

# HIV AND AIDS AND TREATMENT LITERACY

NAMIBIA SURVEY 2008: MAIN REPORT



JULY 2009



The authors' views expressed in this publication do not necessarily reflect the views of USAID or the United States Government.  
Cover photo courtesy Positive Vibes/Namibia.

## Acknowledgments

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## **Executive Summary**

### **Aim of the Study**

The aim of the *HIV and AIDS and Treatment Literacy (HTLS) Survey 2008* was to gather information from health care workers (HCW's), people living with HIV and AIDS (PLWHA), and children of HIV positive HIV and AIDS support group members, on HIV and AIDS-related issues for the purpose of project planning. The PLWHA sample included HIV-positive members of the lesbian, gay, bisexual, and transgender (LGBT) community. Quantitative data was gathered on a range of issues including diagnosis and provision of treatment, access to and means of conveying information on ART, adherence to treatment, discrimination by HCWs, disclosure of HIV status to sexual partners, condom use, PLWHA having children, the concept of "Positive Living", and social support for HIV positive individuals. Quantitative survey work was carried out during October/November 2008. Five focus group discussions with children of HIV positive HIV and AIDS support group members were held during October 2008. A key objective was to learn more about children whose parents are HIV positive, and who may also be infected themselves such as their level of awareness concerning their own and/or their parents' status, as well as their own priorities and concerns.

### **Methods**

Quantitative data was collected in eight regions of the country. Interviews with HCWs were conducted in Windhoek, Oshakati, Rundu and Keetmanshoop. The questionnaire for PLWHA was fielded in Windhoek, Oshakati, Outapi, Eenhana, Rundu, Katima Mulilo, Keetmanshoop, Mariental, and Walvis Bay. The team set a target of 800 cases for the quantitative component of the study. The total valid cases for HCWs interviewed was 50. A total of 720 PLWHA (96% of the intended target) was also interviewed.

Four focus group discussions were conducted in the North of Namibia (Omalala, Ongwediva, Outapi, and Endola), which included an urban (Ongwediva) and a mixed rural-urban (Outapi) site. The discussion held in the Keetmanshoop was mixed rural-urban. A total of 83 children participated of which 59% (49/83) was girls. The majority of the children were aged 13 to 17,

and all of them were attending school. Further, 54% (45/83) confirmed that they were taking care of a sick relative at home.

## **Main Findings**

What follows are key findings and recommendations returned by the HTLS 2008.

### HIV and AIDS Support Groups

The first set of recommendations focus on findings surrounding HIV and AIDS support groups in Namibia:

- There is a trend in the quantitative data collected that HIV and AIDS support group members are generally better informed about HIV and AIDS than non-members, are more optimistic about having children, have better condom use practices, are better at adhering to ART, as well as following other positive living strategies. This positive behaviour change could be linked to the improved self-image and self-esteem that PLWHA respondents belonging to support group seemed to have when compared with PLWHA respondents who were not in support groups. This said, data from one study cannot lead to the conclusion that HIV and AIDS support groups are necessarily the mediating factor in these encouraging findings, but the findings do suggest that a strong correlation may exist, and that longitudinal research could be beneficial.
- Around 23% (136/589) of support group members have to travel more than five kilometers to attend a group meeting. Only 40% (237/589) have to travel less than a kilometer. NGOs should assist in compiling a database of HIV and AIDS support groups in Namibia. Support groups can then be informed of other groups near them. Members who travel far to attend meetings will also have an option to join another support group closer to home. Such a database will also serve to identify locations where new support groups may need to be established. It may also serve to strengthen the network since the groups could meet with one another to exchange information and ideas.
- Consideration should be given to gender as well as sexual identity in the creation of HIV and AIDS support groups. Less men than women join support groups. Roughly 84% (485/577) of female respondents had joined a support group compared to 73% (104/143) of male respondents. Individuals who either have a gay, lesbian, bi-sexual, or

transgender sexual identity may feel threatened within predominantly heterosexual groups.

- Training on income generation needs to be overhauled. As will be explained in Chapter Three, the vast majority of respondents in this study were either unemployed or were earning less than N\$ 500 per month. A comprehensive training package needs to be designed which takes cognizance of government efforts to encourage SME development, explains finance and micro-finance, links the training to institutions capable of providing support in setting up a formal enterprise considering levels of education, and provide interest free micro-loans below N\$ 1,500 where capital needs are basic. In fact, the lack of access to micro-finance is the key ingredient that is missing from the training initiative on income generation in an environment of severe poverty.
- Members of HIV and AIDS support groups are quite positive about having a child or more children. This said, meanwhile, the vast majority of PLWHA respondents found themselves in dire economic circumstances and a high percentage of them were already raising at least one child. Roughly 63% (145/231) of support group members who had a child after testing positive said it was very important for them to have another child. About 35% (12/34) of non-members who had a child after testing positive said the same. Once more, this underlines the need, identified in the preceding studies, to provide integrated sexual and reproductive healthcare (including family planning) for PLWHA. It also could indicate that support groups may not be providing their members with advice on family planning consistent with their socio-economic situation.

### Children of PLWHA

Focus group discussions (FDGs) with children of HIV and AIDS support group members, returned the following recommendations:

- To the extent that their immediate family members can't reduce the burden of caregiving, children look outside the family for the support of caring neighbors, more distant relatives, community leaders, and community-based organizations. These interactions should be encouraged, while at the same time strengthening the support that families can provide their children. These measures can incorporate technological interventions such as long-life crank-operated or solar lanterns that would allow children to read and do homework after dark.

- Children's experience of the group discussions were very positive. Most children asked for more group sessions. Many said that this is the first time they had the opportunity to share their concerns with others in similar life circumstances. This supports current plans by Ibis/Positive Vibes to facilitate the establishment of some 30 time-limited Children's Support Groups in both the north and south over the next 18 months.

### Information, Education and Communication (IEC)

There are a number of findings central to improving the effectiveness of IEC campaigns pertaining to HIV and AIDS:

- In the data, radio repeatedly emerged as the most accessed medium of information on HIV and AIDS. Its use should remain central to any IEC campaign pertaining to HIV and AIDS.
- Future IEC campaigns should be conducted both in English and the home language of the target audience. Though English is the national language of Namibia, less than 1% (2/718) of respondents referred to it as their home language. Respondents were much more positive about interpreting information on HIV and AIDS when presented in their home language. Around 52% (298/570) of respondents had difficulty understanding treatment literacy materials presented in English. When asked how difficult it was to understand the same information in their home language, 96% (540/567) said that it was easy or very easy. This finding is important given that some 42% (133/313) of the sub-sample for Windhoek, Oshakati, Katima Mulilo, and Keetmanshoop could be considered illiterate or semi-literate, i.e. has no or basic reading and writing skills.
- PLWHA interviewed show a strong demand for treatment literacy materials, indicating that they would read them if they were available. There appears to be an even greater demand among those PLWHA on ART. Therefore, if visibility of and access to these resources can be increased, usage should increase accordingly. HCWs are quite likely to read and recommend materials to patients once familiar with them. NGOs have an important role in disseminating these materials, and possibly referring people to public hospitals and clinics for additional information and services.
- Adult PLWHA on ART want information on being HIV positive and the ability to have children. Such information should be linked to that provided on PMTCT. It should be

explained to men what their role in PMTCT is. Three-quarters (38/50) of HCWs considered the participation of men in PMTCT to be poor. The importance of raising awareness of PMTCT increases in the light of the findings that one of the most cited reasons for not using a condom during last sex was the desire to have a child, as well as that having sex with an HIV positive sex partner was the norm.

- Though respondents on the surface had high self-esteem, they were worried about not being able to establish long-term love relationships. Around 70% (467/667) of respondents were no longer interested in pursuing their dreams. A campaign containing a strong message of hope for those who are HIV positive needs to be fielded. This campaign could focus on PLWHA who have lived a long time since being diagnosed with HIV.

### Health Care Issues

A number of general health care issues need to be addressed:

- There is a delay in feedback between when patients undergo a CD4 count test and when they receive the results. A waiting time of two weeks or longer for the majority of patients has not decreased between the 2005 and 2008 surveys. The 2005 sub-sample for Windhoek, Oshakati, Katima Mulilo, and Keetmanshoop indicates that only 53% (132/247) of respondents received feedback on their CD4 tests within two weeks. The 2008 sub-sample returned a figure of 50% (157/311). Factors in this may be the availability of laboratory staff and/or testing equipment. The possibility of assisting with additional capacity building should be investigated by the donor community.
- Only four (4/720) respondents in the 2008 sample owned a vehicle. Only 23% (133/570) have to wait half an hour or less to see a doctor. In the light of the fact that the majority of respondents had difficulty traveling to and from a health care facility, as well as generally had to wait a long time to see a doctor, increasing the number of mobile clinics dedicated to HIV and AIDS management both inside Windhoek, large towns such as Oshakati, as well as in remote rural areas, needs to be investigated.
- Around 35% (251/720) of respondents had contracted TB since testing HIV positive, while 18% (133/720) had been infected with malaria. Combating TB and malaria should

remain a major objective for all NGOs whether by administering dedicated programmes, or providing support to those institutions or organizations which do.

- The perception exists that HCWs discriminate against LGBT persons. If discrimination occurs it is specific to certain HCWs. Improved understanding of the needs of LGBT patients by HCWs may serve to remove or reduce potential conflict. No guidelines exist for the treatment of LGBT patients other than those prescribed for general patient care.
- Only 25% (94/380) of sexually active female respondents go for a Pap smear once a year. The remainder does so intermittently, or not at all. This emphasizes the need for a structured campaign to provide information on the need for a regular Pap Smear especially for sexually active women as part of broader sexual and reproductive health services for PLWHA, particularly given that HIV-positive women can be more susceptible to cervical cancer.

### Training Needs

The provision of HIV-related training to HCWs remains an area where there is opportunity for cooperation between the NGO community and the Ministry of Health and Social Services (MoHSS):

- Training needs exist among HCWs in the areas of ART and PMTCT guidelines, children and ART, monitoring and adherence, side-effects of ARV's, Positive Living, co-infections, and counseling skills.

### Condom Use and Sexual Behaviour

There are a number of important recommendations pertaining to condom use and sexual behaviour change:

- Based on the comparison of condom users and non users, as well as those with multiple concurrent partners (MCP) and those without MCP, the following recommendations are made for behavior change communications programs:
  - Focus on messages encouraging condom use with all partners, especially ones who are HIV negative or those whose status is not known.

- Increase access to condoms. Respondents were asked if they could access condoms within a ten minutes walk from where they live. Only three-quarters (581/720) said that they could.
- Continue the focus on increasing self-esteem and self-efficacy among PLWHA via HIV and AIDS support groups as improved self-esteem seems to be linked with the practice of safer sex by PLWHA.
- Raise awareness of the risk associated with having MCP.

### Psychology of PLWHA

A matter pertaining to the field of Psychology has also been identified:

- Case studies mapping the psychological profiles of PLWHA could lead the way in finding more effective methods of encouraging Positive Living among more PLWHA.

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## List of Abbreviations

AIDS:	Acquired immunodeficiency syndrome
ART:	Anti-retroviral therapy
ARV:	Anti-retroviral drugs
BCC:	Behavior change communication
FGD:	Focus Group Discussions
FHI:	Family Health International
HAART:	Highly Active Antiretroviral Treatment
HATS:	HIV and AIDS and Anti-Retroviral Treatment Survey
HCW:	Healthcare Worker
HIV:	Human immunodeficiency virus
HTLS	HIV and AIDS and Treatment Literacy Survey
IEC:	Information, education, and communication
JHU/HCP	Johns Hopkins University/Health Communication Partnership
LAC	Legal Assistance Centre
LGBT:	Lesbian, gay, bisexual, and transgender
MCP:	Multiple Concurrent Partners
MLSW:	Ministry of Labour and Social Welfare
MICT:	Ministry of Information, Communication and Technology
MoHSS:	Ministry of Health and Social Services
MTI	Ministry of Trade and Industry
M&E:	Monitoring and evaluation
NGO:	Non-governmental organization
NLT:	NawaLife Trust
OVC:	Orphans and vulnerable children
PLWHA:	People living with HIV and AIDS
PMTCT:	Prevention of mother-to-child transmission
SBCGT	The Small Business Credit Guarantee Trust
SMA:	Social Marketing Agency
SME	Small and Medium Enterprise

STI: Sexually transmitted infection  
TLFS HIV and AIDS Treatment Literacy Follow-up Survey  
trp: The Rainbow Project  
TB: Tuberculosis  
VCT: Voluntary counseling and testing (for HIV)  
WSW: Women who have sex with women

## 1. Background

This chapter contains a brief history of the research project presented in this document, as well as an overview of the research methodology deployed to realize its completion.

### 1.1 Introduction

The *HIV and AIDS and Treatment Literacy Survey (HTLS) 2008* is the product of research started during 2003. Lironga Eparu conducted focus group discussions with people living with HIV and AIDS (PLWHA) at various sites across Namibia. The *HIV/AIDS Treatment Consultation Report* provided insight into the plight of PLWHA before the introduction of government sponsored anti-retroviral treatment (ART). This was a major intervention on the part of the Namibian government. In order to determine the impact of this intervention, the *HIV and AIDS Treatment Survey (HATS) 2005* followed. Ibis/Positive Vibes, Lironga Eparu, and the Rainbow Project (trp) fielded three questionnaires: two were fielded among HIV positive members of Lironga Eparu and trp, respectively; and one was conducted among health-care workers (HCWs) involved with the provision of anti-retroviral (ARV) treatment. Valid cases amounted to 380 Lironga Eparu members interviewed, 26 trp members, and 59 HCWs.

The HATS gathered data on a range of issues including diagnosis and provision of treatment, access to and means of conveying information on ART, adherence to treatment, discrimination by HCWs, disclosure of HIV status to sexual partners, condom use, PLWHA having children, the concept of “Positive Living”, and social support for HIV positive individuals.<sup>1</sup> The response rate to the questionnaire fielded by trp was not satisfactory. The organization went back to the drawing board and the *Needs Assessment Survey among LGBTI Namibians* followed during December 2007. That study is the largest of its kind ever conducted among the lesbian, gay, bi-Sexual, transgender and inter-sex (LGBTI) population of Namibia. Valid cases totaled 597. Issues explored included sexual orientation, disclosure of sexual orientation ("coming out"), personal health, perception of the health care system, meeting places of the LGBTI community, gender, inequality and violence, sexual practices, and drug use.

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<sup>1</sup> IBIS Namibia et al (2005) “HIV and AIDS Treatment Survey”.  
IBIS/Positive Vibes – Lironga Eparu – the rainbow project: Windhoek.

During April 2008, five organizations came together with the aim of conducting a follow-up survey to compliment the research mentioned. These organizations included Ibis/Positive Vibes, Family Health International (FHI), NawaLife Trust (NLT), Social Marketing Association (SMA), and trp. The study was termed the *HTLS 2008*. It was agreed that each partner organization would contribute financially to the project, as well as make personnel available for its management. In return, each would contribute survey questions in the research tools which addressed their respective informational needs. The team decided to field two quantitative questionnaires, and to add a qualitative dimension via focus group discussions with children whose parents are were HIV and AIDS support group members.<sup>2</sup> The quantitative questionnaires were administered to PLWHA and HCWs respectively. The team implemented the project in three phases: preparation and planning, field work, and report production and information dissemination. They commenced field work for the quantitative component of the study in October 2008, and spent a total of 28 days collecting data. The team conducted the focus group discussions between 16 and 28 October 2008.

## 1.2 Objectives of the Study

The objectives of the HTLS 2008 were defined as follows:

- To assess whether HIV-related treatment and discrimination issues have changed for PLWHA since 2005.
- To assess PLWHA and HCWs attitudes towards:
  - facility-based services,
  - treatment access,
  - treatment adherence,
  - Positive Living strategies, and
  - the impact of stigma and discrimination on treatment-related issues.
- To discern whether LGBT persons have different needs to other PLWHA.
- To identify priorities for future interventions.
- To learn more about children whose parents are HIV positive, and who may also be infected themselves such as their level of awareness concerning their own and/or their

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<sup>2</sup> The questionnaires fielded, as well as the questions asked during the focus group discussion, can be viewed in the Appendixes of this document.

parents' status, as well as their own priorities and concerns.

- To gather preliminary information on children's exposure to alcohol abuse by parents and/or family violence.
- To gauge the interest of HIV positive parents in having their children participate in a time-limited support/empowerment groups on HIV and AIDS.
- To gauge the levels of recall, uptake, acceptability and referral of treatment literacy materials by PLWHA and HCWs, and to determine how these materials can be improved and distributed more effectively.

### **1.3 The Research Process**

The following section explains the research process followed.

#### **1.3.1 Study Design and Study Population**

Focus group discussions were held with children of HIV support group members ages 11 to 19. The children were identified via the support network of FHI and Positive Vibes. They were selected by facilitators from local PLWHA support groups, having the common characteristic that their parents were support group members, and/or they currently care, or previously cared for someone who is chronically ill in the family. The HIV and AIDS support group network of Ibis/Positive Vibes and SMA was used to recruit PLWHA for interviews. LGBT PLWHA were contacted via the network of trp. Some 82% (589/720) of PLWHA interviewed, including LGBT PLWHA, were support group members. Only persons 18 and older were interviewed. The study population for HCWs was initially limited to doctors and nurses only. However, it had to be expanded to include HCWs providing care and/or support to PLWHA due to difficulty in securing interviews with doctors and nurses.

#### **1.3.2 Sample Size**

The research team was unable to specify in advance how many children would participate in the five discussions mentioned. A major factor in this was obtaining the consent of parents or guardians. A total of 83 children participated of which 59% (49/83) was girls. The majority of the children were aged 13 to 17, and all of them were attending school. Further, 54% (45/83)

confirmed that they were taking care of a sick relative at home. The team set a target of 800 cases for the quantitative component of the study, including 750 PLWHA and 50 HCWs. The total valid cases for HCWs interviewed was 50. A total of 720 PLWHA (96% of the intended target) was interviewed.

### 1.3.3 Survey Areas

In total, eight regions of the country were surveyed. Interviews with HCWs were conducted in Windhoek (21), Oshakati (10), Rundu (9) and Keetmanshoop (10). The questionnaire for PLWHA was fielded in Windhoek (178), Oshakati (85), Outapi (41), Eenhana (61), Rundu (82), Katima Mulilo (100), Keetmanshoop (45), Mariental (33), and Walvis Bay (95). Four focus group discussions were conducted in the North of Namibia (Omalala, Ongwediva, Outapi, and Endola), which included an urban (Ongwediva) and a mixed rural-urban (Outapi) site. The discussion held in the Keetmanshoop was mixed rural-urban.<sup>3</sup>

### 1.3.4 Data Collection Procedures

Parents or guardians signed a permission slip for children to attend the focus group discussions. There were no objections to this. Permission was obtained from the Permanent Secretary of the Ministry of Health and Social Services (MoHSS), Mr. K.S.M. Kahuure, to conduct interviews with HCWs. The majority of interviews took place without prior appointment. The busy schedules of HCWs prevented them from setting fixed times for interviews. Instead, enumerators were assigned to wait at the health care facility until time could be found for the interviews. The average time for an interview was 20 minutes. Interviews with PLWHA were conducted at fixed locations. They received advance notice from local NGO support staff on the day and time of their interviews. These interviews each required roughly 55 minutes to complete.

### 1.3.5 The Study Team

Lucy Steinitz, PhD, was the Senior Research Partner to the study. Deon van Zyl, the Lead Researcher, supervised the quantitative field research component. He was supported by three

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<sup>3</sup> The reason both these sites are termed “mixed” is because some children come from the villages surrounding the town, but stay in a hostel in town, while school is in session.

senior enumerators: Elton Imene, Ferdinand Cloete, and Petrus Mbang. Each of these individuals spoke six languages, with one having eight years of field research experience.

To expand the capacity of the core team, seven additional enumerators were recruited in advance at each research site. A day was set aside at each site to train these individuals in the PLWHA/LGBT PLWHA Questionnaire. The three senior enumerators assisted the Head Researcher with the training. Systematic review of the questionnaire was done. The trainees were encouraged to ask questions. The purpose of each question was explained, wording clarified, and understanding tested. Once the questions were reviewed, role-playing took place where the local enumerators interviewed the three senior enumerators and/or each other. Before the training ended, each was given a questionnaire to study at home. In Keetmanshoop, the seven enumerators also received training on the HCW's Questionnaire. They conducted interviews with the HCWs under the supervision of the three senior enumerators.

### 1.3.6 Quality Control

Quality of data was assured by means of the following:

- Complete objectivity in a social research study is not possible. The researcher is not value-free, nor is his/her objectives and aims. All research has an ideological dimension and can be politicized. To limit the impact of this, research is conducted as a collective enterprise, because it is inter-subjective.<sup>4</sup> Though researchers may not share the same values, or have the same political or social objectives, they should arrive at the same results when duplicating acceptable research techniques. Institutional Review Board (IRB) approval for this study was obtained via the University of Namibia. A survey protocol and all survey tools were presented for evaluation to Diane Ashton, PhD. The objectives of the study were clearly stated. Recommended changes were adopted prior to the pilot phase of the study. Only approved survey tools were used in the field and are available for examination and duplication by other researchers. This final report has gone through repeated phases of peer review before being released to the public.

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<sup>4</sup> Babbie, E. (1995) "The Practice of Social Research (Seventh Edition)". Wadsworth Publishing Company: Belmont.

- The quantitative survey instruments were pre-tested in the pilot phase for the Study. Ten PLWHA and two nurses were interviewed. The last two questionnaires were included in the sample for HCWs because the content of the pilot questionnaire did not change significantly compared to the tool fielded.
- Ensuring the reliability of data involves the reduction of standard error. This was ensured in a number of ways:
  - Drawing the largest sample of any quantitative study to date in Namibia from among the country's private HIV and AIDS prevention and care network.
  - Questions fielded during the HATS 2005 were included in the quantitative survey tools.
  - The Lead Researcher, along with the senior enumerators, checked questionnaires for omissions or errors before respondents departed.
  - Data capturing was verified by, and extensive data cleaning performed by, the Lead Researcher post-fieldwork.
  - Data capturing was done using a standardized template designed by means of Epi-info 3.4.3.
  - SPSS 17 was used for statistical analysis.
- Ensuring the validity of data is about the avoidance of systematic error. One weakness of quantitative research is that an error in the survey tool will be repeated consistently. An explicit effort was made to avoid the use of open-ended questions in the survey tools deployed. Peer review was a fundamental component in the design of said tools. Where scales and indexes were deployed, strong emphasis was placed on adhering to international guidelines. A key determinant to the inclusion of a question in the survey tools used was its usefulness in providing information for the purpose of programmatic planning. There was a clear understanding of what information needed to be collected and why it should be done.

### 1.3.7 Ethics

The guiding principle in research is bringing harm to no one. The secondary principle is to obtain consent. Informed consent was obtained from PLWHA and HCWs before each interview. Their rights were explained as follows:

- An explanation was provided of what the study was about, as well as of the content of the questionnaire.
- It was made clear that the person was under no obligation to complete the interview if at any time he/she felt uncomfortable during this process.
- It was emphasized that the interview was both anonymous and confidential.

At the end of each interview the following actions were taken:

- The respondent was acknowledged for his/her contribution to the study.
- He/she was informed where the findings of the study can be obtained.
- He/she was compensated with taxi fare to and from the venue, as well as a small food package.

The following precautions were taken to protect the minors whom participated in the focus group discussions:

- Consent was obtained from a parent or guardian of the child, as well as the child him/herself.
- A child was to be excused from a focus group at the first sign of distress. This situation never occurred.

## 2. Support Groups, Take Control, and Wings of Life

This chapter on NGO initiatives in the area of care and support appears first in order to provide context to the data presented in the rest of the document. Support groups should not be confused with home-based care groups, although there may be overlap between the two. The primary function of a support group is to unite people who share a common problem or experience which is, or can be, debilitating. The groups referred to here are self-help groups and are not led by professionals.<sup>5</sup> HIV and AIDS support groups in Namibia serve the purpose of creating safe environments for members in which they can share information on and learn about HIV and AIDS, as well as provide emotional, psychological, and even physical support to one another. Each group appoints a leader entrusted with organizing the group, chairing meetings, as well as conveying relevant information to the other members passed on to him/her by the supporting NGO. The support groups involved in this study were participating in projects implemented by Ibis/Positive Vibes and SMA – the Treatment Literacy and Tusano projects respectively. Through these projects, support group members participated in a structured training program that addressed a variety of HIV-related issues

The Ibis/Positive Vibes Treatment Literacy project involved 25 PLWHA support groups from the Ohangwena, Omusati, Karas, and Hardap regions. The project first provided support group members with a series of training activities aimed at building self-esteem and HIV and AIDS knowledge. Then they were provided with media and communication skills that would enable their respective support groups to conduct advocacy and awareness raising within their communities. The project also strove to enable participating PLWHA to overcome social issues that hindered their access to, and effective use of, HIV and AIDS prevention, treatment, care and support programmes - thereby enhancing the programmes' efficacy. A number of the methods and tools piloted by Ibis/Positive Vibes in this project were also made available to members of the Tusano support groups through SMA's Tusano project. Ibis/Positive Vibes was a training partner in this project, along with the Legal Assistance Centre (LAC) and the PEACE Centre.

As was mentioned before, TUSANO is a support group network sponsored by SMA. It focuses on giving PLWHA the confidence to better themselves, as well as improve the quality of life of

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<sup>5</sup> Wikipedia (2009) "Support group".  
[http://en.wikipedia.org/wiki/Support\\_group](http://en.wikipedia.org/wiki/Support_group)

their family if they have one. TUSANO started in 2004 as a post test support group. It was rolled out in four towns where New Start offices were located: Oshakati, Rundu, Katima Mulilo, and Walvis Bay. Since its small beginning, the network has grown to around 20 formal support groups with a membership in excess of 500 members. The HTLS 2008 provided the first opportunity to collect quantitative data from TUSANO members. The TUSANO programme aims to increase consistent (always) condom use with all partners, decrease sex with multiple concurrent partners, increase adherence to ART, increase disclosure to the community, and increase the belief among PLWHA that they can live long and healthy lives.

“Be There to Care” is a theme within the national, mass media Take Control Campaign. It is managed by the Namibian Ministry of Information, Communication and Technology (MICT) with support from partner and stakeholder organizations. The aim of this campaign is to encourage healthy relationships by addressing issues such as faithfulness, condom use with a regular partner, partners testing together, partner and/or family support for a HIV positive partner, and an end to domestic and sexual violence. The “Wings of Life” radio programme is produced and presented by PLWHA for PLWHA and their family members, focusing on a host of palliative care-related issues such as stigma and discrimination, accepting one’s HIV status, disclosing to others, and care and support. This programme was launched in July 2008 in Windhoek, Oshakati, Rundu and Katima Mulilo, and involved PLWHA drawn from the Treatment Literacy and Tusano projects.

## 2.1 Support Group Membership

Some 82% (589/720) of respondents in the HTLS 2008 sample were HIV and AIDS support group members. The majority of support group members attend meetings close to home. Roughly three-quarters travel five km or less to a meeting. They are also very active. The majority of members attend four or more meetings per month.

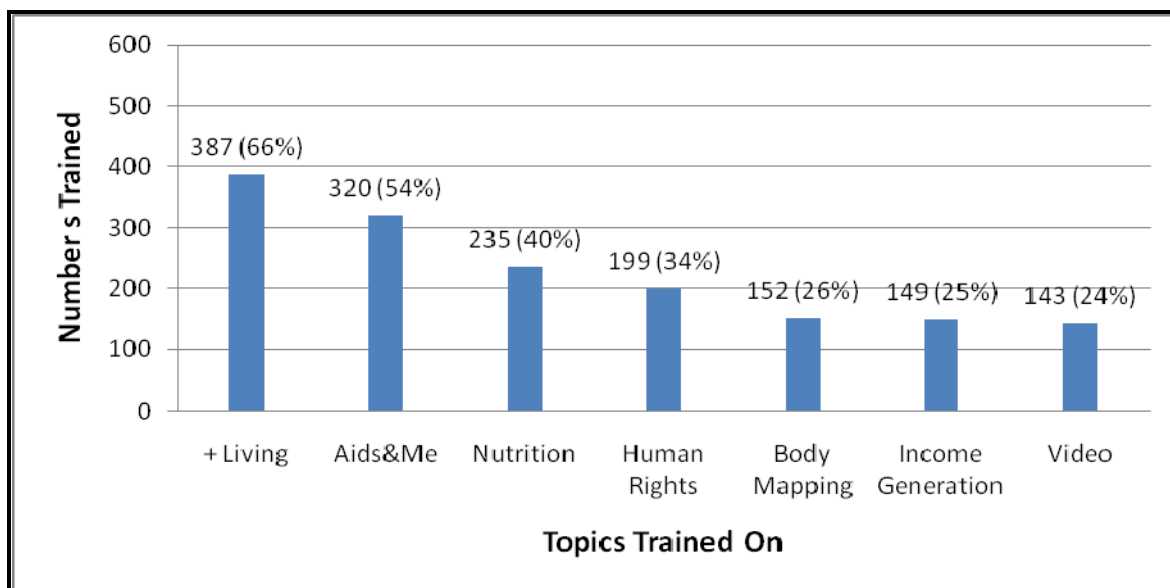
**Table 1: Support Group Attendance**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>Travel &lt; 1 km to meeting</b>	237/589	40%

<b>Travel 2 to 5 km to meeting</b>	216/589	37%
<b>Travel more than 25 km to meeting</b>	39/589	7%
<b>Attend &gt; 4 meetings per month</b>	103/588	18%
<b>Attend 4 meetings per month</b>	207/588	35%
<b>Attend 2 meetings per month</b>	94/588	16%
<b>Attend 1 meeting per month</b>	96/588	16%

Support group members receive training via their peers. Topics on which training is provided include Positive Living, AIDS and Me, nutrition, human rights, body mapping, and income generation. Training on Video Facilitation and Positive Speaking is also offered. Aids and Me is designed to allow participants to explore how HIV and AIDS affects them personally, and thus address HIV and AIDS in their lives. Though the numbers trained on the various themes differ greatly, a common thread is that those trained come away with a very positive experience. Each theme received a good rating by roughly 90% or more of those who had trained on it. As can be seen in Figure 1 (next page), training on Positive Living was the most accessed, with training in Video Facilitation and Positive Speaking ("Video" for short) the least.

**Figure 1: Training for Support Group Members**



N = 589.

Ibis/Positive Vibes have trained the most facilitators in AIDS and Me. Therefore, more Aids and Me workshops were made available through the Treatment Literacy and Tusano projects than for any of the other topics. The fact that the largest number of respondents received training in Positive Living attests to its popularity as a topic, rather than the availability of facilitators to conduct the training. Access to training in Video Facilitation and Positive Speaking is constrained by the availability of video playback equipment, as well as the reality that many support groups lack access to electricity since they operate within informal settlements.

Income generation is one area of training that requires review. This training cannot be presented in isolation of initiatives to foster small and medium enterprise (SME) development by the government of Namibia, nor in the absence of capital to kick-start said development. The Small Business Credit Guarantee Trust (SBCGT) of the Ministry of Trade and Industry (MTI) is to be transformed into a micro-finance institution.<sup>6</sup> It will provide a credit guarantee facility, individual business loans, group-based loans, group savings schemes, SME business planning services, and SME mentorship services. Training on income generation should include information in this regard. However, the NGO community also has a responsibility to ensure that needs-based micro-lending takes place. Many of the poor have very basic needs from setting up a chicken coup to sell eggs to affording a spade, watering-can, and seeds to start a vegetable garden, etc. Micro-loan support does not have to cost tens of thousands of Namibian dollars in order to be effective.

## 2.2 TUSANO

Membership of TUSANO is mostly limited to Oshakati, Rundu, Katima Mulilo, and Walvis Bay. Knowledge of the existence of this support group network is spread wider than its membership. Roughly 44% (258/589) of support group members knew of TUSANO. Of these respondents, roughly two-thirds (168/258) were TUSANO members. The majority of them found out about the organization by one of three means: they were told by a friend (47/168), heard about it on the radio (35/168), or were told by a HCW (34/168). They were also asked where they had seen information on the support group in the three months leading up to the interviews. Roughly 45%

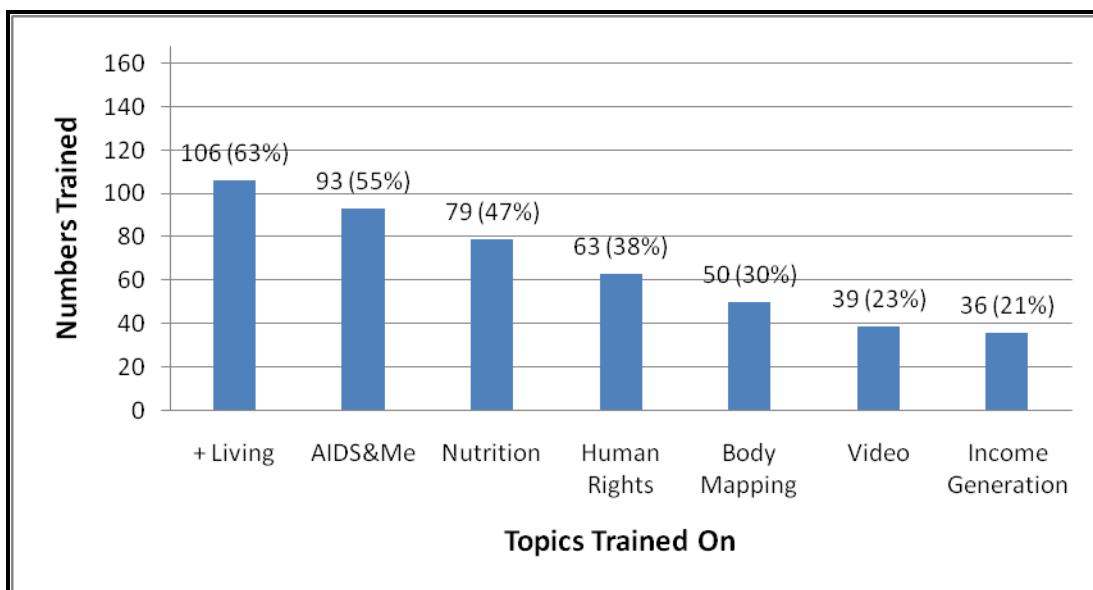
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<sup>6</sup> Ministry of Trade and Industry (2009) "Small and Medium Enterprise: Finance".  
<http://www.mti.gov.na/subpage.php?linkNo=23>

(75/168) recalled seeing it at a TUSANO office. Respondents also saw this information at NGOs offices (46/168) and public hospitals (34/168).

Training activities within TUSANO support groups mirror those of support group members in general. The majority received training in Positive Living and AIDS and Me. Training in the areas of human rights, body mapping, and income generation took longer and reached fewer people. Attendance of Video Facilitation and Positive Speaking training was also relatively low. It is not clear why TUSANO-sponsored radio program had very weak exposure (20/168). One would expect greater exposure given that the support groups are vehicles for promoting the radio programme. One explanation may be that the message is remembered, but that support group members do not know that the programme is sponsored by TUSANO.

**Figure 2: Training for TUSANO Members**



N = 168.

### 2.3 Wings of Life

Though the Wings of Life radio programme had only been on air for roughly three months at the time of the interviews, some 42% (150/360) of respondents who lived in Windhoek, Rundu, and Katima Mulilo said that they have heard of it. Awareness was the highest in Rundu (43/82), followed by Katima Mulilo (40/100), and then Windhoek (67/178). Currently, HIV and AIDS support groups play a very limited role in creating awareness of Wings of Life. Only 21%

(31/150) of support group members living at the three primary sites said that they received information on Wings of Life via their support groups. Not considering support group membership, awareness among all respondents at secondary sites was higher than expected, especially in Outapi, Eenhana, and Oshakati. Respondents in Walvis Bay, Keetmanshoop, and Matiental have also heard of the programme.

**Table 2: Percentage of Respondents Who had Heard of Wings of Life at Secondary Sites**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>Outapi</b>	19/41	46%
<b>Eenhana</b>	25/61	41%
<b>Oshakati</b>	33/85	39%
<b>Walvis Bay</b>	25/95	26%
<b>Keetmanshoop</b>	8/45	18%
<b>Mariental</b>	5/33	15%

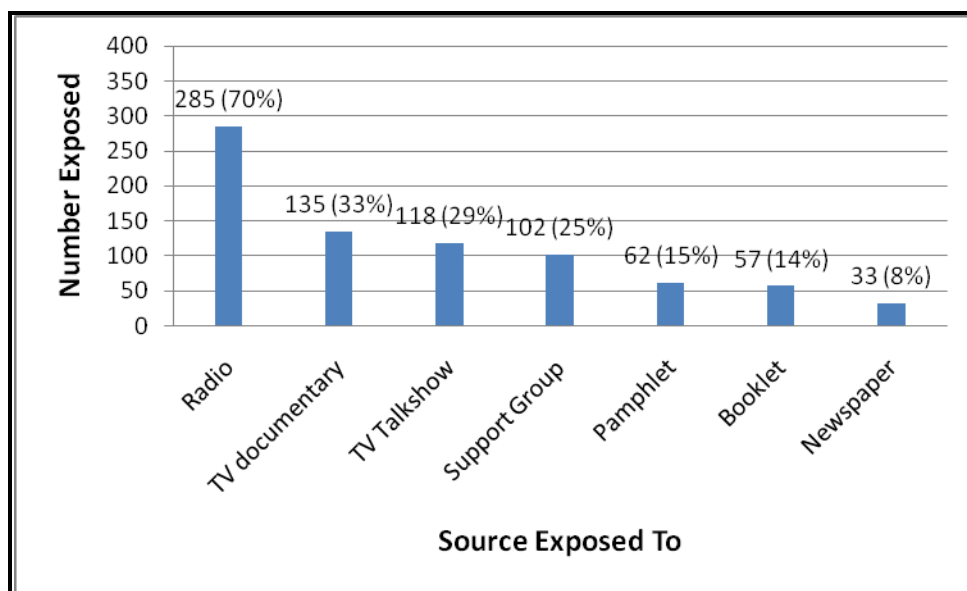
The majority of respondents who have heard of Wings of Life, and who live at the primary sites where it is broadcast, have listened to the programme at least once. In Katima Mulilo 100% (40/40) of those who knew of it had also listened to it often, as did 49% (36/43) in Rundu and 48% (51/67) in Windhoek. Respondents, irrespective of how often they listen to the programme, had the best recall of discussions on ARV medication. Recall was the highest in Katima Mulilo (32/40), followed by Rundu (25/43), and then Windhoek (34/67). Recall of discussions on Positive Living was lower than that for ARV medication, but still above average for Katima Mulilo. Some 63% (25/40) of respondents could recall listening to at least one discussion on this topic. Recall in Windhoek and Rundu was much lower than in Katima Mulilo, though nearly identical at 42% (28/67) and 40% (17/43). Self-stigma by, and discrimination toward, PLWHA are topics discussed on Wings of Life. Katima Mulilo again topped the list with 56% (23/40) recall on these topics. Little more than 40% (18/43) of respondents in Rundu could recall this. Recall was the lowest in Windhoek at 34% (23/67). All round, recall was the lowest on the topic of the importance of support structures for PLWHA. Only a third (13/40) of respondents from Katima Mulilo could recall this topic. Recall was very low both in Rundu and Windhoek at 23% (10/43) and 21% (14/67) respectively.

## **2.4 “Be There to Care”**

The majority of respondents (410/720) in the HTLS 2008 sample had heard of “Be There to Care”. Close to 70% had heard of it via a talk show on the radio. Exposure via TV was also high.

A third had watched a documentary on TV, while 29% had seen a talk show on TV where it was mentioned. Roughly 25% were told of it by someone in their HIV and AIDS support group. Close to 15% read about it in a pamphlet, and 14% in a booklet. Only 8% had seen information on it in a newspaper.

**Figure 3: Exposure to "Be There to Care"**



N = 410.

Close to 99% (405/410) of respondents who had heard of “Be There to Care” correctly said that it is a theme of the Take Control Campaign. They were asked to recall topics addressed by “Be There to Care”. Two thirds recalled information on condom use. Close to 50% mentioned the need for faithfulness in a relationship. Roughly 47% spoke of the importance of family support for PLWHA. Another 38% remembered information on partner support. A third recalled the topic of talking to one's partner about HIV. Around 30% mentioned partners testing together. Only 6% recalled information on sexual violence and 5% remembered issues on domestic violence.

**Table 3: Issues Addressed by "Be There to Care"**

	HTLS 2008 Number	HTLS 2008 %
Condom use	269/410	66%

<b>Faithfulness</b>	204/410	50%
<b>Family support</b>	191/410	47%
<b>Partner support</b>	157/410	38%
<b>Talking to partner re HIV</b>	137/410	33%
<b>Testing together</b>	124/410	30%
<b>Sexual violence</b>	24/410	6%
<b>Domestic violence</b>	20/410	5%

## 2.5 Conclusions

The HIV and AIDS support group network can still be expanded. A quarter of support group members have to travel more than five km to attend a support group meeting. Access to training for support group members on various HIV and AIDS related topics is not only linked to the availability of trained facilitators, but also the popularity of a topic, e.g. Positive Living. The Wings of Life radio programme enjoyed widespread recognition despite being launched only three months prior to the HTLS 2008 survey. Discussion on ARV medication was the topic most remembered by respondents who listened to Wings of Life. Radio proved to be the best means of conveying information on "Be There to Care". Condom use proved to be the most remembered topic dealt with by "Be There to Care", while domestic violence and sexual violence were the two least remembered topics.

## 2.6 Recommendations

- NGOs should assist in compiling a database of HIV and AIDS support groups across the country. Support groups can then be informed of other groups near them. Members who travel far to attend meetings will also have an option to join another support group closer to home. Such a database will also serve to identify locations where new support groups may need to be established. It may also serve to strengthen the network since the groups could meet with one another to exchange information and ideas.
- Radio remains the most effective means of conveying information on HIV and AIDS and should remain central to any IEC strategy.

- Training on income generation needs to be overhauled. As will be explained in Chapter Three, the vast majority of respondents in this study were either unemployed or were earning less than N\$ 500 per month. A comprehensive training package needs to be designed which takes cognizance of government efforts to encourage SME development, explains finance and micro-finance, links the training to institutions capable of providing support in setting up a formal enterprise considering levels of education, and provide interest free micro-loans below N\$ 1,500 where capital needs are basic. In fact, the lack of access to micro-finance is the key ingredient that is missing from the training initiative on income generation in an environment of severe poverty.

### 3. Biographical Statistics

This section of the report contains an analysis of the biographical information provided by the participants to the HTLS 2008. Respondents were asked to answer questions on their citizenship, home language, age, relationship status, level of education, employment, income, and those dependent on this income. Where possible, comparisons were made to the data provided by the HATS 2005 survey.

#### 3.1 Survey Sites

More sites were surveyed during the HTLS 2008 compared to the HATS 2005. Nine sites were surveyed in the following order: Windhoek, Oshakati, Outapi, Eenhana, Rundu, Katima Mulilo, Keetmanshoop, Mariental, and Walvis Bay. The largest sample was returned from Windhoek, and the smallest from Mariental. Table 4 provides a breakdown of cases collected per site. Lüderitz and Ondangwa were omitted from the HTLS 2008 survey, while Mariental, Outapi, Eenhana, Rundu, and Walvis Bay were added.

**Table 4: Cases per Site**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>Windhoek</b>	178/720	25%
<b>Oshakati</b>	85/720	12%
<b>Outapi</b>	41/720	6%
<b>Eenhana</b>	61/720	9%
<b>Rundu</b>	82/720	11%
<b>Katima Mulilo</b>	100/720	14%
<b>Keetmanshoop</b>	45/720	6%
<b>Mariental</b>	33/720	5%
<b>Walvis Bay</b>	95/720	13%

#### 3.2 Citizenship and Home Language

Citizenship is a variable which was not controlled for in the HATS 2005 survey. The HTLS 2008 included a question on Namibian citizenship. Only one respondent (1/720) said that she was not.

Though English is the national language of Namibia, less than 1% (2/718) of respondents referred to it as their home language. The implication is that offering information, education, and communication (IEC) materials on HIV and AIDS in English may not be adequate. Attention must be paid to producing information accessible in all the home languages of Namibia.

### 3.3 Age of Respondents

Direct comparison of the data on the age of respondents obtained via the HATS 2005 and the HTLS 2008 is not possible due to the different sampling sites utilized. What is possible is to compare results for four sites that are common to both surveys: Windhoek, Oshakati, Katima Mulilo, and Keetmanshoop. Table 5 contains a comparison of the statistics. The statistics indicate that on average respondents at the four sites, who participated in the HATS 2005 survey, were six years younger than those interviewed at the same sites during the last survey. Aging is not a factor in this. For the HATS 2005 sample in question, age ranged from 18 to 57. For the comparative HTLS 2008 sample, it ranged from 18 to 65. This resulted in a median age of 35.5 for the four-site HATS 2005 sample, and one of 40 for the comparative HTLS 2008 sample. The modal age for said HATS 2005 sample was 28, compared to 35 for the HTLS 2008 sample. The above is supported by the fact that 72% of respondents in the four-site HATS 2005 sample was 35 and younger, compared to the 43% of the four-site HTLS 2008 sample.<sup>7</sup>

How can the increased participation by older persons in the private HIV and AIDS prevention and care network in Namibia be explained? The HATS 2005 was conducted when the HIV and AIDS support group structure was still in its infancy. Before the establishment of the support network, the broader prevention and care network did not focus on structured involvement by PLWHA *per se* and operated on an informal basis such as word-of-mouth by those who were infected. Focus fell on delivery of service to identified PLWHA via a network of mostly youth volunteers, and not on PLWHA being part of the service delivery. HIV and AIDS support groups devolved responsibility for disseminating IEC initiatives to PLWHA and created opportunities for older PLWHA involvement, who may not necessarily want to be involved in the day-to-day running of the private HIV and AIDS prevention and care network. The difference between the 2005 and 2008 samples is that in 2005 information on those infected was mostly provided by young volunteers. In 2008 a broader audience could be reached via PLWHA themselves.

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<sup>7</sup> In Namibia those 35 and younger are considered youth.

**Table 5: Statistics on Age**

	<b>HATS 2005</b>	<b>HTLS 2008</b>
<b>Sample size for four sites</b>	275	310
<b>Average age of respondents</b>	32	38
<b>Youngest respondent</b>	18	18
<b>Oldest respondent</b>	57	65
<b>Median age (mid-number in range)</b>	34.5	40
<b>Mode (age most frequently encountered)</b>	28	35
<b>% of respondents 35 and younger</b>	72%	43%

### **3.4 Biological Sex, Sexual Orientation and Sexual Identity**

The TLFS 2008 made a distinction between biological sex, sexual orientation, and sexual identity. Biologically, one is born male or female. According to the University of Dallas at Texas<sup>8</sup>: "Sexual identity is the degree to which we identify with the social and biological aspects of being a man or a woman. Many men and women identify primarily with their biological sex but transgendered people identify more with the biological and social characteristics of the other gender. An integral part of sexual identity is sexual orientation, which essentially is defined by who we are emotionally and/or physically attracted to." Important to the study is the fact that a lesbian, as well as a bi-sexual or transgender female, can still fall pregnant irrespective of sexual identity. Roughly 6% (45/719) of the valid sample for the HTLS 2008 were LGBT persons. The small sample (26 cases) of LGBT respondents returned by the HATS 2005 does not allow for direct comparison with the TLFS 2008. Also, the sample size of 45 provided by the HTLS 2008 does not allow for a great deal of analysis below the aggregate level. As such, data pertaining to the LGBT sub-sample will be presented in Chapter 10.

**Table 6: Statistics on Sexual Identity**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008</b>
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<sup>8</sup> University of Dallas at Texas (2008) "Self-help: Sexual Identity and Orientation".  
<http://www.utdallas.edu/counseling/selfhelp/sexual-identity.html>

		%
<b>Percentage of heterosexual respondents</b>	673/719	94%
<b>Percentage of lesbian respondents</b>	17/719	2%
<b>Percentage of gay respondents</b>	15/719	2%
<b>Percentage of bi-sexual respondents</b>	12/719	> 1%
<b>Percentage of transgender respondents</b>	2/719	< 1%

Neither the HATS 2005 nor the HTLS 2008 sample was stratified according to biological sex. In order to compare the data from the two surveys, sites analyzed were again limited to Windhoek, Oshakati, Katima Mulilo, and Keetmanshoop, the sites common to the two surveys. Some 81% (253/313) of the 2008 sample was female compared to 70% (195/277) of the 2005 sample. Stated inversely, the number of male respondents decreased from 30% to 19%. Even though the HTLS 2008 sample was biased in terms of female representation, comparatively more female respondents were HIV and AIDS support group members. Roughly 84% (485/577) of female respondents had joined a support group compared to 73% (104/143) of male respondents. The high number of female respondents in both samples does support the hypothesis that women are more active than men when it comes to participation in HIV and AIDS support network activities. As will be explained under Section 3.7, unemployment is probably not a factor in this.

### 3.5 Personal Relationships

The HATS 2005 did not inquire into the personal relationship status of respondents. The TLFS 2008 included questions on such relationships. This information is useful in identifying single parents, and understanding sexual behaviour. Roughly 18% of respondents were married. Widows accounted for 11% of the sample. Less than 1% of male respondents reported the death of a wife. Some 8% of respondents had gone through a divorce. Roughly 30% had never married and were single. Some 27% reported being in a relationship with a steady male partner, and 6% a female partner.

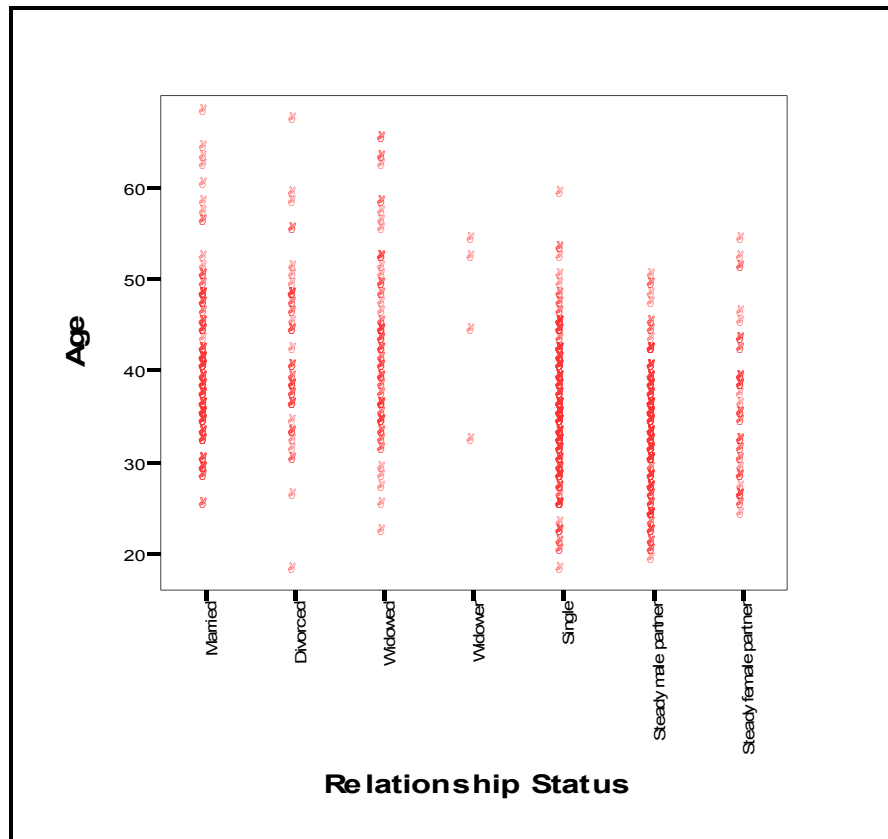
**Table 7: Statistics on Personal Relationships**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>

<b>Married respondents</b>	132/720	18%
<b>Divorced respondents</b>	48/720	8%
<b>Widows</b>	79/720	11%
<b>Widowers</b>	4/720	< 1%
<b>Never married and single</b>	218/720	30%
<b>Never married, steady male partner</b>	194/720	27%
<b>Never married, steady female partner</b>	45/720	6%

Figure 4 below expresses the relationship between age and personal relationship status. Those who reported being married were in their mid-twenties and older. Nearly all of those who had lost a husband or wife were 25 years and older. The majority of widows were aged 30 to 50. Divorce was also prominent from age 30 to 50. Men tend to stay unmarried longer than women. The likelihood of being unmarried and having a steady female partner decreased sharply after age 40. There was a sharp drop-off at age 50 of those who were unmarried and had a steady male partner. HIV prevention campaigns should contain a component dedicated to raising awareness among single men older than 35.

**Figure 4: Age and Relationship Status**



### 3.6 Education

The complexity of information which can be passed on via IEC materials and programmes is dependent on the level of education of the audience. What the HATS 2005 indicated, and *TLFS* 2008 indicates, is that a uniform approach is not possible given the diverse levels of education among HIV and AIDS support group members in Namibia. Though basic literacy is high, addressing the needs of those with lower levels of education may prove more complex. For the purpose of comparison, data analyzed were again limited to Windhoek, Oshakati, Katima Mulilo, and Keetmanshoop. Only 24 respondents in the 2008 sub-sample (n = 313) were not HIV and AIDS support group members. Given the small difference in comparative statistics this results in, it was decided to report on the entire sub-sample only rather than compare it to data for support group members.

Seven percent of the 2008 sub-sample, including six percent (17/289) of support group members, had not completed any formal education in contrast to only one respondent for the 2005 sub-

sample. Those with a primary education of Grade 7 or below comprised 36% of the 2008 sub-sample, compared to 27% of the 2005 sub-sample. The two studies sharply diverge on their findings pertaining to Grade 10 and Grade 12 qualifications. The 2005 sub-sample returned a Grade 10 completion rate of 33%. The 2008 sub-sample returned a figure of 15% for the same grade. It also returned a much lower Grade 12 completion rate, which was 8% compared to 20% for the 2005 sub-sample. No respondent in the 2005 sub-sample had completed a tertiary qualification of any kind. Roughly 9% of respondents in the 2008 sub-sample had completed either a degree or certificate training.

**Table 8: Statistics on Education**

	<b>HATS 2005 Number</b>	<b>HATS 2005 %</b>	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>No formal education</b>	1/259	< 1%	21/313	7%
<b>Grade 7 or below</b>	70/259	27%	112/313	36%
<b>Grade 10</b>	86/259	33%	46/313	15%
<b>Grade 12</b>	51/259	20%	26/313	8%
<b>Tertiary qualifications</b>	-	-	29/313	9%

One explanation for the difference in the statistics is that the membership base of the private HIV and AIDS prevention and care network has broadened since 2005. It was mentioned under Section 3.3 that more people older than 35 years are becoming involved in the this network. In Namibia, still quite a young country, one would expect a decline in the level of education as age increases. Many persons could not access formal education under the Apartheid system. After Independence, the transformation to make schooling available to all Namibians was also not immediate. On the other side of the educational spectrum, more people with tertiary qualifications now appear to be active within the network. This could indicate that the management of HIV and AIDS support groups may improve, as well as the quality of the information that reaches the members.

### 3.7 Employment and Income

A reduced sample was again used in order to compare employment and income data for the HATS 2005 and the HTLS 2008. The same four sites as above were isolated for the purpose of analysis. Respondents were asked to state their current occupation. This ranged from full or part time paid employment, full or part time self-employment (registered for tax), being a student at a school or a tertiary institution, to working in the informal sector (not registered for tax, as well as looking/not looking for other work). Options surrounding unemployment included unemployed and looking for work, and unemployed and not looking for work. No commonly agreed framework for the presentation of employment statistics exists in Namibia. What is used is determined by the report cited. As such, no attempt at comparison to a "national statistic" is made here. Unemployment for sub-samples, using the definitions cited and combining the two categories for unemployment (looking/not looking for work), was 69% for the 2005 sub-sample and 75% for the other. Of those who were earning an income, 66% of the 2005 sub-sample was earning N\$ 500 or less per month. Comparatively, 85% of the 2008 sub-sample was earning the same. Some 94% of the 2005 sub-sample had at least one child as a dependent, as did 88% of 2008 sub-sample.

**Table 9: Employment and Income Statistics**

	<b>HATS 2005 Number</b>	<b>HATS 2005 %</b>	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>Unemployed</b>	185/270	69%	233/312	75%
<b>&lt; N\$ 500 per month</b>	84/126	66%	67/79	85%
<b>Dependent children</b>	118/126	94%	70/79	88%
<b>Disability grant</b>	29/270	11%	19/312	6%
<b>Older than 60</b>	-	-	2/312	< 1%

Income grants, disability grants, and government pensions are central to the welfare of individuals or families who struggle to find employment, or earn a survival wage. The Ministry of Labour and Social Welfare (MLSW) can provide a disability grant to any Namibian identified with temporary disabilities or abnormalities caused by any diseases or illnesses. The nature of this grant will be discussed in more detail in Chapter 6. As such, any Namibian who is HIV positive and suffers disability due to a low CD4 count, which would be considered to be AIDS,

is eligible for this grant. Close to 11% of the 2005 sub-sample reported income received due to a disability grant, as did 6% of the 2008 sub-sample. Less than one percent of the 2008 sub-sample was older than 60, thus making the respondents eligible for a government pension strictly based on age. Within the broader HTLS 2008 sample, men and women were equally affected by unemployment.<sup>9</sup> The employment and income statistics for HIV and AIDS support group members is comparable to that of non-members. Thus, according to HTLS 2008 data, the majority of HIV and AIDS support group members in this sample are either unemployed or very low income earners.

### 3.8 Conclusions

Less than one percent of respondents referred to English as their home language even though it is the national language. This raises the question whether English *per se* is adequate for conveying complex, and often nuanced information on HIV and AIDS to the individual. Also, one interpretation of our results over time is that more persons older than 35 are becoming active in the HIV and AIDS prevention and care network in Namibia. A key factor in this development may be the expansion of the HIV and AIDS support group network which allows for participation according to individual circumstance without the demands set by volunteer work. Women seem to be more active than men when it comes to participation in HIV and AIDS support network activities. Unemployment is not likely a factor in this. If the assumption holds that absence of formal education indicates illiteracy, then roughly six percent of the HIV and AIDS support group members have unique needs when it comes to conveying information on HIV and AIDS non-verbally. The majority of HIV and AIDS support group members are unemployed or earn incomes below N\$ 500 per month, regardless of sex. This situation becomes bleaker given that nearly all take care of at least one child.

### 3.9 Recommendations

- Future IEC campaigns should be conducted both in English and the home language of the target audience. Respondents were much more positive about interpreting information on HIV and AIDS when presented in their home language. This is also an important

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<sup>9</sup> Lambda, Goodman & Kruskal's tau, Uncertainty Coefficient: no significance.

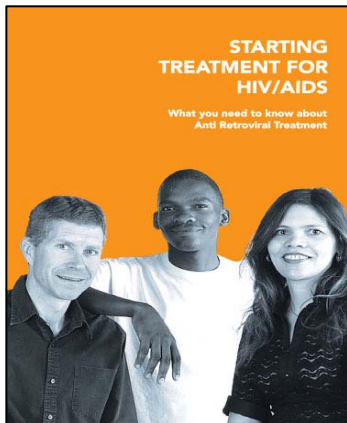
consideration in the light of the fact that some 42% of the sample could be considered illiterate or semi-literate, i.e. has no or basic reading and writing skills.

- Consideration should be given to gender as well as sexual identity in the creation of HIV and AIDS support groups. Less men than women join support groups. Individuals who either have a gay, lesbian, bi-sexual, or transgender sexual identity may feel threatened within predominantly heterosexual groups.

## 4. Treatment Literacy

In 2005, the Namibian field office for Johns Hopkins University/Health Communication Partnership (JHU/HCP)/NLT was commissioned to develop treatment literacy materials for the MoHSS. These materials are intended to strengthen interpersonal communication between HCWs and patients, and deepen client and community members' understanding of ART-related issues. NLT has taken the lead in disseminating these resources, distributing 100,772 of these treatment literacy materials last year through public hospitals via information stands, special events like the Windhoek Show, and through NGOs and Community Action Forums. Through this study, NLT sought to measure the extent to which PLWHA and healthcare workers recognize, use and recommend the following treatment literacy materials:

### 4.1 Starting treatment for HIV/AIDS: What you need to know about Anti Retroviral Treatment



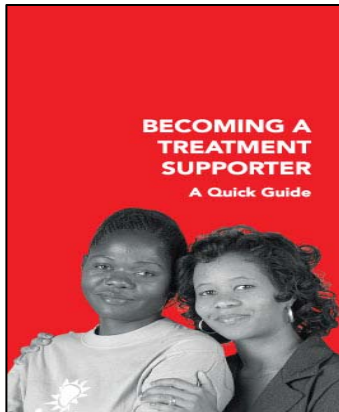
This comprehensive booklet was designed for patients starting out on ART, and contains information about:

- Medical and social criteria for people requiring ART;
- Strategies for maximizing the benefits of ART;
- Possible side effects of it; and
- Positive living strategies including nutritional and emotional tips for PLWHA.

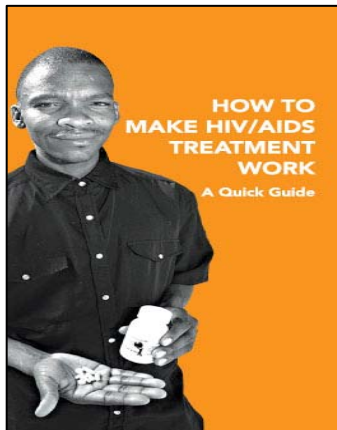
The research findings showed that 67% (483/720) of the HTLS 2008 sample had seen the booklet. The majority of these individuals said that they saw it in a public hospital (49%), followed by a public clinic (17%), and an NGO office (15%). Around 74% (354/478) of those who have seen it, have also read it. Of these respondents, 74% (261/354) recommend that others read it regularly. Respondents receiving ART were slightly more likely to have seen and read the booklet. Just over 68% (383/560) have seen the booklet with 76% (291/383) claiming to have read it. Three quarters (219/291) of them recommend that others read it regularly. The majority of HCWs were aware of the booklet. Around 74% (31/42) of HCWs surveyed have seen it, while 77% (24/31) of them have read it. All of them recommend that others read it regularly. Furthermore, 84% (20/24) recommend the booklet to all of their patients.

## 4.2 Becoming a treatment supporter: A Quick Guide

This quick guide was designed for patients on ART and addresses the role and responsibilities of treatment supporters. The research findings showed that 73% (525/720) of respondents have seen the guide. The majority saw it in public hospitals (52%), followed by public clinics (19%), and NGO offices (14%). Nearly 72% (376/523) have read it. Further, 93% (350/376) recommend that others read it regularly. Survey respondents taking ARVs were slightly more likely to have seen and read the guide. Three quarters (412/560) of them have seen it. Roughly the same proportion (305/411) has also read it. Some 92% (280/305) recommend that others read it regularly. Roughly 69% (29/42) of HCWs have also seen the guide. Of those individuals, 83% (24/29) have read it. HCWs were very complimentary of the guide. All of them said that it should be read regularly. Additionally, 79% (19/24) of them recommend it to all of their patients.

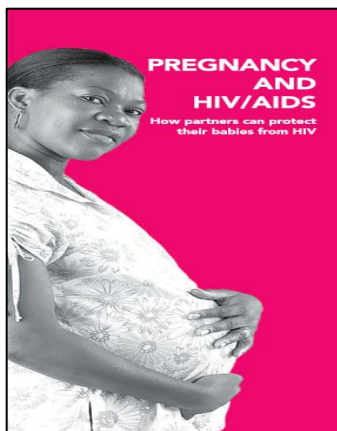


### 4.3 How to make HIV/AIDS Treatment Work: A Quick Guide



This quick guide was designed for patients on ART and underscores the advantages and limitations of ART, offering helpful strategies to maximize treatment benefits. The findings indicate that 74% (534/720) of respondents have seen the guide. The majority (55%) saw this material in public hospitals. This guide was also visible in public clinics (19%) and NGO offices (14%). Of those who have seen it, 75% (398/532) have read it. Around 94% (372/398) would recommend that others read it regularly. Again, respondents on ART were slightly more likely to have seen and read this guide. Just over 76% (427/560) have seen it. Of these individuals, 77% (327/425) have read it. Roughly 69% of HCWs (29/42) said that they too have seen it. Some 97% (28/29) have read it. Around 97% (27/28) would recommend that others read it regularly. Additionally, 79% (22/28) have recommended it to all of their patients.

### 4.4 HIV/AIDS and being pregnant: How partners can protect their babies from HIV



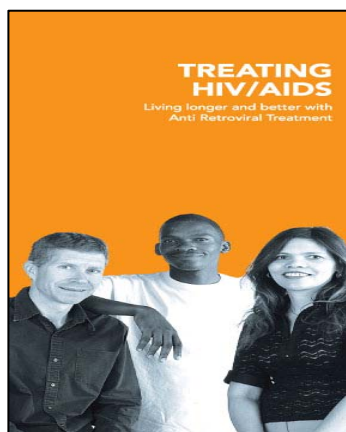
This leaflet was designed for PLWHA who want to have children and provides the following information:

- Basic facts on how HIV is transmitted from an infected mother to her baby; and
- Prevention strategies including breastfeeding only, replacement feeding, and taking Nevirapine to reduce mother-to-child transmission of HIV.

Some 76% (547/720) of respondents have seen this leaflet. The majority (57%) of them saw it in public hospitals, followed by public clinics (22%) and at NGO offices (14%). Of those who had seen it, 76% (414/547) have also read it. Furthermore, 94% (389/413) recommend that others read it regularly. Respondents on ART were slightly more likely to have seen and read this leaflet. Close to 77% (430/560) have seen it, with 77% (333/430) of them also having read it. More than 90% (38/42) of HCWs have seen the leaflet. Roughly 92% (35/38) of them have also

read it. All of them recommend that others read it regularly. Nearly 81% (25/31) recommended it to all of their patients.

#### 4.5 Treating HIV/AIDS: Living longer and better with Anti Retroviral Treatment



This leaflet was designed for community access and provides the following information:

- Basic facts about HIV transmission;
- When ART should be taken; and
- Where ART can be obtained.

Roughly 70% (505/720) of respondents have seen this booklet. The majority (53%) of these individuals saw this material in public hospitals, followed by public clinics (18%) and in NGO offices (14%). Of those who had seen the leaflet, 77% (387/504) have read it. Further, 93% (361/387) of these respondents would recommend that others read it regularly. Respondents on ART were slightly more likely to have seen and read this leaflet. Over 72% (405/560) have seen the leaflet with 78% (315/403) of these individuals claiming to have read it. In addition, 94% (296/315) would recommend that others read it regularly. Around 69% (29/42) of HCWs have seen the leaflet. Of them, 89% (23/29) have also read it. In addition, all of them recommend that others read it regularly. Finally, 83% (20/23) have recommended it to all of their patients.

#### 4.6 Conclusions

The research indicates that significant percentages of PLWHA interviewed recognized each of the five treatment literacy materials. Most of these individuals have seen these materials in public hospitals. For each of the five treatment materials, the research shows that approximately three-fourths of the respondents who saw the booklet, quick guides, and leaflets went on to read them. More than 90% of respondents would recommend that others regularly read these materials, especially the leaflets and quick guides. HCWs were very likely to read the materials once they had seen them. More than three-quarters of these respondents indicated that they had read the noted booklet, guides, and leaflets. They were also very complimentary of these

materials with nearly 100% recommending that people read each of the five resources regularly. Finally, 80% of them have recommended at least one of the five materials to all of their patients.

#### 4.7 Recommendations

- PLWHA interviewed show a strong demand for treatment literacy materials, indicating that they would read them if they were available. There appears to be an even greater demand among those PLWHA on ART. Therefore, if visibility of and access to these resources can be increased, usage should increase accordingly.
- HCWs are quite likely to read and recommend the five materials to patients once familiar with them. This said, roughly 30% of these individuals were unfamiliar with at least three of the five materials. Some 26% of HCWs had never seen the comprehensive booklet for clients, *Starting Treatment for HIV/AIDS: What you need to know about Anti Retroviral Treatment*. It is recommended that a stronger push be made to familiarize HCWs with these reading materials.
- For each of the five treatment literacy materials, HIV positive respondents indicated that NGO offices (preceded by public hospitals and clinics) were the third most common place where they have seen these resources. This indicates that NGOs also have a very important role in disseminating these materials, and possibly referring people to public hospitals and clinics for additional information and services.

## 5. Focus Group Discussions with Children

A total of 83 children participated in five Focus Group Discussions (FGD) that were co-led by Family Health International and Positive Vibes. The children aged 11 to 19 were selected by facilitators from local PLWHA support groups, with the common characteristic that all are children of support group members, and/or they are either currently caring for someone who is chronically ill in the family or else did so in the past. Four focus groups took place in the North of Namibia (Omalala, Ongwediva, Outapi, and Endola), of which one was urban (Ongwediva) and one was mixed rural-urban (Outapi). One group was in the south (Keetmanshoop) which was mixed rural-urban. The reason both these sites are termed “mixed” is because some children come from the villages surrounding the town, but stay in a hostel in town, while school is in session. The focus groups lasted approximately 2 ½ hours each and took place after school at a borrowed venue such as a church, community meeting hall, or multi-purpose centre. They were led by two persons at each site: Tsitsi-Stella Dangarembizi, Nelao Martin and/or Dr. Lucy Steinitz in the north and Ingrid Louis with Lucy Steinitz in the south.

Before the children came to the discussion, their parents or guardians signed a permission slip. This process did not result in any objections or difficulties. As they entered, the children were given sandwiches and a drink; afterwards they received a certificate of participation, a notebook and a pen, and an orange. One group that had been planned for Eenhana did not take place because the person who was supposed to organize it failed to do this work. The FGD in Endola substituted for that group the following week. Thus, all focus group discussions took place between 16 and 28 October 2008. The children ranged in ages from 11 to 19 with few outliers. The majority of the children were between the ages of 13-17 years. Girls (N = 49) predominated in four of the five groups (Ongwediva being the exception), with only 34 boys in total.

The facilitators did not ask any questions related to disclosure such as either the children’s own HIV status or that of their parents’/ guardians’. However, it was revealed privately that at least three of the children were HIV+ and currently receiving treatment. All children were attending school, but in the rural areas most were too old for their grade, i.e. they lost time or had to repeat a grade, and were two to five years below the correct grade for their age. Also, 54% (45/83)

reported that they were caring for a sick relative at home. There did not seem to be any difference in the boys or the girls in this regard, nor in the type of care-giving duties performed.

## 5.1 The Sample Protocol

Each FGD was divided into seven parts. After giving each child something to eat (as all groups took place after school) and explaining the “rules” (see below), the process started with a introductory exercise where everyone had to say his or her name and demonstrate something that he or she likes to do, such as play soccer or jump or dance or make silly faces. Then everyone else had to welcome that person by name and imitate the same action – some of which resulted in peals of laughter. No tape recorder was used, but when it came to the group discussions and dramas, one of the co-facilitators took careful notes. Two exercises involved written information from each of the children and these were handed in afterwards. Thus, the protocol covered the following topics:

### #1: Drawing exercise: use A4 paper and pens

Background information: children outline their hand, and starting with their pinky, they then answer six questions (the last one gets written on the palm or wrist):

1. With whom do you live in regard to adults – relation to child?
2. (a) How long ago was the last time you went to a hospital or a clinic to see a doctor or a nurse? (b) When was the time before that?
3. Your age and what grade you are in school.
4. (a) How many meals did you eat yesterday?  
(b) What foods did you eat in the biggest meal you had yesterday?
5. What do you like to do for fun?
6. If you could have one wish come true for yourself – anything at all you could think of – what it would be?

### #2: Group discussion:

Where do you get most of your information about HIV/AIDS? – This includes radio, family, friends? What do you know about prevention? About caring for someone who is HIV+?

### #3 True-False questions

*Five questions that test the child's knowledge about HIV, and five that address the child's living situation.*

### #4: Group discussion

Do you have to look after any sick people at home (or did you, in the past)? What kinds of things did you have to do, and about how much time did it take each day? Do you have enough time to study? To play? What else can you say about the experience?

### #5: Drama/ charades:

*The children are divided randomly into groups of three to four. They must agree among themselves about one thing that they think would make life easier for children who are living in households where someone is sick or has HIV. Then, they must act it out, with very few or no words. After watching this, everyone else in the room must guess what they are acting out, and the group is told if this is correct or not. (Meanwhile, we record the themes they address.)*

## 5.2 Explaining the Protocol to the Children

One discussion group was conducted predominantly in English (Ongwediva), one half in English and the other half in Afrikaans and Nama (Keetmanshoop) and the rest predominantly in Oshiwambo. Before each FGD began, the children were asked if they knew why they had been asked to come to the group that afternoon. None knew, or at least they didn't want to say. Then, the following explanation was given: *"The reason we are here is that the adults in the room want to know how children cope with daily life – especially children who currently care for someone who is sick, or who have done so in the past, or where there is someone in the house who lives with HIV/AIDS. As adults, we don't know what it is like to be a child – only you do – so we are hoping you will share your thoughts and ideas with us."*

They were then told about three rules that they were asked to repeat each time a few latecomers came – which invariably occurred. The three rules were: (1) *There are no right or wrong answers – all answers are okay.* (2) *We adults won't take any photographs and won't use your*

*names outside this room, meaning that who-said-what is confidential – which is something we all should respect; and (3) If you don't want to answer a question or participate in the discussion, that is not a problem... and everyone will still get an orange at the end (this always got a smile).*

At the end of each focus group discussion, the children were asked to orally evaluate the experience such as what they liked about the discussion and the activities and what they didn't like. Almost all responded enthusiastically that they liked it VERY much and want to meet again to talk more with their peers. No one said anything negative. Only two children acted withdrawn during the discussions: one in Keetmanshoop who looked thin and sickly and was known to the facilitator to be HIV+ (and where the facilitator said she would follow-up to make sure she was emotionally okay), and another where the facilitator reported, as follows:

*I noticed that one child in this group didn't want to contribute to the discussions or do the written exercises, as instructed. I tried encouraging her, yet she distanced herself. Her response was that she just wants her sick relative to get cured and nothing else. She later encouraged the others to base their drama on prayers as a solution that might help. Again, the facilitator who organized the group promised to follow up in a few days' time.*

### **5.3 Group Discussions**

The first of the two group discussions focused on where the children received most of their information about HIV/AIDS, and what they knew about prevention and care. Significantly, only about one-half of the children actively participated in the discussion – more would show their hands if asked a direct question, but otherwise they preferred to stay silent. Of those who spoke, almost all the children said they learned about HIV from school and the public media. In terms of what they knew about HIV, at first almost all the messages offered had to do with HIV prevention; only when prodded did the children talk about care. Here the focus was almost entirely on taking the medications (ARVs) regularly. Messages around positive-living only came later, if at all.

Two direct questions were asked in each group, for a show of hands:

- *How many of you discuss the subject of HIV or AIDS at home?* In the rural sites, about one-third acknowledged they discuss these issues at home; this increased to almost all the children in the most urban site, Ongwediva.
- *How many of you talk about HIV with their peers?* About half said they discussed these issues with peers.

The second discussion focused more specifically on caring for a sick person in the home. By way of selection for the FGD, all children either lived with a chronically ill person previously, or were in that situation right now. Across all groups, one-third of the children spoke freely in this discussion. Most of the quotes about living with HIV in the household suggest that the children are playing the role of the caregiver – in effect, growing up before their time. In describing what they had to do to help care for a sick person in the home, a few spoke of direct personal care (bathing and dressing of wounds), while the rest described household chores, saying that these increased as the person got sicker. Examples were fetching water, cleaning the house, doing the wash, cooking, caring for animals, pounding *mahangu*, caring for the garden. No differences could be observed between the chores boys or girls did. Fetching water came up more frequently in rural areas. These chores are probably not different from those other children perform in their respective communities. However, for these children, it became a matter of magnitude, seemingly taking up most of their non-school daylight hours.

In particular, most of the children who spoke said that they did not have enough time to do their homework. This seems to occur more often in rural and semi-rural areas where households do not have electricity; that is, after nightfall everything is dark so it becomes impossible to do homework then. (Anecdotally, we learned afterwards that most of these households couldn't afford kerosene or candles.) These children also weren't able remain at school after classes end because of the responsibilities that awaited them. This is significant because after-school programmes like 'Window of Hope' are especially targeted to vulnerable children; yet these children are unable to participate.

Several children also said that they didn't have (much) time to play with other children. One facilitator was struck by the fact that this was not said with anger or regret. It was just "matter-

of-fact” – the way things are. When asked what they would say to other children who live with a sick person in the home, the children offered the following advice (selected quotes):

**Ongwediva:**

- Fetch water for the (sick) person.
- You must not always think about death, but you must talk with other people to be encouraged.
- People who live with someone who have HIV must always treat that person with love.
- Comfort them by saying kind words.

**Outapi:**

- If someone has HIV, you should pray with that person and help them get around.
- Remind the sick person to take their medicines.
- Fetch water
- Wash the person’s clothes and bathe the person.

**Keetmanshoop:**

- Tell them, if you are HIV-positive, you shouldn’t drink alcohol.
- Give the person enough love.
- Give emotional support.
- Pray for the person.
- Get the person’s pills if they go to the clinic.
- Bathe the person, if he can’t do it himself.
- If the person needs someone to talk to, then be there for that person.
- When someone is infected with HIV and that person may want to commit suicide... well, then I don’t know what to do<sup>10</sup>.
- You must respect the person who is sick and be willing to do whatever errands or whatever else that person wants you to do. You mustn’t stress about it, just do it.

**Omalala:**

- You must know: you can take medicine but there is no cure.
- Make the person feel like she is still part of the family.
- Take care of the little ones, so that they don’t make too much noise.

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<sup>10</sup> The facilitator of the Keetmanshoop support group said she knew about this situation and would follow up.

- Tell the person, don't worry – you'll get well.
- Give the (sick) person peace and quiet.
- Tell funny stories.
- Get water; help out.

**Endola:**

- Encourage the person and give them hope not to feel lonely.
- Feed them before they take their medicine.
- Fetch water.
- Prepare food.
- Wash clothes.
- Help (the person) do exercise.
- Clean them in bed if they can't get up.
- Wear gloves or a plastic bag when cleaning someone's wound.

## 5.4 Dramas in Mime

The final and perhaps most revealing exercise occurred at the end of the FGDs. The children were divided randomly into small groups of three or four, and asked to act out one thing that would help make life easier for children like themselves who have to help care for a sick person at home. The dramas were acted in mime (without words), and then everyone else had to guess what was happening. On average, the dramas took two to three minutes to perform. The groups had to plan their dramas simultaneously. They were not allowed to copy from one another. Thus, it is significant that all of the dramas in the north (15 drama groups) portrayed virtually the same theme, and that all the drama groups in the south (six dramas in Keetmanshoop) were also largely similar to each other.

All the dramas – both north and south – started out in the same way: the groups portrayed a sick person in the home, lying helplessly on a bed or the floor. Children in the home could be seen caring for that person, and they seemed very busy and at times overwhelmed. Thus, they portrayed themselves feeding the sick person, washing clothes, fetching water, and providing personal care. While caring for the sick person, the children couldn't play or do homework, and

in a few dramas it became clear that they couldn't attend school at all, or else would end up going late. What did the children suggest would help them deal with these issues?

In the dramas in the north (15 dramas), the children acted out scenarios of neighbors visiting at the homestead or house with food, prayer, counseling, and/or direct care. In all but two of the dramas the visits were spontaneous – meaning that the neighbors decided to do this on their own and didn't need to be asked. In the two plays mentioned, the child took the initiative to ask for this assistance – in one case to a neighbor to provide counseling and in the other to a home-based care volunteer. How could we tell that this support made a difference to the child? Most of the dramas ended with a final scene of the children playing or – even more frequently – moving off to a corner so that they could do their homework or read a book. When this was discussed afterwards, the children from the rural areas confirmed that, because their homes don't have electricity and their families can't afford a kerosene lamp or candles, currently they can't do their homework after dark, even though by then their chores are mostly done.

In the south, there were six dramas. They all started out in the same way as in the north, but the burden of care seemed to fall disproportionately on the shoulders of some children more than others. There were no obvious gender differences in terms of responsibilities. One difference from the other sites is that here, in three of the dramas, the children made it clear that it was a sibling who was ill – not an adult. Even more striking was that, in five out of the six dramas, the children portrayed some type of family conflict that affected how the care was being provided in the home: either there was a younger child who didn't want to help, or an older sibling that had left the home and was no longer assisting, or else there were real arguments – even fighting – about who does what in the house.

To resolve the conflict, either the eldest sibling tried to work things out, or else she/he called on someone outside the house to assist. This seemed to be the key theme – to make sure that everyone was not ill in the house was contributing equally to the care that was needed. In some of the dramas, outside assistance was sought. In one case a relative was called in and in two cases, it was a local pastor who was called in to pray and to help get everyone involved. Two dramas also involved calling on a doctor or nurse to visit the house when the sick person's condition worsened, but in one of these dramas the sick person died anyway. The issue of family

conflict was different in the south than in the north, and it was striking that none of the dramas involved spontaneous visits and offers of help from neighbor to neighbor.

## 5.5 Conclusions

All the children interviewed were enrolled in school, and most articulated wishes about becoming a doctor, teacher, or something similar. Despite their hard lives, it was encouraging to see that they still hold on to dreams about a brighter future in which they can continue to help others. There were no differences in the type of care-giving duties reported by boys or girls located in the north or south. The differences that emerged had to do with rural versus urban conditions, e.g. the task of fetching water was more commonly practiced by rural children, and they also had a longer way to travel to the nearest health-centre or clinic. The children revealed that they know quite a lot about caring for a sick person, especially with respect to adherence to treatment, but they were less forthcoming about knowledge concerning positive-living and prevention. With regard to prevention, most of their knowledge came from school and the media, they said. In the dramas the children in the South repeatedly raised issues about family conflict that impeded their care-giving duties. They knew to seek help from others to help resolve these problems, but unlike the dramas in the North, neighbors and other community members did not drop in unasked in order to offer assistance. From the exercises, discussions and dramas, it seems that the children rise to the challenge of care-giving, or at least they try, but need help from others. What they want most is more time for school, homework, and friends.

## 5.6 Recommendations

- To the extent that their immediate family members can't reduce the burden of care-giving, children look outside the family for the support of caring neighbors, more distant relatives, community leaders, and community-based organizations. These interactions should be encouraged, alongside possible technological interventions such as long-life crank-operated or solar lanterns, to allow for nighttime reading and homework.<sup>11</sup>
- The FGD evaluations were extremely positive. Most asked for more group sessions. Many said that this is the first time they had the opportunity to share these concerns with

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<sup>11</sup> Positive Vibes is now carrying on such an experiment in two northern rural villages (40 households), using wind-up torches dubbed "homework lights."

others and now they didn't feel so alone. This response supports current plans by Positive Vibes to introduce at least 30 time-limited Children's Support Groups in both the north and south over the next 18 months.

## 6. Treatment Background and ART

Timely access and adherence to ART is central to ensuring good health for those who are HIV positive. This chapter addresses a number of issues pertaining to access and adherence to ART. Are PLWHA able to access doctors and nurses? Can they refill their ARV prescriptions on time? How effective is ART and what are the side-effects of the medication? Which opportunistic infection poses the greatest danger to the health of PLWHA? Is information on ART freely available and are PLWHA accessing it? How many HIV and AIDS support group members have applied for a disability grant? How many have access to medical aid? Where possible, data from the HATS 2005 was compared to that of the HTLS 2008. The comparison again was limited to the same four sites: Windhoek, Oshakati, Katima Mulilo, and Keetmanshoop. Data is reviewed within the framework of the HTLS 2008 sample where comparison is not possible.

### 6.1 Testing and First CD4 Counts

Confirming that a patient is HIV positive is critical in providing targeted treatment. This includes a HIV viral load test as well as a CD4 count test. Public hospitals, public clinics, and New Start centers proved to be the most accessed testing sites. Roughly 73% of respondents in the HATS 2005 sub-sample tested at a public hospital or clinic, with another 24% testing at New Start. The data returned by the HTLS 2008 indicated that 83% of the sub-sample tested at a public hospital or clinic, with 16% testing at New Start.

**Table 10: Locations most accessed for HIV testing**

	HATS 2005 Number	HATS 2005 %	HTLS 2008 Number	HTLS 2008 %
<b>% testing at a Public clinic or hospital</b>	196/270	73%	259/313	83%
<b>% testing at New Start</b>	65/270	24%	50/313	16%

Broadening the analysis to the entire HTLS 2008 sample, 78% of respondents were taking ARV medication on a daily basis. Roughly 19% did not take ARVs because their CD4 counts were high enough not to warrant treatment. Less than 2% never sought treatment after testing positive, while little more than 1% started but stopped. Some 81% of female respondents were taking ART on a daily basis compared to 65% of male respondents. An explanation for this is that 24% of male respondents reported that their CD4 count was high enough for them not to require ART.

Only 17% of female respondents said the same. Additionally, more male than female respondents did not seek treatment after testing positive. Similarly, more males than females started but stopped treatment.

**Table 11: Treatment Background**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>% who takes ART on a daily basis</b>	560/720	78%
<b>% with high enough CD4 count - treatment not needed</b>	134/720	19%
<b>% who never sought ART after testing</b>	14/720	< 2%
<b>% who started ART but stopped</b>	12/720	> 1%
<b>% of female respondents in sample on ART</b>	467/579	81%
<b>% of male respondents in sample on ART</b>	92/141	65%
<b>% of female respondents in sample with high enough CD4 count</b>	101/579	17%
<b>% of male respondents in sample with high enough CD4 count</b>	34/141	24%

The HTLS 2008 confirms the data of the HATS 2005 in the following regard: the majority of PLWHA in the two sub-samples first tested for HIV by the time they developed AIDS. A healthy person has between 500 and 1500 CD4 (T) cells per cubic millimeter (mm<sup>3</sup>) of blood.<sup>12</sup> Generally, AIDS is diagnosed when a person's CD4 count drops below 200. Roughly 72% of the 2005 sub-sample had a count below 200, compare to 53% of the 2008 sub-sample. There was no significant difference between the first CD4 counts of HIV and AIDS support group members vis-a-vis those of non-members.

Another indicator of how ill a respondent was at the time of testing is how soon he/she was placed on ART after testing for HIV positive. Starting a patient on ART is a process. Theoretically, it should require multiple visits to a doctor with the purpose of making a diagnosis of AIDS, or identifying the risk thereof. Around 47% of respondents in the 2005 sub-sample were placed on treatment within one month of testing HIV positive. Comparatively, 37% of the 2008 sub-sample was placed on treatment within one month of testing HIV positive. For another

<sup>12</sup> Gallant, J.E. & Hoffmann, C. (2008) "Johns Hopkins HIV Guide: CD4 Cell Count".  
[http://www.hopkins-hivguide.org/management/laboratory\\_testing/cd4\\_cell\\_count.html](http://www.hopkins-hivguide.org/management/laboratory_testing/cd4_cell_count.html)

16% of the same sample, three months had elapsed before they were placed on treatment. In short, the majority of the 2008 sub-sample was placed on ART within three months of testing HIV positive.

**Table 12: First CD4 Count and Start of Treatment**

	<b>HATS 2005 Number</b>	<b>HATS 2005 %</b>	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>% with first CD4 count below 200</b>	179/250	72%	148/279	53%
<b>% placed on ART within a month</b>	90/190	47%	89/239	37%
<b>% placed on ART within a three months</b>	-	-	128/239	54%

## 6.2 Re-testing and Adherence

In order to monitor changes in the disease, as well as adherence to ART, regular CD4 re-testing is required. There was no difference in re-testing between respondents who were HIV and AIDS support group members and non-members. One would not expect a significant difference in behaviour patterns since any patient on ART has to see a doctor at regular intervals. Doctors should remind their patients of regular re-testing, though the possibility should not be discounted that due to heavy workloads some doctors may only ask for a CD4 re-test once a patient's health deteriorates noticeably. In order to manage patient loads, the MoHSS recommends that a patient newly placed on ART should see a doctor at least once a month. Established patients should do so roughly every three months. The bulk of respondents in the HTLS 2008 sample who were receiving ART, as well as those who had started and stopped treatment, were aware of these recommendations. When asked how regularly someone on ART should see a doctor, 31% of respondents said once a month, 18% said every two months, and 33% indicated that doctor visits should occur every three months.

**Table 13: Opinions on the need for regular check-ups by a doctor**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>Need to see a doctor monthly once on ART</b>	178/571	31%

<b>Need to see a doctor every 2 months once on ART</b>	102/571	18%
<b>Need to see a doctor every 3 months once on ART</b>	188/571	33%

Re-testing closely conforms to this response pattern. Around 76% of the HTLS 2008 sample had re-tested within the three month period prior to the interviews. It would appear that most doctors recommend re-testing when they have follow-up meetings with patients on ART. Variance in the re-testing pattern may be the result of patients not adhering to the above recommendations such as not seeing a doctor on a regular basis, but only collecting ARV medication refills when needed. A factor in this may be the long waiting time to see a doctor at a public health care facility (discussed in Section 6.4). Other than for those who started and stopped treatment, adherence in the HTLS 2008 sample was very high. Only 8% (47/560) of respondents who were on ART reported that they often forget to take the medication on time. There was nearly no difference between HIV and AIDS support group members and non-members when it came to remembering to take the medication on time.

### 6.3 Feedback on Testing

If the assumption holds that the majority of PLWHA only seek to determine their HIV status once ill, then reducing feedback on a CD4 test to two weeks or less becomes critical. One can also hypothesize that the longer a person's emotional strain becomes greater the longer he/she has to wait for such test results. The 2005 sub-sample indicates that only 53% of respondents received feedback on their CD4 tests within two weeks. The 2008 sub-sample returned a figure of 50%. Though these results show a consistency in the rate at which feedback reaches patients, this represents a best case scenario. Every one-in-two respondents in the mentioned samples had to wait additional weeks, and even months, for feedback. For those testing for the first time, the experience can be emotionally harrowing, and no less so for those who know they are HIV positive yet see a decline in their health and cannot rapidly ascertain why this is occurring. Means of reducing feedback time should be investigated by the NGO community in cooperation with the MoHSS.

**Table 14: Re-testing and Feedback on Testing**

	HATS 2005 Number	HATS 2005 %	HTLS 2008 Number	HTLS 2008 %
<b>% who re-tested less than 3 months before</b>	-	-	241/307	79%
<b>% who received results within two weeks</b>	132/247	53%	157/311	50%

#### 6.4 Access to Doctors and Nurses

Respondents were asked how long one has to wait before seeing a doctor. Close to 41% of respondents have to wait more than two hours. Only 23% have to wait half an hour or less to see a doctor. The waiting time to see a nurse is lower than that for a doctor. This is to be expected since there are more nurses than doctors to assist patients. Regardless, the majority of respondents said that they have to wait longer than half an hour to see a nurse. Only 42% wait half an hour or less. Roughly 24% wait more than two hours.

**Table 15: Access to Doctors and Nurses**

	HTLS 2008 Number	HTLS 2008 %
<b>% who wait &gt; 2 hours to see a doctor</b>	231/570	41%
<b>% who wait ½ hour or less to see a doctor</b>	133/570	23%
<b>% who wait &gt; 2 hours to see a nurse</b>	139/571	24%
<b>% who wait ½ hour or less to see a nurse</b>	241/571	42%

#### 6.5 Access to ARV Medication

Public hospitals are the primary dispensers of ARV medication, followed by public clinics. All respondents experience some degree of difficulty in traveling to a health care facility. Only four (4/720) respondents in the 2008 sample owned a vehicle. The most frequent means of travelling to a health care facility is walking there, followed by taking a taxi, or hitching a ride. Only 43% of respondents have to travel five km or less to obtain a refill of their medication. Despite a lack

of private transportation, only 5% of respondents reported difficulty obtaining a refill on time due to an issue with transportation.

**Table 16: Access to ARV medication**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>% who collect ARV medication at public hospital</b>	540/596	91%
<b>% who collect ARV medication at public clinic</b>	54/596	< 9%
<b>% who walk to collect medication</b>	297/571	52%
<b>% who take a taxi to collect medication</b>	277/571	49%
<b>% who take hitch a ride to collect medication</b>	105/571	18%
<b>% with difficulty obtaining a refill due to transport</b>	30/571	5%
<b>% who travel &lt; 5 km to collect medication</b>	243/571	43%

## 6.6 Accessing Information on ART

The majority of respondents (298/570) in the HTLS 2008 sample on ART had difficulty understanding treatment literacy materials presented in English. However, they comprehend the information more easily when accessing it in their home language. When asked how difficult it was to understand the same information in their home language, 96% (540/567) said that it was easy or very easy. Roughly 53% (300/569) of respondents on ART spoke Oshivambo as a home language. Such a large sub-sample allows a more accurate analysis of needs surrounding home language. It is also the most spoken home language in Namibia. The majority (58%) of Oshivambo home language speakers had difficulty interpreting information on ART presented in English. Roughly 37% (112/300) found it very difficult to interpret, while 21% (63/300) found it difficult. If one compares this experience with that of accessing information in the home language, the feedback is much more positive on the latter. Some 84% (249/298) found it very easy to interpret, while 12% (64/298) thought it was easy. The majority of respondents who are accessing information on ART manage to access it in their home language. Some 39% access it very often, while 30% do so often.

This study found that radio was the most effective a communication medium in conveying information on ART. Some 73% (406/559) of respondents considered a radio talk show as their best source of information. Neither gender nor HIV and AIDS support group membership were associated with listening to the talk shows. Support groups appear to be effective in conveying information on ART to their members. For 57% (270/471) of support group members on ART, the group that they belonged to was their best source of information. Respondents also accessed pamphlets and booklets for information. Some 27% (151/559) had read pamphlets, while 23% (127/559) had read booklets. Neither gender nor support group membership was associated with accessing pamphlets or booklets.

## **6.7 Effectiveness of ART**

ART improved the CD4 count for the majority of respondents who participated in the HATS 2005 and HTLS 2008. A direct comparison of first and last CD4 counts of respondents in the HATS 2005 and HTLS 2008 samples is not viable. Instead, the aim of including the data presented in Tables 17 and 18 is to demonstrate a trend in the data present within both datasets. Table 17 contains a comparison of first and last CD4 counts for respondents who participated in the HATS 2005. Some 65% of respondents had a first count below 200. Following their last CD4 test only 31% reported a count below 200. Counts ranging from 201 to 400 increased from 21% to 39%, and those from 401 to 600 from 12% to 20%. Those above 600 had risen from 2% to 10%. Cases for those respondents who said they could not remember the value of a count were excluded.

**Table 17: HATS 2005 First and Last CD4 Counts**

	<b>First Count Number</b>	<b>First Count %</b>	<b>Last Count Number</b>	<b>Last Count %</b>
<b>Below 200</b>	218/336	65%	84/270	31%
<b>201 to 400</b>	70/336	21%	104/270	39%
<b>401 to 600</b>	39/336	12%	54/270	20%
<b>Above 600</b>	9/336	2%	28/270	10%

A similar pattern emerged in the HTLS 2008 data pertaining to first and last CD4 counts. Some 52% of respondents reported a first CD4 count below 200. Only 12% said the last test they took returned a count below 200. First counts ranging from 201 to 400 had increased from 29% to 36%. Those ranging from 401 to 600 had risen from 11% to 28%, and those above 600 from 8% to 24%. Again, cases where respondents could not remember their last count, or never received the results of their last CD4 test, were excluded for the purpose of analysis.

**Table 18: HTLS 2008 First and Last CD4 Counts**

	<b>First Count Number</b>	<b>First Count %</b>	<b>Last Count Number</b>	<b>Last Count %</b>
<b>Below 200</b>	330/636	52%	66/571	12%
<b>201 to 400</b>	183/636	29%	207/571	36%
<b>401 to 600</b>	69/636	11%	160/571	28%
<b>Above 600</b>	54/636	8%	138/571	24%

Table 19 demonstrates the trend described above in more detail. This data was drawn from the HTLS 2008 sample. Only 12% of respondents who had a first CD4 count below 200 had the same current count at the time of the interviews. For 40% their count had improved to anything from 201 to 400. Some 24% saw it increase to within the range of 401 and 600. Another 24% experienced an increase to a level above 600.

**Table 19: Change in CD4 count below 200, HTLS 2008**

	<b>First Count Below 200 Number</b>	<b>First Count Below 200 %</b>
<b>Current count below 200</b>	33/271	12%
<b>Current count 201 to 400</b>	109/271	40%
<b>Current count 401 to 600</b>	65/271	24%
<b>Current count above 600</b>	64/271	24%

Attention needs to be paid to raising awareness of the importance of a CD4 count. Despite having gone for a CD4 count before, 21% of respondents in the HTLS 2008 sample could not recall their current count. Fewer HIV and AIDS support group members did not know their current count compared to non-members. Some 39% of non-members did not know their current count compared to 16% of support group members. More male than female respondents also did not know their current count. Almost 29% did not know compared to 19% of female respondents.

**Table 20: Recall of Current CD4 Count**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>% of sample who could not recall current count</b>	149/720	21%
<b>% support group members who could not recall current count</b>	98/589	16%
<b>% non-members who could not recall current count</b>	51/131	39%
<b>% female respondents who could not recall current count</b>	108/579	19%
<b>% male respondents who could not recall current count</b>	41/141	29%

## 6.8 Side-effects of ART

ART can have a number of side-effects on a patient. Some of the more common effects could include vomiting, fever, diarrhea, headache, liver toxicity, peripheral neuropathy (loss of feeling in the hands and/or feet), lipodystrophy (irregular distribution of body fat), anemic lactic acidosis

(rapid breathing, stomach pain, vomiting), strange dreams, nervousness, and itching. Data gathered on side-effects by the HATS 2005 is widely divergent from similar data gathered by the HTLS 2008 when analyzing the sub-samples used thus far. Also, data was gathered by the HTLS 2008 on variables not present in the HATS 2005. As such, it was decided to only present findings from the HTLS 2008 sample in this section. The most common side-effects reported were vomiting, headaches, diarrhea, and itching. The percentage of respondents who reported symptoms of peripheral neuropathy is worryingly high. Around 21% of those who reported side-effects suffered this. Even though the incidence of anemic lactic acidosis and liver toxicity was lower, the severity with which it impacts of the general health and quality of life of the patient cannot be denied. Even though lipodystrophy is not as life threatening as the three diseases mentioned prior, it can have a severely negative impact on self-esteem.<sup>13</sup>

**Table 21: Side-effects of ART**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>% who suffered side-effects</b>	295/571	52%
<b>% who suffered vomiting</b>	118/295	40%
<b>% who suffered headaches</b>	92/295	31%
<b>% who suffered diarrhea</b>	85/295	29%
<b>% who suffered itching</b>	80/295	27%
<b>% who suffered peripheral neuropathy</b>	61/295	21%
<b>% who suffered anemic lactic acidosis</b>	41/295	14%
<b>% who suffered lipodystrophy</b>	25/295	8%
<b>% who suffered liver toxicity</b>	19/295	6%

The majority of those who experienced side-effects saw a doctor for treatment. Many cope simply by sleeping. It should be noted that there was no significant difference between male and female respondents in terms of suffering side-effects. Within the context of adherence to treatment it is a positive finding that only 2% of respondents reported stopping treatment due to side-effects caused by of ARV medication. At the personal level this is a tragedy for those

<sup>13</sup> Canadian AIDS Treatment Information Exchange (2009) "Lipodystrophy and Lipoatrophy".  
[http://www.catie.ca/treatmentFAQ\\_e.nsf/c3f8add81db5bbbb85257188005be34b/bc3a49c36bb7b9b585256f0e006df9bc!OpenDocument](http://www.catie.ca/treatmentFAQ_e.nsf/c3f8add81db5bbbb85257188005be34b/bc3a49c36bb7b9b585256f0e006df9bc!OpenDocument)

affected. Reducing the side-effects of ARV drugs must remain a priority for the worldwide network dedicated to the treatment of AIDS.

**Table 22: Coping with side-effects**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>% who saw doctor</b>	227/295	77%
<b>% who slept</b>	38/295	13%
<b>% who saw nurse</b>	29/295	10%
<b>% who stopped treatment</b>	6/295	2%

## 6.9 Danger of Opportunistic Infections

With the weakening of the immune system, susceptibility to disease increases. In Southern Africa the following diseases are typically found among PLWHA: malaria, tuberculosis (TB), pneumonia, hepatitis, sexually transmitted infections other than HIV, Kaposi's Sarcoma, and fungal infections. Comparison between the HATS 2005 and the HTLS 2008 sub-samples was not attempted because it skews the data of the HTLS 2008 sample. As such, it was decided to concentrate on the data provided by the HTLS 2008 sample. A large minority (288/720) of respondents did not contract any of the above mentioned diseases since testing HIV positive. Around 35% of respondents had contracted TB. There was no relationship between having a low CD4 count and contracting the disease as for respondents there was a high risk of contracting TB irrespective of being HIV positive.<sup>14</sup> In short, exposure to TB poses a country-wide risk to PLWHA.

The second most contracted disease was malaria. Around 18% of respondents had contracted malaria. As expected, there was a strong relationship between geographical location and exposure to the disease.<sup>15</sup> Interview sites where malaria is a serious concern include Oshakati, Outapi, Eenhana, Rundu, and Katima Mulilo. Year round, the environment around Oshakati, Outapi, and Eenhana tends to be drier than that around Rundu and Katima Mulilo. The risk of exposure increases moving west to east in northern Namibia. Some 14% (12/85) of respondents

<sup>14</sup> Lamba, Goodman & Kruskal's tau, Uncertainty Coefficient: no significance.

<sup>15</sup> Cramer's V = .431 Approx. Sig. = .000

from Oshakati reported being treated for the disease, compared to 40% (33/82) from Rundu, and 59% (59/100) from Katima Mulilo. Around a third (42/133) of those who had contracted malaria also contracted TB after testing HIV positive. Exposure to hepatitis, STIs other than HIV, and pneumonia occurred less frequently, but often enough to raise concern. Being an HIV and AIDs support group member did not appear to reduce the risk of contracting any of the diseases mentioned above.

**Table 23: Exposure to Opportunistic Infections**

<b>Disease contracted since testing HIV +:</b>	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>TB</b>	251/720	35%
<b>Malaria</b>	133/720	18%
<b>Hepatitis</b>	66/720	9%
<b>STI's other than HIV</b>	45/720	6%
<b>Pneumonia</b>	33/720	5%

## **6.10 Disability Grants and Medical Aid**

The disability grant available to HIV positive patients via the MLSW has been mentioned in Section 3.7. The MLSW can provide a disability grant to any Namibian identified with temporary disabilities or abnormalities caused by any diseases or illnesses. This includes deterioration of immunity due to HIV, liver problems and other illnesses. A person's eligibility for the grant requires a recommendation by his/her doctor. This recommendation also affects the duration of the grant. The doctor completes a standardized form. The patient is then referred to a social worker at the MLSW which processes the case. Cases are reviewed at intervals. In the case of HIV, if a patient's CD4 count had improved to the extent that he/she is deemed fit to seek employment, the grant will be rescinded.

Analysis of the sub-samples from the HATS 2005 and HTLS 2008 indicates that roughly 22% of respondents in the 2005 sub-sample were receiving a disability grant, compared to only 6% in the 2008 sub-sample. It is not clear why the two samples should yield such different estimates, but the effectiveness of ART could be one factor in explaining the decrease in the number of

respondents who were accessing the disability grant. I.e., it could be that fewer people qualify for these grants due to their improved CD4 counts. Also, the availability of these grants does not appear to be widely advertised and it seems that patients are only told about them once they qualify. Some 79% (15/19) of respondents in the 2008 sub-sample who were receiving this grant were told of it by their doctor. In a minority of cases, respondents were told by a nurse or social worker of the grant. Some 35% of former grant recipients had lost access to these funds when their CD4 count improved. Roughly 84% of those who failed to obtain the grant did not receive it because their CD4 count was too high when they applied. Access to this disability grant becomes more important in light of the fact that 96% of respondents in the 2008 sub-sample did not have access to medical aid, as well as were unemployed or low-income earners.

**Table 24: Access to Disability Grant and Medical Aid**

	<b>HATS 2005 Number</b>	<b>HATS 2005 %</b>	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>% receiving disability grant</b>	48/223	22%	19/312	6%
<b>% told of grant by doctor</b>	-	-	15/19	79%
<b>% grants lost due to improvement in CD4 count</b>			19/54	35%
<b>% denied grant due to high CD4 count</b>	-	-	22/26	84%
<b>% with medical aid</b>	28/267	10%	13/313	4%

### 6.11 Conflict with HCW's

More than 84% (602/720) of respondents in the TLFS 2008 sample have never had a negative encounter with an HCW. This statistic is encouraging, considering the large number of patients an HCW must see on a daily basis. Only 9% (64/720) of respondents reported being treated badly by a nurse, and 5% (39/720) by a doctor. This said, a third (13/39) of those who reported bad treatment by a doctor also reported the same by a nurse. This raises the question of what the attitude of the patient is toward the HCW. Other patients in the sample share the same health care facilities without complaint. If incidents were that serious, would more respondents at least have reported this to another HCW? Some 66% (78/118) never reported the incident(s). Only 3% (4/118) sought legal advice. There also is an NGO network, as well as HIV and AIDS support group network, to draw upon for advice. A conclusion that can be drawn is that abuse by HCWs of patients is specific to the HCW and is not systemic. The most effective means of addressing

this issue is to empower the individual with an understanding of his/her rights as a patient, knowledge of complaint procedures, as well as the disciplinary process.

## **6.12 Conclusions**

Public hospitals are the most visited sites for conducting an HIV test. Feedback on testing is slow. One in two cases in this sample had to wait more than two weeks for feedback. Also, the majority of those who go for an HIV test are already ill by the time they do so. Placement on ART mirrors the state of patients' CD4 counts. More than 40% of respondents were placed on ART within 30 days, which is supported by the fact that more than 50% of respondents had a CD4 count below 200 when first tested. Three-quarters of the sample had their CD4 count retested at least three months prior to the interviews. This gives cause for hope in that there is seriousness with the majority of patients in keeping up-to-date with changes in their CD4 count. Very few HIV and AIDS support group members start and stop ART. This said, 25% of the sample had moved beyond a point of safety when it comes to re-testing.

More than 60% of respondents wait two hours or longer when visiting a health care facility. Virtually all respondents have difficulty travelling to and from a health care facility. The majority of respondents either walks or takes a taxi when collecting ARV medication. Nearly a third travel more than 25 km to reach a health care facility. This said, once at the facility, patients do not have a problem obtaining refill medication. There is strong evidence that ART works. For the majority of patients there has been an improvement in CD4 count, with very few not experiencing an improvement, or suffering a major recession in the count. The two greatest dangers to PLWHA in terms of disease are TB and malaria. TB is a danger across Namibia, while malaria is especially potent in Rundu and Katima Mulilo.

## **6.13 Recommendations**

- There is a delay in feedback between when patients undergo a CD4 count test and when they receive the results. A waiting time of two weeks or longer for the majority of patients has not decreased between the 2005 and 2008 surveys. Factors in this may be the availability of laboratory staff and/or testing equipment. The possibility of assisting with additional capacity building should be investigated by the donor community.

- In the light of the fact that the majority of respondents had difficulty traveling to and from a health care facility, as well as generally had to wait a long time to see a doctor, increasing the number of mobile clinics dedicated to HIV and AIDS management both inside Windhoek, large towns such as Oshakati, as well as in remote rural areas, needs to be investigated.
- Combating TB and malaria should remain a major objective for all NGOs whether by administering dedicated programmes, or providing support to those institutions or organizations who do.

## 7. Feedback from Health Care Workers

This chapter contains the analysis of the data obtained via the Health Care Workers' Questionnaire. It provides information from the perspective of HCWs on issues such as CD4 count testing and re-testing, access to doctors and nurses, difficulties faced by patients on ART, access to treatment information, training required by HCWs, PMTCT, contraceptives, and interaction with LGBT patients.

### 7.1 Biographical Information

A total of 50 HCWs were interviewed. Nurses accounted for 46% of the sample, community counselors for 26%, and doctors 16%. Three pharmacists, two nutritionists, as well as one social worker was also interviewed. Oshivambo was the most spoken home language in the sample, followed by English, Afrikaans, and Damara. The youngest person interviewed was aged 20, and the eldest 61. The average age for the sample was 37. Respondent had served in their positions as short as one year and as long as 40 years. The HCW sample had an average of 11 years of health care experience. Roughly 30% of the sample held a diploma in health care. Close to 20% had completed a degree, and another 16% held a post-graduate degree.

**Table 25: Sample Breakdown**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>% nurses in sample</b>	23/50	46%
<b>% community counsellors in sample</b>	13/50	26%
<b>% doctors in sample</b>	8/50	16%

### 7.2 CD4 Count Testing

Three doctors based in Windhoek were of the opinion that a CD4 count could be available within a week from testing. One said it could be available on the same day if needed. The doctor interviewed in Keetmanshoop said that it could take up to a week to obtain the results. Opinion was divided in Rundu where one doctor stated that it could take up to a week, and the other up to two weeks. The doctor interviewed in Oshakati said it takes up to two weeks. Doctors in Windhoek disagreed on the question of how regularly their health care facility can provide a

patient with a CD4 count reading. One doctor said these results can be provided once a week, two felt the results could be provided every two months, and the other said they could be offered every six months. The doctors in Rundu were consistent in saying that readings can be given once a week and the other saying it could be offered once every two weeks. The doctor in Oshakati also said these results could be provided once every two weeks. The doctor in Keetmanshoop said these results could be offered once every six months.

All the doctors agreed that a CD4 count below 200 is a condition which has to be present for a patient to be placed on ART. Six of the eight doctors wanted to see a positive HIV test as well. Doctors were subjective about other indicators in placing patients on ART. Four recommended that a patient on ART sees a doctor any time after two months (meaning see a doctor as soon as possible once the two months have passed). Three doctors said these patients should be seen every two months, while one recommended monthly visits. Four of the doctors meet more than three times with a patient before placing him/her on ART. Three of the doctors meet with patients three times, and one of them meets twice. Five of the doctors interviewed considered the greatest constraint to providing effective ART at their health care facilities to be a shortage of doctors. Four said that there are also too few nurses to assist HIV positive patients.

### **7.3 Access and Care**

Some 53% (26/49) of HCWs felt that they are able to spend enough time with patients on ART. The remainder did not agree and felt that they could not spend enough time with their patients. Doctors said they spend between 5 to 20 minutes with patients on ART. Nurses spend anywhere between 5 to 90 minutes. The average time all HCWs spend with patients on ART is 24 minutes. Four doctors said that they did not spend enough time with their patients, and one felt it was not nearly enough. Only three doctors said they spend enough time with patients. Nurses were divided on the issue. Around 48% (11/23) felt that the time spent with their patients was too short. Nearly half of the HCWs interviewed felt that they were not spending enough time with patients. The majority (37/50) rated their ability to monitor adherence to ART as either good or excellent. With respect to patient referrals, doctors mostly refer patients to other doctors, specialists, and social workers. Nurses refer patients to doctors and social workers. Only one doctor considered the cooperation between HCWs at his/her health care facility to be poor. The other HCWs said that such cooperation was either good or excellent.

## 7.4 Provision of Treatment Information

HCWs were asked about the format they provide ART information to patients or people interested in HIV/AIDS-related matters. The majority of HCWs provide patients with pamphlets and booklets. Close to 40% make use of a translator to explain what the treatment involves. A third shows them posters, and roughly a quarter makes use of pictures to explain treatment issues to patients.

**Table 26: Sources of Information on ART**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>% who hand out pamphlets</b>	28/50	56%
<b>% who hand out booklets</b>	23/50	46%
<b>% who make use of a translator</b>	19/50	38%
<b>% who show posters</b>	16/50	32%
<b>% who show pictures</b>	13/50	26%

Sixty-two percent of HCWs routinely provide information to patients on the dangers of re-infection, 60% on STIs, 50% on co-infection, 48% the risk of sharing ARV medication, and 44% being able to have children. The majority (34/50) of HCWs thought that it was either difficult or very difficult for illiterate people to understand information on ART. In contrast, 98% (44/50) felt that it is easy or very easy for literate people to grasp the information.

**Table 27: Health Care Topics Routinely Addressed by HCWs**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>Dangers of re-infection</b>	31/50	62%
<b>STIs other than HIV</b>	30/50	60%
<b>Dangers of co-infection</b>	25/50	50%
<b>Risk of sharing HIV medication</b>	24/50	48%
<b>Being able to have children</b>	22/50	50%

## 7.5 Difficulties of Patients on ART

HCWs were asked to choose one issue which they felt created the greatest concern for patients on ART. From the health care workers' perspective, stigma was the biggest issue for PLWHA. Patients are also concerned about being able to have children. Many of them are too poor to afford quality nutrition. For many PLWHA, the distance to travel for follow-up visits is a problem.

**Table 28: Major Concerns of Patients on ART**

	HTLS 2008 Number	HTLS 2008 %
<b>Fear of stigma</b>	14/50	28%
<b>Being able to have children</b>	9/50	18%
<b>Too poor to afford quality nutrition</b>	8/50	16%
<b>Travel for follow-up visits</b>	6/50	12%

Poverty was the cause most cited for patients dropping out of ART. Lack of transport was considered the second greatest cause, followed by lack of social support for the patient. The fourth biggest concern was alcohol abuse. Stigma was the fifth most cited cause, followed by the side-effects of ART.

**Table 29: Reasons for Dropping Out of ART**

	HTLS 2008 Number	HTLS 2008 %
<b>Poverty</b>	35/50	70%
<b>Lack of transport</b>	29/50	58%
<b>Lack of social support</b>	27/50	54%
<b>Alcohol abuse</b>	26/50	52%
<b>Stigma</b>	16/50	32%
<b>Side-effects of ART</b>	14/50	28%

## 7.6 Training Opportunities

The MoHSS has issued guidelines for the prescription of ART. Around 20% of the HCWs interviewed have never received any training on these guidelines. The bulk of them are nurses

and community counselors. The minority of those who did not receive training thought that their understanding of the guidelines was poor. Around 78% (39/50) of the sample thought that their understanding ranged from good to excellent. Strong interest was expressed in training on monitoring of adherence, Positive Living, and prevention of mother-to-child transmission (PMTCT). HCWs also felt that it was important to receive training on topics about children and ART, side-effects of ART, and co-infections. Seventy eight percent (39/50) of HCWs rated their counseling skills as being good or excellent.

**Table 30: Training received by HCW's on ART Guidelines**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>% trained at workshop of MoHSS</b>	28/50	56%
<b>% trained at workshop of NGO</b>	9/50	18%
<b>% who trained at educational institution</b>	3/50	6%
<b>% who studied on their own</b>	4/50	8%
<b>% who have received no training</b>	6/50	12%

## 7.7 PMTCT and Contraceptives

As is the case with ART, the MoHSS issues guidelines on PMTCT. The majority of HCW respondents were trained on these guidelines at a workshop organized by the Ministry or sponsored by an NGO. Close to a third of the HCW sample has not received any training on PMTCT.

**Table 31: Training received by HCW's on PMTCT**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>% trained at workshop of MoHSS</b>	23/50	46%
<b>% trained at workshop of NGO</b>	18/50	18%
<b>% who trained at educational institution</b>	3/50	6%
<b>% who studied on their own</b>	6/50	12%
<b>% who has received no training</b>	9/50	18%

HCWs were asked to rate the quality of the PMTCT program at their health care facility. The vast majority (45/49) rated it as good or excellent. One pertinent issue surrounding PMTCT in Namibia is the low level of participation of men in this process. Three-quarters (38/50) of HCWs considered the participation of men in PMTCT to be poor. The majority (32/50) believed that HIV positive women should be allowed to have children. More than 60% (31/49) also agreed that HIV positive men should be allowed to father children. Around 88% (44/50) always recommend contraceptives to HIV positive women. The remainder never recommends any, only recommends when the women do not want to have children, or only recommends when asked to do so. Male condoms (38/50) are the most recommended contraceptives, followed by female condoms (35/50), and hormone injections (26/50). The least recommended contraceptive include the pill (12/50), fitting of an intrauterine device (4/50), or a vasectomy (4/50).

### **7.8 Interaction with LGBT Patients**

Some members of the LGBT community have reported maltreatment by HCWs to the Rainbow Project (trp). Are these incidents isolated, or is there a systematic bias towards LGBT patients among HCWs? Sixty percent (30/50) of the HCWs sampled provide treatment to LGBT patients. The majority (16/30) of those who treat LGBT patients disagreed that they had different needs to other patients. This said, roughly two-thirds (19/29) of them felt that their training as health care professionals allow them to effectively address the needs of LGBT patients. One would expect a professional attitude from a HCW irrespective of whom they treat. If LGBT patients have special needs these have never been officially acknowledged within the Namibian health care system. Stated differently, no guidelines exist for dealing with LGBT patients other than those prescribed for general patient care. If different needs exist, the onus may rest on the LGBT community in Namibia to communicate the nature of these needs, and to work with the MoHSS in incorporating training in this regard into health care training programs. The majority (23/30) of HCWs do not believe that LGBT patients complain more than other patients. Stated differently, a minority of HCWs thought that LGBT patients are more demanding. HCWs were also asked whether they thought a person is born lesbian or gay. This question was included because it has caused a major debate both inside and outside academic circles. It may also predict stigma toward LGBT patients, as those who believe that LGBT persons are born that way may be more accepting of their sexual identity. "Nature" (born this way) versus "nurture" (raised this way)

arguments are central to debates on human behaviour. The split among HCWs on the debate was close to 50/50. A slight majority (16/30) supported the nurture argument, believing that individuals are lesbian or gay because of the way they were raised.

## **7.9 Positive Living**

HCWs were asked to name the recommendations they typically make to patients on ART in order to encourage Positive Living. The most common recommendations HCWs make to ART patients is to quit drinking alcohol (44/50), quit smoking (43/50), and to change their diet (36/50). The fourth most frequent recommendation is to join a support group (35/50). HCWs were least likely to recommend taking massages (8/50) or practicing reflexology (8/50). The majority of HCWs discouraged patients to use traditional medicines while on ART (44/48).

## **7.10 Conclusions**

There was discrepancy between HCWs on how long it takes to receive the results of a CD4 count test versus how frequently a patient's CD4 count can be re-tested. Feedback occurs within two weeks, but obtaining the results of a re-test can take months in certain instances. Roughly half of HCWs believe that they do not spend enough time with patients on ART. The reason for this appears to be a shortage of staff. Issues that patients on ART face include stigma, the ability to have children, lack of quality nutrition, and lack of transport. Poverty is considered the main cause for patients discontinuing ART. Pamphlets and booklets are the most widely distributed materials on ART. Illiterate patients have the greatest difficulty understanding information on ART. HCWs need more training on the MoHSS's guidelines on ART and PMTCT. HCWs expressed a strong interest in receiving training on monitoring of adherence and promotion of Positive Living. The participation of men in PMTCT programs is very poor. Not all HCWs recommend contraceptives to HIV positive women all the time. There are no guidelines for HCWs on the needs of LGBT patients.

## **7.11 Recommendations**

- Training needs exist among HCWs in the areas of ART and PMTCT guidelines, children and ART, monitoring and adherence, side-effects of ARV's, Positive Living, co-infections, and counseling skills.

- Adult patients on ART want information on being HIV positive and the ability to have children. Such information should be linked to that provided on PMTCT. It should be explained to men what their role in PMTCT is.
- The perception exists that HCWs discriminate against LGBT persons. If discrimination occurs it is specific to certain HCWs. Improved understanding of the needs of LGBT patients by HCWs may serve to remove or reduce potential conflict. No guidelines exist for the treatment of LGBT patients other than those prescribed for general patient care. In order to help create common ground, the LGBT community should produce a document which explains the needs of LGBT patients, and how to address those needs.

## **8. Sexual Activity and Reproductive Health**

Effective use of barrier protection is critical in preventing re-infection of PLWHA, as well to protecting HIV negative sex partners. This chapter contains information of the types of barrier protection used among PLWHA, preference in condom use, reasons for not using a condom, beliefs surrounding condom use, and access to information on condom use. The ability to have children is an important issue among PLWHA. This chapter deals with the sexual health of HIV positive females, parenting issues, and issues surrounding HIV positive children.

### **8.1 Sexual Activity**

Around 70% (500/717) of the HTLS 2008 sample had a regular sex partner. Some 12% (89/717) did not have a regular partner. Roughly 7% (49/717) of respondents reported that their regular partner had died. Some 63% (451/717) of respondents said that they had sex 12 months prior to the interviews. Of these respondents, 97% (439/451) had been with a regular sex partner, 5% (22/451) a casual sex partner, and slightly more than 1% (6/451) a commercial sex partner. A very high percentage of respondents were being faithful to one partner only. In fact, less than 5% (22/451) had more than one partner at the same time. Of those who had a regular sex partner, some 3% (12/439) had sex with a casual sex partner as well. Less than 1% (3/439) respondents who had a regular sex partners said that they also had sex with a commercial sex worker during the year before the interviews. Neither gender nor HIV and AIDS support group membership was significantly associated with abstinence.

### **8.2 Disclosure between Sex Partners**

It is important that an HIV positive person discloses his/her HIV status to a sex partner. Failure to do so could lead to infection of that partner. It is equally important to know the status of that partner in order to prevent re-infection. Disclosure is an important component of Positive Living. Disclosure does not only pertain to the HIV status of a person, but also to his/her sexual identity. In the LGBT community the term used is "coming out of the closet", which means telling a partner of the sexual orientation preferred.

The findings on disclosure of the sub-sample of Windhoek, Oshakati, Katima Mulilo, and Keetmanshoop for the HATS 2005 and HTLS 2008 were compared. Pertaining to the 2005 sub-sample, 84% (135/160) of those respondents who had a regular sex partner had disclosed their HIV status to that partner. The level of disclosure was higher in the HTLS 2008 study. Around 96% (220/230) of respondents in the 2008 sub-sample had revealed their status to their main sex partner. Both samples were small, as well as gender-biased. As such, it is not possible to state without a high degree of error that gender was a factor in the above. Broadening the base of the sub-sample for gender to data from the HTLS 2008 sample only did not provide reliable comparative data, either. HIV and AIDS support group members (392/587) are slightly more likely to reveal their status to their main partner than non-members (78/130). Higher HIV and AIDS support group membership may explain the higher estimates of disclosure in the 2008 data. Strong emphasis is placed inside support groups on disclosing one's HIV status.

Knowing the HIV status of a main sex partner is equally important as disclosure to that partner. Around 32% (56/177) of the respondents in the HATS 2005 sub-sample did not know the HIV status of their main sex partner. Some 93% (113/121) of those who knew the status of their partner had an HIV positive sex partner. In contrast to the findings from the 2005 sub-sample, only 20% (47/232) of the 2008 sub-sample did not know the HIV status of their main sex partner. Of those who knew the status of this partner, 87% (161/185) had an HIV positive sex partner. Two aspects of these findings are worth examining in more detail. First, the percentage of respondents who did not know the HIV status of their main sex partner is lower in the 2008 study. As explained before, HIV and AIDS support groups may be a factor in this decrease. Emphasis is placed within the groups on disclosure between partners, whether they are sexually active or not. Second, a large percentage of PLWHA have HIV positive partners. This raises a number of questions. Are these figures so high because the one partner infected the other? Or are PLWHA actively seeking out other PLWHA for partner relations? If the latter is true, then why is this happening? Is there a sense of obligation not to spread the disease to others who have not contracted it? Alternatively, is this a matter of affinity born through shared experience, i.e. sharing the same problems, being HIV and AIDS support group members, etc.

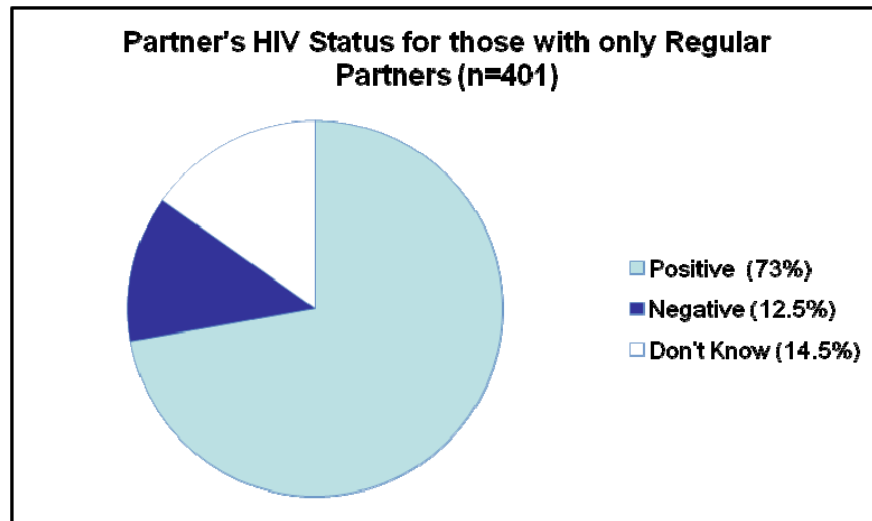
### 8.3 Condom Use

Information gathered on condom use during the HATS 2005 survey was very basic and will not be presented here for the purpose of comparison. Around 91% (452/498) of sexually active respondents have made use of a male condom since testing HIV positive. Only 24% (121/498) of them ever made use of a female condom since testing HIV positive. The most preferred brand of condom was Smile (304/498), followed by Cool Ryder (93/498). The majority (260/498) of respondents obtain their condoms at a public hospital. Public clinics (77/498), shebeens (64/498), and NGO offices (33/462) are secondary supply sites. Barrier protection extends beyond condom use. Dental dams and medical gloves also provide protection against STIs. The latter two forms of protection hardly garnered use among respondents in. Only two (2/498) respondents reported ever using dental dams, and five (5/498) said they had ever used medical gloves.

As important as using protection during intercourse, is using it consistently. Both the MoHSS and the private HIV and AIDS prevention and care network emphasize the message that a condom should be used every time a person has sex. Around 92% (409/443) of respondents who had sex during the 12 months before the survey used a condom the last time they had sex. There was no significant difference in usage between HIV and AIDS support group members and non-members. In the three months prior to the survey, consistent use of condoms occurred in 85% (385/451) of cases. This figure also accounts for those respondents who had multiple concurrent partners, meaning they had multiple sexual relations at the same time.

Around 97% (439/451) of sexually active respondents had sex with a regular sex partner during the year prior to the survey. Close to 5% (22/451) had been with casual partner, while only 1% (6/451) had visited a commercial sex worker. Self-reported condom use with a regular partner during last sex was very high. Roughly 91% (400/439) of regular partners reported using a condom the last time they had sex. Condom use with partners that are HIV positive is essential to prevent infection of sero-negative partners and re-infection of sero-positive ones. Of those with only a regular partner (n=401), 73% knew that their main partner was HIV positive, 12% had a partner who was HIV negative, and 15% did not know their partner's status. Numbers for those with only casual or only commercial sex partners are small and not presented here. Around 98% of those with only a regular sex partner agreed that condoms can be used to prevent re-infection.

**Figure 5: HIV Status of Regular Sex Partner**



Of those with a regular HIV negative partner and no other partners, 86% (43/50) used condoms at last sex, as well as used condoms consistently during the three months prior to the interviews. Of those not using condoms, all (7/7) disclosed their status. Of those with a regular HIV positive partner and no other partners, almost 95% (278/293) used condoms at last sex and 89% (260/293) used condoms consistently during the prior 3 months. Of those not using condoms, all (15/15) disclosed their status. Around 20% (89) of sexually active respondents provided a reason for not using a condom the last time they had sex without one. The main barriers to condom use included the desire of having a child (43%) and a partner objecting to the use thereof (35%).

#### **8.4 Comparing Condom User with Non-Users**

In order to make evidence-based program decisions, behavioral determinants were compared between condom users and non condom users. Those who used condoms consistently over three months (n=386) were compared with those who seldom or never used condoms over the same period (n=65), while controlling for population characteristics.<sup>16</sup> Determinants of condom use can broadly be classified into opportunity, ability, and motivation.<sup>17</sup> The risk group consisted of those respondents who had sex up to 12 months prior to the survey. The behaviour controlled for

<sup>16</sup> Likert scales were used to rate scale items from 1 to 4, where 4 indicated the desired behavior. Availability of Condoms consisted of 2 scale items, Knowledge of 4, Self Efficacy of 2 and Outcome Expectations of 1 scale item.

<sup>17</sup> Population Services International (2006) "Behaviour Change Framework".  
<http://www.psi.org/research>

was consistent condom use over a period of three months prior to the survey. Results are set out in the Table 32:

**Table 32: Determinants of Condom Use<sup>18</sup>**

INDICATORS	Users N=386 (85.6%)	Non Users N=65 (14.4%)	OR	Significance
<b>OPPORTUNITY</b>				
<i>Availability of condoms</i>	3.380	3.049	1.640	**
<b>ABILITY</b>				
<i>Knowledge about Condoms and HIV prevention</i>	3.416	3.604	.408	***
<i>Self-Efficacy</i>	3.668	3.342	4.250	***
<b>MOTIVATION</b>				
<i>Outcome Expectations</i>	3.372	3.131	1.577	*
<i>Self Esteem</i>	-	-	-	NS
<b>POPULATION CHARACTERISTICS</b>				
<i>Age (29yrs and below vs 30 and above)</i>	-	-	-	NS
<i>Sex (female vs male)</i>	-	-	-	NS
<i>Socioeconomic Status (Low vs medium-high)</i>	-	-	-	NS
<i>Level of Education (None to Primary vs Secondary and above)</i>	-	-	-	NS

\*p <= 0.05, \*\* p <= 0.01, \*\*\* p <= 0.001, NS = Not significant

Condom users were 1.6 times more likely to have access to condoms than non-users<sup>19</sup>. Condom users also had higher self-esteem. They were 4.3 times more likely to use condoms due to higher self efficacy.<sup>20</sup> Condom users were also more optimistic about life. They were 1.6 times more likely to have positive outcome expectations than non users.<sup>21</sup> In contrast, condom users were 2.5 times less knowledgeable on condom use.<sup>22</sup> All behavioral determinants included in this model were significantly correlated<sup>23</sup> with self esteem, though the correlations were not very strong. Non-users were mainly female, married or cohabiting, unemployed or low income earners, with some secondary schooling, older than thirty, who tested for HIV more than two years before the study. Table 33 contains a comparison of data for condom users and non-users.

<sup>18</sup> Binary Logistic Regression using composite scores for reliability scale items on Opportunity, Ability, and Motivation.

<sup>19</sup> Spearman Correlation, p<0.01

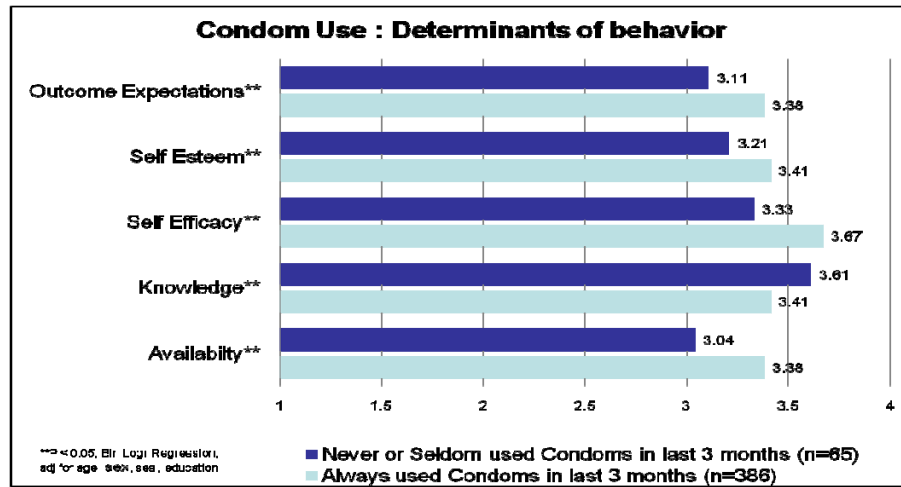
<sup>20</sup> Spearman Correlation, p<0.01

<sup>21</sup> Spearman Correlation, p<0.01

<sup>22</sup> Spearman Correlation, p<0.05

<sup>23</sup> Spearman Correlation, p<0.05

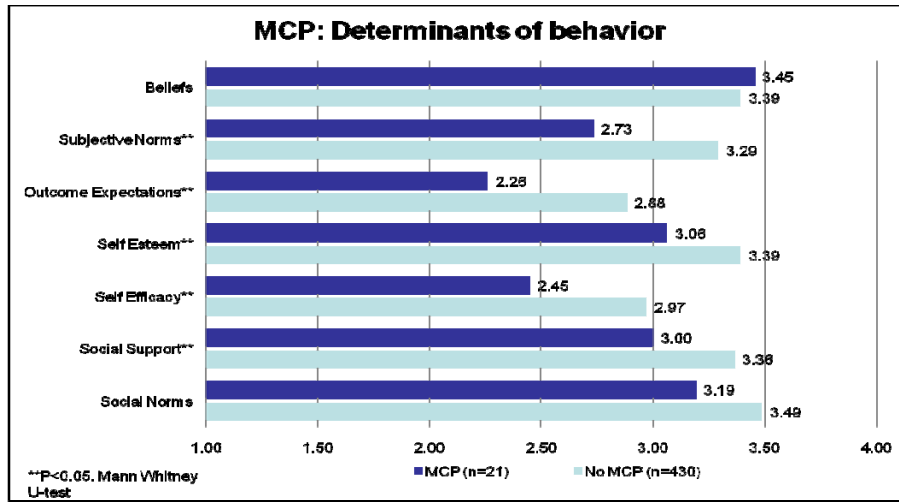
**Table 33: Analysis of Behavior Surrounding Condom Use**



### 8.5 Multiple Concurrent Partners

Almost 5% (21/451) of respondents who were sexually active in the 12 months prior to the survey reported having multiple concurrent partners (MCPs). Some 76% (16/21) had two overlapping sex partners, while the remainder had more than two partners at the same time. In order to make evidence-based program decisions, behavioral determinants were compared between respondents with MCPs (n=21) and those without (n=430). As with condom use, composite scores were calculated for scale items related to opportunity, ability, and motivation to have MCPs. As can be seen in Table 34, the belief system of those with MCPs had a major impact on their sexual behavior. They were less positive about life, had lower self-esteem than those without MCPs, and had a weaker social support system to rely upon.

**Table 34: Respondents with Multiple Concurrent Sex Partners<sup>24</sup>**



### 8.6 Beliefs Surrounding Condom Use

Respondents to the HTLS 2008 were asked if they could access condoms within a ten minutes walk from where they live. Close to three-quarters (581/720) said that they could. Around 88% (606/720) did not think that condoms were too expensive. There was a strong conviction within the sample that condom use is important. Around 94% (639/683) of respondents disagreed with the statement: "I do not need to use a condom". When asked if sex with a condom was enjoyable, 86% (605/704) agreed. Roughly 95% (673/709) also agreed that they could convince whoever they have sex with to use a condom. Knowledge of the benefits of condom use is another important factor in encouraging consistent use. When asked if condoms can protect against any STI, around 98% (703/718) of respondents agreed. This belief is wrong. Condoms do not offer universal protection against STIs. They do offer partial protection against HIV infection or re-infection. Around 98% (704/718) of respondents agreed that condom use can prevent HIV infection, while 97% (702/718) said that use can prevent re-infection. Part of an education campaign on condom use involves raising awareness that condoms are not 100% safe. Male condoms can fall off during use. Both male and female condoms can break. If informed of this, one would expect disagreement by the majority of respondents with a statement that condoms are 100% safe in preventing HIV infection. Only 37% (264/717) of respondents disagreed with the statement.

<sup>24</sup> U-test of Mann Whitney, p<0.05

## 8.7 Access to Information on Condom Use

Respondents to the HTLS 2008 were asked about their best source of information on condom use. Some 70% (504/720) said that it was a talk show on the radio. Around 52% (371/717) received their information from a support group. Close to 28% (199/716) read pamphlets, and 26% (182/713) accessed booklets. Roughly 24% (170/713) watched a talk show on TV which provided this information, while 19% (135/713) watched a documentary. Only 13% (95/714) had read a poster on condom use. Oil-based lubricants can damage male condoms. Female condoms are resistant to damage from oil-based lubricants because they are physically stronger. It is not safe to use a product such as Vaseline as a lubricant with male condoms. It is safe to use K-Y Jelly, which is a water-based lubricant. Some 90% (624/693) of respondents correctly said that Vaseline is not safe to use with male condoms. K-Y Jelly appeared to be less well known among respondents. Forty-nine percent (316/663) incorrectly said that that it is not safe to use K-Y Jelly. Pertaining to female condoms, 79% (533/677) correctly said that it is a false statement that using any kind of oil based lubricant with a female condom, makes them more likely to break.

## 8.8 Female Sexual Health

Around 67% (384/574) of female respondents have been sexually active since testing HIV positive. Of these respondents, 37% (141/384) became pregnant. Of those who became pregnant, 77% (108/141) participated in a PMTCT programme. Roughly 44% (62/141) also breast-fed. Of those who breast-fed, 63% (39/62) participated in a PMTCT programme. Around 80% (308/384) of sexually active females had ever used male condoms as a contraceptive, some 24% (92/384) female condoms, and 15% (56/384) had ever used hormone injections to prevent pregnancy. Roughly 75% (42/56) of those who received hormone injections also used male condoms. Only 7% (4/56) of those who received hormone injections used female condoms. About 6% (22/384) said that they did not use any kind of contraceptive. A Pap smear is a medical procedure used to identify cancer of the cervix. It is recommended that sexually active women undergo the procedure roughly every three years.<sup>25</sup> A lot still remains to be done to raise awareness on the topic. Around 36% (137/380) of sexually active women said that they have never heard of a Pap

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<sup>25</sup> American Academy of Family Physicians (2008) "Pap Smears".  
<http://familydoctor.org/online/famdocen/home/women/reproductive/gynecologic/138.html>

smear. Close to 31% (117/380) have heard about this test, but have never gone for one. Only 25% (94/380) go for a Pap smear once a year.

## **8.9 Parenting**

A large percentage of respondents to the HTLS 2008 were parents. Some 77% (556/720) were parents before testing HIV positive. Roughly 76% (123/163) of respondents who were not parents said it was important for them to have a child. More than a third (266/720) of the sample had a child after testing HIV positive. Around 39% (232/589) of support group members became parents since testing positive compared to 26% (34/131) of non-members. Roughly 63% (145/231) of support group members who had a child after testing positive said it was very important to have another child. About 35% (12/34) of non-members who had a child after testing positive said the same. Around 69% (169/244) of respondents had one child since testing positive, while 15% (36/244) had two children. For 59% (157/265) of these parents, it was important to have another child. Around 86% (612/716) said they were raising a child (either their own or someone else's). Table 35 below shows the number of children being cared for, which includes biological children as well as those of a relative, and a friend. This table also includes counts of male and female orphans. These figures only include youth younger than 18 years. In total, the respondents indicated that they were caring for 1,969 children.

**Table 35: Percentage of Respondents Raising Children, by Type of Child**

	HTLS 2008 Number	% of Total
<b>Biological boys</b>	711	36%
<b>Biological girls</b>	692	35%
<b>Boys of a relative</b>	191	10%
<b>Girls of a relative</b>	196	10%
<b>Boys of a friend</b>	17	1%
<b>Girls of a friend</b>	26	1%
<b>Boy orphans</b>	64	3%
<b>Girl orphans</b>	72	4%
<b>Total</b>	<b>1,969</b>	<b>100%</b>

Table 36 contains a breakdown of the percentage of parents/guardians according to the number of children they raise.

**Table 36: Parents/Guardians by Number of Children Raised**

	HTLS 2008 One child raised	HTLS 2008 One child raised %	HTLS 2008 Two children raised	HTLS 2008 Two children raised %	HTLS 2008 Three children raised	HTLS 2008 Three children raised %
<b>% of parents raising biological boy(s)</b>	209/612	34%	122/612	20%	41/612	7%
<b>% of parents raising biological girl(s)</b>	242/612	40%	134/612	22%	35/612	6%
<b>% of respondents raising boy(s) of a relative</b>	72/612	12%	33/612	5%	-	-
<b>% of respondents raising girl(s) of a relative</b>	73/612	12%	27/612	4%	-	-
<b>% of respondents raising boy(s) of a friend</b>	9/612	1%	-	-	-	-
<b>% of respondents raising girl(s) of a friend</b>	10/612	1%	-	-	-	-
<b>% of respondents raising boy orphan(s)</b>	24/612	4%	8/612	1%	6/612	1%
<b>% of respondents raising girl orphan(s)</b>	31/612	5%	12/612	2%	3/612	1%

## 8.10 HIV Positive Children

Around 70% (430/612) of respondents said that none of the children that they were raising were HIV positive. Another 9% (54/612) said that they did not know if the children were HIV positive. Table 37 provides statistics on infected children being cared for by respondents. Out of

the 1,969 children, the status of 208 (11%) was not known. Thus, of those children whose HIV status is known, 7% (120/1,761) are infected.

**Table 37: Percentage of Children Being Raised Who Are Infected**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>% of biological boys infected</b>	46/649	7%
<b>% of biological girls infected</b>	40/646	6%
<b>% of boys of a relative infected</b>	6/157	4%
<b>% of girls of a relative infected</b>	6/158	4%
<b>% of boys of a friend infected</b>	5/15	33%
<b>% of girls of a friend infected</b>	4/24	16%
<b>% of boy orphans infected</b>	6/54	11%
<b>% of girl orphans infected</b>	7/58	12%

Roughly two-thirds (71/110) of those respondents who looked after HIV positive children agreed that children should be encouraged to join an activity group that educates them on their HIV status. Around 18% (20/110) were not certain whether children should be encouraged to join such activity groups. The remainder (18/110) was against this idea.

## 8.11 Conclusions

Sexual activity within the sample was fairly low, with only two-thirds of respondents having had sexual intercourse in the year prior to the survey. Having sex with a casual partner or commercial sex partner was not common. HIV and AIDS support groups may have had a positive impact on increasing disclosure of the HIV status among sex partners. For those who were sexually active, having sex with an HIV positive sex partner was the norm. The male condom is the primary contraceptive used. The bulk of these are obtained at public hospitals with the favoured brand being Smile. Shebeens are also popular spots for obtaining condoms. Consistent use of condoms with a regular partner was high. Reasons cited for not using a condom during last sex include wanting a child or the partner objecting. Condom users tend to have a higher self-esteem than non-users, but tend to be less knowledgeable on the subject. Those respondents with MCPs were less positive about life, had lower self-esteem than those without MCPs, and had a weaker social

support system to rely upon. Roughly two-thirds of the sample thought that condoms are 100% safe in preventing HIV infection. The best sources of information on condom use are the radio and HIV and AIDS support groups. Knowledge of the use of KY-Jelly was low. Three-quarters of female respondents do not go for a Pap smear at any interval, while a quarter who fell pregnant after testing HIV positive did not participate in PMTCT. HIV and AIDS support group members are more likely to want to have more children than non-members. Roughly seven percent of children of respondents were known to be HIV positive. The majority of parents who were raising HIV positive children were in favor of the children joining activity groups aimed at educating them on their HIV status.

## 8.12 Recommendations

- The importance of raising awareness of PMTCT increases in the light of the findings that one of the most cited reasons for not using a condom during last sex was the desire to have a child, as well as that having sex with an HIV positive sex partner was the norm.
- Only a quarter of female respondents regularly go for a Pap smear. The remainder do so intermittently, or not at all. This emphasizes the need for a structured campaign to provide information on the need for a regular Pap Smear especially for sexually active women.
- Members of HIV and AIDS support groups are quite positive about having a child or more children. Though an aim of HIV and AIDS support groups are to promote a positive attitude towards being HIV positive, the message sent is not consistent with family planning. The vast majority of respondents found themselves in dire economic circumstances and a high percentage of them were already raising at least one child.
- Based on the comparison of condom users and non users, as well as those with MCP and those without MCP, the following recommendations are made for behavior change communications programs:
  - Focus on messages encouraging condom use with all partners, especially ones who are HIV negative or those whose status is not known.
  - Increase access to condoms. A third of non-users said they cannot access condoms within 10 minutes walk from home.

- Continue the focus on increasing self-esteem and self-efficacy among PLWHA via HIV and AIDS support groups.
- Raise awareness of the risk associated with having MCP.

## 9. Stigma and Acceptance

This chapter addresses issues related to discrimination experienced by PLWHA, and also examines the incidence of self-stigma. The findings raise a number of questions: Are Namibians becoming more accepting of those who are HIV positive? How are PLWHA coping with being HIV positive? What is their self-image like, and are they adopting positive living strategies?

### 9.1 Community, Family and HIV

Political leadership plays a prominent role in creating a social climate where PLWHA are treated as equals. Respondents were asked if leaders in their community are supportive of PLWHA. Though the majority agreed community leaders support PLWHA, the split was narrow. Only 58% (389/666) agreed that community leaders are supportive of PLWHA. There was no difference in outlook between HIV and AIDS support group members and non-members. Men are slightly more likely to agree than women that community leaders support PLWHA. Elders also exercise a lot of influence in Namibian communities. Respondents were asked if elders in their community encourage people to reveal their HIV status. Again, respondents were evenly split in their opinions on this matter. About 59% (389/668) agreed that elders are supportive. HIV and AIDS support group members were more likely to report this: 61% (333/545) of them agreed that elders encourage PLWHA, compared to 46% (56/123) of non-members. This response is consistent with the fact that a large part of the sample was elderly. Also, the support group network allows for more interaction with elderly persons. There was no noticeable difference between the sexes on this issue.

Fear of discrimination is a major factor presumed to be inhibiting PLWHA from revealing their HIV status to others. Acceptance and support are key elements in creating a safe social and political environment for those who are HIV positive. Close to three-quarters (480/663) of respondents agreed that it was safe for them to reveal their status. HIV and AIDS support group members feel more secure about this than non-members: 75% (407/542) agreed it was safe for them to reveal their status compared to 60% (73/121) of non-members. There was no apparent difference in opinion between men and women on this issue.

An important indicator of self-confidence in someone who is HIV positive is the ability to inspire others to reveal their HIV status. Respondents were asked if they believed that they could inspire others to reveal their status. Some 77% (552/667) agreed that they could so inspire someone. This demonstrates a high degree of acceptance among respondents of their own HIV status. HIV and AIDS support group members demonstrated a very high level of confidence. Close to 85% (463/544) said that they could inspire others to reveal their status, compared to 72% (89/123) of non-members. There were no differences by sex. Even more important than acceptance by the community is acceptance by the family. Around 87% (577/665) of respondents felt confident that they could reveal their HIV status to members of their family. Though this figure is high, it is worrying that it was not closer to 100%. Family, whether close or distant remains a cornerstone of social support for PLWHA. There was no apparent difference between HIV and AIDS support group members and non-members in terms of support from their families. Gender also was not a factor in this.

## **9.2 Discrimination against the HIV Positive**

Some people fear becoming infected with HIV by sharing eating and drinking utensils with an infected person. As a result, some PLWHA are forced to use separate utensils when eating or drinking. Around 10% (67/666) of respondents reported instances where they had to use a different plate, knife, and fork than those used by everyone else, while 4% (25/666) are always forced to do so. The situation was the same for drinking from a separate cup or mug. Roughly 12% (82/665) of respondents said that family members sometimes avoid them, while 4% (26/665) experience this type of rejection all the time. In addition, 8% (54/653) of respondents said they are sometimes excluded from family events, while 5% (31/653) are never invited to such events.

Human beings are social creatures and as such have a need for broader social contact beyond the family milieu. Participation in community events helps to create a sense of belonging. Around 10% (63/659) of respondents are sometimes excluded from these events, while 3% (21/659) never get to participate. What is interesting is that slightly more respondents are sometimes excluded from community events compared to family events, but that more of those who are always excluded from family events attend community events. Friendship is critical for any

human being in avoiding isolation, as well as having a more balanced view of life. Around 12% (81/662) of respondents are sometimes avoided by friends, while 3% (22/662) face isolation from broader human contact.

PLWHA do face aggression because of their HIV status. Visits by community members, intended to put the person to shame, is a subtle form of aggression. There is no physical violence, but the intention is to break down the self-image through the imposition of a supposedly superior moral framework. This practice is more common than expected. Around 15% (96/661) of respondents have received such "visits" a few times. In the case of 3% (23/661), visits by community members are always intended to put them to shame. A problem that is equally prevalent is the degree to which PLWHA suffer verbal abuse. Respondents were asked if they have ever been called bad names, insulted, or sworn at because of their HIV status. Around 8% (51/658) of respondents reported always being called bad names, insulted, or sworn at. Physical attack remains a reality for PLWHA, though it is the least likely form of abuse to occur. Around 2% (10/661) are always beaten up, kicked, or attacked because of their HIV status.

Employment is a basic need of any adult. Participation in a capitalist society on equal footing depends on income. In Namibia, a wage or salary remains the primary means of income. Therefore, being able to access a job remains crucial to the wellbeing of any Namibian. Around 5% (35/664) of respondents report having been denied at least one job based on their HIV status, and another 5% (33/664) report not finding employment because of this. People may also lose a job because of their HIV status, and especially when they develop AIDS. Unfortunately, a person requires steady income the most when their health deteriorates due to medical costs and the need for better nutrition. Around 5% (31/664) of respondents say they have lost a job because of their HIV status.

### **9.3 Self-image of the HIV Positive**

Questions were asked to understand respondents' self-image. On the surface respondents were very positive about themselves and their ability to face life. Around 97% (642/669) of respondents felt that they had a number of good qualities. Again, 97% (651/667) of these individuals believed they could do things as well as most other people. Around 98% (646/664)

believed that they could live a long and healthy life. Close to 96% (639/665) felt that they were in control of their lives. The positive exterior hides fears about the future, as well as personal relationships. Some 13% (86/665) felt ashamed because they were HIV positive. HIV and AIDS support group members demonstrated fewer feelings of inadequacy in this regard: around 89% (483/542) did not feel ashamed, compared to 78% (96/123) of non-members. Around 14% of women (74/535) felt ashamed compared to 9% (12/130) of men.

The majority (57%) of respondents did not think they could have a serious love relationship with someone in their community. HIV and AIDS support group members were somewhat less positive than non-members about the possibility of having a long-term relationship: roughly 52% (64/122) of non-members felt that a serious love relationship was not possible, compared to 59% (317/541) support group members. Around 57% (302/534) of women thought the same compared to men 61% (79/129) of men. Being able to dream about the future is a strong personal motivator, especially when those dreams become achievable goals. Around 70% (467/667) of respondents were no longer interested in pursuing their dreams. There was little difference in outlook between HIV and AIDS support group members and non-members. Male respondents had a less positive outlook than female respondents: 81% (105/130) of men no longer felt interested in pursuing their dreams, compared to 67% (362/537) of women.

#### **9.4 Positive Living**

Respondents were most likely to first disclose their HIV status to a sister (365/715). The person most likely to be told next is the mother (336/717). A brother (243/715) tends to be told third. Respondents seemed more reluctant to disclose to the father (147/714). If there is a daughter (117/713) or a son (107/714) they will be told last. Though a comparison based on gender would be useful in understanding differences in how the sexes deal with disclosure, is not possible because respondents were only asked whom they disclosed their HIV status to - not whether it was possible for them to disclose to a specific person, e.g. it cannot be assumed that a respondent's mother was still alive at the time of the interviews.

Positive Living involves making changes in the lives of HIV positive persons which improve their quality of life. This can range from quitting smoking, exercising, to speaking to a

psychologist, joining a support group, and/or doing public speaking on HIV and AIDS. As part of a Positive Living strategy, around 58% (417/719) of respondents joined a HIV and AIDS support group. Roughly 43% (308/713) talked to a family member regarding their status. Some 39% (281/714) attended a workshop on HIV and AIDS. Close to 37% (267/715) started participating in church activities. Another 37% (261/714) changed their diet, while the same percentage (263/713) quit drinking. About 34% (242/714) started speaking to a friend. Lastly, some 25% (180/714) quit smoking.

## **9.5 Conclusions**

Respondents were divided in opinion on whether community leaders and elders are contributing to creating a safe socio-political environment for PLWHA in Namibia. A large percentage of respondents did not think they are making a positive contribution. HIV and AIDS support group members are more open about their HIV status than non-members. A quarter of the sample did not think it safe to reveal their HIV status within their community. HIV and AIDS support group members demonstrated a very high level of confidence in being able to inspire others to reveal their status. This shows that, to some degree, they have come to terms with being HIV positive. Family support of PLWHA was not as high as one would have expected. The most frequent form of discrimination faced by PLWHA is verbal abuse, followed by visits by community members intended to put them to shame. Though respondents on the surface had high self-esteem, they were worried about not being able to establish long-term love relationships. Many had also given up on their dreams.

## **9.6 Recommendations**

- Case studies mapping the psychological profiles of PLWHA could lead the way in finding more effective methods of encouraging Positive Living among more PLWHA.
- A campaign containing a strong message of hope for those who are HIV positive needs to be fielded. This campaign could focus on PLWHA who have lived a long time since being diagnosed with HIV.

## 10.LGBT PLWHA

Due to the small sample size returned for LGBT respondents, it was decided not to use it for comparative purposes in the earlier chapters of the report. This said, given the small number of studies which have been done to date in Namibia among LGBT PLWHA, it was decided to dedicate a chapter to the data irrespective of not meeting strict criteria of probability sampling. LGBT persons who participated in the study were recruited by trp via representatives in Windhoek, Oshakati, Walvis Bay, and Keetmanshoop. The data presented here is destined for in-house use by trp, and should not be used to draw conclusions below the level of the sample aggregate.

### 10.1 LGBT Sample

The size of the LGBT sample returned by the HTLS 2008 was 45. Of these, 38% considered their sexual identity to be lesbian. Roughly 31% was gay, 27% bi-sexual, and 4% transgender.

**Table 38: Sexual identity of LGBT sample**

	<b>HTLS 2008 Number</b>	<b>HTLS 2008 %</b>
<b>Lesbian</b>	17/45	38%
<b>Gay</b>	14/45	31%
<b>Bi-sexual</b>	12/45	27%
<b>Transgender</b>	2/45	4%

### 10.2 Relationships

Namibia does not recognize same sex partnerships as legal as can be seen by High Court judgment in the case of Frank vs. Minister of Home Affairs<sup>26</sup>, and the current domestic violence law. Such a legal and policy environment creates structural vulnerabilities for LGBT persons to access the criminal justice system and public health services. It also makes it difficult form close and stable relationships that are recognized by law and the community. Three lesbian and two

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<sup>26</sup> Legal Assistance Centre (?) " LAC Constitutional and Human Rights Unit Key Cases in 1999/2000".  
Legal Assistance Centre: Windhoek.

bi-sexual respondents said that they were married to persons of the opposite sex. Some 57% of gay respondents (8/14) had a steady male partner, while 42% (6/14) was single. Some 41% (7/17) of lesbian respondents had a steady female partner. Data on bi-sexual relationships was mixed and ranged from married, divorced, widowed, being single, and having a steady male partner. One transgender respondent was single and the other had a steady female partner. The trend among LGBT respondents was toward knowing the HIV status of a regular sex partner, though 44% (4/9) of gay respondents did not know the status of their regular partner.<sup>27</sup>

### **10.3 Employment and Dependents**

Half of bi-sexual respondents (6/12) were unemployed, with roughly a third of lesbian and gay respondents having been in the same position. Both transgender respondents were also unemployed. Some 35% (6/17) of lesbian respondents said that a child was dependent on their income, as did 42% (5/12) of bi-sexual respondents. Roughly 36% (5/14) of gay respondents said that their mother was dependent on the income they generated.

### **10.4 Testing and Feedback on Testing**

Some 47% (8/17) of lesbian respondents tested at a public hospital, 24% (4/17) at New Start, and another 24% (4/17) at a private hospital. Roughly 43% (6/14) of gay respondents tested at New Start and 36% (5/14) at a public hospital. Close to 83% (10/12) of bi-sexual respondents tested at a public hospital. One transgender respondent tested at a New Start Centre and the other at a public hospital. Feedback on the CD4 tests tended to be quick. Some 41% (7/17) of lesbian respondents received their CD4 count within a month, and 24% (4/17) received such results within a week. Roughly 79% (11/14) of gay respondents received their CD4 count within a week. Both transgender respondents received their counts within a week. Some 42% (5/12) of bi-sexual respondents received their results within a week, and 33% (4/12) within a month. Roughly 65% (11/17) of lesbian respondents had tested less than three months before the interviews. Some 78% (11/14) of gay respondents had done the same, as did both transgender respondents, and 75% (9/12) of bi-sexual respondents.

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<sup>27</sup> This is a tiny sub-sample, and may not provide an accurate reflection of gay sexual behaviour. This data is mentioned because it contradicts the general pattern.

## **10.5 Treatment and Response to ART**

Roughly 77% (13/17) of lesbian respondents were on ART. Two had not sought treatment after testing positive, while two had a high enough CD4 count to not require treatment. Some 57% (8/14) of gay respondents also had a high enough count and did not require treatment. Four did not seek treatment, and one started but stopped. Only one was on treatment. Both transgender respondents were on treatment, as were 92% (11/12) of bi-sexual respondents. The majority of LGBT respondents showed an improvement in their CD4 counts since starting on ART. Only two lesbian and two bi-sexual respondents had current CD4 counts below 200. The remainder of the respondents on ART had counts above 200, except for three gay respondents who did not know their current CD4 counts.

## **10.6 Side-effects of ART, Adherence, and Opportunistic Infections**

The majority (31/45) of LGBT persons had experienced at least one side-effect of ART. Headaches (7/45), as well as itching (6/45) were the most commonly reported side-effects. There was no incidence of liver toxicity. Respondents were most likely to see a doctor (10/45) or a nurse (5/45) to cope with side-effects. LGBT persons on ART are not forgetting to take the medication on time. The colour of the pills also is not confusing. None of the respondents have stopped taking ART because they felt better. Affordability of ART is also not an issue. The disease that was most prevalent within the LGBT sample was TB. Six lesbian, one gay, one transgender, and three bi-sexual respondents had contracted TB. LGBT persons are conscious of STIs. Only one lesbian respondent reported having been treated for an STI.

## **10.7 Accessing Information on ART**

None of the LGBT respondents reported using the internet to access information on ART. DVDs were accessed but not videos. Some 53% (9/17) of lesbian respondents listened to a talk show on the radio, as did 75% (9/12) of bi-sexual respondents. Some 47% (8/17) of lesbian respondents read pamphlets on ART. They also read booklets. GBT respondents did not show much interest. Roughly 41% (7/17) of lesbian respondents obtained information on ART from a HIV and AIDS support group, as did 67% (8/12) of bi-sexual respondents. The remainder did not obtain such information.

## **10.8 Discrimination by HCW's**

Discrimination against LGBT patients by HCWs is exceptional. Only one LGBT respondent had had a negative encounter with a doctor, and two said that they had been treated badly by a nurse. Complaints centered on negative verbal exchanges. The situations were dealt with by either telling another doctor or nurse.

## **10.9 Support Group Membership**

Roughly 75% (9/12) of bi-sexual respondents were HIV and AIDS support group members, as were 59% (10/17) of lesbian respondents. Both transgender respondents also attended support group meetings. Only three gay respondents had joined a support group. Some 88% (8/9) of bi-sexual respondents attended AIDS and Me training, as did 70% (7/10) of lesbian respondents. All round, training on Body Mapping was very weak. Some 90% (9/10) of lesbian respondents received training in Positive Living, as did 88% (8/9) of bi-sexual respondents. No gay or transgender respondents participated. Only four lesbian respondents received training on human rights, as did one transgender respondent. Access to video facilitation was very weak. Only two LGBT respondents have ever listened to Wings of Life. Some 66% (6/9) of bi-sexual respondents received training on nutrition, as well as 60% (6/10) of lesbian respondents. No gay respondents received such training. Lastly, 60% (6/10) of lesbian respondents were trained on income generation, as were 44% (4/9) of bi-sexual respondents. Again no gay respondents received such training.

## **10.10 Disability Grants and Medical Aid**

Only two LGBT persons were receiving a disability grant. Both were told about it by a doctor. Based on the requirement of a CD4 count below 200, most would not qualify as the idea is to provide disability to persons unable to work due to AIDS. None have ever lost a grant. Only 15% (7/45) of LGBT respondents had access to medical aid.

## **10.11 Use of Barrier Protection**

Some 83% (10/12) of bi-sexual, 76% (13/17) of lesbian, and 71% (10/14) of gay respondents have been sexually active since testing HIV positive. Both transgender respondents have also

been sexually active. Of the nine female bi-sexual respondents, seven have been sexually active. Some 75% (9/12) of bi-sexual respondents used male condoms during sex, as did 57% (8/14) of gay, and 53% (9/17) of lesbian respondents. Both transgender respondents used male condoms. Only three lesbian and three female bi-sexual respondents used female condoms. Around 18% (3/17) of lesbian respondents used no protection. The use of dental dams and medical gloves by any LGBT respondents was an exception to the rule. The most preferred brand of male condom among LGBT respondents was Smile (18/45), followed by CoolRyder (8/45). Respondents were most likely to visit shebeens (14/45) to obtain condoms. Some 77% (35/45) said that their best source of information on condom use was a talk show on the radio.

Roughly 47% (8/17) of lesbian respondents preferred a male condom, as did 50% (7/14) of gay respondents. Both transgender respondents, and 67% (8/12) of bi-sexual respondents, had the same preference. LGBT respondents were asked if they could access condoms within a ten minutes walk from where they live. Around 53% (9/17) of lesbian respondents and 86% (12/14) of gay respondents cannot obtain condoms by walking ten minutes. Both transgender respondents and 81% (9/11) of bi-sexual respondents can access condoms in this time. Close to 60% (9/15) of lesbian respondents, 78% (11/14) of gay respondents, both transgender respondents, and 81% (9/11) of bi-sexual respondents agreed that sex with a condom is enjoyable. Some 76% (13/17) of lesbian respondents, around 93% (13/14) of gay respondents, both transgender respondents, and 72% (8/11) bisexual respondents disagreed that condoms are 100% safe in preventing HIV infection. Around 88% (40/45) of LGBT respondents correctly said that it is not safe to use Vaseline as a lubricant with male condoms. About 68% (31/45) incorrectly said that it is not safe to use K-Y Jelly as a lubricant. Some 40% (18/45) also incorrectly said that using any type of oil-based lubricant with female condoms makes them more likely to break.

## **10.12 Female Sexual Health**

One lesbian and three bi-sexual respondents had become pregnant. The lesbian mother had participated in PMTCT as well as breastfed. Two of the bi-sexual mothers also participated in PMTCT. The contraceptive most prescribed to women who have sex with women (WSW) was the male condom. Work is needed in increasing awareness of the importance of a Pap smear.

Around 42% (6/13) of lesbian respondents and 14% (1/7) of bi-sexual females have never heard of this test. Two lesbian respondents and two bisexual females have heard of a Pap smear, but never gone for this test.

### **10.13 LGBT Respondents, Community, Family and HIV**

Lesbian and bi-sexual respondents tended to agree that community leaders are supportive of PLWHA, while gay respondents tended to disagree. Around 53% (8/15) of lesbian respondents and 81% (9/11) of bi-sexual respondents felt that community leaders were supportive. Some 66% (10/15) of gay respondents did not feel these leaders were supportive. One transgender respondent agreed, and the other disagreed. Opinion was divided on the question whether elders in the respondents' community encourage people to reveal their HIV status. Some 72% (8/11) of bi-sexual respondents agreed. One transgender respondent agreed, while one disagreed. Roughly 56% (9/16) of lesbian respondents and 80% (12/15) of gay respondents believed that their community encouraged people to reveal their HIV status.

The majority of bisexual, lesbian, and transgender respondents felt safe to reveal their HIV status within their community. Gay respondents disagreed. Some 81% (10/11) of bi-sexual respondents agreed, as did 53% (8/15) of lesbian respondents. Roughly 60% (9/15) of gay respondents did not agree. Gay respondents feel more comfortable to reveal their HIV status to family members. Around 73% (11/15) of gay respondents agreed that it was safe to reveal their status to family members. This was the same for 72% (8/11) of bi-sexual, as well as 57% (8/14) of lesbian respondents. One transgender respondent agreed and one disagreed. Gay respondents felt the least empowered to inspire others to reveal their HIV status. Some 90% (10/11) of bi-sexual and 53% (8/15) of lesbian respondents agreed that they could inspire others. Roughly 66% (10/15) of gay respondents felt they could not do so.

### **10.14 Discrimination against LGBT Respondents**

Around 33% (5/15) of gay respondents are sometimes forced to drink from a separate cup, or eat from a different plate. Some 33% (5/15) of them have also been avoided by family members a few times. Roughly 30% (3/10) of bi-sexual respondents have been avoided by friends a few times, as were 27% (4/15) of gay respondents. About 29% (4/14) of lesbians have been excluded

from family as well as community events a few times. Some 53% (8/15) of gay respondents have been called bad names a few times, as were 46% (5/11) bi-sexual respondents, and 27% (4/15) of lesbian respondents. This has also happened a few times to one transgender respondent, while the other has to endure this kind of abuse all the time. Roughly 13% (2/15) of gay respondents have been physically attacked. Around 50% (5/10) of bi-sexual respondents have received visits from community members interested in putting them to shame, as did 20% (3/15) of lesbian respondents, and 20% (3/15) of gay respondents. Transgender respondents also reported visits from time-to-time. Bi-sexual respondents encounter the most difficulty with employment among LGBT respondents. About 18% (2/11) of bi-sexual respondents have lost a job once their HIV status became known, as did one transgender respondent. Some 46% (5/11) have been denied at least one job because of their HIV status, while 18% (2/11) cannot find employment. Close to 13% (2/15) of lesbian respondents too have been denied at least one job, with another 13% (2/15) struggling to find employment.

### **10.15 Conclusions**

LGBT respondents tended to know the HIV status of their regular sex partner, though gay respondents had the lowest awareness. A large number of LGBT respondents did not seek treatment after testing HIV positive. Gay respondents are the most likely not to know their CD4 count. TB was the most prevalent disease within the LGBT sample. LGBT persons are conscious of STIs. Lesbian respondents access information on HIV and AIDS the most, while gay and transgender respondents do so the least. Discrimination against LGBT respondents is perpetuated by a small number of individuals. Gay respondents are the most likely to suffer such discrimination. They are also the least likely to join an HIV and AIDS support group. Access to medical aid within the LGBT sample was very limited. The most used contraceptive among LGBT respondents is the male condom. Knowledge of the use of KY-Jelly was poor. Few WSW are aware of the importance of a Pap smear. Gay respondents felt the most victimized by the actions of community leaders and elders. Their safest environment is among family members. Gay and bi-sexual respondents suffered the widest range of discrimination.

## 10.16 Recommendations

- Gay respondents appear to suffer the greatest amount of discrimination compared to other members of the LGBT community. This may be a factor in many of them not knowing their CD4 count, or not joining HIV and AIDS support groups, or accessing information on HIV and AIDS. It may be necessary to create support groups specifically for them.
- TB remains a major threat to the wellbeing of LGBT PLWHA. Raising awareness of the danger posed by this disease, as well as that of seeking treatment, should be made a priority.
- Information on the use of KY-Jelly needs to be provided.
- WSW should be made aware of the importance of going for a regular Pap smear.

## 11. Appendix 1: Addendum to FDG Hand Analysis

		<b>Omalala (N=11)</b>	<b>Ongwediva (N=11)</b>	<b>Outapi (N=14)</b>	<b>Endola (N=14)</b>	<b>Keetmanshoop (N=20)</b>
1	With whom do you live (i.e. adults – relation to child)?	2 = 2 parents  5 = 1 parent (sometimes also grandparent)  1 = no adult mentioned	1 = 2 parents  4 = 1 parent 3 = grandparent  2 = with (elder) brother or sister  1 = with uncle	4 = 2 parents  5 = 1 parent 3 = Grandparent/s(1)  2 = Aunt	4 = Parents  1 = 1 parent 2 = 1 parent & grandparents  2 = Siblings 3 = grandparents  1 = Aunt*Mother late	5 = 2 parents  6 = 1 parent 5 = grandparents  4 = aunt
2a	How long ago was the last time you went to a hospital or a clinic to see a doctor or a nurse?	6 = went sometime within the past six months  1 = said she has never gone to the clinic	10 = went within the last six months;  1 = went most recently about a year ago.	8 = went within the last six months;  6 = went most recently about a year ago.	10 = went within the last six months;  3 = Over six months ago.	18 = went irregularly
2b	When was the time before that? ( <i>to see if any child goes monthly – a possible indication of ARV treatment</i> )	Only one child reported “last month & 2 weeks before that.” For the rest, the interval was very long	2 children reported that their last two visits were both recent, about a month apart from each other. Others	4 children reported that they had been to the hospital/clinic recently.  8 had last been a year ago and 2 did not mention.	4 children reported that they had been to the hospital/clinic recently;  6 had last been more than a year ago and 3 did not mention.	2 = went recently + one month ago  (one child who did not arrive in time for this exercise is also known to be on ARVs).
3	Your age and what grade you are in school. ( <i>to see if children are still in school</i> )	Ages 11 up. All are in school, but some are way behind, e.g. age 16 in grade 6 & age 16 in grade 5.	Ages 12 and up. All are in school and only one is at a grade far below his age	Ages 13 and above up to 18 years. All are in school. 5 are in a grade below their age. I did not mention his/her age.	Ages 12 and above up to 16. All are in school, none are in the grades that they should be in, and this varies from 2- 5 years below the correct grade. E.g. One is 16 years and in Grade 8.	Age 11 – 16. All are in school, and at most a year or two behind 1 grades
4a	How many meals did you eat yesterday?	4 = 3 meals  6 = 2 meals  1 = 1 meal (porridge & fish only)	1 = 4 meals  9 = 3 meals  1 = 2 meals	1 = 5 meals  8 = 3 meals  3 = 2 meals  2 = 1 meal	1 = 4 meals  5 = 3 meals  5 = 2 meals  1 = 1 meal	1 = 4 meals  19 = 3 meals
4b	What foods did you eat in the biggest meal you had	7 = well rounded meal  2 = porridge &	8 = well rounded meal  3 = rice and	2 = 1 meal per day  3 = 2 meals	All reported that the big meals eaten consisted of porridge with relish like fish,	All reported more than starch; that one example reported only bread.

	yesterday?	local fish 1 = porridge & bread 1 = porridge & coffee	macaroni (nothing else reported)  Note: much more rice & macaroni reported generally; less mahangu than at Omalala	8=3 meals  1 did not mention how often he/she gets meals but that there is main meal with porridge. All reported that a main meal consists of Mahangu porridge and vegetable relish / 3=cat fish.	meat, milk, eggs, and beans ch. 5 = these various relishes; Only 1 reported eating with Traditional spinach and 7 = meat (6 Beef and 1 chicken).	
5	What do you like to do for fun?	Play soccer, play with friends, dance, tell jokes	Play soccer, spend time with friends/ sports, running, watch television, stamp feet	2= playing soccer  1= swimming & netball  1= helping parents  2= story telling  7= playing  1=dancing and singing	3= soccer  3 = netball  3= Running  2= Reading/ Studying  1= Dancing  1= story telling	All children spoke in terms of playing soccer, netball, listening to music, doing homework+
6	If you could have one wish come true for yourself – anything at all you could think of – what it would be?	All wished to be a doctor, nurse, or teacher when grown up.*	4 children wished to become a doctor (2), mechanical engineer (1) or scientist (1). 2 others said they want to “become someone” in their lives. 3 spoke of material things they wanted: clothes, soccer clothes**, and a bicycle.	2 children wished there would be help spiritual and treatment for PLWHA. I wished there would be treatment for his/her parents.  2 children wished to become doctors and 2, nurses. 1 wished for someone to pay school fees and 2 said they would like to pass school. 1 wanted to be a pilot and another become president.	2 expressed career wishes i.e. to be a doctor & police officer.  4 made wishes about dealing with HIV and AIDS, specifically to find a cure and one of these made a wish about orphans being cared for.  3 made a wish about continuing education – 1 of these mentioned with assistance from government. 3 wished for good advice and for children to respect parents. Only one made a wish for a table.	2 children said they want to be nurse; 2 a teacher; and 2 a doctor; 1 a musician and 1 a singer. 4 wrote they wanted to do well in school; one said he wants to be a bank manager; and 2 want to own a big house. One spoke about alcohol abuse, and another about ending discrimination, and 1 about being famous.+