STREET LAW
With the
NATIONAL
DEMOCRATIC INSTITUTE
FOR INTERNATIONAL AFFAIRS (NDI)

HIV-AIDS AND COMMUNICATION STRATEGIES: "ENTERING THE WORLD OF PUBLIC SILENCE AND DENIAL"

Focus Group Research Project

Research Report
April 2000
Final Draft

By
SUSAN BOOYSEN

With
BHEKI GUMEDE, Street Law
ZAKHE ZONDO, National Democratic Institute

69 Gomery Place
Summerstrand
6001 Port Elizabeth
083-2901636

CONTENTS

EXECUTIVE SUMMARY

The world of silence, fear and denial (Section 1)

- The world of HIV-AIDS in South Africa is still a shadow world. It is a world, these focus groups show, that is a dark reality for "persons living with HIV-AIDS". It simultaneously is a world which inspires fear in the minds of the sexually active population. One of the current ways of dealing with the fear, is denial. Denial is enhanced by the world of public silence. A socially threatening culture obstructs disclosure and inhibits the communities from openly engaging with preventative education and care for the victims and their families.

- Participants in these focus groups have no illusions about the meaning and the impact of HIV-AIDS. This inter-linked viral infection is definitively associated with "death", the "death sentence" and "incurable". Yet, there is a definitive defiance in sexual behaviour. It manifests itself, for instance, in belief in "invincibility", or in the "need" that young people feel to experiment. Reckless sexual behaviour also finds shelter in the commonly held knowledge that "even the innocent" can get AIDS.

- Yet, almost everybody feels vulnerable. The youth and women often felt the most vulnerable, or were seen by others as highly vulnerable. Upon the slightest reflection participants drew the conclusion that "everybody is vulnerable". They include the innocent and the "relationship faithful" in their lists of the vulnerable ones. Nobody can be guaranteed to escape it, they conclude. Participants did not have the answers, but often raised the question of why it happens that black South Africans – Africans – seem to be more frequently affected than the rest.

- It is in this common vulnerability context that the research reveals a high level of acceptance of, and sympathy for, victims of HIV-AIDS. Community sanction, however, still intervenes. There is reluctance at this stage to be seen to be speaking out in favour of victims. The community, it is felt, will still equate the sympathisers with the carriers, and the latter are still stigmatised and isolated from the community.

- This world of fear and public silence is delicately balanced against the "quietly real" world of acknowledging that "I could be next", some talk of HIV-AIDS to friends and peers, and the near-pervasive (albeit often low-key and indirect) acknowledgement that "people living with people living with AIDS" has become a most common social category, often describing the social world of the focus group participants.

- A crucial part of the communication environment therefore is the way in which the silent world of denial and fear is contrasted with a hushed world in which people discuss HIV-AIDS with friends and peers, where they

know or suspect that people are dying of AIDS, in which care-taking of victims and “living with people living with AIDS” has become a major daily reality.

Sexual behaviour, personal power relations and HIV-AIDS (Section 2)

- The communication environment as reflected from these focus groups is further characterised by the stark contrast in sexual behaviour between “what we know” and “what we do”. On the individual level both women and men related their stories of sexual risk-behaviour. Whereas many participants talked about the necessity to use condoms, there were far fewer who gave the impression that they are adamant about practicing safe sex. There are worlds of difference between knowing the dangers of infection (and some do not know it beyond the broadest of brush-strokes) and doing safe sex.

- Various explanations were offered for discrepancies between “know” and “do” (also see section 1). These include bravado and a sense of invincibility, denial beliefs, blind belief that partners do not carry the virus, heat of the moment irrationality, stigmatisation of women for being too smart, and lack of capacity of many married or relationship women to impose faithfulness or condom sex on partners.

- Amongst younger urban and more professional women in these groups there was evidence of more assertive approaches. They often raise their right to insist and to dictate conditions for sexual intercourse to existing or prospective partners. Yet, almost inevitably, they also refer to the problems of the stigmatisation of women trying to protect themselves, and of the near-impossibility to start introducing condoms into existing relationships.

- The communication environment is further complicated typically, the younger men in these groups assert the "stupidity" of not doing safe sex, but they often place the onus for safe sex on their female sexual partners. Older men in this project appeared more likely to deny (at least verbally) the existence of AIDS; younger men tended to be the invincible players of the Russian roulette of HIV-infection.

- Poverty was a crucial dimension in potential receptivity to HIV-AIDS communication. Migrant labour plays a role – both through men engaging in additional sexual relations away from home, and in the low women to men ratio in the rural areas for most of the year. Dimensions of culture, such as patriarchy and polygamy in more traditionally oriented communities, impact on women's capacity to negotiate safe sex. For young and more desperately poor women sex presents a route for escape from poverty – a route that leaves little scope for negotiating safe sex.

- Generational change and sexual relations at young ages pose further challenges to behavioural change. Young people in these groups embrace the notion of growing up in a relatively normal society. There is a common exuberance of being able to get into "grooving" and "a good life". Sexual freedom is part of this process, and it was only in some cases that this early and new freedom was balanced with sexual circumspection.

Existing knowledge, sources of information and information needs on HIV-AIDS (Section 3)

- Existing knowledge on the HIV-AIDS phenomenon is characterised by a complex blend of, for instance: what we know as facts (for example that unprotected sex, especially heterosexual, can lead to HIV infection; or that infection rates are epidemic in scale); stereotypes (which often are used to stigmatise either women, or those who propose safe sex); myths ("sleeping with" virgins, or young children, will cure AIDS).

- Politically correct public (focus group) discourse often contrasts with reports of enjoyment of the "good life" and sexual experimentation, making it challenging to pinpoint commitment to safe sexual practices.

- Despite overt acknowledgement that AIDS is incurable there is a common preoccupation with either a cure or a vaccine against HIV-AIDS being found. Participants in these groups frequently request information on

progress. They also express the need for more details of all of the “do’s” and “don’ts” of sexual intercourse -- and very precise information on what constitutes risk behaviour. They are actively looking for the survival skills in a highly affected world, a world in which existing or prospective sexual partners may be known PLAs.

- The participants in these groups tended either to have “title knowledge” only of previous anti-HIV / AIDS campaigns (know the names or symbols of campaigns but cannot link these to specific messages or content in general) or had a fair amount of accumulated knowledge, but very little recollection of where (or in which campaign) the information was obtained.

- Friends, peers, low level medical practitioners and the media, or materials, were the major sources of AIDS-HIV information. The discussions gave clear directions on who these people would like to see engage in public discourses on HIV-AIDS.

- Various individuals, organisations and institutions exert authority and possess credibility in HIV-AIDS communication. Credible political leaders, celebrities, entertainers, sport stars and religious leaders should prepare the field and legitimise acceptance and prevention. In continuous, second waves of communication these participants wish to see medical staff and AIDS educators pass on the desired detailed information. In the third place, youth leaders, and political and community leaders need to take forward continuous community level project for consciousness, tolerance and caring for victims and their care-takers (also see section 5).

Government in HIV-AIDS support and communication (Section 4)

- The dominant public-mind image of what Government currently is doing on the HIV-AIDS front pertains mostly to the AZT issue. There was consistent support for Government making available all possible drug treatments to HIV-AIDS victims, even if expensive and with minor prospects of success. Only three of the groups felt that social spending on water or housing, for instance, should take precedence over the treatment of HIV-AIDS.

- Group participants commonly insisted that government should be seen to be taking action on every possible front. Government should also be seen to be helping people understand the nature and range of its efforts to make a difference to the world of HIV-AIDS. If necessary, and participants frequently pointed out that it was essential, public funds should be directed away from wasteful public spending.

- Despite some evidence of low government credibility, the flow of the focus group discussions showed that participants were impressed when given precise information on government initiatives and statements. Participants expressed the need for Government to enter into joint actions with the people of South Africa living with HIV-AIDS and living with people living

with the disease. There was deep-seated trust and expectations of government to take the lead, in line with the trust that ordinary South Africans invest in government. In effect, these participants were asking for a specific HIV-AIDS contract between government and the people.

- The major fields of responsibility of Government, in the minds of these group participants, can be construed in the form of a hierarchy. Government should make drugs and all possible medical treatments available to victims. It should facilitate and fund research into finding a cure and a vaccine. It should take the lead in social and welfare caring of victims, and provide information on all aspects of the disease and government actions around it. Government should also help change behaviour (through information, direct communication and "leading by example").

Components, formats and approaches for future communication (Section 5)

The voices of these focus group participants suggest that a series of Government actions might help address the need for action in order to curtail the spread of HIV-AIDS, and assist ordinary people in living with the realities of HIV-AIDS infection in the community.

Broad communication activities:

- Government making a definitive statement on its commitment to action, on its sincerity of dealing with HIV-AIDS, together with the people of South Africa.
- Government legitimisation of public debates, with community involvement in taking forward the issues;
- Government helping to build a heightened culture of tolerance of HIV-AIDS victims in order to facilitate disclosure and public debate. A tolerant culture in turn could lead to more people living with AIDS being prepared to go public and "educate" vulnerable groupings;

Phased events in Government communication:

- Upfront Government announcement of its plan and contract with the people;
- Legitimisation through, for instance, high-profile public forums and summits in which all significant groupings of leaders would be engaged (including religious leaders, traditional leaders, sangomas, party political leaders). This could take the form of rolling summit actions;
- High-profile sport and entertainment events at which celebrities could present their commitment to fighting HIV-AIDS together with their supporters and admirers;

- "Information sweeps" through the countryside and cities, for instance conducted by youth task forces. Such task forces could, simultaneously mobilise the youth into action;
- Youth leaders and public figures could co-ordinate community forums, and, in particular, youth forums and could facilitate "speak-out events". Local level political and community leaders would play crucial roles;

Messages and themes:

The findings furthermore indicate that a range of positive (asserting the chance to decide for life over death), positive-negative mixes (mostly empowerment and the right to chose safe sex) and highly negative (death) messages could combine to provide the message content of a future communication plan.

The following are essential components of the HIV-AIDS messages:

- Government entering into a "contract" with the people:

  The core start-up message might be that Government, together with the people, are to tackle the HIV-AIDS problem in an open and caring but "brutally honest" way. A message could be that of a caring government living out the trust of the people in addressing this issue. The Government's orientation might be that of "We are a caring government … We need your help, on our own, we cannot do it". People want to see evidence that Government is "living the problem" with them, that Government does more than talking. A contract between government and the people, government can and will do that much, and all that it can, but cannot succeed on its own

- Breaking the public silence:

  These messages would have the objective of leading people to make the move from talking on the individual level, and living with HIV-AIDS (or living with people who live with HIV-AIDS) to the level of openly addressing the issue in public and on community level. Privately-felt sympathy would be extended into the public domain. Messages would also encourage the "breaking of the public silence". People would be encourages to "be real" and to acknowledge that "we are already living with HIV-AIDS, we care for the victims or their dependents, we talk about it to our friends and peers, it is a major fear in daily lives of many of us, let's talk about what we can do together with the community and government."

- Sexual behaviour and prevention/cures:

  Such messages would bring home the vulnerability of all of the sexually active (both the reckless and the innocent), it would block denial, and

lead people to face up to the implications of reckless sexual behaviour. It would reinforce the knowledge of the evasiveness of a vaccine and low probability of a cure.

- Gender and sexual power relations:

  Empowerment of women and vulnerable people in general (with segmentation of messages in terms of the gender-age-socio-economic dimension) has to be addressed in campaign messages. There is a need to focus on gender empowerment in relation to “the right to protect your life” -- women have “the right to say no”.

INTRODUCTION AND RESEARCH METHODOLOGY

This research report is based on 32 focus group discussions. The first 16 of these groups were conducted in December 1999 in the four provinces of KwaZulu-Natal, Gauteng, the Western Cape and the Eastern Cape. A further twelve focus groups were conducted in January and early February 2000, this time in Mpumalanga, the Northern Province and the Free State. In this period there were two further groups in Gauteng, one in the Eastern Cape and one in KwaZulu-Natal.

The project was undertaken at the request of the Government Communication and Information System (GCIS), after a funding offer from USAID and facilitation by the National Democratic Institute for International Affairs (NDI). The fieldwork was conducted by the university-based NGO, Street Law, in co-operation with NDI. NDI engaged the partnership of Street Law for the dual purpose of organisational capacity-building and conducting grassroots research in South Africa. With its national grassroots presence and diverse staff, Street Law is able to conduct research in South Africa's eleven languages, in metropolitan, urban and deep rural areas. The two organisations have been co-operating in this way since 1997.

Susan Booysen, an independent political research consultant, professor of Political Science and primary author of this report, was contracted by Street Law and NDI to design the discussion guide, train and brief fieldworkers, monitor large sections of the fieldwork, observe some of the groups, analyse data and to draft the research report. She also conducted capacity-building workshops in qualitative data analysis with Street Law and NDI research co-ordinators.

Street Law facilitated the logistics regarding the implementation of this research project. Street Law also undertook the transcriptions and translations of the focus group discussions. For the implementation of the fieldwork, the Street Law moderators were chosen on the basis of compatibility with participants in terms of language, culture and gender. They received special training to bridge the age gap between themselves and some of the group participants.

Composition and location of the focus groups

In the first three weeks of December 1999 and throughout January 2000, up to early February 2000, a total of 32 focus groups were conducted in seven of South Africa's provinces. These focus groups represented a spread across metropolitan, urban and rural landscapes, gender, age, socio-economic status, employment status and HIV-status. The planning of the focus groups also took care to provide a distribution across racial categories. These groups were conducted in various parts of KwaZulu-Natal, Gauteng, the Western Cape, Eastern Cape, Mpumalanga, the Northern Province and the Free State.

Table 1:
Composition and location of the 32 focus groups

Date	Location	Demographic profile of group	Group Number*
		KWAZULU-NATAL	
7/12/99	Durban	Women, living with HIV, mixed age, African, Zulu/English-speaking	1
8/12/99	Ulundi	Men, 18-24, black, town, African, Zulu-speaking	2
8/12/99	Babanango	Women, rural, 37 and older, African, Zulu-speaking	3
8/12/99	Babanango	Men, African, rural, 26-36, Zulu-speaking	4
9/12/99	Chatsworth	Indian, women, 18-25, English-speaking	5
14/01/00	Durban metro	Indian, men, 26-36, working class, English-speaking	**17**
		WESTERN CAPE	
12/12/99	Guguletu	Men, metropolitan, African, 18-25, Xhosa-speaking	6
12/12/99	Guguletu	Men, metropolitan, African, 18-25, Xhosa-speaking (control group)	7
13/12/99	Ceres	Men, rural/farms, coloured, 26-36, Afrikaans/English-speaking	8
13/12/99	Worcester	Women, town, 26-36, African, Xhosa-speaking	9
		GAUTENG	
21/12/99	Rockville, Soweto	Women, metropolitan, African, 18-25, Sotho/Mixed African languages	10
22/12/99	Soshanguve	Men, metropolitan, African, 18-25, Sotho/mixed African languages	11
22/12/99	The Reeds, Pretoria	Women, metropolitan, 26-36, professional, African, multi- language	12
23/12/99	Reiger Park	Women, coloured, metropolitan, Afrikaans/English-speaking, 18-25	13
19/01/00	Baragwanath	Men, PLA, mixed ages, African, Zulu-speaking	**18**
07/02/00	Pretoria	Men, young, white, Afrikaans/English-speaking, students/employed	**19**
		EASTERN CAPE	
15/12/99	Stutterheim	Men, African, town, 26-36, unemployed, Xhosa-speaking	14
15/12/99	Bolo	Women, African, rural, 18-25, un/employed, Xhosa-speaking	15
16/12/99	Mgwali	Men, African, rural, 18-25, unemployed/school, Xhosa-speaking	16
04/02/00	Port Elizabeth	Women, 25-35, coloured, Afrikaans-speaking, unemployed	**20**
		MPUMALANGA	
27/01/00	White River	Men, African, 18-25, Swati-speaking, students/school-going	**21**
28/01/00	Barberton	Men, 26-36, African, Swati-speaking, employed/unemployed	**22**
28/01/00	Barberton	Women, 26-36, African, Swati-speaking, employed/unemployed	**23**
		NORTHERN PROVINCE	
27/01/00	Bushbuckride	Women, 18-26, African, Swati-speaking, students	**24**
26/01/00	Ha-Magoro	Women, 18-26, African, unemployed / students, Pedi-speaking	**25**
26/01/00	Mavambe	Men, 26-36, African, unemployed, Tsongo-speaking	**26**
25/01/00	Louis Trichardt	Men, 26-36, African, unemployed, Pedi/Northern Sotho-speaking	**27**
25/01/00	Soekmekaar	Women, 18-26, African, Pedi/Northern Sotho –speaking	**28**
		FREE STATE	
12/01/00	Mangaung	Men, 18-25, unemployed/school, African, Sotho-speaking	**29**
12/01/00	Masilo/Theunissen	Women, 18-25, unemployed/employed, African, Sotho-speaking	**30**
13/01/00	Tierfontein	Men, 26-36, farmworkers, African, Sotho-speaking	**31**
13/01/00	Bloutrip	Women, 26-36, farmworkers, African, Sotho-speaking	**32**

- The numbers in the right-hand column of Table 1 are the numbers in brackets after each of the quotations in the text. In reading the text, please refer to the current table; the numbers 1-16 refer to the focus groups conducted in December 1999, and the number 16-32 (in bold) to the groups conducted in January and February 2000.

SECTION 1:
THE UNSPOKEN HIV-AIDS WORLD OF SILENCE, FEAR AND DENIAL

"AIDS was spread by silence … We never heard about it before … You cannot tell who is spreading it" (22)

SECTION EXECUTIVE SUMMARY

- The world of HIV-AIDS in South Africa is still a shadow world. It is a world, these focus groups show, that is a dark reality for "persons living with HIV-AIDS". It simultaneously is a world which inspires fear in the minds of the sexually active population. One of the current ways of dealing with the fear, is denial. A manifestation of denial is continued unsafe, high-risk sexual behaviour. Denial is enhanced by the world of public silence. A socially threatening culture obstructs disclosure and inhibits communities from openly engaging with preventative education, sharing of knowledge and care for the victims and their families.

- This world of fear and public silence is delicately counter-posed with a world of acknowledging that "I could be next", living with someone living with HIV-AIDS, caring for victims and hushed discussions of HIV-AIDS with friends and peers.

- Participants in these focus groups have no illusions about the meaning and the impact of HIV-AIDS. This inter-linked viral infection is definitively associated with "death", the "death sentence" and "incurable".

- Everybody feels vulnerable. The youth and women often felt the most vulnerable, or were seen by others as highly vulnerable. Upon the slightest reflection, however, participants drew the conclusion that "everybody is vulnerable". They include the innocent and the "relationship faithful" in their lists of the vulnerable ones. Nobody can be guaranteed to escape it, they conclude. Participants did not have the answers, but often raised the question of why it is that black South Africans – Africans – seem to be more frequently affected than the rest.

- It is in this common vulnerability context that the research reveals a high level of acceptance of, and sympathy for, victims of HIV-AIDS. Community sanction, however, still intervenes. There is reluctance at this stage to be seen to be speaking out in favour of victims. The community, it is felt, will still equate the sympathisers with the carriers, and the latter are still stigmatised and isolated.

- The research therefore points to a phenomenon of a lopsided "two worlds at war" – the one of denial and unsafe or reckless behaviour, the other a world of quiet recognition of realities of danger. It is possible that the ascendance of this second world can be facilitated by a culture of open communication and "bringing home" of stark realities (see rest of the report).

The reality of HIV-AIDS appears to have penetrated the consciousness of South Africans of all walks of life. This consciousness also encircles the knowledge of the deadliness, the probable death sentence status, of infection. Yet, these realisations continue to stop short of definitively affecting change of behaviour into safe or safer sexual practices (to the extent that such change will translate into declining rates of infection). In many cases the discussions indicate virtually no "correlation" between knowledge of HIV and manners of infection, and sexual safer practices.

A culture of denial, individual-personal "bravery" or beliefs in invincibility, blind or socially enforced trust in partners, determination to live life "to the full", fear of disclosure and refusal to listen and act on knowledge contradict participants' knowledge of the HIV-AIDS epidemic, or even pandemic.

Whilst Section 2 explores the context of sexual relationships and sexual power politics, and cultural disempowerment, the current section maps the culture of knowledge about HIV-AIDS, the perceptions of vulnerability, and the issues of denial, disclosure, acceptance and sympathy regarding victims, and the phobia and persecutionism that continue to exist in society. The current section presents evidence of a series of contrasts and contradictions in the minds of ordinary South Africans across language, regional, age and racial boundaries, as these relate to knowledge and practices around HIV-AIDS.

Issues of health and living in the post-1994 South Africa

South Africans in these focus groups share a bitter-sweet sense of progress in their lives since 1994, albeit often with strong metropolitan-rural, provincial and some class-racial variations. Political rights, sympathetic and often-caring government, and improvements in basic social services help distinguish pre- and post-1994.

But post-1994 life is "brutal" in many other ways. In relating their stories and concerns about life in South Africa and their communities, participants shared their worries about unemployment, poverty and crime. Shortly on the heels of these "big three" followed the issues of health and living that present a picture of a continuously brutalised society, in which women suffer more than men.

"We thought our lives would be better when blacks took over,
but instead, we suffer more" (25)
"Change may be somewhere else, but definitely not here" (32)
"These days we no longer have jobs. Democracy does not help us" (25)
"We hear the news that there are changes in the townships, but
there is nothing here on the farms" (32)

In many cases, participants already volunteered the issue of HIV-AIDS when asked, in general, about their major issues of concern in contemporary South

Africa. Had they not already done that, they volunteered references to the epidemic upon being asked specifically about the issues of health and living that concern them. HIV-AIDS has become acknowledged as part of the social landscape of South Africa.

The focus groups were mostly split between conveying a picture of violence, decay and despondency, and, in comparison, experience of life as “fine, albeit with problems”. A few of the groups did convey an overall feeling of contentment and positive experience of contemporary South Africa. Many do volunteer information on improvements in, for instance, housing, electrification and roads. Poverty and unemployment, however, are the two phenomena that negate the positives.

The following are typical lists of reasons that groups put forward in explaining disappointment and disillusionment about community life in post-1994 South Africa:

- crime, rape, alcohol, drugs and poverty; crime, AIDS, unemployment;
- violence, jobs; drugs, alcohol, unemployment, women abuse;
- poverty, low prospects for education, no job prospects;
- AIDS, alcohol, drugs, refuse removal, rape, breakdown in law enforcement;
- crime, alcohol, unemployment.

Corruption, education and inadequate health care (despite acknowledged post-1994 improvements) occasionally were added. Hijackings and terrorism featured as well, the latter specifically in the Western Cape groups; and taxi violence in northern parts of the country. Poverty, poor education access and an absence of jobs were prevalent in rural groups.

In addition, poverty and unemployment permeated discussions on “life in the community”. There were frequent and explicit references to the connections between poverty and crime, and between poverty and sexual activity (the latter especially by men regarding women). In some of the discussions, for instance the one of young men in Soshanguve, the weak economy, unemployment and AIDS rivalled one other as the most serious issue affecting post-apartheid South Africa. Men of all ages, for instance in the Free State and the Northern Province, scorn what they observe as young women “using their bodies” to beat poverty.

Many woman participants, ranging from coloured women in the Eastern Cape to African women in Mpumalanga, lament the fact that young women are sexually active at a very young age, marry very young, or are already caring for babies at ages when they themselves still ought to have been on school benches. Older women protest cultural disintegration; younger women appear to have assimilated sexual freedom into their social repertoire. Only some of these young women in discussions refer to their right to insist on safe sex, or a preference for safe sex.

WOMEN FROM MAGORO:

"We as the youth engage in sexual relationships at a very young age" (24)
"The youth do not go to school. Instead, they walk around with their boyfriends. They do not even hide it when elder people appear. It is affecting the community" (24)

WOMEN FROM REIGERPARK:

"As women we always feel unsafe due to the high level of rape incidents" (13)
"Law enforcement is no longer the same" (13)

There was little difference between the youth groups and both the "26-36" year old and the "37 or older" groups. Amongst the youth there was a greater emphasis on the alcohol-drugs-sex dimension of their lives. Women, especially younger and urbanised women, related their fears for personal safety. Fear (in various intensities) of rape proved to be an ever-present part of women's community experience.

The burden and exuberance of youth

The phrases of "no direction", "doomed future" and "hopeless", "bleak future" frequently became associated with the experience of "youth". Many of the young participants conveyed a sense of dissipating hope, especially with regard to uncertainty about education and job prospects. Others talked about the fact that they bring high expectations and hope that they "will be the future" into their period of young adulthood. They enjoy the space of being young, to enjoy a life of normality where they can "just have fun and be young". Almost all have the hope of still finding opportunities, or making further advances. Yet, the metropolitan young conveyed more of a sense of exuberance and hope than their town and rural counterparts. Rural youth groups, more often than their metropolitan counterparts, often had the doubts of "having been forgotten ". Uncertainty about prospects for employment combined with insecurity about economic well-being to dampen their optimism.

Yet "grooving", the "nice time", a life of substance experimentation, and exploring sexuality and possible partners, infused most of the discussions amongst the younger participants. The issue of HIV-AIDS also continuously informed the youth discussions.

"The people who are dying are the young people, dying of diseases, shooting or stabbing" (4)
"We do not care about dying" (6)
"The problem is that young people are crazy about nice time… You can live longer if you can stick to a clean life" (18)
"The youth here are mostly concerned with drinking and going to taverns" (30)

"Teenage pregnancy", "rape" and "unemployment" are the three most commonly used negative concepts associated with "youth" in the younger women's groups. "Grooving", "having a good time" and equation of youth with "the future" presented the positive side of their associations. Young rural women often refer to desires to get more schooling – something which they experience as being prevented by poverty.

The meaning of HIV-AIDS

Most groups had consensus that the definition of HIV-AIDS as provided by the moderators was adequate. Other insisted that definitions should include references to how one gets infected with the AIDS virus, and specifically also that it is spread through sexual intercourse.

"HIV is a punishment for sleeping around" (21)
"AIDS is something that affects everybody who has blood in the body" (30)
"This definition does not mention anything about sexual intercourse. I think the main focus should be sex" (22)
"The main focus should be on the person's health" (22)

Some of the groups, notably also those of People Living with AIDS (PLA), wanted the distinction between HIV and AIDS statuses built into the definition. The Durban PLA group, for instance, felt that is was bordering on criminal to approximately equate the conditions of HIV and AIDS. The Baragwanath PLA group felt that community consciousness of the difference would lead to greater acceptance of HIV-positive persons.

THE DEFINITION USED IN THE DISCUSSIONS:

"AIDS is a disease that affects many people in South Africa and across the world. It is caused by a virus called HIV (Human Immunodeficiency Virus) that slowly weakens a person's ability to fight off other diseases until the person eventually dies".

A small number of other participants did distinguish between HIV and AIDS in the course of the discussions (even if these distinctions sometimes contained other misconceptions).

"They say when you have HIV there is still hope, but only if you are going to abstain from sex or use condoms" (3)
"The problem of talking about AIDS is that it is negative, as if

there is no hope" (12)

There is no doubt in the minds of the focus group participants about the nature of HIV-AIDS as a "killer disease". Some of the frequently used words and phrases that emerged in a "word association game" were:

> 'Killer disease", "no cure", "death", "affects all people", "you are certain to die", "the three letter illness", "the end of life", "worst nightmare", "punishment", "merciless", "slow poison", "destroying the body's soldiers", "diseases using the victim's body as playground", "end of the world", "soul taken", "isolation", "discrimination", "loneliness".

As an illustration, the following was the sequence of associations with the words HIV-AIDS that rolled out in the discussion by the group of young women from Bushbuckridge when they were asked what "HIV-AIDS" makes them think of: "death", "the end", "sex without condoms", "ignorance of people", "silence", "AIDS is alive".

"It is the most dangerous and merciless disease" (8)
"It does not forgive anyone like God does" (12)
"Once you are infected you are the playground of almost all diseases" (18)
"Once you get it, it is Amen" (32)

Denial of the existence of HIV-AIDS

Forgetfulness, personal bravado, belief in personal invincibility, "no space to remember in the heat of the moment", all represent the special forms of denial of HIV-AIDS that emerged in these focus group discussions. A more explicit form of denial regularly appears to surface when people with the message or the knowledge of infection (or simply authority figures) confront "erring" persons.

"Having unprotected sex is like crossing a busy road without checking the oncoming traffic" (18)
"I tell people that we should learn from one another. We can learn. Animals do not learn from others" (18)

It was only in a few cases that participants indicated that they really do not believe in the severity of the HIV-AIDS occurrence. For instance, young women, in Bolo in the Eastern Cape, associated HIV-AIDS with "blown out of proportion". A couple of young men, for instance, suggested either that HIV "does not really exist", or that "it is a white man's disease, used to try and scare us". Women from Bloutrip in the Free State do not deny the existence of

HIV, but reckon that it is much more important to spend time on priority issues such as jobs, water and electricity. These cases, however, are the exceptions.

Discussions regularly turned to the issue of death through AIDS, and whether the shock of seeing people in the community die would contribute to preventative sexual behaviour. There was evidence (especially amongst men) that such "shock treatment" sometimes soon fades again, and might not have a lasting impact on sexual behaviour. A consistent message, from a range of groups however, was that seeing people living with AIDS, and having them in the community as messengers, would be the only effective way to lead people to confront the realities of the results of reckless and unprotected sex.

Doubts about "shock treatment" was consistently overshadowed by people wanting the reality of HIV-AIDS to be brought home through direct observation of People Living with AIDS (see section below on "Messengers"). Several participants stressed that even more forceful than "messages through the observation of death" would be the experience to see and listen to the stories and messages of persons living with various stages of HIV-AIDS. Women from Rockville, Soweto, for instance confirmed that "we first see someone who denies, then we acknowledge that AIDS exists".

"Many people want to see someone they know die of AIDS before they believe that it does exist" (10)
"Sometimes we do not want to face reality" (17)
"There are people who still say it is a superstition. They say: 'If it is real, why has it not come to me?'" (4)
"Information about HIV-AIDS is everywhere, but people just do not care about being conscious of the dangers" (18)

BABANANGO PARENTS ON DENIAL BY THEIR CHILDREN

"Even if you tell your child, seeing that he is fooling around, he will tell you that he does not believe there is AIDS" (3)
"Sex is really a problem, but children do not want to listen. Our young ones are finished" (3)
"Our children do not care, not unless they hear that so and so is sick, or so and so is dead … then they are terrified for the time being, and thereafter they quickly forget" (3)

BABANANGO WOMEN ABOUT DENIAL BY THEIR HUSBANDS AND PARTNERS

"Even fathers too are in love with young girls; these fathers do not want to listen" (3)
"The older men are fooling around with girls while you are sitting at home. They refuse to use condoms. Old men call young girls 'omanakazi', the lovely ones" (3)

"He simply thinks he won't be infected. Other people get infected because they were stupid, he thinks. But he himself, he thinks he is too smart to be infected …" (3)
"I once tried to warn this guy about AIDS. He asked me if I was implying that people no longer ride fast cars because of the accidents they cause" (3)
"They just forget. They don't even care about it. They leave the picture where they see it. He forgets having seen and buried his friend. On his way back (from the funeral) he does not use a condom" (3)

Young men from Ulundi, in the following chronologically unfolding discussion, tell their story of learning and acknowledgment of the disease, accompanied by their continued, particular forms of denial:

- "Now we have to come to believe the information about HIV-AIDS, because it has been repeated over and over again" (2)
- "It does get into my head, but I still don't believe it wholly" (2)
- "I don't believe it, that is why I can't explain something like this (deaths in the community)" (2)
- "I do believe it, because it was a friend of my cherry who got sick and lost weight. She called us, she told us the whole story … that her time was up. Then I believed that it is not a joke that AIDS kills" (2)

Sense of differentiated but all-pervasive vulnerability

Gut-level reactions that distinguish the youth and women as most vulnerable immediately were followed by intensified reflections, and then conclusions that "all persons are vulnerable". Age and gender were the obvious categories of differentiation in vulnerability. Gender empowerment and assertiveness provided further differentiation. In a number of the groups the dimension of race featured. These participants (black) had either the knowledge or the suspicion that black-African South Africans were more vulnerable than white, coloured and Indian.

"It has no mercy. Even the innocent people get it" (11)
"Anyone is vulnerable to the epidemic" (8)

Part of the top-of-mind reaction, especially from the youth themselves, was that young people are more vulnerable than other age categories. Both the youth themselves and the somewhat older groups matter-of-factly refer to the reality that the youth are the ones who are more sexually active, who experiment more and therefore are more vulnerable. Older participants, mostly women, often refer to the early sexual activity of very young men and women, and combine these with references to the disintegration of respect for norms and older people.

"The youth need (AIDS education) most, because they are the most sexually active … Their hasty decisions go into adult territory" (10)
"The young people need it. Older people have stable relationships, but it is the young who are always on the move" (29)
"The youth are infected in numbers, because they are the most sexually active group and they like to experiment" (8)
"I wish young people could wait until 21 before they live like adults" (20)
"Some young girls get married early so that they can survive" (25)

There were also widespread perceptions, especially amongst women, that women are far more vulnerable than men. This was attributed to male promiscuity, perceived higher reluctance amongst men than women to wear condoms, domination of male culture and the possibility of the rape of women. The group of Indian women was concerned that people in the squatter areas, as well as rural people, should be receiving more AIDS-education, and should be made aware of "the need to use condoms".

"Females are the ones who die most, whereas the men bring it to them" (3)
"The men take a long time to show it. A man may inhibit it for a long time, while he spreads it. He suffers, but it happens slowly. (Us women) we get finished quickly" (3)
"Even if we live very carefully, we live in a big danger of being raped, and then get AIDS anyway" (5)
"The mistresses will disrespect me if I tell my husband to use a condom" (28)

Men, in turn, often referred to women selling their bodies, and women being more likely than men to be infected (even if they rejected the discussion message that infected status amongst women implies unfaithfulness in their relationships with their men).

"Women sell their bodies for money and I think if they knew the causes of AIDS this would not be happening" (22)
"Prostitution brings more AIDS" (27)
"Women of Barberton do not like themselves, they sleep with anybody, as long as they have money" (22)

Participants fairly regularly refer to, and wonder about, the fact that African people apparently are more affected than other races. Most references were in the form of questions; they were wondering why this might be the case. It was left to participants living with AIDS to try and suggest some answers.

"Young people from the other races have been using condoms for a long time, but not the African young …" (1)

"It is not only blacks that are infected. Indians and whites have access to better medication, whilst the black people are not so privileged. They die in big numbers" (1)

"Culture predisposes African people more than whites", was the observation of the Baragwanath group of PLAs. They anchored this prognosis in the dual phenomena of polygamy and patriarchal gender relations.

"Our culture and traditions encourage the spread of AIDS. For instance, in the Zulu culture a man can marry up to six wives and still have girlfriends, and have unprotected sex with all of them. And traditionally men dominate sexually, hence in most cases they decide when to have sex and whether a condom is used or not" (18)

Anxiety about being infected or not

Various respondents talked about anxiety of not knowing whether they might already be HIV victims or not. This was the theme of a substantial part of the discussion amongst women from Babanango. Amongst others, Coloured men in Ceres, as well as the men in Babanango, also referred to the issue.

The discussion by men from Barberton, as well as from Ulundi, implied that "living with people living with AIDS" had become part of the reality of everyday South African life. Many of the questions in the minds of the sexually active amongst the participants have a bearing on the details of the possibilities of infection, and the safeguards that can be used to help negotiate a path of "sexually safe behaviour in an ocean of infection". The discussions clearly indicated that sexual intercourse between victims of HIV infection and the presumably non-infected is a part of "normal" sexual life.

"If you read in the papers and think about our brothers that have died, you become scared not knowing if you have AIDS or not" (4)
"I think everyone must have some sort of ID that shows he is HIV positive or negative, so that we could know" (21)

Acceptance and sympathy for victims

The communities in which these focus groups were conducted fear both the present and future impact of the HIV-AIDS epidemic on their lives. The omnipresence of the disease, as well as evidence of people dying of AIDS, has brought a great sense of sympathy and empathy for the victims. These sentiments extend to both the direct victims and the relatives and AIDS-

orphans. There is a feeling that few people will remain untouched, directly or indirectly. There also is a sense of "I could be next". This means that the fear *generally* does not translate into hatred and ostracism. There is mostly a common refusal to condemn as "immoral" those who have become infected.

"You don't see suffering from AIDS as a disgrace, because you can get it, even if not from sex. This is a widespread disease like flu. If I talk, maybe there are people who can help me" (3)
"We must give them support, because tomorrow it might be me or you" (21)
"It is not right to say that people who get AIDS deserve getting it, because even the innocent people get it" (12)
"This person would continue to be my friend. I cannot forsake him" (4)
"Getting more information will make people understand that AIDS victims are not responsible for their plight" (13)
"People like to judge. Nowadays you are even scared to have flu, because people will say you have AIDS" (22)

Participants conveyed their belief that the HIV-AIDS victims also have rights. Many expressed disbelief that the sufferers might stand to lose employment and be ostracised by society.

Yet, a high degree of uncertainty regarding community reaction remains. It was mostly the persons that expressed the greatest lack of information and uncertainty about causes who also suggested possible action against people living with HIV-AIDS. Upon closer reflection, participants often added qualifications to their earlier statements that "even the innocent can get it" or that "everybody is equally vulnerable". There is a recognition of the malicious and/or conscious spread of the disease, as well as the cultural facilitation of its spread.

Participants argue, for instance that young girls, often between 10 and 13 years of age, "go out with taxi men, sometimes for the status, sometimes for the money". Or, that "young boys get involved with older women, because they want to leave them with the disease". Somewhat older women, from rural or from more traditional settings, reflect on the fact that their husbands or partners may go off with younger women, and that they themselves are seriously exposed through polygamy. They point out that polygamy combines both with migrant labour and with rural women sharing a small number of available men in rural areas to contribute to the possible spread of HIV.

A range of group discussions veered in the direction of HIV-status persons posing threats to the community, and that these people ought to be isolated or removed from society. It was on messages of this nature that group discussions most often tended to diverge between "agree" and "disagree" with the message posed.

"We cannot live with people who are HIV-positive, the government should take these people to stay somewhere else until they die" (28)
"The government should start by clearing up the informal settlements, they must do a check on people every three months" (30)

Fear of disclosure and community reaction

Contradictions prevailed. When confronted with the issue of disclosure of HIV status, group participants living with HIV relayed powerful experiences of suspicion amongst family members, potential partners who refuse to believe their disclosure of their status and still insist on unprotected sex, or who run and then spread the word of "tainted women".

The research revealed the gap between, on the one hand, acceptance of the rights of AIDS victims and the realisation that "next it could be me", and, on the other hand AIDS-phobia in which people still want to isolate and excommunicate people living with HIV or AIDS.

THE "FEAR OF DISCLOSURE" MESSAGE:

One of the messages specifically tested participants' perceptions of possible negative community reaction in the event of persons disclosing HIV-positive status.[1] There was general agreement that as long as fear of disclosure remains, it might be impossible to expect communities openly to engage in HIV-AIDS dialogues. Various possibilities of negative reactions were recalled, ranging from isolation and neglect to fear for personal safety. Whereas many participants initially went for the "more correct answers" the continuous trend was an acknowledgement that there might very well be highly negative reactions from the community.

> Agree that there might be retribution:
> "If they could know that someone had HIV-AIDS they will neglect and stay away from that person" (15)
> "Some may influence other people not to talk to the victim" (15)
> "It is true that conditions are not conducive to opening up" (12)
>
> Feeling that it will be fine to disclose:
> "There are many people who are willing to listen and talk about HIV-AIDS" (10)
> People are protected by the law, at the workplace, so they cannot lose jobs because they declared their HIV-status" (10)
> "All people have rights, and the government protects those rights" (9)
> "It is now law that AIDS victims should work until the end" (8)

MESSAGE TESTING TOLERANCE OF HIV-AIDS VICTIMS:

This message asserted that people who have AIDS are a "threat to the community" and that contact should be avoided.[2] Few participants agreed with

[1] **"Our people in the community will never openly listen to and talk about HIV-AIDS as long as we are scared that other people will insult us or victimise us. It is just not practical to expect people to talk about them having AIDS. They could lose their jobs. They could even get killed."**

[2] "There are many people in our community who have AIDS, who are HIV-positive. They are a threat to the community. We should avoid contact with them."

the statement, yet there was a sub-text of fear that led to some tentative assertions that isolation from the community might be desirable. Participants offered various reasons, ranging from the personal to the politically correct.

Generally there was tolerance, but often also strains of mixed feelings. Not only did various groups feel that government should take action against people living with HIV-AIDS (for instance "clear up informal settlements" or do "better border controls on people from the region coming into South Africa"), they even thought that these people should be sent back into the community, without choice, to inform the community about their status.

WOMEN FROM MASILO

"The government should not support AIDS victims, but should ask them to go into the community and tell everybody that they are HIV-positive" (30)
"The government should not protect them as such, but should keep them away from those who are HIV-negative" (30)

Disagree that contact with victims should be avoided:
"I disagree, because tomorrow it can be you or me" (6)
"Some AIDS victims eventually die due to lack of support" (12)
"These people need support and comfort" (8)
"It is irresponsible to say that. It is not true either" (13)
"Statements like that are wrong. They will fuel hatred" (11)
"People who say that just need more education about the facts of AIDS" (11)
"We cannot get AIDS by just being in contact with them" (6)
"Sane people would never say that" (4)
"If your girlfriend has AIDS you can still have sex with her using a condom, but if she is taken to another place, who is going to sex her there?" (2)
"They are people like us" (9)
"A friend with AIDS is still my friend" (15)

There is a widespread fear of disclosure, and participants motivated their fears:
"Once she is known, the communities want to get rid of a person who has AIDS, because they believe she's gonna infect them. So, people living with AIDS definitely cannot appear on television programmes to help spread the message ..."(1)
"People gossip behind their backs, saying 'they are three'[3] and the victim ends up dying without getting any help" (3)
"If people have AIDS, they sweep it under the carpet, because others in the community tell them they are immoral" (5)

[3] Reference to HIV as the "three letter illness".

THE CASE OF THE BABANANGO WOMEN

Babanango women openly talked about them caring for AIDS orphans, about young people dying of the "three letter illness", about the possibilities that they themselves might be infected but do not yet know it (and they do not know how to go about having themselves tested). But it was from this same discussion that a suggestion emerged that, perhaps, people living with HIV-AIDS should be removed from their communities.

"We even said when we were discussing it at home that it would be better if a person, once diagnosed, is killed, or even just sent in to hospital, to prevent him from spreading the virus". We were just saying that seeing that this thing is spreading …" (3)

MEN IN BABANANGO

"It is dangerous for the community to know about your status, because the community does not like you" (4)
"I heard about the girl in KwaMashu who was stoned to death… so it is dangerous to be known" (4)

YOUNG WOMEN IN BOLO

"Prostitutes should be arrested" (15)

WOMEN IN WORCESTER

"Victims should not be punished, and AZT should be provided. But those who get AIDS by being loose can be punished" (10)

WOMEN IN CHATSWORTH

"Those carrying HIV should be punished" (5), followed by:
"But why? What if she contracted it after rape?" (5)

YOUNG MEN IN ULUNDI

"I don't think it is wise to imprison people … but through counselling people might change their life-styles" (2)

YOUNG MEN IN GUGULETU

"The rights of homosexuals should be revisited, because they encourage the spread of AIDS" (7)

The realities of continued feelings of feeling threatened by people living with HIV-AIDS therefore impose direct constraints on disclosure. Several participants shared this dilemma.

"I am worried that if this virus attacks my family, I will not be able to disclose such information" (3)
"I may say now that I would disclose, but when it comes, I will hide it. She may say that her friends will shy away from her" (3)
"If we are at the same school, I would suggest they kick out this person who has AIDS" (28)

Participants may be aware of "politically correct talk", but there was little in the discussions that indicated that given a more socially encouraging environment for talking about and dealing with AIDS, their level of social acceptance would not become higher.

THE "LOW MORAL VALUES" MESSAGE:

One of the messages assessed the possible association in people's minds between "low moral values" and "deserving to get AIDS".[4] Most responses reflected the trend that participants thought virtually anybody was vulnerable. They were reluctant to issue moral condemnations, although there were various suggestions that perhaps some people are less innocent than others.

The group of young white men from Pretoria, for instance, were quick to assume high moral ground in debates on ways in which society should address the problem of HIV-AIDS. When confronted with the specific message, however, they retracted and were adamant that it was not just those of low morals who were vulnerable.

> <u>Disagree that infection and immorality are related:</u>
> "I disagree that it is people with low moral values who get it. One partner may be faithful, while the other one is not …" (15)
> "Even people with high moral values can get AIDS" (10)
> "My husband can be unfaithful to me and next thing *I can have it*" (28)
> "Even very religious people can get AIDS" (9)
>
> "Your partner can bring the AIDS virus home" (9)
> "What about innocent babies?!" (8)
>
> <u>Agree that there is a connection between getting infected and behaviour:</u>
> "I am not saying that those who get it deserve it, but some people seem not to care about their health" (10)
> "Obviously if a person has unprotected sex with a person she does not know the history of, she deserves getting it" (10)
> "If you behave yourself and only have sex with one partner you will not be affected" (9)
> "People have stupid ideas about not using condoms, they deserve it" (5)

These trends therefore point to a further dilemma in addressing the issue of creating both tolerance and safer sexual behaviour. On the one hand, there is the knowledge that anybody, even the innocent (rape, blood transfusions, unfaithful partner) can become HIV-positive. This enhances tolerance and the possibility for victims to speak out. Yet, this tolerance also creates space for

[4] "People who get AIDS deserve getting it. They have low moral values."

continued unsafe sexual practices – those who are willfully reckless and careless could claim innocence and blame it, for instance, on partners.

SECTION 2:
SEXUAL BEHAVIOUR, POWER RELATIONS AND HIV-AIDS

"Babanango people admire polygamy ... Then he returns with a disease from another woman… If we were ten in this marriage, we are all destroyed" (3)
"My husband knows that I do not tolerate shit" (12),
"When you are young, you always want to get it all. So, we do not use condoms. Which leads to us getting AIDS" (15)
"It is true that we are looked down on for protecting ourselves" (12)
"My partner can go to hell if he does not want to do safe sex" (28)
"When you are young, you always want to get it all. So, we do not use condoms. Which leads to us getting AIDS" (15)

SECTION EXECUTIVE SUMMARY

- The participants were quite willing to speak about their personal, continued high-risk sexual behaviour. There continues to be a reluctance to practise safe sex. There are worlds of difference between knowing the dangers of infection (and some do not know it beyond the broadest of brush-strokes) and doing safe sex. Various explanations are offered for such discrepancies. These include bravado and a sense of invincibility, especially amongst men, both genders' preference for "the real thing", denial of the existence of HIV, blind trust that partners do not carry the virus, heat of the moment irrationality, stigmatisation of women for being too smart, and lack of capacity of many married or relationship women to impose faithfulness or condom sex on regular or long-time partners.

- Women, much more than men, suffer from various forms of disempowerment, which differentially inhibit them from practicing and insisting on safe sex. These range from social stigmatisation of women who want to protect themselves, to cultural dominance in power relations with men, and practices of polygamy and migrancy.

- Amongst younger urban and/or more professional women there is a more strident approach. They often raise their right to insist and to dictate the conditions for sexual intercourse to existing or prospective partners. Yet, almost inevitably, they also refer to the problems of the stigmatisation of modern and assertive women.

- The realities of continued high-risk sexual behaviour therefore can be linked to all of the cultural-social dimensions of sexual power relations, the individual dimension in which persons either deny the existence of HIV, deny their own susceptibility, do not assert themselves, or simply prefer condomless sex irrespective of possible consequences.

- These findings point to the two worlds syndrome – the one of what we know, the other of what we do. This part of the study also showed the extent to which sexually active people live out a series of contradictions in denial of and disdain for the dangers of infection.

This section elaborates the context of sexual behaviour. It offers illustrations of how participants view and explain their own sexual behaviour. It also explores the terrains of cultural and gender control over personal and sexual relationships, and notes subtle forms of control through stereotyping and stigmatisation. These sexual behaviours and personal power relations set the context which either could facilitate the encouragement of safe sexual practices, or obstruct and undermine future communication strategies and campaigns to affect attitudes and behaviour.

The group discussions revealed only a limited amount of ignorance about the broad causes and manners of infection associated with HIV. Participants had clarity that sexual behaviour, and in particular also heterosexual intercourse, constitutes a major cause of HIV in South Africa.

Self-identified sexual behaviour patterns that are risk-prone

Younger people in this study often spoke out about their own sexual behaviour and the risks that they take. Most of the young people in these groups, for instance, referred to the fact that "teenagers are the people who get HIV, because they are the most active sexually".

About the prevalence of HIV amongst the youth, and the trend that young Africans seem to be more vulnerable, a person living with AIDS observed:

"Children of other races have been using condoms for quite some time, but not ours. We don't like this plastic. This feeling is everywhere amongst us" (1)
"Most sexually active people think that it is a waste to have protected sex" (31)

It appeared to be a fairly common trend that men, and especially younger men (for instance the men from Barberton), feel that it is the responsibility of women to insist on them using condoms. It was in this context that several groups of young men particularly liked the AIDS education materials which stated that women have "the right to say no to unprotected sex". This trend extended into young men defiantly stating that there is no-one to police them in the privacy of place where they have sex. Some stated that not even their partners would know for sure whether they actually had been using a condom or not. This indicated that there is a belief that sexually safe behaviour is required only as long as there is public or shared scrutiny. This might be referred to as the "invincible, I am wrong if I get caught" syndrome.

The following two sets of quotations provide illustrations of how categories of men and women observe the risks of their own sexual behaviour:

MEN ACROSS A SPECTRUM

"The problem is that sometimes you see that the girl is too beautiful for you to use a condom and you end up doing it without a condom. Thereafter you think why should I use a condom, because you have already started doing it without a condom" (4)

"Even if we know about the deaths, we continue to have unprotected sex" (6)

"We get sexually transmitted diseases having condoms in our pockets" (11)

"We are only told now that we should use condoms. So, I want to know, what is it that I will be preventing now, while I was never protected ten years ago" (22)

"We mess around, hoping that a cure will be found before we die" (11)

MEN FROM TIERFONTEIN

"We will only believe that AIDS kills once we get it" (31)

"It is true that sometimes we force women to have unsafe sex" (31)

Men also acknowledge that alcohol and sexual risk behaviour go hand in hand:

"We know that there is AIDS, we also know that there are condoms, but sometimes we drink. And, once you are drunk, you think condoms are a waste of time… But you only realise the danger in the morning when you are sober again" (4)

YOUNG WOMEN

"When you are young, you always want to get it all. So, we do not use condoms. Which leads to us getting AIDS" (15)

"Of course, it is not so easy to use a condom. When a woman is so fresh and young, we do not even think of AIDS" (15)

"It is after intimacy that you think about the condom" (1)

Risk-prone sexual behaviour might be advanced through fairly commonly held perceptions that "condoms are not safe anyway". Alternatively, this perception might be offered in group discussions as a rationalisation of risk-prone behaviour. Participants in various groups observed that "condoms are not safe anyway, because they often have holes". Others recognise the fallibility of condoms but advocate usage.

"Condoms are not 100% safe, but we just have to use them, regardless of their weak points" (27)

MESSAGES ON "UNSAFE MALE SEXUAL PRACTICES":

Two of the messages that were presented to the male groups wanted to establish some of the perceptions regarding virility and pursuit of the opposite

sex, in as far as these might lead to "unsafe sexual practices".[5] The young men generally rejected unsafe sexual practices when discussed in this direct form. They tended to be politically correct. In other parts of their discussions, however, there was more evidence of continued unsafe practices. This suggested that they have become sensitised to sexually safe practices, but the transition into the domain of action has not happened.

> Politically correct answers offered:
> "Forget about the young ladies, your life and health come first" (8)
> "Sex is not at all about making babies. We can get AIDS" (5)
> "It is stupid for people to say it is the old people who want to preach to us. We know AIDS is here" (11)

High-risk sexual behaviour observed amongst others

Women, as well as men, in these groups offered series of observations of the sexual behaviour of other men and women.

WOMEN ABOUT MEN

"Boys seem to have the attitude that they can mess around and others will find a cure in time" (12)
"Men are capable of convincing us to sleep with them, so I think we should learn to say no and mean it" (30)
"Men don't mind whether they are infected or not by the virus, but they are willing to use a condom" (1)
"I want to know how we can protect ourselves besides using a condom, as our partners will never agree to use it" (25)

MEN ABOUT WOMEN

"When you sleep with a woman you know that it is possible to get AIDS" (4)
"There was this girl I had from Eshowe, she would not let me use a condom at all. I had to lie to her and said I had an STD, but still she did not want me to use a condom. The problem is because of people like her" (4)
"Women have a great need for education about AIDS. They sleep around too much" (14)
"The young girls go out with a man because he has a car and lots of money… There are cases where the woman has no alternative but to surrender her body. It is not that they do not have self-control, it is because of hunger-pangs" (4)

MEN ABOUT MEN

"There are far less boys here than girls. That sometimes leads to some guys ending up with three women from one street" (4)

[5] "I want to say. Let it kill me, because I will never abandon the young ladies. AIDS is something that the older people dream up to make the youth conform to their values", and "Young men have to show their virility. This business of safe sex and condoms will just interfere with what we have to do."

WOMEN ABOUT WOMEN

"Some girls go out monthly and sleep with boys for money. They even have more than one boyfriend. And they don't use condoms" (1)
"It is the women who often go ballistic when men use condoms, saying they are not to be treated like bitches" (1)
"Ladies just don't like to use condoms. They don't like having it from the plastic" (1)

Gender disempowerment and inability to protect against HIV-AIDS

Generally, a picture emerged of women often feeling disempowered vis-à-vis their husbands, partners or boyfriends. There are strong differences, however, between women, depending on their cultural / social and their personal orientations. In a multi-front "war of sexual relations" these focus groups displayed three dimensions of responsibility and liability for safe sex. First, both men and women recognise that they themselves often are responsible for unsafe sex. Second, both men and women mutually accuse the opposite gender of being reckless and unreliable. Third, many men give credit that "women tend to respect themselves, it is rather the men who tend to have multiple partners", and many women feel sufficiently strong to dictate their own terms of sexual relations.

Women voices from the more traditional cultures spoke in frustration about their inability to enforce safer sexual practices. Male cultural dominance, practices of polygamy, and migrancy contributed. Working class women from a coloured community echoed worries about the ability of men to dictate the conditions of sexual intercourse. Young women, both rural and urban, noted how male stereotyping and stigmatisation of women who want to practise safe sex sometimes inhibit them in pursuing these safer practices.

Yet at the same time professional, modern and / or urbanised women, talked about being more forceful in imposing their own conditions for sexual relationships and intercourse. Younger women in general, but especially those from more urbanised backgrounds, are more outspoken than their rural counterparts about being able to instruct their partners to use condoms. These women exuded confidence on being able to "do it on our terms". Yet, these women simultaneously talked about how difficult it is to retain this edge, especially in longer-term relationships.

The discussions also indicated, however, how personal sexual preferences for "having it all sex" (as opposed to condomised sex) bring about unsafe sexual practices irrespective of cultural background or social empowerment, especially among younger women. Furthermore, women across the board expressed the need to have more knowledge about and access to female condoms. Many had only heard of it, and never seen it.

"Our marriages, relationships will have problems. Our boyfriends and husbands will say we insist on using condoms because we get a better service somewhere else" (32)
"Even if we suspect our husbands are unfaithful, there is nothing we can do" (32)
"If we insist that they use condoms, they will either desert us or no longer give us money" (32)

FRUSTRATIONS OF MARRIED OR OLDER BABANANGO WOMEN

"I get scared when I am sick, because no matter how much you take the precautions, our husbands don't. As they sleep around they tell you that they can't use condoms at their age, that one has to use them from the word go" (3)
"Our husbands will tell us that if he must use a condom, it means you have an affair" (3)
"If you tell him to use a condom, he may even chase you away and claim that you are disrespectful. You may even be separated from your children" (3)
"I always wonder how I would really begin using a condom" (3)
"It is easy for him to say that you are here because of marriage. 'If you don't want to have sex, I will report you to the family.' We still believe that if there is disagreement in bed, it should be discussed with the family" (3)
"In Babanango people admire polygamy ... And then he returns with a disease from another woman… That woman, myself, we are all destroyed. If we were ten in this marriage, we are all destroyed" (3)
"Besides marriage, if you tell your man to use a condom, it implies that you are getting satisfaction somewhere else" (3)

URBAN, PROFESSIONAL WOMEN

"My husband knows that I do not tolerate shit" (12)
but, these women also agreed:
"Men think we suspect they are having affairs when we ask that they use condoms" (12), and "It is true that we are looked down on for protecting ourselves" (12)

SOME YOUNGER RURAL WOMEN

"My partner can go to hell if he does not want to do safe sex" (28)

WOMEN ON THE STIGMATISATION OF PROTECTING THEMSELVES

"I agree that women are seen as experienced or loose if they protect themselves … This is what is happening" (13)
"If you have condoms in your purse it is said that you sleep around" (30)
"These guys think that we know too much if we want to protect ourselves" (13)
"These men are threatened by a woman who can decide what she needs or wants" (13)

WOMEN GENERALLY IN RELATIONSHIPS

"The problem is that one gets STDs from sleeping with someone that

one trusts" (1)
"In most cases when women tell their husbands about being infected, the marriage falls apart because each one points at the other for having transmitted the disease to the partner" (1)
"We need help in how to protect ourselves if our husbands are not faithful to us" (28)

MESSAGES TO MEN ABOUT THE SEXUAL BEHAVIOUR OF WOMEN:
Several messages that were posed to the male focus groups were designed to establish male perceptions of gender relations as well as possible responsibility of "women infecting the men".[6] Opinions diverged.

Men's perceptions that women are responsible for infecting men:
"It is true that young women often are responsible for spreading HIV, because they get offers from all these men" (7)
"If a woman is unfaithful she will get the virus and pass it on to her husband" (31)
"Sometimes the wife would have something on the side and the man gets affected…" (4)
"I think women are dangerous…" (8)
"It is because women get propositioned wherever they go" (31)

Feelings that women are not the "guilty parties" any more than men are:
"I know for a fact that women are faithful in most cases and are not infecting men because of the women sleeping around" (7)
"Most of the diseases are spread by men" (7)
"It is men who in most cases become unfaithful to their partners" (11)
"It is nonsense that women who are infected are persons who have been unfaithful to their partners" (11)
"As far as I know young women respect themselves, and generally stick to their one partner" (11)
"Young women respect themselves, it is not that the single and the educated are spreading the disease" (31)

MESSAGES TO WOMEN ABOUT THE SEXUAL BEHAVIOUR OF MEN:
Several messages regarding male perceptions of women's sexual status and behaviour elicited lively discussions in the female groups.[7] The women, both

[6] "If my wife, or one of my wives, or my girlfriend, has AIDS, I will know that she has deceived me. It hardly ever happens that women get the virus from their husbands or partners"; "If a woman is infected with the virus, it means that she has been unfaithful, a "loose woman"; "It is young women, you can see them, they are often single and educated, who are responsible for spreading the disease."

[7] "As a married woman I do not have the right to tell my husband (or my partner) to use a condom, or practice another form of safe sex"; "I know that my husband also has other women in his life, but I cannot tell him that I want protected sex" and "If a woman seeks knowledge and equips herself with condoms or even mentions the need for preventive measures, men think 'this is someone of experience', and think we are loose or prostitutes."

married and single, often related information about multiple standards being applied, stereotypes and male domination (the latter especially in the case of women from more traditional and rural societies).

Women about negative male perceptions and stereotypes:
"Sometimes women are forced by the fact that they do not have their own income. Then they have to keep quiet and cannot tell their husbands to use condoms" (12)
"Men say we suspect they have affairs if we ask them to use condoms" (12)
"It is true that men think we are loose if we want condoms" (13)
"Some guys think that we know too much if we talk about condoms" (13)
"We must have the right to tell men to use condoms. But in most cases we do not have proof … We just suspect they have other women in their lives" (9)
"Even if we know about the other woman, we never ask for protected sex" (10)
"We just cannot tell our partners to use condoms" (20)
"Once you raise the issue of your husband using a condom, there no longer will be peace in the house" (9)
"Sometimes we get evidence about the other woman, but the whole thing will end up on the level of confronting him and nothing more" (10)
"There are many people in our communities who think we are loose if we talk about condoms" (9)
"Men think about us in stereotyped ways, they always think we are loose if we want safe sex. Even our boyfriends think like this" (10)
"Men do think that we are loose if we know that we want condoms. They feel threatened" (15)
"The guys talk bad about us if we want safe sex" (10)

Women on men being fair, or about women having sufficient rights to protect themselves:
"All women have their rights, but women can be very submissive" (12)
"I will tell my husband to use a condom if I know there are other women in his life, otherwise I will end up getting strange diseases" (12)
"My husband knows that I do not tolerate shit" (12)
"I have the right to protect myself" (13)
"In some relationships there is trust and respect, and it is easy to talk about using condoms or not" (9)
"I will simply refuse to have sex with my husband if he has other women in his life" (15)

Willful spreading of the virus

Participants in these groups spoke with trepidation about infected persons possibly willfully going around and infecting others around them. In one of the groups it was suggested that this was one of the areas where the government should be assuming a more assertive role.

"The problem is that (those who are infected) say that they do not want to die alone" (3)
"I once gave this infected man advice on how to deal with HIV status … But he did not want to listen. He said a girl gave it to him and now he was going for every woman in the street" (1)

Unwillingness to do safe sex

Both genders refer to persons of both their own and the opposite gender who either refuse, or are simply unwilling to engage in safe sexual practices. There were more frequent references, however, to men than women being unwilling and reckless. Whereas the references pertained to men of all ages, it was mostly *young* women who were marked as unwilling to pursue safe sex.

"Mom told me that she overheard girls at her work saying they don't want to be sexed with rubber. They said that it is insensitive, they don't feel anything", were the words of a young Ulundi man (2). "I tell men that I like, 'I am infected, we have to use a condom', but then they say it will make them happy if a woman as beautiful as me infects them" (1), was the crux of the story told by a young woman living with HIV.

Motivation for lack of willingness to follow practices of condomised sex, assumed a range of hyperbolic expressions in these discussions. The following are the major examples:

"I don't wear a hat to church. I don't do sex with a condom either" (8)
"People say that they can't eat a sweet wrapped in a paper. They prefer flesh to flesh" (15)
"One man said 'how can you eat a banana inside the peel'!" (2)
"I once tried to warn this guy about AIDS. But he simply asked me if I was implying that people no longer ride fast cars because of the accidents they cause" (3)
"Some people say they would be happy to die the same way the came to earth, through the vagina of a woman … And they would tell you that they prefer dying of the thing they are fond of" (2)
"Even after this discussion I will find it difficult to eat a banana with its cover" (32)

THE "TWO WORLDS" MESSAGE:
The "two worlds message" was uniformly supported by group participants.[8]

"When you are young, you always want to get it all. So, we do not use condoms. Which leads to us getting AIDS" (15)

[8] "Many people know about HIV-AIDS, but they don't change their behaviour, they don't practice safe sex. It is just two different worlds. One cannot take that type of knowledge into the situation where one is going to have sex with a person that one likes."

"You know it is hard to cut someone from your life, but you must think about your future, your life ahead. But sometimes it is hard to call it off" (2)
"The heat of the moment makes us forget all about safe sex" (9)
"The whole pleasure of sexual intercourse makes us forget about the dangers" (31)
"Knowing is not enough. We must practice what we know" (30)

The following chronologically unfolding excerpt from the discussion by young women from Rockville, Soweto illustrates thinking on the topic:
"I agree, because I am also one of those people who do not practise safe sex" (10)
"I agree, also because we have a tendency of endangering our partners' lives by having more than one sexual partner" (10)
"I agree, most sexually active people think it is a waste of time to have sex with a condom" (10)
"I agree, it is not easy to use a condom once one is turned on" (10)
"Most people only use condoms for the first few sessions, but once they get used to each other, they go for the flesh" (10)
"Most people just assume that their partners are HIV negative" (10)
"People prefer flesh to flesh. They don't want the sweets wrapped in paper" (15)

THE "WHAT WE KNOW-WHAT WE DO" MESSAGE:
Participants also readily acknowledged the continued difference between "what we know" and "what we do".[9]

"I agree, because we get sexually transmitted diseases having condoms in our pockets" (11)
"I agree, this is what everybody is doing!" (7)
"We do not play safe, even when we suspect something could be wrong" (7)
"Yes, we tend to trust our partners and forget about our health" (8)
"It is this knowledge that we put aside. And then we regret it later" (8)
"It is not that people forget about the information, they do it without condoms fully aware that they could have signed their death warrant in those few minutes" (9)
"As soon as we meet a nice guy, we forget all about AIDS information" (10)
"It is not easy to remember that information once the heat is on" (10)

The "two worlds syndrome" – what we know and what we do

As the rest of this analysis will indicate, there are two worlds of sexual behaviour that are encapsulated in the minds of sexually active persons as

[9] "We do get a lot of information about AIDS, but we forget about it again, as soon as we leave these clinics, training sessions. There is still a difference between what we know and what we do."

they think and act on HIV-AIDS. The first is the world of knowledge. On the one hand, there a consistent and high level of awareness of HIV and the fact that it is largely caused by unprotected, heterosexual intercourse. On the other hand, there is the world of either "heat of the moment" or of "gender disempowerment" compulsion to enter into unprotected sex.

Participants, both women and men, talk about the fact that they are severely constrained in the actual introduction of condoms (as the major form of protected sex) into intercourse. Women, often because they are afraid of being seen as "experienced and loose", or because partners suspect that they have been unfaithful and therefore are insisting on condoms, or simply that they are distrustful of their partners' sexual behaviour. Men, mostly because they see themselves as invincible. They sometimes express sentiment that beautiful women won't infect them, or that it would be an "honour to be infected by a beautiful women". Married men are highly distrustful of their own wives possibly requesting them to use condoms.

These patterns of dilemma-ridden sexual behaviour strongly contrast with the existing levels of knowledge about HIV-AIDS. The "two worlds" message received consistent and strong support from focus group participants across the board. It was further elaborated by equally consistent support for the message that we easily forget about the knowledge once we leave the clinics. It was even elaborated by the funeral story – that we only learn if people around us die, but then, we forget about the death on the way back from the funeral. Some of the men added that once alcohol starts talking, we "commit suicide with the condoms in our pockets".

The big need clearly is the empowerment and facilitation in social and intimate interpersonal skills to bridge the divide between deathly knowledge and passion-filled personal action.

People living with AIDS in these groups observed that training and information can indeed make a difference:

"There are people who change their ways after attending sessions" (18)
"People are starting to take action" (18)

THE "INFLUENCE OF OBSERVING DEATH BY AIDS" MESSAGE:

One of the messages assessed the impact that community knowledge of AIDS-related deaths might exert.[10] Most participants agreed that the "scare effect" would have a sobering influence on sexually active persons. Others in the groups felt that they have already been witnessing people continuing with reckless sexual behaviour despite those persons having knowledge of AIDS-related deaths.

[10] "As more people are dying of AIDS, the rest of us in the community are becoming more careful. It is important for the community to know that people they know or are living around them, or working with them, die because of AIDS. In this way they will be influenced to change to safe sex and other steps that prevent infection."

Agree that it would lead to safer sexual practices:
"Once a person knows the facts, she will take action"
"I agree, I want to see somebody with AIDS" (11)
"What people see happening will make them realise that HIV-AIDS is a reality" (10)
"I would ask myself, 'what if it was me?' Would I have the courage to tell other people?" (24)

Disagree:
"Even if one can see a person dying of AIDS, he will continue having unprotected sex" (11)
"We are so ignorant. We continue doing it" (5)
"The problem is that a person who dies of AIDS does not die alone, by the time he dies he would have left a number of infections" (2)
"Some of us don't care. We would be happy leaving the earth in the way we also came into it" (2), followed by: "There is too much influence by people who pretend not to care" (2)

HIV-AIDS and the world of silence and contradiction

A number of far-reaching contradictions were confirmed in the current research:

- HIV-AIDS is most emphatically associated with certain death, no cure, and its status of killer disease. Discussions, almost without exception, attested to these realisations.

- For young women experimentation and "grooving" equal condom use, but they also talk about the difficulty of continuing the use of condoms once a relationship becomes established.

- When it comes to partners, sex and relationships, the grey world of "spur of the moment", "decisions in the middle of the act" and "what does it mean about trust?" issues enter. Participants were open about it – it becomes virtually impossible to stick to original intentions, or to confront one's regular partner and insist on a condom.

- In the generalised discussions, in contrast, participants (and especially women) frequently and emphatically discussed the fact that they have rights and that they will reject their partners (prospective partners) in case of refusal to condomise.

- Young men, more than their female counterparts, convey a sense of simultaneously living with both awareness and a conviction of personal invincibility. Older men, and especially lower educated and rural, often seem to live with denial that the disease exists.

- A further contrast was that whilst HIV-AIDS is roundly associated with being incurable, there is a low-key but pervasive sense that a vaccine is achievable. It is a matter of the world's scientists, the South African government, the political leaders encouraging and funding research, and to allow experimentation with new drugs.

This chronologically unfolding discussion illustrates the case of risk-prone behaviour:
:

BARBERTON MEN:

"Once we have fun, we forget about the facts of AIDS" (22)
"I disagree. You find people not using condoms, not because they have forgotten, but they want to see what will happen" (22)
"We tend to say that nobody knows or will know that I did not use a condom, so why should I worry?" (22)
"It is just between you and your partner as to what happened in the bderoom. Sometimes our partners are not even sure whether we use a condom or not" (22)
"In a situation where you are involved with two partners, you won't be sure who is the one who is HIV-positive. You use protection with one, only to find it is with the other one that you are in danger" (22)

SECTION 3:
EXISTING KNOWLEDGE, SOURCES OF KNOWLEDGE AND INFORMATION NEEDS ON HIV-AIDS

"I wonder if condoms also spread the HIV-AIDS virus?" (31)
"Is it true that if you sleep with a virgin you can be cured?" (6)
"I want to know if 'African potato' can really cure AIDS" (27)

"If all people get involved and 'own' the virus, then we will win the fight" (18)
"You find people lowering their voices when they speak about condoms … We should talk about condoms, even at the taxi rank" (22)

SECTION EXECUTIVE SUMMARY

- Existing knowledge on the HIV-AIDS phenomenon is characterised by a complex blend of, for instance: what we know as facts (for example that unprotected sex, including heterosexual, can lead to HIV infection; or that infection rates are epidemic in scale); stereotypes (which often are used to stigmatise either women, or those who propose safe sex); myths ("sleeping with" virgins, or young children, will cure AIDS).

- Despite overt acknowledgement that AIDS is incurable there is a common preoccupation with either a cure or a vaccine against HIV-AIDS being found. Progress on this front is the topic that the participants in these groups most frequently request information on. They also express the need for more details of all of the "do's" and "don'ts" of sexual intercourse and very precise information on what constitutes risk behaviour. They are actively looking for the survival skills in a highly affected world in which existing or prospective sexual partners may be known PLAs.

- The participants in these groups tended either to have "title knowledge only" of previous anti-HIV / AIDS campaigns (know the names or symbols of campaigns but cannot link these to specific messages or content in general) or had a fair amount of accumulated knowledge, but very little recollection of where (or in which campaign) the information was obtained.

- Friends, peers, low level medical practitioners and the media, or materials, were the major sources of AIDS-HIV information. The discussions gave clear directions on who these people would like to see engage in public discourses on HIV-AIDS. Credible political leaders, celebrities, entertainers, sport stars and religious leaders should prepare the field and legitimise acceptance and prevention. In continuous, second waves of communication these participants wish to see medical staff, AIDS educators, youth leaders, and political and community leaders of all levels enter into action.

EXISTING KNOWLEDGE

The range of existing knowledge

This study confirms that the level of awareness of HIV-AIDS is fairly uniformly high. This awareness, the study also confirms, is quite superficial. Types of knowledge can be distinguished as basic factual knowledge (held with certainty), "question mark knowledge" (participants think it might be true, but need help to clarify some uncertainty), and beliefs in the form of stereotypes and myths.

Participants in these groups, for instance, tell that they know that HIV-AIDS is a "killer disease", that there is no cure, that it is most commonly caused by unprotected sexual intercourse and that one of the particular strains of HIV had its origins in Africa.

TYPES OF KNOWLEDGE AND PREVALENCE IN DISCUSSIONS (Illustrations)

Types of knowledge about HIV-AIDS	Level of occurrence in discussions
"UNDISPUTED FACTS"	
AIDS is a killer disease	Uniform
There is no available cure	Uniform
Sexually active population is the most vulnerable	General
Number of people with HIV-AIDS increases daily	General
The innocent are also affected	General
"QUESTION-MARK KNOWLEDGE"	
HIV-AIDS originated in Africa	General
African people are the most affected in South Africa	General
"STEREOTYPES"	
Women practicing safe sex are loose, experienced	General
Gays and lesbians largely are to blame	Sporadic
Partners insisting on safe sex have been unfaithful	Sporadic to general
"MYTHS"	
AIDS was introduced into SA by whites in the apartheid system (e.g. Eugene de Kock)	Sporadic
Sleeping with a virgin, or child, can cure the infected	Isolated
It is a monkey disease; and : It affects whites only	Isolated
"DENIAL BELIEFS"	
Beautiful women cannot infect me	Sporadic
AIDS does not exist	Sporadic

ACCEPTED AS FACT

"I learnt that using a condom or abstaining is the only 'cure'" (10)
"AIDS is incurable" (10)

QUESTIONS

"Is it true that AIDS was brought by homosexuals?" (6)
"I wonder if condoms also spread the HIV-AIDS virus?" (31)
"Is it true that if you sleep with a virgin you can be cured?" (6)
"I want to know if 'African potato' can really cure AIDS" (27)

MYTHS

"They say when you have HIV there is still hope, but only if you are going to abstain from sex or use condoms" (3)
"People believe that if you sleep with a child you will get cured" (24)
"If you have HIV and continue with sex, that is when it kills you the most" (3)
"Is it true that it was Allan Boesak who brought AIDS to South Africa?" (6)
"If people see a beautiful lady has AIDS, they say 'Hey, I thought this disease wears one down, but she is really beautiful …" (1)
"You can also get AIDS through mosquitoes" (21)
"AIDS is a whites' disease" (22)

MISCONCEPTIONS

"AIDS is caused by different types of fluids in a human body, resulting from sleeping with different sexual partners" (22)
"Most people who are HIV-positive become infected not through sexual intercourse, but through things like car accidents and blood transactions" (22)

MESSAGES ON HIV-AIDS STATISTICS:

Messages regarding the rising statistics on infection, especially in Sub-Saharan Africa and South Africa, were introduced into the discussions.[11] The general trend was that participants were not perturbed at all. They appeared to have been aware of the scale of the problem. In some instances they also said that their impression had been that the actual infection rates were higher. Generally the statistics were accepted as fact. They elicited little reaction and virtually no emotion. The impression from the discussions was that participants often "dutifully played the role" of being perturbed by the high incidence, but that there was really no shock reaction at all.

Typical reactions:
"It is good information, which can help us adjust our behaviour" (13)
"I heard about that. I suppose it is true" (11)

[11] "Four million South Africans live with AIDS. 1700 new cases get added in South Africa every day. This is an epidemic that can destroy our communities. We can no longer pretend that nothing is happening" and "More than half of all new infections with HIV occur in people under the age of 25 years. Across the world nearly 3 million young people aged 15-24 years were infected with the virus in 1998, nearly 2 million of them living in Africa. This is an epidemic that can destroy our communities. We can no longer pretend that nothing is happening."

There was also occasional skepticism about AIDS statistics, for instance in the Soekmekaar group, who felt that statistical statements often are inaccurate, or could even be fabricated.

"Are the statistics of AIDS-related deaths a true picture of what is happening?" (29)

INFORMATION NEEDS

Information needs -- preoccupation with learning about progress on finding cures and vaccines

The minds of South Africa's sexually active population, as represented in voices in these focus groups, uneasily hover between acceptance that there "simply is no cure" and a preoccupation with "progress on finding a cure and a vaccine".

"Progress on finding a cure" is one of the most frequently expressed needs for information on the HIV-AIDS front for these focus group participants. When prompted on what kind of information it is that they need, the cure-vaccination progress issue emerges about as frequently as the need for continuous details on infection and spread of the disease (for the latter, see below).

Various groups in this project offered the opinion, or the rumoured information, that a cure was well under way. The discussions always were vague around this point. For instance, one group "heard a politician say that…", and another reported that "a cure is on the way, but as to where it comes from they do not say" (22). Others refer to the mass media as their source for information, but mostly report with much more certainty than had been implied or reported in the media.

This cure-vaccination progress information need is also one of the needs most frequently associated with government responsibility (see below). For instance, government is not only expected to keep the population fully informed on progress, but also should be contributing through encouragement, facilitation and the funding of research.

"Information on a vaccine. That is what we would like to get" (8)
"We must just give government a chance. They are trying, and one day they will find a cure" (6)
"Government has to find a vaccine soon… We cannot go on and on using condoms" (20)
"Why is it that doctors all over the world fail to come up with a cure?" (32)
"I want to know why scientists can't fight the epidemic" (8)

Several participants, especially in the rural provinces of the Free State, Northern Province and Mpumalanga, referred to "having heard" that the government might have found a cure, or a vaccine. It is also in these

provinces that participants most frequently report on sangomas who might have made some progress. They also urge government to give more assistance to sangomas in the quest to find a cure (see below).

THE "FINDING A CURE" MESSAGE:

Despite this preoccupation and implied belief that a cure can be found, few participants agreed with the message that "even if we get infected, by the time our lives are in danger, a cure would have been found".[12] The tone and the context of the discussions suggested that participants might have attempted to be politically correct.

> The following were the typical, "politically correct" answers that the groups uniformly offered:
> "I disagree, because AIDS kills, it does not play games" (6)
> "I disagree, because it is ignorant and crazy to say that" (13)
> "It is irresponsible and dangerous to say that" (9)
> "This person who thinks like that will be wasting her life, as nobody knows when a cure will be found" (9)
> "That is like sentencing yourself to death"(10)
>
> Tentative support for the message:
> "Boys seem to have that attitude"(12)
> "I heard that they are finding a cure for it… A cure is on the way" (30)
> "We mess around, hoping that a cure will be found …" (11)
> "They are already halfway there in finding a cure" (28)

Information needs -- more detailed information on infection

Despite a general level of awareness and a fairly consistent level of knowledge of the basics of HIV-AIDS, participants talked about their need for more information on various aspects of the disease.

Participants expressed the need for more information on the following:

- Causes and the reasons why it is so difficult to find a cure;
- Details of how infections happen;
- Exact details on what forms of sexual and other intimate contact are dangerous;
- Details on the risks (and minimisation of risks) in intimate and sexual contact with people living with HIV or AIDS;
- Details on the symptoms to watch out for (in oneself, partners, family or friends);

[12] The message read to the groups was:
> "We are not very worried about HIV-AIDS, even if the rate is very high at this stage. We are still young. Even if we get infected, by the time our lives are in danger a cure would have been found."

- The process to go about to find out one's own status, as well as the possible effects of the information reaching employers, etc.;
- Details on how to handle the situation of living with AIDS.

"Is there any other way to avoid the virus without using condoms and abstaining?" (31)
"Is it true that the saliva of an infected person can bring about infection?" (17)
"After I was told how you get AIDS I was shocked, because I know somebody who had three boyfriends" (30)

One of the great uncertainties and information needs concerned the process to establish one's own status, either through testing or by watching out for possible symptoms. A number of participants appeared anxious about themselves perhaps already being victims.

"These days losing weight is a bad sign. I am now scared, because this can also mean that I suffer from the disease" (3)

A wealth of voices fill in the details on the nature of the information needs that were expressed in the focus groups:

"I am married and I don't like men fooling around. I want him to sit at home. We are scared of this virus. It is bad. I just don't like this, and also don't know how to avoid this" (3)
"The main problem is that we do not really know what AIDS is. We do not know how it starts and how it shows with the victim. Our eyes are closed, we only realise later when it is too late" (3)
"We want to know how we can see if someone is developing AIDS" (2)
"I want to know how women can protect themselves, besides through the use of condoms" (10)
"Can I get AIDS by kissing an infected person?" (7)

Various participants were also interested in finding out the origins of myths and "urban legends" about HIV. It was especially women who were intrigued about the origins of the myth that sex with a virgin can cure AIDS.

Awareness of anti-AIDS-HIV campaigns

Knowledge of previous or existing HIV-AIDS campaigns was dismal, in virtually all of the groups (people living with HIV and a group of Durban-based, well-educated Indian men were the exceptions).

The discussions explored awareness of the following three campaigns:

- At best, many participants were aware of the "existence" of the campaign "Partnership against AIDS". They were not able, however, to pinpoint

exactly the type of information that they had derived from that campaign. Most had knowledge about the basics of HIV-AIDS, but could not draw links between the specific campaigns and their knowledge. Rather, the cumulative build-up of knowledge was confirmed (see below, the sources of knowledge on HIV-AIDS).

- There was virtually no awareness of the campaign "Beyond Awareness". Only a small number of individuals (also in the group of Indian men) said that they had heard of it, but could not associate it with any content or message.

- This contrasted with the symbolism of the "folded red ribbon". The symbol has achieved great recognition value, and generally is not being stigmatised. (Only two voices explicitly associated the red ribbon with "person having AIDS".) Participants were keen, at the end of the discussions, to start wearing the tiny lapel badges that were handed to them.

- Although specific campaign knowledge appeared to be low, most participants showed an awareness, even a fair level of knowledge, of HIV-AIDS. This knowledge had been accumulated over time, from a range of sources, which participants were not able to dissect.

"The folded ribbon has now become a fashion trend" (8)

THE "NEED FOR MORE INFORMATION" MESSAGE

Participants had differences in opinion on whether they continue to need more information on the causes of HIV-AIDS.[13] Most felt that they knew the basics regarding HIV and infection. However, they frequently talked about some issues, mostly regarding details of causes and symptoms, which they continued to be uncertain about.

Disagree with the message:
"By now lots of people know. The information is all over the place" (10)
"I disagree, because we know what causes AIDS, but we just ignore the facts" (10)
"People just do not want to play it safe. By now we have all seen in the media what HIV-AIDS can do to a person" (10)
"I do not think there is anybody who at this stage can claim they know nothing about AIDS" (9)
"Everybody knows as long as you have sex without a condom you can get AIDS. It is rather that they do not understand how the virus came about" (9)

[13] "We still do not really understand what it is that causes HIV-AIDS. We need information in the community. We need to be able to discuss it, all of the time, and with all of the people we come across in the community."

Agree with the message:
"I agree, because there are rumours about the causes of AIDS" (8)
"There are many people who do not know about AIDS" (6)
"Our people are ignorant" (7)
"People know that it is sexually transmitted. But then they do not know much more" (11)

TWO MESSAGES TO TEST KNOWLEDGE AND PERCEPTIONS:

Various messages were inserted into the discussions with the objective to get direct information on knowledge and perceptions. The messages concerned the appearance of people living with AIDS-HIV and association with homosexual persons.[14] Groups generally were certain about the appearance and the sexual orientation of persons who might be living with HIV-AIDS. There were few direct indications that more than a handful of participants believed that "healthy-looking" men or women might not be carriers. In other parts of the discussions, however, it emerged that men appear to believe (or at least say they believe) that beautiful women cannot infect them. On a less explicit level, several groups expressed the desire "to see what people with HIV-AIDS look like". There might be sores, for instance, by which they thought they would be able to recognise carriers.

AIDS-victims are not easily recognised:
"AIDS is not written on people's faces" (11; 28)
"You can never tell that a person is positive just by looking at them" (6)
"It is hard to tell, because people do get ill, or lose weight, from other diseases" (4)
"All people can have it, whether they look sick or not" (12)
"Everyone can get AIDS" (13)
"I once got an STD from a very beautiful, healthy woman" (7)
"Any person who is sexually active can spread the disease" (11)
"Those who look healthy are the ones who really are dangerous" (8)
"It is impossible to see AIDS in a persons after just some months" (2)
"I once saw someone on TV who was HIV positive, who looked healthy, so anyone can get AIDS" (9)

Most participants were clear that HIV is very much a heterosexual disease, even if often associated with homosexual men:
"Homosexuals do spread it, but so do heterosexuals" (12)
"Heterosexuals spread it more than homosexuals" (11)
"Gays and lesbians spread HIV, because they are generally badly behaved, but you cannot be sure" (4)
"Even normal people can spread AIDS" (9)

[14] "It is easy enough to protect oneself against getting AIDS. Healthy- looking guys, women are not affected. It is the ones who look sick that we have to be careful not to have sex with" and "HIV-AIDS is spread by homosexual men. It is not something that affects normal, heterosexual people."

Others, however, disagreed:
"They are responsible. Homosexuals are deviants from society" (11)

Or they had peculiar perceptions about homosexuality:
"Homosexuals don't spread AIDS, because they do not engage in sexual intercourse" and "Homosexuals do not have sex, they cannot spread the disease" (28)

SOURCES OF KNOWLEDGE AND SOCIAL COMMUNICATION PATTERNS

Existing sources of knowledge about HIV-AIDS

There was no single dominating source of existing knowledge on HIV-AIDS. Instead, participants regularly referred to the gradual accumulation of bits of information, ranging from professional pamphlets and AIDS education materials to word of mouth and information provided by friends, peers and partners, and occasionally by siblings.

There appeared to be an unquestioning acceptance of the information that had been received from these sources. The group discussions mostly showed a lack of critical assessment of sources. Information was generally considered to have been both of good quality and credible.

A few of the small number of exceptions to this trend were:

"Some of the things these people said were not clear" (8), and
"They portray sex as a bad thing" (8)

EXISTING SOURCES OF KNOWLEDGE ABOUT HIV-AIDS	
SOURCES	**Level of mention in discussions**
Health workers, AIDS organisations	Uniform
Clinics	Uniform
Newspapers	General
Radio	Sporadic
Pamphlets	Sporadic

"I disagree that it is by talking about it that we can stop the spread of the disease. Everybody is talking about it. So why is AIDS still spreading?" (22)
"People talk about it all over the place" (25)
"In our communities discussing sex is taboo, there is a gap between parents and children. They tell us there was no AIDS in their days, because they were not sexually active" (26)
"Young people know more about AIDS than us, because most of us think that AIDS and sex are taboo subjects" (31)

Existing community communication structures on HIV-AIDS

The sources of information on HIV-AIDS only show some extent of overlap with the circles in which participants report that they generally speak about HIV-AIDS.

The discussion of these sources, however, does not imply that all participants discuss HIV-AIDS in their social circles. It appeared to be more common amongst men than women to assert that they "do not really" discuss the issue. This might be a "culture of group bravado", or it might truly be the case. Others pointed out that men do talk about it, but often in the context of joking references.

EXISTING SOCIAL COMMUNICATION STRUCTURES IN TALKING ABOUT HIV-AIDS	
PARTIES IN COMMUNICATION	**Level of mention in discussions**
Friends	Uniform
Peers	Uniform
Health workers	General
Parents	Sporadic

The following voices indicate some of the participants' assessments of their social communication on HIV-AIDS:

PARENTS
"My mother does talk to me about it, but she is not free to talk about it" (10)

"Some parents have more information about the disease (than us), but they discuss things in bits and pieces … Most parents do not even call certain things by their name" (10)
"Eish, you can see for yourself that we don't speak to parents about this" (2)
"The parents have a shy way about it, but the teenagers are outspoken" (5)

FRIENDS

"If we are just chilling, we don't talk about it at all" (2)
"I never talk to anybody about it" (8)

HEALTH WORKERS

"I have spoken to a nurse. The doctors … they don't have time to listen to your problems when there is a long queue of people seeking his attention" (2)

THE "BE ABLE TO DISCUSS IT IN THE COMMUNITY MESSAGE"

Participants often acknowledged that it remains exceedingly difficult to openly discuss HIV-AIDS and possibilities of infection in the community.

"The people in the community will say we think we are smart if we discuss it with them" (10)
"It is not easy to discuss AIDS in the community" (10)
"Our people are ignorant, hence they have a problem with people who take the initiative to discuss things like AIDS" (10)

Others stressed how essential "talking about HIV is":

"It is important to talk about HIV daily. Educating people about AIDS should be an ongoing thing." (18)
"If all people get involved and 'own' the virus, then we will win the fight" (18)
"The more we talk about it, the more people will learn" (18)
"We need to be taught twice a week about the virus" (21)

And the importance of being able to talk about condoms:

"You find people lowering their voices when they speak about condoms … We should talk about condoms, even at the taxi rank" (22)
"We should divorce the dirty mind that we have about sex, let us not make it an issue. In that way I think we won't feel ashamed about what people say about condoms" (22)

Proposed structures for community talking actions

Participants had a range of suggestions on structures to use in taking forward "community ownership campaigns". These might be conducted in the form of workshops – women for women and men for men, or government working

together with NGOs, or Saturday morning youth forums, or entertainers dedicating chunks of their performances to “HIV ownership actions”.

SECTION 4:
GOVERNMENT IN HIV-AIDS SUPPORT AND COMMUNICATION

"The government will have to help us adjust our behaviour … One way of doing it would be to make sure that all our leaders will be talking about it, also the community leaders and people in local government" (6)
"People living with AIDS need financial support for medical attention" (11)
"Orphans should be cared for, so that we can truly see that the government is concerned" (31)
"Our traditional leaders should do research, using their own methods" (22)

SECTION EXECUTIVE SUMMARY

- The dominant public-mind image of what Government in the period of the fieldwork was doing on the HIV-AIDS front pertained mostly to the AZT issue. There was consistent support for Government making available all possible drug treatments to HIV-AIDS victims, even if expensive and with minor prospects of success. Only three of the groups felt that social spending for instance on water or housing should take precedence over the treatment of HIV-AIDS.

- There was also an insistence that government should be seen to be taking action on every possible front, and that government should help people understand the nature and range of its efforts to make a difference to the world of HIV-AIDS. If necessary, and participants frequently pointed out that it was essential, public funds should be directed away from wasteful public spending and concentrated in countering the epidemic.

- The major fields of responsibility of Government, in the minds of these group participants, can be construed in the form of a hierarchy. Firstly, government should make drugs and all possible medical treatments available to victims. Secondly, they should facilitate and fund research into finding a cure. Thirdly, they have the responsibility to take the lead in social and welfare caring of victims. In the fourth place government has to provide information, and help change behaviour (through information, direct communication and "leading by example").

Participants unambiguously felt that government has the responsibility to play a central role in combatting HIV-AIDS. Others, in contrast, felt that the task would be better achieved by health workers, or that government would only have credibility in information functions should they also be seen to be taking more action. There were also strong sentiments in favour of government extending and amplifying their efforts.

"Whatever government is doing, they are not doing enough" (17)

What government is seen to be doing on the information front

Participants were asked what they have heard politicians say about HIV-AIDS. The trend was that the information that was received was seen as educational and cautionary -- most groups reported that they had heard politicians warn against the dangers and give advice on sexual and social behaviour.

The following is an overview of things that they reported having heard from politicians:

- Practice safe sex, condomise, be faithful to your partner, have one partner, "no condom – no sex".
- A friend with AIDS is still your friend, we must respect people with AIDS.
- AIDS is incurable.

What government ought to be doing on the information and caring front

Government had a poor image amongst these participants in terms of action on the HIV-AIDS front. Government is generally associated with dissemination of health information that is relevant to HIV-AIDS (also through health workers), information disseminated through the media, and involvement in the battle to find a cure or a vaccine. In addition, the involvement of politicians, public officials and the current and previous presidents generally are viewed favourably.

<u>Government action on AZT:</u>

Participants very commonly held the view that the government, and President Mbeki himself, had erred in the decision to withhold the administration of AZT to pregnant women. They mostly flatly rejected the assertion by President Mbeki that the drug could be harmful. At best, participants insisted that better reasons be supplied for his statements and the associated withholding of the drug. Most participants (both women and men, but women more emphatically than men) felt that government had the responsibility to make funding available for proper drug care in the face of what they are experiencing as a national crisis. They occasionally referred to wasteful government expenditures (including public sector salaries, luxury cars, inaugurations and

other ceremonies) that make a mockery of the perceived government stand that drugs such as AZT are not affordable for a country such as South Africa. Several participants said that the only proof that government can now give that it actually cares about South Africans would be the act of making AZT available to pregnant women.

"I feel that the government is ignorant because they do not allow pregnant women to use AZT" (10)
"The government seems to contradict itself by saying that they care about the issue of AIDS, whilst they disallow the use of AZT" (29)
"Think of people's souls, because you don't know how much they cost… They should be given AZT" (2)
"It is not enough for the government to say they are concerned about HIV-AIDS while they do nothing" (10)
"How can the government say that the drug is dangerous? How can they differ from medical specialists? I can see the government has very little to offer" (4)
"If government cares so much about the well-being of South Africans, why do they not allow the use of AZT to pregnant women?" (8)
"We know that the government will give AZT to pregnant women" (14)

Government responsibility for research:

Government is seen as the agency ultimately responsible for encouraging and facilitating the finding of a cure or a preventative vaccine. The discussions attested to either a trust in government (as the agency responsible for finding solutions to all problems), or conferring the responsibility on government because they simply do not know who else is to assume such responsibility.

It is government's job, in the views of these participants, to do the following in terms of helping to find a cure:

- ensure that adequate funding is made available for research;
- encourage research into finding cures and vaccines;
- bring the latest on international research to ordinary people;
- allow experimentation with promising new drugs;
- give "inyangas" or sangomas a chance to prove themselves.

Participants wish to feel that they, together with government, were engaging in a mutually trusting and fully informed relationship on medical progress. Despite criticisms, there were feelings of deep general trust in government. The voices in these focus groups suggest that government will be trusted to set the tone and the agenda for funding, encouraging and conducting research. Yet, these people want government to come "down to the community". As ordinary South Africans they feel they know the needs, and want to see government act on precisely these issues.

In this process, the government would have to overcome various negative images which prevail regarding government and its facilitation of research.

"The government turns down South African findings about AIDS" (15)
"Government should allow all drugs that researchers come up with, so that there can be enough experimentation" (10)
"Sometimes I see the government getting confused. If someone said here is a cure, like Virodene, the government opposes that and claims that Virodene does not cure AIDS" (2)
"There are complaints that whilst Panados are easily available, the one that can help for AIDS is not affordable …" (2)
"Government should monitor the progress made by scientists all over the world" (8)
"Government should continue with the experiments to find a cure" (6)

Participants, especially from the rural areas, also want government to enlist the help of sangomas in research on HIV-AIDS. This was anchored both in cynicism about western medicine being able to make a breakthrough, and in hearsay that some sangoma, mostly unidentified, had indicated that he knows about a cure. Various participants reported having heard that "a sangoma" is reputed to have found a cure. Some believe that the government should give more encouragement to sangomas to do research and find a cure. Others simply state that the western medical profession has not been successful, so rather give traditional medicine a chance.

"There is a traditional leader in our community who says he can cure the disease, but there is nothing he can do due to lack of money" (22)
"Our traditional leaders should do research, using their own methods" (22)
"There is a traditional leader who people say can cure AIDS, so he should be given a chance" (28)

Sangomas received various generally favourable mentions, especially in KwaZulu-Natal, Mpumalanga and Northern Province groups.

"We know there is no cure for it, although I heard that one sangoma can cure it" (4)
"The traditional healers should be given a chance, and government should stop undermining them" (4)
"I think traditional leaders know about the human body, so I think they are better than doctors" (22)
"When our parents were young AIDS was curable, and the traditional leaders used to help in this regard" (26)

<u>Action in social caring:</u>

Government could be doing much more to demonstrate their concern and caring for the victims of the HIV-AIDS epidemic.

Participants strongly felt that government has the following direct social caring responsibilities:

- Better clinic availability and more access to HIV-AIDS materials at clinics;
- Caring for the AIDS orphans, a responsibility that is already placing huge burdens on the community, and especially on women;
- Improved access to centres for testing and therapy;
- Caring for the AIDS-ill people in society, and at least equipping ordinary people with information and advice, and facilitating community assistance in this caring function.

"Government should take care of the terminally ill in their last days" (10)
"Why does government put such little effort into helping AIDS victims?" (8)
"Government should go to the rural areas, these people have no clinics, and they are ignorant" (28)
"People living with AIDS need financial support for medical attention" (11)
"Orphans should be cared for, so that we can truly see that the government is concerned" (31)

Government as information provider:

The core function of government is seen as taking the lead in the provision of information. Many participants felt that government cannot assume the function of changing people's behaviour. But the strongest voices were those that felt that government has to take the lead in facilitating change in behaviour.

- Participants often lamented the fact that they did not have easy and complete access to all health information that concerns them and in particular relates to their social and intimate actions.

- They also felt the need to receive regular and full, yet accessible, information on social support services and available medical support services.

- Married and rural women often expressed the need for information that they could use to empower them vis-à-vis the men in their lives.

- Various groups stress that government should act to start systematic AIDS education at school level.

"The speeches that I have heard so far have been irrelevant. They were talking about AIDS and how prevalent it is among the youth, giving us lots of statistics, but they did not talk about how it is transmitted. Only if they can come up with speeches that tell us how it is transmitted, without beating about the bush …" (2)

"Change our behaviour … Start from school level" (30)
"More information will definitely help change people's behaviour" (31)

In various groups there were mixed feelings about government supplying condoms. They were not convinced that it actually is useful. The overall feeling was that free condoms should be supplied, and in larger volumes than at present, but only in contexts where they actually will be used and not get used for fun and joking.

Government responsibility in changing people's behaviour:

Most of the focus group voices stressed that government should make all possible contributions to help change risk-behaviour. They stressed that ultimately government bears the responsibility for what happens in the country. There was realism too, however, in that most participants also acknowledged that, in the final instance, it is only the individuals themselves who can ensure altered behaviour.

"I don't think the government can change people's behaviour, only a person is capable of changing his own behaviour" (6),
And later on in the same discussion:
"The government will have to help us adjust our behaviour … One way of doing it would be to make sure that all our leaders will be talking about it, also the community leaders and people in local government" (6)
"Only the people themselves can change their behaviour, but it is the job of the government to try and influence them" (11)

Government's role in verbal demonstration of caring and leading by example:

There were diverse feelings about government's image in expressing care for the victims of AIDS. All agreed that it is good that government will show caring and concern. Many, however, expressed doubt whether government has been sincere in its expressions so far. This scepticism resulted from government's position on AZT, the perception that government is not doing all it might to help find a cure, and the experience of the paucity of social support services.

There nevertheless was near-consensus that it is good that government does express concern. The Mbeki statement on government commitment to address the HIV-AIDS problem, with intensified commitment, mostly elicited highly positive reactions.

"The president is an influential figure, so, surely his involvement will have a good impact on people being aware of AIDS" (10)
"Mbeki is respected. He will influence many people" (19)
"He leads by example. He can review what has been done so far. But we also want action" (8)

“The president loves his country, so he will do anything to save his people” (14)

Participants, however, also expressed doubt about President Mbeki’s sincerity and commitment to action:

“He does not know what it is like to have AIDS. Reviewing the work that has been done so far, is something else. All that we want is practicality … We want action” (8)
“Government can show they care by tightening the laws… Too many foreigners come here” (25)

SECTION 5:
COMPONENTS AND FORMATS FOR FUTURE COMMUNICATION STRATEGIES

"If I see someone that I admire, like Lucas Radebe, holding someone with AIDS and I also have AIDS, that will help me find acceptance" (4)
"Mbeki's speaking about it shows that it is everyone's problem" (5)
"I think there is nothing better than actually to get people who are experiencing infection to come and say 'This is how I am living, and I am going to die, and you do not do the same'" (5)
"I think I believe the information that I get, but I want to hear it from somebody who is already AIDS diagnosed" (30)

SECTION EXECUTIVE SUMMARY

- The inputs from these focus group participants suggest that there are several communication actions through which the Government might start a new intervention into the HIV-AIDS issue. Government could launch action through a definitive statement of its commitment to deal with HIV-AIDS, and to do this in co-operation and in contract with the people of South Africa. There is also a need for Government to legitimise public debates and to do this with full community involvement. Furthermore, Government should help build a heightened culture of tolerance of HIV-AIDS victims. This will facilitate disclosure and public debate.

- The discussion further indicates the need for a phased Government communication strategy. Beyond the affirmation of a "contract with the people", there can be legitimisation through high-profile forums engaging, for instance, celebrities and religious leaders. All significant community leaders need to be involved. "Information sweeps" through the countryside and cities should be built to satisfy the widespread need for detailed information. Youth leaders and other public figures need to co-ordinate "speak-out" events.

- The findings indicate that a range of positive (asserting the chance to decide for life over death), positive-negative mixes (mostly empowerment and the right to chose safe sex) and negative messages could combine to provide the message content of a future communication plan.

Essential components of HIV-AIDS messages would be :

- Government is entering into a "contract" with the people
- The time has arrive for the "breaking the public silence"
- Sexual behaviour and prevention/cures – end denial, face up to realities
- Gender and sexual power relations –empower women and children, and do this in the context of the gender-age-socio-economic realities.

This section will highlight the “credible and effective messenger” aspect of communication strategies, select communication actions, and potentially effective formats for communication actions. It also gives a summary of a number of the pivotal messages that emerged from the research.

MESSENGERS – CREDIBILITY AND ROLE DIFFERENTIATION

The research assessed a range of possibly effective and credible messengers in future HIV-AIDS communication processes and campaigns. First, there was the high-profile celebrity and political leader category. Participants regard these communicators as essential in giving stature, credibility and role model status to HIV-AIDS communication. Second, there are the messengers that would be best suited to communicate the more intricate details of infections, cures (or the lack thereof), safer sexual practices, and information on social support structures (both in medical and community caring terms). Third, there are the community support and communication anchors, which can drive and help sustain extended and continuous community communication actions.

Messengers with celebrity and religious leader status

Entertainers, television presenters and sport stars were the first tier choice of almost all group participants upon being asked who they thought would be effective in helping carry forth messages of AIDS-prevention. In addition, religious leaders and the churches were highly rated as top-communicators.

> Their reasons for choosing celebrities as communicators:
> “Celebrities are the role models. People will listen if they talk” (5)
> “Being famous can make people listen and consider what you say” (31)
> “If we can get Kaiser Chiefs to come and play against a squad from Ulundi and have speeches after the match, perhaps if Odameesta could come, people would listen” (2)
> “If I see someone that I admire, like Lucas Radebe, holding someone with AIDS and I also have AIDS, that will help me find acceptance” (4)
> “I think entertainers will do the trick because many people like them. They can spread the message at music concerts or festivals” (10)
>
> Religious leaders and churches:
> “We need to talk about this, even in our churches. And they must do it in ways that people can relate to. They must not talk about abstaining. Then they lose the people” (1)
> “Use celebrities, because some people do not like going to church” (31)
> “Entertainers seem to encourage sex with their lyrics and the way the dance. Churches and religious leaders can help us learn, because at the end of the day we are all gonna die” (10)
> “Religious leaders because the community respect them” (11)

The role of politicians – initial ambivalence followed by support

Participants in these groups often had mixed feelings about government in anti-AIDS campaigns. On the one hand, they most strongly felt that the government had a massive responsibility to try and do something to prevent the spread of the epidemic, to inform and to provide and facilitate care of the victims (also see Section 4). On the other hand, across groups there was a strong sense of cynicism about "government just talking and not doing much". There is also cynicism about government's sincerity.

"They do not commit themselves; all they do is just talk" (17)
"The government is just concerned about the rich people in the cities. They will not come here to the rural areas" (30)
"The government and politicians just take their own decisions. They never care about the next person's feelings" (22)
"I don't think they care, they just want our votes" (29)

On the micro-level, this was reflected in opinions regarding statements of Thabo Mbeki. Quite commonly, there would be some cynicism, especially with regard to the Mbeki statements on AZT. However, as soon as participants heard quotations of commitment to fight AIDS, even the cynics turned around. Participants appear to be holding out hope that indeed government will be proactive.

"His (Mbeki's)speaking about it shows that it is everyone's problem" (5)

Politicians of high standing would be as acceptable as entertainers to help spread the initial message on countering HIV-AIDS. Many thought that it was indispensable that high-ranking politicians be associated with HIV-AIDS communication campaigns, especially to raise consciousness and to clarify the roles and activities of government. This was not only because of the need for politicians to show compassion, but also because the effects of the disease ultimately would impact directly on government.

Participants stressed, however, that not all politicians might be seen as "leading by example". Thabo Mbeki was seen as a credible politician in "leading an exemplary life". Many KwaZulu-Natal women in these groups for instance regarded King Goodwill Zwelethini as "inappropriate" because of his polygamous status. The Minister(s) of Health (referred to in the discussions in terms of both the previous and the 1999-appointed ministers) were poorly rated as "good sources of information", with low credibility on the issue of HIV-AIDS.

<u>Politicians:</u>

"When you are trying to fight for your rights as a woman, seeing that the situation is bad, they tell you that it is a Zulu tradition to have many wives, even the King himself has many wives" (3)
"If politicians of high standing talk about it, then people will believe it, because (the politicians) know what they are doing" (2)

THE "ALL OUR LEADERS SHOULD BE TALKING ABOUT IT" MESSAGE:
There was general support for the message that included the phrase that all the leaders of the country should be talking about the "epidemic of AIDS".[15]

Agree that it will help if the leaders speak out:
"If our leaders talk about it, we will know that AIDS is real and that it is killing people" (15)
"If our leaders talk about it I am sure we will practice safe sex" (15)
"Influential people are listened to when they talk to people" (10)

Feeling that it will not help:
"There is nothing that the government could do to help us adjust our behaviour. Only we ourselves can do it" (9)

Communicators on the medical and personal details

Participants were virtually unanimous in their identification of community leaders and HIV-AIDS specialists who need to be involved in HIV-AIDS communication programmes. None of the groups chose just one type of specialist communicator to take forward the message of HIV-AIDS prevention and care. Community leaders, health workers (for instance clinic staff), specialised NGOs, local leaders, youth leaders, and community church and religious leaders were the most commonly identified types of participants required for HIV-AIDS communication.

MAJOR CATEGORIES OF HIV-AIDS COMMUNICATORS	
CELEBRITY STATUS	**COMMUNITY STATUS**
Entertainers, sport stars	Church and religious leaders
Television and radio presenters	Health workers
Politicians	Community leaders
	Youth leaders
	Teachers and educators
	Local government leaders
	Politicians and political parties

[15] "If we are serious about fighting the epidemic of AIDS, the Government will have to help us to adjust our behaviour as well. One way of doing it would be to make sure that all our leaders will be talking about it, also the community leaders and the people in local government."

THE RANGE OF COMMUNITY LEVEL COMMUNICATORS

"Community leaders should know more about AIDS, so that they can call meetings about it" (4)

"The teachers should help, because they are with the children all of the time" (4)

"Schools can help, because children will be conscientised while they are young" (12)

"Youth leagues must go around and visit people. They must work with the community structures" (1)

"Political parties, because people know they have always been there for them" (31)

Role differentiation in HIV-AIDS communication

Various institutions, organisations and individuals exert authority and possess credibility in HIV-AIDS communication. There are also different fields of authority. The following table presents the "types of credibility and authority" as reflected in the focus group discussions.

INSTITUTION, PERSON, ORGANISATION	TYPE AND ROOTING OF AUTHORITY
Government, the President	General authority inspired by notions of responsible, caring government; ability to "help find a cure" through inspiring research and dedicating resources
Entertainers, media personalities	General authority based on role models and aspiration to good life
Religious, community leaders, traditional leaders	Authority founded in caring and knowledge of the people
Health professions	Authority rooted in expertise in the field of medical, infection trends
Teachers, educators	Authority in contact, understanding and knowledge of the youth
Youth leaders	Ability to mobilise and speak in the language and experience of the youth
People living with HIV-AIDS	Authority on the issues that is derived from the credibility of "being there", living with the infection

Phased activation of communicators and messengers

First tier messengers:

This tier of messengers should convene high-level, high-visibility unifying action in a commitment to address the problem of HIV-AIDS (for instance in the form of general and specialised summits, "rolling action" across the country). These messengers are:

- Media personalities (actors, announcers) and entertainers;
- Government (especially the President);
- Religious leaders;
- Sport stars and sport celebrities;
- Leaders of all political parties;
- Provincial and traditional leaders.

Second tier messengers:

This tier of messengers would, for instance, act in forums on both the national and especially the community levels. They would provide both the much-needed detailed information, and legitimise and facilitate community debate. These messengers are:

- The health professions;
- The teaching professions;
- Youth leadership;
- Traditional leaders.

Third tier messengers:

These messengers would take national initiatives forward on the challenging level of community engagement in activities, including public debate and "adoption" of the issue of HIV-AIDS. Messengers on this level include:

- Youth task forces in information sweeps of the local living areas, workplaces and places of relaxation and entertainment.
- Community and local political leaders.

All-tier messengers:

PLAs could engage on all levels of communication. Because of the widely expressed need to see, hear and talk to PLAs, this category of messengers might be engaged both in high-profile national events and in community action (see the more detailed section below). PLAs operating in groups might be most effective, because of the portrayal of the "range of faces of people living with HIV-AIDS. "People living with people living with AIDS" (and HIV) could supplement actions by PLAs.

People living with HIV-AIDS as the optimal communicators

Participants across the board had consensus that communication from people who actually live with HIV, and especially AIDS, would the most powerful of all messengers. It would drive home the message that everybody could be

affected. It would reinforce the message that there is nothing that protects except for protected sex.

"I think there is nothing better than actually to get people who are experiencing infection to come and say 'This is how I am living, and I am going to die, and you do not do the same'" (5)
"I think I believe the information that I get, but I want to hear it from somebody who is already AIDS diagnosed" (30)
"These are just the statistics. We also need to see these people living with AIDS, so that we can believe it's true" (22)
"Most people do not practice safe sex because they do not see people living with AIDS, or dying from it, in person" (31)
"I did not believe the information we got from the youth project, not really, because I have never seen an AIDS victim" (26)
"I would prefer a victim, because he would know what it is like, or you would be seeing the physical symptoms" (30)
"It is only those who lose friends and relatives who learn" (31)
"People can only learn by seeing things happen in front of them" (31)

Amongst people living with AIDS there was a willingness to act to carry forward the message, provided that there is a minimal and safe level of tolerance in society.

"It is people living with AIDS that the ordinary people will come and listen to" (18)
"Ostracisation happens, but that does not mean that we have to keep quiet about our status, because, if we do, the figure will keep on rising" (18)

The need for communities to unite and start talking

Women in these focus groups lent strong support to the notion of uniting and supporting other women in their dealing either with AIDS or with other victims of AIDS. A number of these women mentioned that it needs to be more than just women uniting, but most felt that there was more certainty in getting women together (possibly in tasks that already have fallen on their shoulders).

SELECT COMMUNICATION ACTIONS

A number of suggestions emerged regarding ways in which Government might approach renewed initiatives to counter the HIV-AIDS issue. Detailed information, accessibility of information both on infection and on caring / "living with AIDS", and the facilitation of community engagement in the process of countering HIV-AIDS emerged as three core aspects. (These actions are apart from the direct Government responsibilities that were analysed in Section 4.) The suggestions emerged either directly from the discussions or could be deduced from the needs expressed in the course of the discussions.

Suggested actions include:

- Government legitimisation of public debates and community engagement;
- Legitimisation might include calling high-profile public forums and summits in which all significant groupings of leaders would be engaged (including religious leaders, traditional leaders, sangomas);
- Building a heightened culture of tolerance of HIV-AIDS victims in order to facilitate disclosure;
- A tolerant culture in turn could lead to more people living with AIDS being prepared to go public and "educate" vulnerable groupings;
- Youth leaders and public figures co-ordinating "speak-out events" might inspire safer sexual behaviour;
- Political leaders (on all levels) leading by example in organising, facilitating and supporting community care efforts;
- Youth movements and government doing joint "information sweeps" across the provinces, in which all villages, towns and cities / townships are saturated with relevant information.

The case for public disclosure

Public disclosure and community engagement in all efforts, but particularly in actions to prevent and to care for victims, emerged as crucial bottom-up components of HIV-AIDS management strategies.

"Our children may get to realise the seriousness if victims would confess" (3)
"People should confess, because it is becoming obvious that this disease is going to kill us all" (3)
"People living with AIDS will be listened to … People want to see for themselves if AIDS is real or not" (10)
"The information we get tells us about what causes AIDS and how it affects the body, but we wish we can see a person living with AIDS" (9)
"It should be said that so and so is suffering from this disease as this may alert us. We may get to realise that it may soon be our turn" (3)

The message from these groups also was that disclosure could only realistically be expected if government can guarantee both the care and the safety of individuals should they still be "excommunicated" from their own communities and even be physically threatened.

POTENTIALLY EFFECTIVE FORMATS FOR COMMUNICATION MATERIALS

Research participants had various suggestions on communication formats that might, or might not, work for them. There was consistent support for accessibility, relevance and straight-talking as points of departure in whatever communication materials might be used. Different groups and individuals had preferences for different types of materials and communication methods. There was consensus that whatever the print and electronic communication methods, these cannot substitute for direct talking in the communities – both talking by leaders and public figures and talking / education within the communities.

Talking:
In the words of these participants living with HIV-AIDS:

"Talking works better than pamphlets. People read a bit of pamphlets and then they leave them on the streets. They often are too scared to take the pamphlets home. Their families will suspect them" (1)
"Some people throw away pamphlets… It is important to distribute them into the home, not to wait for people to take them home" (18)
"It is better for things to be communicated orally, like in the church, or in Saturday morning meetings with the youth. There should be open discussion, talking in a way that parents can't do with their children …" (1)

Pamphlets:
There were different feelings about the use of pamphlets. The bottom-line appeared to be that pamphlets work, but not in isolation, and not in situations where people are still afraid to be seen publicly reading these pamphlets.

"We really will like pamphlets and posters, even to put up in our homes. Then our husbands will be reminded … And it will be easier for us to talk about this thing" (8)
"Giving people pamphlets is like overloading them" (1)

Posters:
The groups' discussions around AIDS education materials indicated that posters might be useful, but only if they convey a message in clear and accessible ways. For instance, people walking by have to be able to take in information in "one glance", and posters should also be clear to semi-literate and even illiterate persons.

"We are lazy to read. We have no time when we are walking in town to stop and look at posters …" (1)

Radio and television:
Radio was a major source of HIV-AIDS information for many research participants. It was also the case for both rural and urbanised people. People living with AIDS, who have been involved in AIDS education, stressed that television would be highly effective in reaching target groups of youth.

> "Our fellow black people do not want to read anything … They just want to watch it on TV" (1)

OPTIONS FOR STYLE AND FORMAT

Participants offered the following points of advice regarding the style and format of communication materials:

- The language should be simple;
- Pamphlets and brochures should be accessible, no information overlaod, yet offer significant information;
- Speak in the language of the age group;
- All languages should be used; not just the major languages;
- Use pictures and colour.

See Appendix 2 (in handout form) for details on participants' assessments of existing HIV-AIDS education materials.

A SELECTION OF POTENTIALLY EFFECTIVE MESSAGES

Indications from these focus groups were that both positive and negative messages will work, both to empower people to assert themselves in sexual relations and to motivate them to change behaviour into safer sexual habits. (Note that Sections 1-4 provide the essential backdrop to the current "Selection" of messages.) This section first outlines potential messages along the "positive"-"mix of positive and negative"-"negative" dimension, and then specifies a number of essential content directions for messages in a campaign to help address the HIV-AIDS issue.

Positive, positive-negative and negative messages

Positive messages:
The message "Protecting one's health and with this disease, one's life, is never silly, never ever. This is what learning about AIDS is all about", for the obvious components of life-protection-health-learning, elicited an almost visceral level of agreement in all of the groups.

Furthermore, messages of personal empowerment (especially of women vis-à-vis their sexual partners of the male gender) would enhance the ability of most women to engender safer sexual relationships. It was particularly women

from the more traditional, rurally-based cultures who needed external help in asserting themselves in marriage relationships (often also polygamous situations). However, even highly urbanised, assertive and single women related experiences of men stereotyping them as loose and immoral when they want to ensure safe sexual relationships.

Positive-negative mixes:
Repeated evidence in these discussions suggested that shock messages, and with shock on the personal rather than for instance the attempted statistical level, are likely to have the most effect.

Both men and women (of all ages and relationship statuses) acknowledged continued unsafe sexual practices. Furthermore, they recognise these practices as unsafe. But few of the participants appeared to be able to envision the transition from unsafe to safe.

Fear and uncertainties, these discussions show, form essential parts of the sexual lives of the focus group participants. It is part of the reality within which communication strategies would have to be situated in order to have the ring of realism and to have effect.

Negative messages:
The participants' own dialogues and stories mostly suggest that images of death often enter into their sexual relationships. Even if they, at the times of sexual intercourse, "choose" to forget about safe sex, it is on their minds much of the time both before and after. For others, there continues to be denial and beliefs in invincibility ("it will not happen to me"). Many are conscious of the fact that their practices of sexual intercourse equate flirtations with death. The reality of delayed consequences make this a relatively "easy" game.

Reinforcements of the message that "cures" and "vaccines" in all likelihood will come too late to save the lives of the "currently-sexually-active-and-irresponsible" generation would reduce beliefs of invincibility.

> Participants, almost unanimously, denied that they believe that a cure is in sight was influencing them in practising unsafe sex. In other parts of the discussions, however, there was a consistent preoccupation with the discovery of a cure, or a vaccine. Most participants felt that the government was not doing enough and should be doing much more in facilitating the finding a cure or a vaccine. A small number of participants blindly asserted a belief that the government will find a cure (because they care about the people of South Africa). There is a need for honest and detailed information to the public on the lack of medical solutions.

Participants repeatedly related their desire to encounter victims who can, directly, bring them the message of possible death. Many were convinced that this would help them change their ways.

The group discussions delivered mixed evidence on the deterrence value of fear. At this stage, unprotected sex often prevails, despite seemingly clear deaths from AIDS in the communities. The weight of evidence, however, suggested that the observation of deaths in society was busy driving home messages on the necessity of adjusting sexual behaviour. Sexually active people, it appears from the research, have already taken the first step – that of recognising "that we commit suicide with condoms in our pockets". Given the suitable encouragement and empowerment, actions of safe sex might follow.

Presentation of the evidence of the process of unfolding illness emerged as a potentially powerful message. Most of the groups articulated the need to know more about symptoms. They were unsure about what people look like at different stages in the HIV-AIDS process. Graphic linkage of the early, healthy-looking phases to the slightly ill and terminally ill person (even if this could take on many different manifestations) might drive home the message of "playing with death".

Essential elements of the messages

Government entering into a "contract" with the people:

- Government, together with the people, to tackle the HIV-AIDS problem in an open and caring but "brutally honest" way; the caring government living out the trust of the people in tackling the issue.
- "We are a caring government … We need your help, on our own, we cannot do it". People want to see evidence that Government is "living the problem" with them, that Government does more than talking.
- A contract between government and the people, government can and will do that much, and all that it can, but cannot succeed on its own

Breaking the public silence:

- Make the move from talking on the individual level, and living with HIV-AIDS (or living with people who live with HIV-AIDS) to the level of openly addressing the issue in public and on community level; extending privately felt sympathy into the public domain.
- Breaking the public silence… "Be real, we are already living with HIV-AIDS, we care for the victims or their dependents, we talk about it to our friends and peers, it is a major fear in daily lives of many of us, let's talk about what we can do together with the community and government."

Sexual behaviour and prevention/cures:

- Bringing home the vulnerability of all of the sexually active (both the reckless and the innocent), blocking denial, facing up to the implications of reckless sexual behaviour, reinforcing the knowledge of the evasiveness of a vaccine and low probability of a cure.
- Exercise "the right to protect your life".

Gender and sexual power relations:

- Empowerment of women and vulnerable people in general (with segmentation of messages in terms of the gender-age-socio-economic dimension);
- Gender empowerment in relation to “the right to protect your life”; women have “the right to say no”.

APPENDICES

APPENDIX 1:
DISCUSSION GUIDE

Note:
Discussion guide available from Susan Booysen

APPENDIX 2:
ASSESSMENTS OF EXISTING HIV-AIDS EDUCATION MATERIALS

Note:
Available in handout form