earlier in this report (Green 1995:507).

- **Testing**

Confirm places for HIV Testing in the Communities as already identified in this study: NCPs, Gogo Centers, schools for Youth, and try to make work place testing possible.
Have someone from outside appointed for certain days in these places to do the testing. Especially target youths with listening centers.
Put in place a follow-up structure for positively tested individuals for a $CD_4$ count (in the near future ideally with viral load) in such a way that those testing positive are not immediately identified as such.
Do door-to-door testing emphasizing the three Cs: Convenience, confidentiality, and credibility.

- **Media**

Use the radio to transmit positive messages about treatment and testing and as a reminder to take the drugs at 7am and 7pm with an encouraging positive life message for the day.

**Conclusion**

Focusing the whole MSF program on two major strategies: prevention and treatment. But all the activities should be discussed with the key persons in the community in order to make the communities actively participate, to ensure co-ownership and most importantly, shared responsibility.

Relevant to the whole community approach, the psychosocial officer of the TB team should be part of the psychosocial team enabling him/her to participate in their discussions, to share experiences and profit from their knowledge and expertise because HIV and TB go hand-in-hand.

The TB team needs knowledge about HIV and AIDS and the HIV/AIDS team needs knowledge about TB.

• Clear Image of MSF what we do and what is our message

• Division of the community-based program into two major target groups: youth and adults

  - Youth: the creation of “listening centers” with trained counselors, peer educators and condom demonstration and provision
  - Adults: men and women as leaders (could be simultaneously the community expert clients) in every region, to motivate, mobilize and organize the communities and empower them to participate actively

• Influence the churches for a positive message on prevention and treatment, influence young religious leaders (e.g. the school for pastors FEA in HLK health zone near New Heaven Clinic)

• Strong focus on PLWHA and the disease itself to minimize stigma (this is already very well in place through our expert clients)

## Concluding Remarks

In this project MSF is focusing on a real community approach which tries to make the communities active stakeholders in the response to HIV and AIDS. To be able to apply this methodology MSF will step back from a one-dimensional top-down intervention and give these communities space and voice to become appreciated and helpful partners reinforcing their dignity and self-esteem and empowering all actors to work together.

The success or failure of health programs depends on how well they adapt to the characteristics and needs of the population. Potential difficulties in fieldwork can be avoided with a deeper understanding of the local society with which we engage. To train health personnel to be responsive and respectful with the populations' traditions, religion and customs in the environment they are going to work in should be a basic prerequisite in the preparation phase.
The success of a project is derived from the population's accepting it. Being close to the people is meant literally and not just a distant metaphor.

Sexual behavior of men/women/adolescents is different and needs different approaches. Knowledge and understanding of illness are socially and culturally constructed as are actions taken with regard to treatment. To understand beliefs is the clue to having an effective program strategy. The success of a project appears in the population's acceptance.

To conclude with a comment by Standing: "… the need for cultural knowledge cannot be overestimated. It is vital to know what degrees of sensitivity exist in relation to sexual matters. This includes sensitivity to the age and gender of the researcher(s) and to whether there are cultural embargoes on the discussion of sex between different age, gender and socio-economic groups" (Standing 1992:482). In Swaziland, especially with its long lasting tradition of multiple concurrent partnerships, sexual behavior and the meaning of sexuality are key points and have to be understood.

With personality and sympathetic understanding, a sensitive intervention and respect to the people and their culture, we were able to create a fruitful collaboration with the communities in Shiselweni region for an accepted treatment-as-prevention approach.

## Acknowledgements

Carrying out this study for MSF in the Shiselweni region in Swaziland was an enormous challenge for me. I gathered a lot of new and interesting information additional to the study I did in 2008 on perception of TB and MDR TB and was able to add many aspects to my medical anthropological knowledge during this field research, with a special focus on HIV and AIDS in relation to perception of testing and treatment. As the various missions with MSF add up, I can enhance and improve by doing comparisons of the different countries and experiences. I realize that every mission is obviously distinct, but it is of utmost interest to find numerous similarities that support the understanding and validating the results of this report.

I would like to thank all the people in Swaziland who worked with me in order to make my study possible and constructive. It was an enriching and often touching experience to speak with them. I would especially like to thank them for all the openness with which they shared their personal experiences associated with HIV and AIDS. Personal life stories and stigmatization after disclosing their positive HIV status, treatment experiences, their own sexual behavior and that of their partners were all overlain by their personal fears and worries.

A researcher cannot give immediate assistance, but I hope that the information I gathered and the conclusions I have drawn will enable us to strengthen our interventions and create a successful community capacity-enhancement approach that is culturally appropriate to raise the awareness of communities about testing and treatment.

I would like to thank the MSF Team in Swaziland and in headquarters in Geneva and Vienna for their valuable support. I particularly want to thank my international and national MSF colleagues in the project in the Shiselweni region for their professional attitude, their in-depth knowledge of

the country and its people and our enlightening discussions. My small team for this anthropological study, composed of an assistant, a female translator and a driver, was incredible both work-wise and personally in taking extraordinary care of me. I want to thank them for their warmth. They turned my stay into a period of my life I will always remember. In particular I thank the Swazi people, for all their knowledge and wisdom, their problems and worries that they shared with me. They are the experts of their culture. I can only learn from them and bring their knowledge to paper with my analysis as a medical anthropologist. Finally a special thank goes to Tim Fox who was of great help in editing the report.

My experiences with MSF, my colleagues and the people of Swaziland are precious to me; they have all my respect for their ability to cope with their difficult living conditions and their consequences. To all those who may continue to work in Swaziland.

**Glossary siSwati – English**

| | |
|---|---|
| Akushiwo | You don't say that |
| Babelekisi | Delivery assistant-midwifery |
| Bucopho | Inner councilor (he is the link between the Inkhundla and the Umphakatsi) |
| Emaphilisi latsintsibalisa ligciwane | Tablets that suppress the virus |
| Emasotja emtimba | The body soldiers, **$CD_4$** |
| Gcunsula | STI |
| Gogo | Grandmother |
| Indvuna | Community headman (Chief's assistant) |
| Ingati | Blood |
| Inkhundla | Constituency Centre |
| KaGogo | Traditional Grandmother's house, now refers to a place of refuge within the umphakatsi |
| kucatseka | Enema, traditional treatment to clean the intestine and the waist, (Klistier) |
| Kucheche | Female liquids in the vagina ( I suspect kucheche is not spelled correctly as I have never had of such (comment from Assistant)) |
| Kufukama | Staying in one place like a chicken on its eggs. That term is also used when someone is mourning. |
| Kuhhema | Confusion-it is to say something that doesn't make sense. (hallucinating) |
| Kukhuma | Licking the pills, biting the pills |
| kuloya | To bewitch, to curse |
| Kuloywa | To be bewitched |
| kumtsebula | To make somebody confused-it can also mean to take a photo |
| kumunya | To suck out something, |
| kumunyisa | Breastfeeding |
| Kwecwaya | To avoid a person, stigma |
| Libangalala | Sex stimulant (medicine for sexual strength) |
| Libhande | Looks like a belt, **herpes** |
| Ligciwane | Germs referring to the HI **virus** |

| | |
|---|---|
| Ligola | Some form of STI, which is very much related to someone who just gave birth, breaking a taboo |
| Lijwabu | Foreskin of the penis |
| Likhubalo | It is when a man has actually bewitched his wife so that whenever she sleeps with another person that person would die at times it depends on what he wants to do to that person at times that person would fail to withdraw his penis and he would find them. |
| Lugedla | Traditional healer who only deals with herbs |
| magama lamatsatfu | The 3 letters (HIV) |
| makhonjwa ngemuno | Being pointed at |
| Mashayabuce | Wiping all out, wiping out everything (HIV/AIDS) |
| Mgumuzo | ARV, something you eat every day |
| Ngculaza (Zulu) | HIV/AIDS |
| sandanezwe | A plant that destroys the fields, is not a good plant as it is damaging |
| Sicitfo, sinyama | Sores and blisters in the face. It is associated with being bewitched and thus having bad luck as well. |
| Sidvodza | Sperm |
| sifo | Disease |
| sifo lesibulalako | Killing you softly, killer disease |
| Sihlati | Medicine for good luck (tihlati pl) |
| Silwane | Animal, beast (compare with tilwane, is it the same, evil spirit?) |
| sivikelo semtimba | $CD_4$, cells of the body, shield, something that protect you from getting ill, the soldiers, |
| Thinkhobe | Boiled corn |
| Tibi tendlu | You cannot expose family matters in public |
| tilwane | **Animals**, they put some evil spirits into you, you start behaving madly and strangely, you become violent like an animal, evil spirit |
| Timbita | Concoction of wild plants (traditional medicine made out of herbs) |
| Tinkhundla | Constituencies |
| ukusoma, ukufema | Thigh sex without penetration |
| Umbulalave | Killer disease, world killer |
| umdlavuza | Cancer, causes cancer in the body |
| Umfomo | Body liquids (sweat) |

| | |
|---|---|
| Umkhumbi | The boat, word used for female condoms |
| umklwebho | Something that is put on the ground, sprinkled on the ground, on the doorstep; if you step over it, you will be struck down by something and in consequence you get a swollen leg or a painful foot or arm, a person bewitched. |
| Umphakatsi | Chief's residence and headquarters of the community |
| Umtsakatsi | Witchdoctor who kills people, who uses the umutsi to kill people, wild doctor |
| Umutsi | Something that can heal you, herbs that can heal you, concoctions that could cause death, (medicine), also to win a football game. |

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**Anthropologist's work schedule 30th April – 20th May 2011**

| | | |
|---|---|---|
| Saturday | 30 April | Departure Vienna |
| Sunday | 1 May | Arrival in Johannesburg/Mbabane |

**week 18**

| | | |
|---|---|---|
| Monday | 2 May | Briefing with HoM, Medco and Roger Teck |
| Tuesday | 3 May | Arrival in Nhlangano, briefing with research assistant |
| Wednesday | 4 May | **Matsanjeni Health zone/Qomintaba**<br>I 1: 2 female expert clients, I 2: male expert client, I 3: female HBC giver, I 4: MSF MD Nhlangano health centre |
| Thursday | 5 May | **Matsanjeni Health zone/Hluti**<br>I 5: FGD women at NCP, I 6: 2 female support group members, I 7: high school boy, I 8: high school boy |
| Friday | 6 May | **Matsanjeni Health zone/Qomintaba**<br>9: 2 female HBC giver, I 10: gogo RHM, I 11: female Sangoma, I 12: 2 teachers at bottle store, I 13: CAA, MSF |
| Saturday | 7 May | **Matsanjeni Health zone/Hluti**<br>I 14: FGD women NCP, I 15: HIV+ woman on ARV and TB treatment, I 16: prophet on ARV and TB treatment |
| Sunday | 8 May | Lit review |

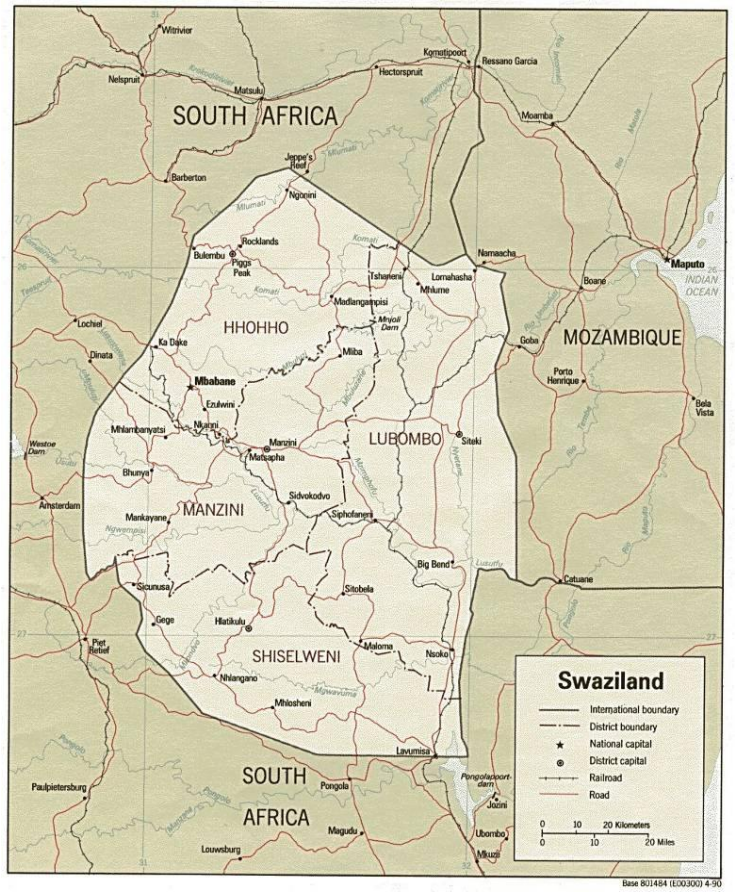
**week 19**

| | | |
|---|---|---|
| Monday | 9 May | **Nhlangano Health zone/ Zombodze**<br>I 17: community expert client, I 18: community head man, I 19: support group member gogo, I 20: household |
| Tuesday | 10 May | **Nhlangano Health zone/Gege + Mbita**<br>I 21: male Inyanga, I 22: female Sangoma, I 23: support group member Mbita, I 24: household Mbita |
| Wednesday | 11 May | **Matsanjeni Health zone/Lavumisa**<br>I 25: male Inyanga, I 26: patient HIV positive on ARV, I 27: young woman, I 28: male bottle store owner |
| Thursday | 12 May | **Hlatikulu Health zone/New Heaven**<br>I 29: mother of chief, I 30: pastors school, I 31: female traditional healer sangoma, I 32: FGD expert client |
| Friday | 13 May | **Nhlangano Health zone/Nhlangano, Mashobeni**<br>I 33: MSF Community facilitator, I 34: NATICC programme manager, I 35: female Expert Client Nhlangano health centre, I 36: female Expert client, I 37: FGD high school boys |
| Saturday | 14 May | **Nhlangano Health zone/Magubheleni, Dinga**<br>I 38: indvuna, I 39: youth meeting, I 40: woman HIV+ on ARV |
| Sunday | 15 May | Study review |

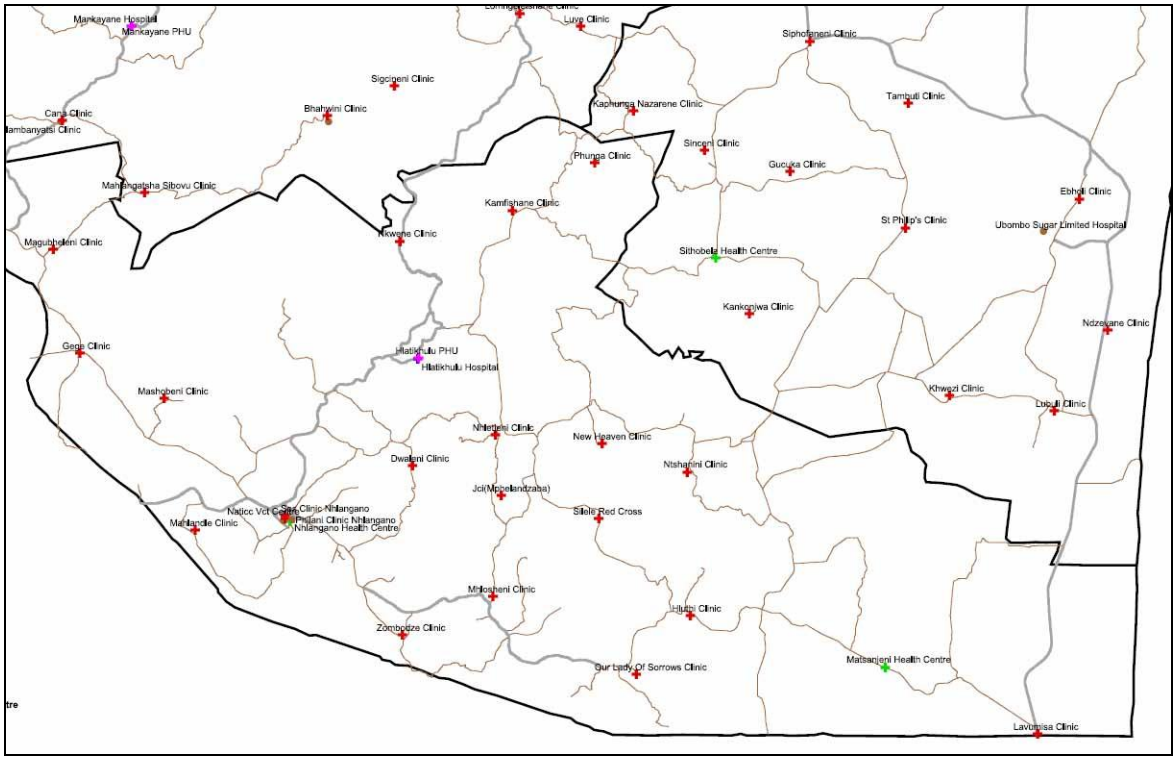
**week 20**

| | | |
|---|---|---|
| Monday | 16 May | **Nhlangano Health zone/Hlatikulu, Gwene**<br>I 41: MDR TB patient on ARV, I 42: MDR TB support group, I 43: elderly man worked in the mines in SA, I 44: MSF TB coordinator |
| Tuesday | 17 May | **Hlatikulu/Moti**<br>I 45: woman on ARV, I 46: child on ARV, I 47: community expert client, I 48: community expert client |
| Wednesday | 18 May | **Hlatikulu Health zone/Sidlangatsini**<br>I 49: female HBC giver on ARV, I 50: female Sangoma/Prophet, I 51: female traditional beer drinking place owner, I 52: 2 clients at traditional beer drinking place |
| Thursday | 19 May | Feedback and debriefing Nhlangano field team |
| Friday | 20 May | Departure from Mbabane to Johannesburg |

## Map Swaziland




## Map Shiselweni region/Health Facilities



# Report on Labour Migration and Community Dynamics

**Compiled by Velibanti Dlamini**

**Table of contents**

## 1.0 LABOUR MIGRATION

### 1.1 Objectives of the study

● Outline the functioning of the communities; hierarchy, roles of their representatives, social and cultural activities.

● Assess the extent of labour migration as an important factor contributing to high risk behaviour but also to loss to follow up for ART.

### 1.2 Sampling

The stratified random sampling method was used for this study and it targeted chiefs, Tindvuna, community elders as well as young adults. 40 people were encountered for this study but only 38 interviews were transcribed and translated because the other two interviews were poorly recorded

### 1.3 Interviewing techniques

In-depth and focus group discussion were used to obtain information. Digital voice recording machines (Dictaphones) were used to record information. Data collection took 15 days: three interviews per day. The fieldworker collected the data by using a data collection tool to guide interviews and discussions.

### 1.4 Data collection

One fieldworker trained in qualitative data collection techniques gathered information from the participants. He conducted 40 interviews and transcribed and translated thereafter. The fieldworker went through a briefing exercise prior to fieldwork in which he was oriented to the research design and contributed in the development of the data collection tool.

### 1.5 Transcription and Translation

After collecting the data, the fieldworker transcribed and translated the interviews they conducted. Transcription and translation was verbatim, which implies that all words and nuances recorded are shown in the transcript to capture the essence of the meaning of what the respondents said. To ensure quality and validity of the information, the fieldworker then checked the transcripts against the recorded audio files prior to analysing the data.

### 1.6 Analysis and Reporting

Throughout the process data was rapidly analysed into themes. A rapid analysis is a process where the data is developed into themes with each theme coded with a specific colour or shade of colours. The themes were then used to analyse the results of the study. The field worker analysed the data and compiled a report.

Quotations from the respondents are indicated in italics to substantiate the narrations of the themes as they emerged.

## 2.0 Level of labour migration

It is believed in this region (Shiselweni) there're no job opportunities and so a lot of people here look for employment out side the country and since they're living just a few metres\kilometres away from the border line they opt to go the SA to look for employment. They go to places like Pongola, Piet Retief, Durban and there're those as well who go to the mines of Johannesburg. Those that are working in these towns mentioned above, work as manual labourers in the sugar cane fields or in the forestry industry. And then there're those as well who are employed as truck drivers. These are mostly young male adults aged between 20-40 years old and there're very few women working that side and the few that is working there: work as maids. These young men and women cross the border line unlawfully (informally) because there are options or places where it is easy to cross the border without any hassles.

*Respondent: we have got many people who are working in Johannesburg, Pongola and Durban…and as I'm talking to you I'm one of them and I'm on my way after this discussion.* Inner councillor-male

*Respondent: it is mostly young male adults…other respondents agreeing.*

*Respondent: we have a few number of women.* Young male adults

*Respondent: because most of them are illiterate and so they cannot get decent jobs so they end up working as manual labourers.* Indvuna YeNkhundla.

*Respondent: I think I can say more than 65% of the population of this community are working outside the country, reason being: we're very close to the border and that in this community we don't have job opportunities. Some of them don't even need passports because there're places where we cross the border unlawfully and also because jobs that side pay better than in the country.* Community elder- male-Nhlangano

*Respondent: they work in Piet Retief and the surrounding towns and then some of them are working in the mines.* Community elder-female

*Respondent: I think the population of the people that we have in this community as we speak is far less than that of the people working outside this country because in this community we don't have any employment opportunities.* Community elder-male-Hlathikhulu

*Respondent: they work in the mines and some of them are employed in factories and some are working in the farms as well.* Young male adult

*Respondent: it depends but most of them are my peers…which means they are about 25 yrs to 35 yrs.* Young male adult

**2.1 Information on changed jobs**

In some cases they (community elders\superiors) wouldn't know when a person has left the country to go and work in South Africa up until that person is ill or dead and that is when they have to go and help that person in order for him to cross over to the country and to seek medical help as well. These young men and women, especially those working in the sugar cane fields don't really have fixed jobs as they move from one employer to the next. Only the truck drivers and those working in the mines have fixed jobs.

*Respondent: I wouldn't tell but then it happens, coz with some of them we get to hear when they have to use the border to come yet they didn't use the border when they went there but instead they crossed the border illegally …* Community elder-male-Matsanjeni

*Respondent: some are truck drivers as well… some of them are having fixed jobs and some of them move from one employer to the next especially the ones who're working in the farms.* Indvuna YeNkhundla-male.

*Respondent: at times you find that we're not told when this person has to go and work that side but then when he is ill and has to come back home, that is when we'll be told that he was working in South Africa and so now we have to go and help that person.* Indvuna yemphakatsi.

*Respondent: it is only those who're truck drivers that have fixed jobs and then as for those who're working in the sugar cane fields they don't really have a fixed job.* Young male adult

**2.2 How often they visit**

They come home during the Easter and Christmas holidays. But then there're those who come home once in two weeks and once a month, and these are the ones who're working closer to the border. And then there are those as well who go to work in the morning and they come back in the evening, which means they work right across the border but then they don't stay that side.

*Respondent: they usually come home during the Easter holidays and during the festive season, and those are the only times they're able to come home.* Umgijimi (chief's runner)

*Respondent: they come home during the Easter holidays and Christmas holidays.*

*Respondent: and then as for those that are working right across the border: they come home at any time as some of them sleep this side and they work that side and also school going children, some of them are staying that side and come home during the weekend and some of them sleep this side and they spend the day that side.* Young male adults

*Respondents: they come home at the end of the month and then there're those as well who come home every after two weeks.* Community elder-male

### 2.3 Causal factors for migration

Most of these people aren't learned as they dropped out of school due to many reasons and so they would then go and look for employment in the mines. And some of the parents encourage their children to go and look for employment opportunities in SA and it has somehow become the norm in this community that once you complete your high school or you drop out of school; you have to go and look for employment that side.

*Respondent: they go there because there are no employment opportunities in the country.* Community elder-male.

*Respondent: a lot of them are working at Pongola and even our parents are the ones that are encouraging us to go and look for employment that side since they can't stand to watch us stay at home and doing nothing.*

***Facilitator: so they go there because of their parents…?***

*Respondent: it is the norm in this community that once you're grown up you have to then go and look for job opportunities in SA, some of them are working in the sugar cane fields in Pongola and some are truck drivers. (Young male adult)*

*Respondent: okay…in this community in the past a lot of people would go as far as grade 7 and then they drop out of school to further other avenues such as finding employment in the mines and so education wasn't taken that serious…* Gogo centre manager-female

### 2.4 High risk behaviours

These young people have sexual relationships that side and some of them end up marrying people they met in South Africa. Some of them end up not coming home as often as they did in the past because they have sexual partners and also when they come home they don't really bring something tangible and one can tell that they actually spent their money with their partners that side. Most of the respondents believe that such behaviours actually spread the virus because some of them have got wives this side and so you find that when they leave the country they're actually HIV negative and then they will get infected and then when they come to the country they then infect their partners as well and some of them come home when they're ill.

*Respondent: some of the men leave their wives behind when they go to the mines and at times it happens that you find that they don't come home because they're having extra marital relationships in that country. Let me make an example since in the mines when you don't have a partner then you would stay within the compound but then when you have someone you then have find another place to rent and that is why you find that they don't come home because they have sexual partners.* Community elder-male

*Respondent: it has a negative impact on the fight against HIV because you find that they don't really know the status of their partners because at times you find that he'll leave for the mines HIV negative and then he will come back and infect his wife with the virus he got that side.* Community elder-female-Nhlangano

*Respondent: it is somehow impossible not to have a sexual partner that side as some of us have got wives and children that side and so are my colleagues…*Inner councillor-male

*Respondent: since some of them leave their wives this side and so you find that they'll have a relationship that side and then they wouldn't come home such that the wife would pack her things and leave her matrimonial home and so to answer your question, I'd say they do have sexual relationships.* Community-Male-Hlathikhulu

*Respondents: this actually puts everyone in the danger of getting infected with the virus because no one knows whether they use condoms or not, the next thing they get infected and then they transmit it to their partners they left in the country.* Community elder-Female-Matsanjeni.

### 2.5 ARV's and labour migration

There are people who are taking the treatment (ARV's) and they are working outside the country and they do come for their refills. At the same time we have those people who are called defaulters because they actually default taking the treatment and thus putting their lives in danger. Some of them take the treatment when they are not feeling well but then as soon as they recover they leave the country and then they decide to stop taking the drugs and they opt for traditional medicine. Most of the respondents believe that the ARV's provided in the country are far better than those they get in South Africa.

*Respondent: there's someone I know who is taking the drugs and he s not part of our support group because he said he doesn't want people to know that he is taking the drugs.*

***Facilitator: and how does he get the drugs?***

*Respondent: he comes back to get his refills and I know because I have been following him all along.*

***Facilitator: and where does he get them?***

*Respondent: he gets them at Nhlangano health centre.*

***Facilitator: and it has never happened that he defaulted?***

*Respondent: he hasn't yet defaulted because he started with the TB treatment and then he was later initiated on the treatment.* Support group chairlady

*Respondent: a lot of them come home very ill and what we have noticed with regards to HIV, they don't really get proper health care while they're in South Africa and I don't know why because here in the country we have saved a lot of these people and I think that is because our ARV's are stronger or something, but they have actually helped a lot of them, and they usually come here for their refills. Even my son as well, he got ill while working in Durban and so he came home and he started the treatment and after he recovered he had to go back to work and after a while he got ill again and that is after he wasn't getting them in the country and so I had to go to Durban to fetch him and he had to be admitted at Matsanjeni health centre again but then he recovered and so I had to fetch the ARV's on his behalf at the clinic on a monthly basis and eventually he had to get a referral letter which was stating that he has to get the very same drugs and he is taking them as we speak and he gets them in SA.*

***Facilitator: okay…***

*Respondent: and it happened some time back while I was talking to the doctor at Matsanjeni and I asked him if he knew that since we're staying within the border: some of the South Africans are coming to this hospital because they say the ARV's in that country are very weak and he responded to the affirmative, they say the ARV's they get this side are strong.*

***Facilitator: so tell me, your son stopped taking the treatment because he couldn't come back for his refills or he wanted to get them in SA?***

*Respondent: I think he stopped because in that country they believe a lot in traditional medicine and so I think he stopped and took the traditional medicine and then he got ill again, and then when I fetched him that side the doctor scolded at him for stopping taking the drugs and after that he has never stopped taking them ever since he got ill the second time.*

***Facilitator: okay…and how was he getting them when you were taking them at the facility on his behalf?***

*Respondent: he would ask for permission at his place of employment to come home and then he would find them at home and go back the following day.* (Community elder-Matsanjeni)

*Respondent: I know someone who has been working is SA and then his health deteriorated and he had to come home and he tested positive and he started the treatment and then after recovering he went back to work with the idea that he was going to take his drugs in the SA hospital but then in that hospital he was told to come back to the country to get transfer papers but then in this hospital they refused to give him those papers but they insisted that he should come and get them in this facility from time to time. Many people in this community were getting their drugs at* ***Etje juba*** *but then they were not getting any better and so the presence of* ***MSF*** *has actually helped a lot of people in this community as they have since recovered and that also brings the confusion as to why are the drugs different from the ones they get in SA because it seems the ones they get in the country are stronger than those they get that side.* Community elder-Male-Nhlangano

And then there're those who would come to the country when they're ill and they would start the treatment and after they recover they then have to go back to work and then while they're still that side they then decide to stop taking the drugs and so when the expert clients or rural health motivators trace them they discover that these people are dead or very ill because they stopped taking the drugs. And then as for those working in the mines: they get the drugs through their wives who bring them to the mines.

*Respondent: I have seen many people in mines taking the drugs and for those who keep on taking them, they are looking good…*

***Facilitator: and how do they get the drugs?***

*Respondent: you find that they sent their wives to bring them to the mines and that is how they get them.* Community elder-Nhlangano-Female

*Respondent: yes I do…and most of them are HIV positive...and getting ARV's has proved to be a problem because you find that they go and buy them at special doctor's clinics and when they don't have the money it means he will not get them as there's no place to get them free like in the country.*

***Facilitator: and then what do they do when they don't have the money?***

*Respondent: they have got no alternative but to relax because they don't have the money and that is why most of them are sick and you can tell from a distance that so and so isn't not okay, health wise.* Umgijimi-Male

*Respondent: I know someone who started the treatment while he was ill and then when he recovered he left the country for work and then I think while he was that side he stopped taking the treatment or he didn't come for his refill and then he got ill again and he died.* Gogo centre manager-Male

### 2.6 In conclusions

Labour migration is an important factor contributing to high risk behaviour and also to loss to follow up for ART. The reasons above state clearly that once people are working far away from home they tend to have other sexual partners and thus putting themselves and others at risk of getting infected with the virus. I think those who are already known to be taking the drugs should be motivated and followed at the same time to make sure that they don't stop taking the treatment because it is evident that once they stop taking the treatment the virus gets resistant.

## 3.0 COMMUNITY DYNAMICS

### Traditional structure

### 3.1 Hierarchy and roles

**The leader**
The leader of a chiefdom is the chief and in Lavumisa there is one chief who is responsible for 16 chiefdoms. The chief basically is the overseer of the king's land and he reports to the king.

*Respondent: the chief is "**umfana wenkhosi"** (king's messenger) and he is looking after the king's land and he is also responsible for the welfare of his people.*

*Respondent: I think he has put it right when he says the chief is "**umfana wenkhosi"** and then the Indvuna is "**umfana wa chief"**.* Indvuna yemphakatsi and Bucopho

*Respondent: okay, this community is different from the other chiefdoms, here we have about 16 chiefdoms and only on chief and that is Umntfwanenkhosi Gasa WaNgwane.* Bucopho-Male

*Respondent: he is actually the leader of this area and he is actually responsible for the king's land, and that is all.* Bucopho-Male

*Respondent: his role is to maintain peace and stability within the community.*

***Facilitator: and what else?***

*Respondent: he is responsible for the land and welfare of the people of that area.* Community elder-Female

**3.2 Indvuna Yemcuba (senior headman) and his role**
This is basically the chief's assistant and whenever the chief is not there he takes over his responsibilities. He is the "prime minister" in the sense that he is above all the other 16 headmen and he reports directly to the chief. He has to deal with issues\cases coming with the Tindvuna temphakatsi.

*Respondent: his role is to assist the chief in every way, it is like this, the chief is actually the eyes and ears of the king and then the Indvuna Yemcuba is the eyes and ears of the chief.* Community elder-Female

*Respondent: the role of this Indvuna is to deal with matters that are coming with the other Indvuna and he does that together with the chief's advisory committee.* Community elder-Male

*Respondent: since he is closer to the chief, the tindvuna telisango report to him and then he reports to the chief…*

*Respondent: and he also has to take it from the chief and report back to the tindvuna.* Young male adults

*Respondent: like I mentioned earlier that there're about 16 of the community headmen (tindvuna) and so when they preside over cases in the communities and you find that they come with a fine or judgement in that case and the person has a right to appeal, he can appeal to the Indvuna yemcuba which means it is sort of a high court within this community.* Bucopho-Male

**3.3 Emalangeni\Bantfwabenkhosi (Chief's uncles/brothers to his father)**
And right next to both the Indvuna and the chief is the chief's advisory committee commonly known as **Bantfwabenkhosi or Emalangeni** and the Indvuna Yemcuba is also a member of that committee**.** This is the committee which comprises of the chief's uncles (brothers to his father). And they advise the chief on arising matters and also when he has to make a decision.

*Respondent: according to my understanding he is supposed to advise the chief and as someone who is elder he has to counsel him as well. And also when the chief is someone who is humbled, before doing anything he also has to consult with the **umntfwanenkhosi** so that he can be able to advise him on what he is planning to do.* Community elder-Matsanjeni-Male

*Respondent: we have **emalangeni**…*

***Facilitator: tell me more about lamalangeni.***

*Respondent: I forgot to mention them; they are actually the chief's advisory committee. Like I mentioned that there's the Indvuna yemphakatsi, if he has failed to deal with a certain case he then brings it to the Indvuna that is superior and they can handle that case together with the chief's advisory committee and then that committee can take it further to the chief if there's a need or as means of reporting.* Gogo centre manager-Female

*Respondent: and right next to the chief and the Indvuna there's emalangeni and these are the ones who advise the chief and he also consults with them before he can do anything because these are brothers to his father so he respects them and the Indvuna has to be part of that committee…*community elder-Male

*Respondent: I don't think they're above the chief and the Indvuna and they're also not below and that means they're at par with the two, so they also have to know what is happening in the community as well because they're respected.* Young male adult

*Respondent: I think the Indvuna is also part of that committee and also the other elders of that household where the chief is coming from form part of the committee.* Community elder-Female

### 3.4 Indvuna yemphakatsi\yemmango (community headman)

In Lavumisa and surrounding areas the Indvuna yemphakatsi reports to the Indvuna Yemcuba but then in the other areas where the chief is responsible for that chiefdom the Indvuna report directly to the chief. The Indvuna is chosen by the Emalangeni\Bantfwabenkhosi. His role is to preside over cases at community level together with the inner council and also to maintain peace and stability in that chiefdom. He is also responsible for development issues in that chiefdom.

*Respondent: he is responsible for that umphakatsi and everything that happens in that umphakatsi is reported to him and then he also has to report to the Indvuna yemcuba as well.* Bucopho-Male

*Respondent: he's actually responsible for maintaining peace and stability amongst the community members and if he faces any challenges then he can take that matter to the Indvuna Yemcuba or the chief.* Community elder-Male

*Respondent: he is also responsible for the welfare of his people and also he has to know everything that is happening in the community and if there's something that has to be reported to the chief, he has to do that also report back to the people on what the chief has sent him to deliver to his people. And also to bring people together especially those that are in conflict. He is also responsible for development issues through encouraging them to start cooperatives and so he is responsible to see to it that it is done.* Indvuna Yemphakatsi-Male

*Respondent: his role is to preside over cases and then report what he feels is beyond his scope to the "prime minister".* Community elder-Female

*Respondent: like when people are having a conflict it is the role of the Indvuna to make sure that they eventually smoke a peace pipe. And also the safety of the community is a responsibility of the Indvuna. He is also responsible for development issues.* Indvuna YeNkhundla

### 3.5 The Inner Council

This is the council that works together with the Indvuna Yemphakatsi. It actually supports the Indvuna especially when presiding over cases and the also to advise him. This committee is made of men and women who are chosen by the community at large during a community meeting. Their role is to preside over cases together with the Indvuna and also to facilitate development projects. The Indvuna and the inner council are actually the ***entry point*** for any intervention or development program that is coming to the community. When presiding over cases and one of the concerned parties is not happy with the judgement he\she can appeal in the "*high court*" and that is the Indvuna Yemcuba and the chief's advisory committee.

*Respondent: they're going to help me. The role of the inner council is to assist the Indvuna in every way, and also to hear cases together with the Indvuna, in other words they are the leaders of that community.* Inner councillor-Male

*Respondent: the inner council is the one brings peace and stability in the community through bringing concerned parties together in trying to find a solution in their impasse.* Indvuna Yemphakatsi-Male

*Respondent: and also to look after the welfare of the people of that community.* Umgijimi-Male

*Respondent: the inner council is actually the entry point; this is where you bring whatever issue or case you've got.* Community elder-Female

*Respondent: I think the inner council works with the Indvuna when presiding over cases at community level and then if one of the concerned parties is not happy with the judgement and then he can appeal in the "high court" and that is the umphakatsi where there's also another Indvuna which is superior to all the tindvuna of the communities.* Community elder-Matsanjeni

*Respondent: they deliberate the cases together with the Indvuna Yemcuba and that is the only role of the inner council.* Bucopho-Male

**3.6 Umgijimi (messenger)**

These men are usually part of the inner council together with the Bucopho. These men are also chosen during a community meeting. Their role is to actually take messages from the inner council to the people concerned since the inner council preside over cases together with the Indvuna Yemphakatsi. They are basically the messenger boy of the Indvuna and the inner council. When there is a conflict the Indvuna first send the Umgijimi to go and speak to the concerned parties and if he fails to bring peace he has to then go back to the Indvuna and report on his visit to the parties concerned and then the Indvuna will send him again to summon the people to appear before the inner council.

*Respondent: like when people are having a conflict the Indvuna have to first send the Umgijimi to first try and talk to these people in trying bring peace but then when he fails to do that the case is then taken to the inner council where it will be heard.* Community elder-Male-Matsanjeni

*Respondent: he is actually the messenger for the Indvuna.* Male Community elder.

*Respondent: the Umgijimi is the messenger "boy" for the Indvuna, like when the Indvuna need a certain household to come to him, he sends the Umgijimi to deliver the message. And he also plays as an arbitrator when people are having problems and so when they fail to come to terms, it is when that the case comes to the inner council.* Inner councillor-Male

*Respondent: the Umgijimi is chosen just like the inner council which is chosen through a community meeting and he is the messenger boy for the Indvuna and the inner council.* Young Female adult.

*Respondent: he has to take students to the ministry for scholarships and also when we're supposed to have a community meeting and he does that together with the community policemen.* Community elder-Male

**3.7 Umsumpe (knowledgeable man in terms of knowing the area)**

Most of the time Umsumpe is also part of the inner council. He has to be someone who is well versed or rather who knows that area or place very well and has vast information about that area.

*Respondent: these men are also part of the inner council and they know a lot of things concerning the area…in fact they're well versed.* Community elder-Male

*Respondent: Umsumpe is responsible for allocating people land after being told to do so by the chief as they are believed to know better about the area.* Community elder-Female

**3.8 Bucopho (inner councillor)**

Bucopho is actually the link between the Inkhundla (political structure) and the Umphakatsi. He serves in both structures as he is part of the inner council and as well as the Inkhundla committee. He has to deliver messages to the Inkhundla from the **Indlunkhulu,** he also has to report back to the Umphakatsi on latest developments. He is the development officer in the sense that in both structures he deals with development issues.

*Respondent: he is actually the messenger boy of the umphakatsi, they send him to take things to the Inkhundla and also take things from the Inkhundla and back to the umphakatsi.* Bucopho-Male

*Respondent: bucopho is the messenger boy of the Indlunkhulu. He actually transports messages from Inkhundla to the umphakatsi and vice versa.* Community elder-Female

*Respondent: bucopho is actually the link between the umphakatsi as someone who has been sent by the people of the community to take development issues and concerns from the umphakatsi to the Inkhundla and then after deliberation at the Inkhundla he has to then report back to the people on what has transpired from what they sent him to ask for at the Inkhundla, so in short he is the link between the Inkhundla and the umphakatsi.* Indvuna YeNkhundla-Male

*Respondent: bucopho is the one serves in both the Inkhundla committee and the inner council…he is the one who deals with development issues within the community.* Young male adult

**3.9 Bosigodzi (responsible for the sub-chiefdom)**

These are also members of the inner council most of the time and they're also chosen by the community. Their role is to be responsible for sub-chiefdoms within the chiefdom and they're actually helping the Indvuna since at times you find that the chiefdom is huge and so the Indvuna needs helpers in order to reach each and every corner of that chiefdom and to make sure that peace is maintained. And at times these men are the chief's runners.

*Respondent: And then under inner council, we then have **bosigodzi** and these are the chief's runners at times and they are responsible for that small community under that chiefdom, since we know that there're many communities under one chiefdom and so they're responsible for those communities.* Bucopho-Male

*Respondent: like this is a huge area and so **Bosigodzi** are actually helping the Indvuna because when he is alone he cant reach everyone but then with the help of these men he is able to have all the information he might need coz they report to him from time to time just to keep him abreast with what is happening.* Community elder-Male

*Respondent: these men are chosen by the community and their role is to help the Indvuna because they're responsible for that small community and so they have to know everything that happening in that small community and they then have to report to the Indvuna.* Community elder-Female

*Respondent: they're also part of the inner council where they also preside over cases together with the Indvuna.* Young female adult

**4.0 Community policemen**

These are men and women who are responsible for police work within that chiefdom. The security of the residents is their first priority and they also help the police with information related to a crime committed in that area. Their immediate supervisor is the chief's runner.

Respondent: *We then have community policemen after that and they actually share the work in terms of who is responsible for this area and the other one will be responsible for the other area and they report to the chief's runner.* Umgijimi-male

*Respondent: their first priority is the safety of the community and they also help the police with information like when there is a crime committed.* Community elder-Male

*Respondent: they also arrest people and hand them over to the police after interrogating them.* Young male adult

*Respondent: they work together with the chief's runner and they then report to the inner council after reporting to the police.* Community elder-Female

**4.1 Lihlombe lekukhalela (shoulder to cry on)**

Under the inner councillor there're many organizations and cooperatives but worth mentioning is the Lihlombe lekukhalela. This is the committee responsible for orphans and vulnerable children as well as the abused and the under privileged. These individuals are trained with the skills necessary to carry their duties. And then below these cooperatives which are under the inner council, we then have the rest of the community members.

*Respondent: they're actually doing a wonderful job because they're taking care of the orphans and vulnerable children and as well as the abused.* Community elder-Female

*Respondent: under the inner council we have the many cooperatives and support groups, but then what I would like to talk about is the Lihlombe lekukhalela for they play a very crucial role in this community, they take care of the vulnerable children and the orphans by providing them with food and counselling.* Community elder-Male

*Respondent: their role is to take care of the children who don't have parents and they are trained to do that by the child welfare.* Young Female adult.

## 5.0 Political structure

### Hierarchy and roles

**The leader**

The leader here is the Member of Parliament (MP) for that Inkhundla. The Member of Parliament is voted into that office through national elections which are held every 5 years and that means he has to serve a 5 year term. Amongst his duties is to make policies and also to mobilise resources and also to advocate for development in his constituency. He is paid for being a Member of Parliament together with the Indvuna YeNkhundla.

*Respondent: the MP is elected through national elections and as well as the Indvuna and then as for the bucopho it is a different case all together because they come from all the communities, they come from Indlunkhulu and they are actually the "**umfana wendlunkhulu**".* Community elder-Male

*Respondent: his role is to mobilise resources and bring them to his constituency in the hands of the Indvuna.* Young Female adult

*Respondent: the role of the MP is to make policies and that all.* Bucopho-Male

*Respondent: he has been voted into that office together with the Indvuna YeNkhundla and after five years we'll have national elections and the process then has to start afresh and if the people are happy with him they're going to give him another term but then if they're not happy they're going to vote for someone else.* Umgijimi-Male

*Respondent: being a member of parliament is a nice thing because you get paid and it is up to you whether you improve your constituency or not but then again when the next elections arrive you're in for a tough time.* Young male adult.

*Respondent: yes he gets paid but then he also has to mobilise other resources for his constituency now so that the Indvuna can coordinate the development programs.* Indvuna YeNkhundla

### 5.1 Indvuna YeNkhundla (constituency headman)

Since the Member of Parliament is in parliament most of the time, so the leader of the constituency is the Indvuna YeNkhundla as he is the one who coordinates activities within that constituency. He is also voted into that office (5 year term) and he also gets a salary as well. His role is to welcome development projects and also to coordinate them as well. He works together with bucopho or rather the Inkhundla committee. The Inkhundla reports to the Ministry of Tinkhundla through the Regional Administrator (RA).

*Respondent: the leader of the Inkhundla is the Indvuna YeNkhundla and then we have members of the Inkhundla and the Indvuna YeNkhundla actually coordinates activities within the Inkhundla. Here I'm talking about development programmes and it depends coz when these programmes haven't reached the Inkhundla it is the member of parliament that has to deal with that and when he brings it to the Inkhundla, the Indvuna is the one who has to oversee that programme and the bucopho has to then take it to the Indlunkhulu if there's a need.* Community elder-Male

*Respondent: they report to the Regional Administrator and they also report to the ministry of Tinkhundla.* Bucopho-Male

*Respondent: actually this is the leader when considering the work he is doing, coz the MP only brings the resources and then everything is left in the hands of the Indvuna and the Inkhundla committee.* Bucopho-male

*Respondent: he works together with the bucopho and the MP in trying to develop that constituency. They have meetings with the MP and bucopho and this committee is called Inkhundla committee.* Indvuna yemphakatsi-Male

### 5.2 The Inkhundla committee (constituency committee)

This is the committee that works together with the Indvuna. It comprises of the bucopho of the chiefdoms under that Inkhundla. Like in Lavumisa where there're 16 chiefdoms under one chief

but then they have three Tinkhundla centres which are: Lulakeni, Matsanjeni South and Qomintaba. So the bucopho comes from the chiefdoms and they represent their chiefdoms in the Inkhundla centres.

*Respondent: at the top we have the Member of Parliament and then we have the Indvuna YeNkhundla (constituency headman) and then we have the bucopho and in this Inkhundla we have 7 of bucopho. And we have this committee called Inkhundla committee and the bucopho, Indvuna YeNkhundla and the MP form part of that committee.* Bucopho-Male

*Respondent: the Indvuna works together with the Inkhundla committee which is made of the bucopho from the chiefdoms under that Inkhundla…and I think the MP is also part of that committee and I think the hierarchy of this structure is just like that.* Community elder

*Respondent: this structure is very simple as it is made of Indvuna YeNkhundla and bucopho and they form a committee called Inkhundla committee.* Bucopho-Male

**5.3 Bucopho (Inner Councillor)**

Bucopho is actually the link between the Inkhundla (political structure) and the Umphakatsi. He serves in both structures as he is part of the Inner Council and as well as the Inkhundla committee. He has to deliver messages to the Inkhundla after being sent by the **Indlunkhulu,** he also has to report back to the Umphakatsi on latest developments. He is the development officer in the sense that in both structures he deals with development issues.

*Respondent: he is actually the messenger boy of the umphakatsi, they send him to take things to the Inkhundla and also take things from the Inkhundla and back to the umphakatsi.* Bucopho-Male

*Respondent: bucopho is the messenger boy of the Indlunkhulu. He actually transports messages from Inkhundla to the umphakatsi and vice versa.* Community elder-Female

*Respondent: bucopho is actually the link between the umphakatsi as someone who has been sent by the people of the community to take development issues and concerns from the umphakatsi to the Inkhundla and then after deliberation at the Inkhundla he has to then report back to the people on what has transpired from what they sent him to ask for at the Inkhundla, so in short he is the link between the Inkhundla and the umphakatsi.* Indvuna YeNkhundla-Male

*Respondent: bucopho is the one who serves in both the Inkhundla committee and the inner council…he is the one who deals with development issues within the community.* Young male adult

**6.0 Social and cultural activities**

In these communities they do not really have social and cultural activities except for a few. During the ***buganu*** (traditional beer made out of a fruit) season residents would bring their ***buganu*** to the Umphakatsi. During this occasion they would dance traditionally. This is usually done by the Lutsango regiment which is also responsible for the maintenance of the Indlunkhulu. In these communities they also attend national events such as Umhlanga and Lusekwane. In these communities there are traditional weddings from time to time. It used to happen in the past where MSF through their expert clients; they would have a dialogue which is commonly known as ***kudliwa inhloko*** but then it does not happen any more.

*Respondent: even though it doesn't happen that often but then there're some occasions where the people of this area would bring the seasonal traditional beer (emaganu) and vegetables to the chief. And there're also national events like Umhlanga and Lusekwane: people of this community are encouraged to attend these events without fail for they remind us of who we are.* Bucopho-Male

*Respondent: we have the Lutsango and those are the women who come and perform traditional dances at the umphakatsi and that is all I can think off right now.* Community elder-Male

*Respondent: like at times the HIV\AIDS activists (expert clients from MSF) would come to the community and we would convey and have that meeting where we would discuss a lot of things pertaining to HIV **(Kudliwa Inhloko)** and in terms of cultural activities I don't know what to say because it has been a while since we've had any cultural activity.* Community elder-Female

*Respondent: we only have soccer games and then when it comes to culture, there's nothing that I'm aware off…* Young adult-Male

*Respondent: in fact there're no cultural activities.* Young Male adult

*Respondent: we have Lutsango and they're there to maintain Indlunkhulu and it is their cultural role. And we also have national events where people of this community attend to serve their king.* Community elder-Male

### 7.0 HIV and AIDS information

**Young people and HIV**

Young people are the ones said to be at more risk of getting infected with the virus because if alcohol abuse and also because they do not want to listen and to take good care of themselves.

*Respondent: it's the young men and women because they like to move around at night while we're asleep and so you don't know where they're going to and what they'll be up to and so I think they're the ones who're at risk*. Indvuna Yemphakatsi

*Respondent: I would say it is the youth because they are still sexually active and I think if they can also be counselled because the virus is going to finish them.* Community elder-Female

*Respondent: I think it is the youth because they're the ones who sleep around and as for those that are not sexually active I feel they're a bit safe...laughter…but then as for the youth, I fell they are at risk of getting infected because they're sexually active.* Community elder-Male

*Respondent: young people are the ones at risk of getting the virus because they don't want to take care of themselves and they abuse alcohol like no body's business*. Community elder-Female

### 7.1 Everyone is at risk

as much as young people are said to be at risk, some respondents believe everyone who is not using condoms is at risk of getting infected with the virus, as well as adults who are married are at risk if they are not faithful to their partners.

*Respondent: And also married couples, you see if one of them isn't faithful then they're both going to get infected in the process.* Indvuna Yemphakatsi-Male

*Respondent: I would say everyone who doesn't use condoms when having sex; those are the ones that are in danger.* Young Male Adult

*Respondent: it can be anyone but then I think those that are sexually active are the ones that are at risk of getting infected.* Bucopho-Male

*Respondent: I would say everybody is at risk of getting the virus because if you have sex then you might get infected with or without a condom.* Young Female adult

*Respondent: I would say we have adults and I'm sure they are also sleeping incautiously especially when they're drunk or they are from a drinking spree and that is why I'm saying everyone. And as for the youth I also think it can be the abuse of drugs and alcohol as well that can result in one getting infected.* Indvuna YeNkhundla-Male

### 8.0 Recommendations based on responses

**On ART**

● *Respondent: I think for a long time people living with the virus have been discriminated and so I think they don't want anyone to know that they're taking ARV's. And even the chief mentioned that should anyone be discriminated he\she should report that to him so that he can duly punish that person. So I think those that are taking the ARV's should be told that we're past the discrimination period and so they shouldn't think that they would be treated badly and so they should be encouraged to keep on taking the drugs.* Bucopho-Male

● *Respondent: what is happening here is that whenever there's a community meeting people are encouraged to test and know their statuses and even the king himself when he has summoned the nation to the cattle byre he talks about HIV. And so even our chief I usually hear him telling the people that those who have already started the treatment shouldn't stop taking the ARV's because that is actually their life and also because once you stop taking the treatment you'll die.* Community elder-male

● *Respondent: I think maybe if the services or rather HIV services should be decentralised in the sense that if the people we going to get the ARV's closer like here at the gogo centre and I think in that way they can be*

*encouraged not to stop taking the ARV's because as it is now they have to go to Matsanjeni which is far from here and I think it discourages them in that way*. Gogo centre manager

● *Respondent: these drugs need you to have something to eat and yet people are living below the poverty line and so when he has to take the drugs he decides to postpone because he doesn't have anything to eat and then he ends up postponing for ever and that is actually a challenge for those who are taking the treatment.* Community elder-Female

**8.1 On HIV**

● *Respondent: I think maybe if circumcision can be encouraged everywhere including in the church because a lot of people are dying even in the church and so the pastors as well should encourage circumcision as that can actually help in the reduction of the prevalence rate*. Community elder-Male

● *Respondent: I think polygamy has to be discouraged because you cant satisfy all of them and people be encouraged to have one partner but then in the event that the man already has more than one wife everyone in involved in that relationship shouldn't then move out and have other sexual partners*. Community elder-Male

● *Respondent: I think that maybe if there can be a clinic in this community because as it is they have to walk about 4 to 5km to Matsanjeni health centre, and so I think a clinic or health centre can be well received.* Umgijimi-Male

**9.0 Recommendations**

**Recognize community/traditional structures**

According to my understanding MSF is doing a good in this region but then there is need to strengthen the relationship with the communities. The right person or people to talk to or rather to first have a workshop with; is the Indvuna together with the inner council. This then becomes the entry point (contact person).

**Organization should attend community meetings (senior staff members)**

Once they understand your mandate they are bound to call a meeting where you can then have a workshop with these people. I would recommend that during these meeting or workshops MSF's senior staff should be there other than to send the expert clients. As much as they do a recommendable job but then it is of great value to the community to know that these are the people who actually sent the expert clients to the people.

**Sensitize community membership on HIV/TB related issues**

You can also train some of the community members in order to encourage or to influence common knowledge amongst the community with regards to issues of HIV\AIDS.

**Strengthen referral system**

Local (Swaziland) referral networks should be considered, that is for Swazis migrating to the urban areas within the country. It is quite difficult to track or follow a person that has crossed the border. Labour migration is an important factor contributing to high risk behaviour but also to loss to follow up for ART.

**Encourage adherence to treatment**

Those who are already known to be taking the drugs should be motivated and followed at the same time to make sure that they don't stop taking the treatment because it is evident that once they stop taking the treatment the virus gets resistant.

**Sensitize traditional healers**

Bring on board traditional healers, share critical information with regards to HIV/TB so that they are on the same wavelength in terms of understanding such issues.

**Glossary**

| | |
|---|---|
| Bantfwabenkhosi or Emalangeni | Chief's uncles/brothers to his father |
| Bosigodzi | Someone responsible for a sub-chiefdom-equivalent to a ward in urban areas |
| Bucopho | Inner councillor |
| Etje juba | Name of SA hospital |
| Indlunkhulu | Traditional chief's homestead |
| Indvuna Yemcuba | "Chief" headman |
| Indvuna yemmango/yelisango | Headmen |
| Indvuna yenkhundla | Constituency coordinator |
| Inkhundla | Constituency |
| Kudliwa inhloko | Dialogue |
| Umfana wendlunkhulu | Messenger boy of the chief's homestead |
| Umgijimi | Chief's runner |

## Organisational Chart Community Dynamics