

Beyond denial – women’s dilemmas and choices around HIV-testing, treatment and disclosure

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abstract

The experiences of a group of women from the Lower South Coast region of KwaZulu-Natal highlight the ways in which lack of information, fear and denial, gender inequality, stigma and discrimination together maintain a deadly grip on women’s efforts to make choices about their reproductive and sexual well-being. Interviews conducted with four women, who are all living openly with HIV and are all involved in counselling or care work, reveal the blame and judgment that even relatively ‘empowered’ women face from partners, family and community members, and from predominantly female health workers.

While the women relate their personal histories and discuss the challenges they have overcome as individuals, their stories draw attention to a range of issues that affect many women’s sexual and reproductive health rights. Based on their experiences and their encounters with other women who face dilemmas about testing, disclosure and treatment, the interviewees offer insights into the changes that need to happen to secure women’s rights to control and care for their bodies.

keywords

HIV, denial, dilemma, choice, pregnancy, testing, treatment, disclosure, stigma

Pam’s story¹

‘My name is Pam and I live in Murchison. I am 31 years of age and a mother to two boys, one aged 17 years, and the other 10 months. I have been living with HIV for 13 years because I did my HIV test in 1995. My first pregnancy was a result of rape by my boyfriend. I would say I am not sure if I contracted the virus then but my son is healthy.

‘Shortly after I gave birth to my first son, my father passed away due to political violence. He was the breadwinner at home, my mother

could not look after us and I just had a baby. What my mother told us was that we have our bodies so we must use them in order to survive. I started to sleep around with different people so that I could support my son.

Testing

‘Eventually, I started to be sick with headaches, STIs. I did not want to use my local clinic because of what the nurses could have said about the STIs, I went to see the private doctor. After few consultations he suggested that I should consider doing an HIV test. I

delayed because I was scared about the results, because I thought that after the life I had been living, my chances of being HIV-negative were few.

'When I went for my test I did it with my doctor. There was no counselling done; he wanted us talk about it but I told him that I was only interested in knowing the results. I had to wait for three months for my results. I told my friends that I went for an HIV test but I was still waiting for the results and I promised them that I would tell them what happened. I would say, I think I was fine at that time. I told myself that I should know. When my doctor told me to see him and when he told me that I was HIV-positive, I was worried and I thought of dying, and I never informed my friends about my results and when they enquired I told them there was a mistake at the laboratory so I had to redo my test. I felt they were going to stop being my friends if I told them the truth. I blamed my mother and the father of my son, who raped me and never took the responsibility as a father.

'I wanted to be a doctor, to have my own house, car and everything that young people dream of when they are growing up but this all changed after the rape and when my father passed away.

'At school, I started to bunk classes because I did not see any reason for continuing with my studies since I was going to die. If I knew that, by now, I would still be alive, I would have continued with my studies.

Disclosure and acceptance

'I did not accept my status in the beginning, I thought there was a mistake, although I knew about my sexual behaviour. I changed doctors to get other opinions. I only accepted [my status] after about six HIV tests.

'My mother was the first person that I told about my status and she was supportive shortly after I knew that I was HIV-positive. It took me six years to come out in the open about it. There were mixed reactions from people in my community. Some were supportive, i.e. religious leaders. Other people reminded me of the life I had been living, of having many sexual partners and they told me that being HIV-positive was the result of that behaviour; others wanted to know what I was using to keep me alive, was I not scared that I knew I was going to die?

'This all happened after I had been sick for a long time and it was for this reason that I decided to disclose my status to other people, so that they can see that if you are HIV-positive it does not mean you are already dead or you must wait for your dying day. I felt that I was given a second chance in life.

'What helped me to cope with my status was the involvement in projects within my community. Physically, I looked well but emotionally I was dead. But sharing my story with other people that I have been working with made me realise that other people have a lot to deal with so that is why I decided to look at the positive side of life.

Second chance, second challenge

'My second pregnancy was also unplanned. It occurred despite what the doctors told me when I was raped, that my womb was damaged and the chances of having more babies were very slim, and despite the fact that we were using condoms.

'My current relationship is with a married man, and he knows about my status since I disclosed a few years ago. Our son is 10 months old. When I found out that I was



OBINNA ANVADIKERINI

Home based care workers on their rounds in Mashonaland, Zimbabwe. In southern Africa the volume of people infected and affected by HIV and AIDS has overwhelmed public health systems and social services.

pregnant, I panicked and thought that I should terminate the pregnancy. When I went to the hospital, I was more shocked to find out that I was already six-and-a-half months pregnant. I told my partner and he was excited and supportive at that time.

‘Emotionally, I was devastated, I was scared that I was going to die or that I will infect my baby, although I was aware about Nevirapine but I knew that it was not 100 percent [guaranteed]. Another thing that worried me was that I was not working and had no income. I was depending on my boyfriend for everything.

‘During my second pregnancy, the health care

workers were supportive. I was on a PMTCT programme and immediately after he was born they gave my baby treatment. I was worried though about his health but I had to wait for six weeks for his results.

‘I attended an ante-natal clinic and I was given Nevirapine when it was my time to deliver. After giving birth, the support that I had from my boyfriend changed and I had to rely on other people to make ends meet.’

Nomsa’s story

‘My name is Nomsa. I am 42 years of age and a single mother of three children, aged 24, 14 and 11. We all live in Gamalakhe.

'I took care of my sick aunt for eight years without knowing what was wrong with her. She was bedridden. My aunt told the family that I was bewitching her in order to have her house when she dies. These allegations made my life very hard because some of the family members were planning to get me killed. When my aunt was sick, her boyfriend was also very sick and he died before my aunt. His family attacked me and they were claiming that I also bewitched him. But when my aunt was about to die, she confessed and disclosed that she was dying of AIDS and asked for my forgiveness. After her death, I decided to have an HIV test. That was in 1997. The test came back positive.

He refused to test saying that he can't contract AIDS because he uses traditional medicines

'I did not blame anybody because I think I contracted the virus while I was looking after my aunt, not knowing that she was HIV-positive. At that time I was staying with the father of my children and he was the first person to know about my status. He did not say much about it, he just said: "I told you that you are asking for problems now what are you going to do? Thinking that you are going to die soon?" I told him to also go and test but he refused, saying that he can't contract AIDS because he uses traditional medicines to clean his system. I think he thought he knew a lot about AIDS or he was in denial. I was dependent on him financially. Then I fell pregnant with my third child. I must say he did not want to use a condom and I did not know much about AIDS then so I did what he wanted. I knew he had many sexual partners and I think he was aware of his status that is why he used all the traditional medicines.

'I was not on contraceptives and I did not know much about them also. There is one incident that I remember, at the hospital when my second child was born, I asked the nurse what should I do if I want to do the procedure of not having babies again and she said I must not do it because I still need to have one more child, which is number of children allowed for caesarean mothers. I'm not that educated, so with that in my mind I knew I must have a baby soon. During my pregnancy, I was never told about any preventative measures since my status was known. I was not given Nevirapine.

'When my third child was eight months old, she started to be very sick and was hospitalised. She was tested for HIV and the results were negative but I am worried because she is always sick and suffers from seizures. My daughter's left side was affected by this sickness. Now she receives a disability grant and it helps us a lot.'

Nomsa has left her partner and is living with her children. 'I am also a member of Hospice because I think it is very important to prepare for the time when I fall sick. I'm not taking anything unless I feel sick. I try to take care of myself and do my CD4 count twice a year. In December I did one and it was over 500 and at the end of May it has dropped to 189. I am stressed about this and I think the cause is my new boyfriend who is very sick. I just found out that he is HIV-positive since 2001 and he did not tell me about this. His CD4 is 6 but he is in denial and he just went through a ceremony of initiation as *isangoma*. I am angry because he is lying to his family, and to himself.

'After my disclosure and my work as a care worker, a lot of people disclosed their status but did not want to tell their families. I'm working as a care worker in my community. We are



KRISTY SIEGFRIED/IRIN

Women are often blamed for bringing illness into a home.

employed by an NGO on contract basis. Most of the time we don't get paid and there are no places to report this because we are told that we are volunteers. We are only doing the work because people need us, although we are struggling to make ends meet.

'In general, people approach me if they need help. Sometimes they would tell me that they are HIV-positive and would like me to help them in telling their families about it. There is a case in my community where a young woman is very sick. She would like to tell her mother but her mother's attitude when it comes to AIDS is bad; she once told her that if she found out that one of her children had AIDS she would disown them.'

Ntokozo's story

'My name is Ntokozo. I live in Gamalakhe, on the Lower South Coast of KwaZulu-Natal. I am 28 years old and have been living with HIV for seven years. I am a mother of a 10-year-old girl. I went for my HIV test after I gave birth to my daughter, because I was sick with severe headaches and I used to be hospitalised. Nobody told me to test; I just thought I should go because I was aware of the situation around me, with people dying and talking about diseases that are not curable and that they are part of AIDS.

'At the clinic, when they told me that I was positive, I could not accept it. I was admitted to hospital for two weeks and whilst in hospital they counselled me more. My mother was the

first person I told about my results and I was crying a lot. She comforted and supported me. She seemed as if she was accepting everything but after a while she started to be sick with diabetes and when she was counselled, she told the nurses that after she heard about my status everything fell apart.

'I reflected on my past relationships, and remembered that my boyfriend had a lot of sexual partners that I was aware of, since he did not hide anything. I did not blame him or anyone for that matter. I knew that I was also responsible for taking care of myself or for using preventative measures like a condom.

I think I was scared to know that I was also HIV positive. I did not want to die

'After being in hospital, I agreed with my mother that we should tell the family because they were also concerned about my state of health, since I was in and out of the hospital. A family meeting was called where uncles, aunts and family elders were present. My mother told everybody. They were surprised and some were shocked because most of them thought that I should be thin and one of them said: "You look well to have AIDS. How do you know that you have it?" Then I told them about my headaches that they were the reasons I decided to have a test. Others did not believe me but were happy that at least I know what the problem is.

'In the beginning, I used to take some pills but decided to stop using them after realising that almost everybody uses them even if they are HIV-negative although I thought they were specially for HIV-positive people. I don't use anything at the moment.

'My daughter is also sick, she has a skin problem, and she visits the clinic regularly then one day the nurse asked me to consider taking my daughter for HIV test. I agreed, it was not a hard decision to make because I knew it was for the best. She is 10 years now I told her about it and she wanted to know if she was going to die and I reminded her that as she was raped when she was six she needs to do these tests so that we can be sure about her health. She tested negative. When she was raped, I found out the next morning and I took her to the clinic and we were referred to the hospital. I did not know much about these things then, and when we were taken to the social workers they asked me if my daughter was given the pill that you are suppose to take within 72 hours after being raped and that is when I realised she was not given anything.

'I think my daughter after her rape she was disturbed a bit because there are changes in her behaviour and for instance, while they were counselling her she was asking questions like "will I die now and I wish I can have AIDS so that I can get the grant and buy medicines and other things that I need so that I won't die." I'm worried about her because she is still sick but the results are showing that she is negative and we can't do anything about it.'

Zinhle's story

'My name is Zinhle and I am a married woman of 32 years of age living in Mkhholombe, Boboyi, on the Lower South Coast. I am a mother to 20-month-old twins – a boy and a girl. I would say I have AIDS because I'm already on ARVs. I would like to start from when I think I was infected; in 2002, I was involved with a man who looked well physically but who was taking a lot of pills every day. I never questioned anything about his medication because I thought when you have AIDS you lose weight and you are always sick.

'We never used a condom and one day we had an argument because he wanted us to have sex every day and I told him I was tired. I decided to go home because we were fighting. Three days later I received phone calls from different people saying that he was in hospital and was asking to see me. I ignored him but at the end I went to see him. When I arrived at the hospital I was shocked to see him in the condition he was in, he looked like he had been sick for a long time. He held my hand and told me that: "*Zinhle, ingculaza iyangibulala*" (AIDS is killing me). I think I fainted because I woke up the next morning at the same hospital he was in. He died shortly after disclosing his status to me.

'When I was discharged from the hospital, I still had no idea that he died and I learned about his death on my way home. I was even more shocked because I still had a lot of questions to ask him about why he chose to infect me and why he did not tell me about his status. I felt lost, scared of dying and frightened to think about the future. The hospital phoned and checked how I was doing and they told me to consider doing the HIV test. I refused to do it. I think I was scared to know that I was also HIV positive. I did not want to die. I remember that while I was talking to the counsellor she said something about cases in some relationships where you can find that one partner could be positive and the other one is negative however they were not using protection. When she said this she was not aware that she was giving me more reasons for not doing the test. I just told myself that I am one of those rare cases.

'I did not want to talk or think about it and the fact I had to accept that I was involved with someone who had died of AIDS made me angry. I was confused about what should I do,



High-quality counselling services are critical to ensuring women are supported to take decisions about their reproductive health.

especially about being sick and losing weight because people in my community were going to start talking about me behind my back. That is what happens where I come from, so that is why I was scared and worried. I even resigned from work because of the thought of how my colleagues are going to behave around me. Because I worked with my boyfriend, I thought everybody knew about him [and] I was the only one who was not aware.

'I started to be sick and my family believed that I was bewitched because I was not losing weight like my older sister, who was also very sick and losing weight. One day, we had to take my sister to hospital and I



Fear and denial lie behind many women's resistance to test for HIV.

had to accompany my mother so that I could assist her with administration. My cousin, who works for the Department of Health, arranged that my sister should be tested for HIV and had her CD4 done. My sister started by refusing, saying that she did not have AIDS because she had only slept with one man in her life and that was her husband. When she was told that our cousin had asked them to do it she agreed because she trusted our cousin's decision. She was asked if she would need some privacy and she said she was comfortable if we were there with her as her family. They counselled her and did the HIV test and her results came back positive and her CD4 was 40. She passed away shortly after this.

'All of this was happening in front of me and my mother. I was shocked and could not believe that my sister could die of AIDS. That is how I decided to do my HIV test. I did not want to be tested in front of my mother and I did not tell her about it. I was counselled, tested and my results came back positive and my CD4 was 129. That meant I needed to start ARVs. I felt empty, shocked, I cried. I knew that I was going to die soon. I was advised that I should tell my mother because I would need someone to accompany me when I attended the ARV classes at the hospital. When I went back to my mother, she thought I was crying for my sister and I did not tell her about my status. The first person I disclosed to was my younger sister because I needed someone to accompany me for ARV classes. If things were different I would not have told anybody.

'From that day I was sick and bedridden. I told my mother that at the hospital they said I had arthritis. I was in bed for three months, before I could even start the ARV programme. My cousin suggested that I should contact hospice so that they could help me at home. I refused – because of the stigma that is attached to its name and everybody that I knew who was helped by the hospice they all died.

'I lied to my mother that I needed to go for physiotherapy at the hospital for four days – which is the duration for ARV classes – and I went with my sister. I was taught about different types of ARVs: for males, adult females who are no longer going to have children, and I was put on the one that is for females who are still going to have children. This one included Nevaripine and combined eating correct food and taking our treatment at the right time. On the fourth day, I had to see the doctor who interviewed me [to check] if I knew what kind of treatment I would be

taking, and how I would be taking it. If you forget something about your treatment you have to start the programme again. We were given food parcels and we were eligible for a disability grant but these two ended when my CD4 was above 200. This was in 2004. I visit the hospital once a month for regular check-ups.

'After four months on treatment, I met someone, I did not tell him about my status and my ARV treatment, I told him that I had arthritis. We had unprotected sex. I wanted to infect as many people as I could. I started to have seizures after sex... He took me to hospital every time after seizures and the doctor asked me if I was on some kind of a treatment. I denied it, because I did not want my partner to know the truth.

Disclosure

'One morning, my mother told me that she had dreamt that I had AIDS and that the pills that I was taking were for that. I told her the truth and asked for her forgiveness in not telling her in the beginning. She was devastated and cried a lot. I think it was because I was going to be the third person at home to die of AIDS.

'My boyfriend proposed and he wanted us to get married. For the first time, I asked him if he did not want us to do an HIV test. He refused... Whenever I started talking about going for an HIV test, he did not want to talk about it and said we were fine, we didn't look sick so why did we have to stress ourselves. He still had no idea that I had AIDS.

'Shortly after our wedding, we decided that we wanted a baby. I stopped using contraceptives and I fell pregnant. During my pregnancy, I started to worry about [my husband]. I asked him to do the test but he refused. After my

children were born, I had to go back home as [there is] a custom that as a new bride, and if you are having your first child, you have to go home for a certain period before going back to your husband's family. I decided that it was right time to tell my husband about my status. I was not worried because I saw his excitement about the babies and I was sure that he was not going to abandon us.

'I told him that I had AIDS, and that I had known all along... I asked for his forgiveness. His main concern was the well-being of our babies. He told me about his past experience with his girlfriends, that he had lost three of his children who were born sick and two of his girlfriends had died. He assumed it was AIDS. He also considered himself a carrier, although he had never tested. I told him to consider doing his test and when he did his results were positive but his CD4 count was still high... When the children were six weeks old they had their HIV test and I'm happy that they are both negative and are growing well. I think Nevirapine helped a lot in this.

'I would say disclosing my status and talking about his past had a positive effect on our relationship because before we spoke I knew that he had other girlfriends but now his attention is all on me and the babies. My family is supportive because they know, except for my father. [My husband] has not disclosed to his family and he is not prepared to do it. Some of our friends are supportive but some have stopped visiting us. I did not tell them about my status but most of them learned about it through my work, because they only employ HIV-positive women, who are on ARVs and have disclosed their status. Many women do not want this job because of the stigma and the fact that everybody will know that you have AIDS. The health care workers are very supportive.

'I'm living my life one day at a time, I feel lucky that I am on ARVs because my children are healthy. Maybe I could have died long time ago if this treatment was not available.'

Facing judgment and discrimination

All the women experienced a level of discrimination, either due to testing positive or because of becoming pregnant. Pam said: 'I had a fear of what the community were going to say to me since everybody knew about my status and I was giving talks and advising people at public gatherings. When they realised that I was pregnant they started blaming me for being careless, for not using a condom whereas I told them to use it. Others said what kind of an example was I portraying. I had to live with all these remarks and when I tried to give my side of the story people were not interested. Some people were supportive at this time and I trusted [them] for our survival because I had nothing for the baby.'

When they realised that I was pregnant they started blaming me for being careless, for not using a condom whereas I told them to use it

Nomsa was reluctant to test at her local clinic 'because I did not want to deal with the nurses and their big mouths' so she decided to test at the hospital. 'I refused counselling because I thought it was not necessary; it was not going to change what the results would be. I had to wait for seven days for my results. When I went back for my results, the counsellor on duty asked me my name and she phoned the laboratory because my results were still not available. She... wanted to know over the phone, claiming that it will save time rather than to have somebody to fetch them. They gave her the results and whilst holding the receiver she just said to me "You have AIDS" and that I must go. I did not move; not that I was in shock but I was waiting for some proof or something of that sort. When she had finished her

conversation on the phone she asked me what I was waiting for. I told her and she said she can't give me anything written; I must just tell people that I have AIDS – and she chased me out of her office.

'I was so disturbed by the counsellor's behaviour that I decided to see a social worker about the way I was treated. The social worker suggested that I do the test again but at another site. This time I agreed to be counselled because of the trauma I went through. Again in this clinic I was told that I would have to wait for seven days for my results. Coincidentally, when I was about to leave the clinic, a messenger arrived with boxes that were carrying the new form of a test – a rapid test. I was called back in and they told me about it and asked if I would like to do it rather than to wait seven days. I agreed, and they counselled me again and I received my results after 15 minutes. They told me I was HIV-positive. I accepted the results and asked for a written proof so that I could show my live-in partner. And they gave me the results.'

Ntokozo went to test at her local clinic and faced negative reactions from the nurses. 'They were saying "Why do you have to come and test? Where was the condom when you were having sex? By the way, why in the first place do you have a boyfriend?" They were saying all this in front of my mother. These statements continued. One nurse was passing through the consultation room that I was in and said, "Do you know that if you test positive you are going to die?"'

'As much as I had a fear of being tested, their statements made me more scared and persistent to continue. They confirmed all the stories that I was hearing around about AIDS. The counsellors were more understanding. I was counselled and I had to wait for one week for my results. The week seemed like

a year. I could not concentrate on anything; I was thinking of dying, losing weight and all the sicknesses that comes with AIDS.'

After Ntokozo discovered and disclosed her HIV-positive status, most family, friends and community members accepted and supported her. 'Except for our neighbours; when they heard about my status they stopped talking to my family and not eating or drinking anything that we offered them at home because I had AIDS. But after some time, when one of their family members was sick and dying of AIDS, things started to get better because they approached me and asked for my assistance.'

Mentoring other women

Pam works as the site coordinator in her local hospital, for a project called MOTHER to MOTHER. 'We mentor pregnant mothers, discussing issues pertaining to testing and disclosure. We are based at the maternity ward, where we have one-on-one talks with expectant mothers, telling them the importance of testing so that they can receive treatment. We also monitor them after their results to encourage them to disclose or to attend ARV classes when it is needed.'

Zinhle works in the same clinic as Pam. 'My job at the hospital is to mentor pregnant mothers; to encourage them to test for HIV, [explain the] advantages of knowing their status so that they can take treatment, in order that we can bring an AIDS-free generation onto this earth. We promote PMTCT, testing, acceptance and disclosure.'

Ntokozo has also become involved in education and mentoring. 'One Tuesday I was at the clinic, because I was not feeling well. When I arrived there was some sort of an educational talk on HIV and AIDS, which was done by the sister-in-charge and a lady who was living with HIV... I approached the sister-in-charge and she referred me to the lady, and from that day I decided that I was going to talk about my status and teach other young women. I joined those sessions in



Access to information is an important step to realising sexual and reproductive rights.

EVA LOTTA JANSSON/IRIN

my local clinic. I also attend workshops related to HIV that are hosted by the municipality or other stakeholders.'

Nomsa felt that her choices and decisions were severely limited by lack of information and her dependency on and deference towards her children's father. She was motivated to support other women to seek information and support. Yet she still faced stereotyping and discrimination. 'There is one incident that I remember which was negative. There were posts advertised in my local clinic for Home-Based Care workers, I applied and was appointed. The sister-in-charge asked me how did I get the job because I'm the one who needed to be taken care of, not the other way around. This made me angry and even today our relationship with that nurse is not good.'

Fighting fear and denial

Pam has encountered several challenges in her counselling and mentoring work:

‘Women don’t want to share their results with their partners; they fear that they are going to be blamed for bringing AIDS into their families. Another challenge is denial; they refuse to take treatment even if their CD4 is below 200 and they mix feeding. Some don’t want to use the formula that is provided by the government because people will know that they are HIV-positive. Others don’t want their babies to

One patient did not receive ARVs because she could not remember the names of the pills

be tested for HIV even when the doctors tell them that it’s going to determine what treatment will be needed. They refuse but the doctor does it for the benefit of the baby. For instance, there are cases where a doctor will test a baby and find out that the baby needs to take ARVs, so the mother must attend ARV classes. The mothers refuse to do it and they are told to bring someone else to attend, and the doctor discharges the mother and keeps the baby in the hospital until the mother attends the classes. The longest period a baby stayed in the hospital was six weeks and the mother came and attended classes. I think they are scared of telling their families about this, that is why they don’t want treatment.’

Zinhle agrees that fear and denial lie behind women’s resistance to testing. ‘It is very hard to make them understand and to make informed decisions about their life. I think they are too dependent on their partners. When they test they don’t want to accept their status and are scared to tell their partners or their families.’

Pam advocates for more education

interventions with men especially ‘because most of the women that we work with at the hospital tell us about their partners who are going to blame them.’

Nomsa agrees on the importance of encouraging acceptance and especially educating men:

‘If I could change or make a difference in my community where AIDS is concerned, I would educate people more about it so that they can accept their sickly [relatives]; it is important to run workshops for males only because with my experience I think most of them are in denial and are infecting innocent women.’

Nomsa also argues that ARV treatment sites must to change the way that people ‘qualify’ for ARVs.

‘There are people who are illiterate and cannot remember the names of the pills. I’m saying this because there is a case where one of my patients qualifies for ARVs and had attended the classes. I accompanied her because her mother is old. She did not receive ARVs because she could not remember the names of the pills that she qualifies for; now she is very sick and can’t walk to the clinic. Also the government needs to monitor all the NGOs who are funded to do the home-based care work, so that we can’t be exploited.’

Integrated services and support systems urgently needed

These dialogues outline the challenges that face women with regard to making decisions about their sexual and reproductive health. The women interviewed have acquired a lot of information through their experiences of seeking health services and through receiving training; and yet they still face discrimination and stigma. The attitudes they faced from partners, families, community members and health workers often

reinforced their fear and denial. As these women attempt to support other HIV-positive pregnant women and mothers, they witness the same ongoing fear and denial. Information about family planning, HIV prevention and treatment is not readily provided and women are reluctant to seek this from the health care workers because they anticipate negative attitudes and lack of respect.

Pam and Nomsa give examples of how medical staff have taken over decision-making from women, ostensibly in their best interests: they talk of doctors coercing or forcing women to have their babies tested for HIV and of a patient who was denied treatment because she was unable to remember the names of the different medication. Such approaches to provision of HIV and AIDS services have serious human rights implications and should be the subject of further inquiry.

Fear of being blamed or rejected by partners or by family members, friends and society at large leads women to deny their status even if they want to disclose. They prioritise their immediate needs, such as food for the family, over risks to their health and survival.

Male partners are largely absent from the narratives other than in terms of dependency or abandonment. It is notable that Zinhle's partner

remained with her after she disclosed but when she apologised for hiding her status, she discovered that he believed he had AIDS and that his previous partners had died. The discourse of women as the carriers of HIV and the duty-bearers for HIV prevention and for care and support of people living with AIDS features strongly.

The women interviewed are all involved in caring and counselling work within their communities. They have clear ideas and insights about the things that need to change in order for women to realise their rights to make informed decisions and genuine choices about their reproductive rights. These include provision of high-quality, sensitive and supportive counselling at public health facilities. Confidentiality and privacy, as well as respect for clients are paramount. Integration of family planning services and active measures to include and involve male partners in supporting women to make informed choices that will safeguard their lives and health are essential. The interviewees also highlight the need for interventions from government to ensure home based care workers, overwhelmingly women, have adequate resources to provide an appropriate level of care for those who are sick without being exploited themselves.

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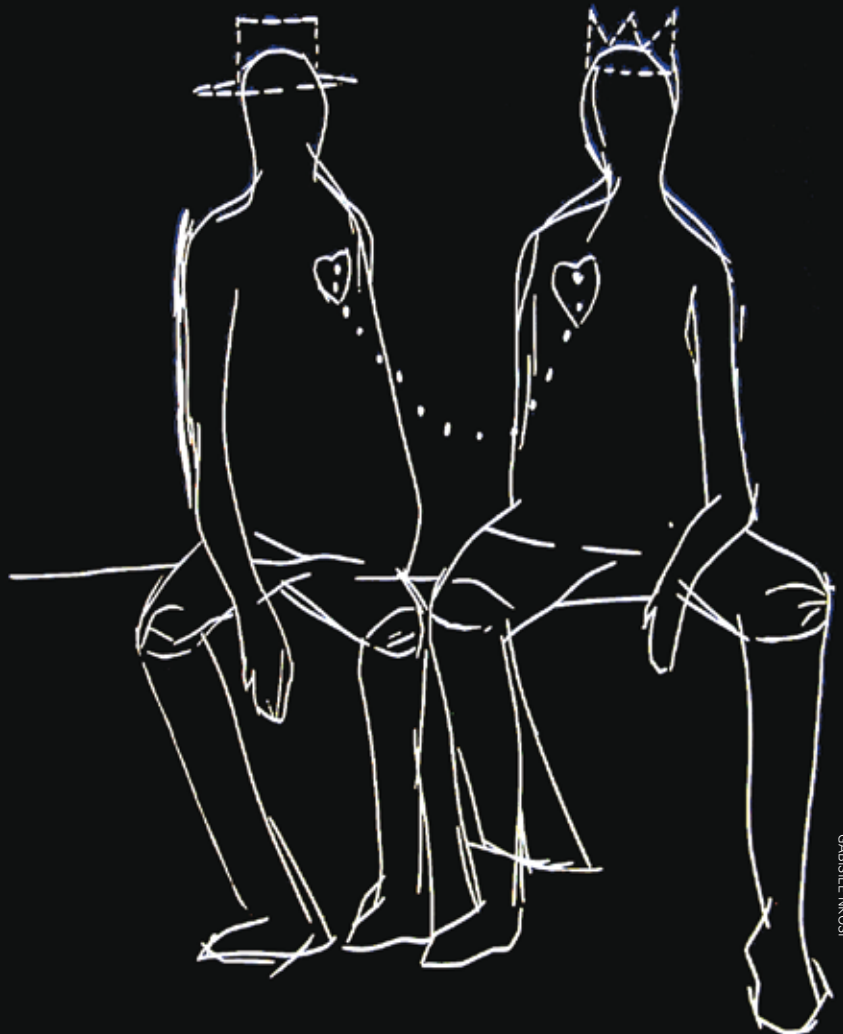


You Told Me You Loved Me

You told me you loved me
"Do not worry
I am clean"
I saw your truthful eyes
your sure hands
your trusted smile
your pink persuasive tongue
and I yearned for you

You have infected me
you bastard – with your HIV
infection with your AIDS and lies
Lying with me
you infected my body, my soul
my brain, my womb -
I am a dead woman
a dead woman walking

Hannah Lurie



GABISILE NKOSI