Gender, hiv aids and stigma assignment

ASSIGN BUSTER

Gender, HIV/AIDS and Stigma: Understanding prejudice against women living with HIV/AIDS 1. Background and rationale.

Introduction

The focus of the World AIDS campaign for the years 2002-2003 has been particularly on stigma, discrimination and human rights. The main objective of the campaign was to prevent, reduce and ultimately eliminate HIV/AIDS stigma and discrimination, wherever, it occurred and all in all its forms. HIV/AIDS-related stigma and discrimination are universal, occurring in every country and region.

It is triggered by many forces, including lack of understanding of the disease, myths about how HIV is transmitted, prejudice, lack of treatment, irresponsible media reporting on the epidemic, the fact that Aids is incurable, social fears about sexuality, fears relating to illness and death (Peter Aggleton & Richard Parker, 2002: 5). Throughout the world, shame and stigma associated with HIV/AIDS have silenced open discussion, both of its causes and of appropriate responses.

This has caused those infected with HIV and affected by the disease to feel guilty and ashamed, unable to express their views and fearful that they will not be taken seriously. And they have led politicians and policy-makers in numerous countries to deny that there is a problem, and that urgent action needs to be taken. The power relations that underscore gender relations and that tightly intersect with discrimination of women mean that women are unable to say “ No” to unwanted or unprotected sex.

There are well-documented cases of people with HIV/AIDS being stigmatised, discriminated against and denied access to services on the grounds of their serostatus. At work, in education, in health care and in the community, people may lack the education to understand that HIV/AIDS cannot be transmitted through everyday contact, and they may not know that infection can be avoided by the adoption of relatively simple precautions (Peter Aggleton & Richard Parker, 2002: 5). HIV stigma doesn't just come out of the blue; it is about deep-rooted social fears and anxieties.

So, understanding more about these issues and the norms they reinforce, is essential to adequately responding to HIV/AIDS related stigma and discrimination. Otherwise, we run the risk of developing programmes and interventions that are not comprehensive, thus achieving little impact. What is stigma? Stigma is a process of devaluation. The origins of the word " stigma" can be traced to classical Greece where outcasts groups branded, or physically marked as a permanent measure of their status.

A stigma is any characteristic that sets an individual or group apart from the majority of the population, with the result that the individual or group is treated with suspicion or hostility (Giddens, 2000: 127). AIDS is an example of illness as stigma. Most forms of illness arouse feelings of sympathy or compassion among non-sufferers. When an illness is seen as uncommonly infectious, however, or is perceived as somehow a mark of dishonour, the ' healthy' population may reject sufferers.

This was true of people afflicted with leprosy in the Middle Ages, who were thought to be sinners punished by God, and were hence disowned and forced

to live in separate leper colonies (Giddens, 2000: 127). Even, in South Africa, the famous Robben Island has been a place where leprosy patients where kept away from society. Stigma is not unique to HIV/AIDS only. It has been documented with other infectious diseases such as TB and Syphilis. It is common with diseases that are seen as incurable, disfiguring and severe.

In a less extreme way, AIDS often provokes such stigmatization today, in spite of the fact that, like leprosy, the danger of contracting the disease in ordinary day-to-day situations is almost nil. While a person who is HIV positive may live for many years without developing AIDS, once the disease appears, it is effectively ” a death sentence” (Giddens, 2000: 127). Its effects are tragic, in this respect it is seen as unlike other major killer diseases in industrial societies today, which mostly strike at older age groups.

When analyzing the roots and results of stigma it is important to demonstrate how both men and women experience stigma and how both these are differently affected by it. Studies of stigma have shown that the stigma associated with HIV is greater than that of other stigmatised illnesses (Lee, kochman & Sikkema, 2002: 309). According to Miles, 1991: 42 whatever meaning is given to health by lay people, ill health represents a breakdown in the normal, expected state of health and well being, a situation when things go wrong, a deviation from how things should be, and usually are. . Literature review Different scholars, academics and authors have tended to differ on gender differences in relation to both men and women. Moreover, they also differed on the importance of biological versus social and cultural influences on human sexual behaviour. An important similarity in the research on gender differences and on sexuality has been

that both fields have looked to the animal world for trying to understand humans (Giddens, 2000). There is a biological basis to sexuality since female anatomy differs from that of the male.

Biologists argue that there is an evolutionary explanation of why men tend to be more sexually promiscuous than women. Judith Lorber distinguished about ten (10) different sexual identities among human beings: (1) Heterosexual women (2) Heterosexual men, (3) Lesbian woman, (4) Gay man, (5) Bisexual woman, (6) Bisexual man, (7) Transvestite woman (a woman who regularly dresses as a man), (8) Transvestite man (a man who regularly dresses as a woman), (9) transsexual man (a woman who becomes a man) and (10) Transsexual woman (a man who becomes a woman).

Due to the fact that sexual practices are diverse, the accepted types of sexual behaviour also do differ between different cultures. Now regardless of the different sexual identities, it is important to note that the values of society in general have traditionally been patriarchal in nature. And because of this, sexism, religion and western attitudes have also tended to perpetuate myths about the differences in gender and sexual behaviour. Christianity and various different denominations have held divergent views about the role and place of society.

In the 19th century, religious presumptions about sexuality were partly replaced by medical ones . In Victorian times, there was sexual hypocrisy, in that many men who were thought of as behaved, were the ones who regularly visited sex workers or even kept mistresses. Yet such kind of behaviour was treated leniently, whereas women who took lovers were

labeled, shunned, branded adulterous and scandalous. The differing attitudes towards the sexual activities of men and women formed a double standard, which has long existed and still applies currently.

Religion and the medical and health professions have allowed sexism, gender and sex stereotypes to influence their practices as well. Most studies have shown that most patients in therapy, for instance, are women (Sue, Sue & Sue, 1997). The role of patient is highly consistent with a female sex role characterized by weakness, dependency, irrationality, and acceptance of care (Williams, 1977 quoted in Sue, Sue & Sue, 1997). Relative to the incidence of physical and medical illness among women and men, women are more likely to seek medical and psychiatric help. This tendency may be explained in terms of socialization: a woman's sex role ermits her to seek help, whereas men may consider it " unmasculine" to do so (Chesler, 1971, Shapiro et. al, 1984 quoted in Sue, Sue & Sue, 1997). Modern feminist psychologists (Chesler, 1972, chdorow, 1978, Williams, 1977, Dworkia, 1984, Gilligan, 1982 & Holraya, 1980) have pointed out several socio-cultural factors (rather than inferior biology) as contributing to the denigration of women. Images of women throughout history have been fearful or unflattering. In some cases, women were portrayed as seductress, lustful, evil, needing to be controlled, subordinated and devalued.

They were and are still treated as property, burned, raped and accused of being witches and excluded from positions of power. All these factors perpetuated and justified men's need to control women. Sexual relations in much of Africa are characterized by high levels of partner change among single young women, and among men of all ages, married and single

(Jackson quoted in Zimbabwe Women's Resource Centre & Network News Bulletin, 1993: 15). A survey conducted in 2002 among some 1, 000 physicians, nurses ad midwives in four Nigerian states showed disturbing findings.

One in 10 doctors and nurses admitted having refused to care for an HIV/AIDS patient, or having denied HIV/AIDS patients admission to a hospital. Almost 40% thought a person's appearance betrayed his or her HIV-positive status, and 20% felt that people living with HIV/AIDS had behaved immorally and deserved their fate. A lack of knowledge about the virus (often flanked by denigrating attitudes towards people living with HIV seemed to be one factor fuelling the discrimination. Another was fear among doctors and nurses about exposure to possible infection as a result of lack of protective equipment.

Also, at play, it appears, was the frustration at not having medicines for treating HIV/AIDS patients, who therefore were seen as doomed to die. Studies in other regions show that such attitudes and actions are commonplace. In the Philippines, a recent study among persons living with HIV/AIDS found that almost 50% of respondents had experienced discrimination at the hands of health care workers, while in Thailand, 11% of respondents said they had been denied medicine because of their seropositive status, and 9% had experienced delays in treatment.

Some 70% of people living with HIV/AIDS in India said they had faced discrimination, most commonly within families and in healthcare settings, according to the recent International Labour Organisation (ILO) research.

Such experiences have prompted efforts to promote the greater involvement of people living with HIV/AIDS in India, where several NGO's (Non-Governmental Organisations) and networks of HIV positive people are working to reduce discrimination in local hospitals. Many people living with HIV/AIDS do not get to choose how, when and to whom to disclose their HIV status.

When surveyed recently, 29% of persons living with HIV/AIDS in India, 38% in Indonesia, and over 40% in Thailand said their HIV positive status had been revealed to someone else without their consent. In many cases, test results were shared with persons other than the spouse or family members; one in nine respondents in a Thai survey said their status had been disclosed to government officials. These kinds of violations of the right to privacy undermine HIV/AIDS programmes by deterring people from finding out their serostatus and thus threaten public health as individuals unknowingly transmit HIV to others.

Given the close links between HIV/AIDS related stigma, discrimination and human rights violations, multiple interventions programmes are needed. Stigma devalues and discredits people, generating shame and insecurity. Stigma is harmful, both in itself since it can lead to feelings of shame, guilt and isolation of people living with HIV and because it prompts people to act in ways that directly harm others and deny them services or entitlement-actions that take the form of HIV related discrimination. Such njust treatment can be tantamount to a violation of human rights. People living with HIV/AIDS have been stigmatised and discriminated against worldwide since the epidemic began. In South Africa instances of overt discrimination, including

violence remain common. Worse still, in South Africa up to 37% of rural women attending antenatal clinics test positive in annual anonymous surveillance surveys (Harrison, Smit & Meyer, 2000). Women are seen to be the axle around which HIV infection in Southern Africa revolves.

Men primarily through sexual intercourse may infect them and, in turn, they frequently infect their infants through pregnancy, childbirth and breastfeeding. Worldwide women are more vulnerable than men to HIV infection during unprotected vaginal intercourse (Fowler, Melnick & Mathieson, 1997; UNAIDS, 2000) HIV/AIDS is today seen as the most serious epidemic and threat to public health systems around the world. Since its discovery in the 1980’s the number of infections has increased every year. In South Africa, by the year 2000 there were estimations that about 5 million South Africans were infected with HIV/AIDS.

It has also been estimated that more than 60 million people worldwide have lived with HIV/AIDS since its genesis and 20 million of these people have as a result since died (UNAIDS, 2002). By 29 January 2004, estimated worldwide HIV infections were put as 55 769 791 at 12: 40 pm (Mail & Guardian HIV Barometer, January 30 – February 5 2004). Despite these debates about the statistics on the prevalence of the HIV pandemic, over the years women have tended to be labeled or branded as the transmitters of the HIV/AIDS disease. A number of studies have focused on women and HIV/AIDS.

However, most of these studies have also focused more on women’s vulnerability to the HIV/AIDS epidemic. Evidence presented has indicated that certain people are more vulnerable to infection than others. This has

been seen in demographic characteristics, geographic distribution and access to resources of those infected (Strebel, 1993). People's constructions and conceptions of gender identity, as well as sexual attitudes and inclinations linked to them, are formed early in life that as adults people take them for granted. HIV/AIDS remains a highly stigmatized disease among African communities and other communities world-wide.

Stigmatization is currently the biggest obstacle to beating the pandemic. There is the challenge of combating the stigmatization of condoms as well. Many people with HIV/AIDS experience discrimination from strangers, families, friends, lovers, healthcare workers and government. Discrimination is a result of ignorance (HIV in our lives, 2003: 67). Many people still do not know how HIV is transmitted and because of lack of knowledge this often leads them to fear about HIV. Stigma has been studied by relatively few social scientists.

According to Levett (1995: 4) stigma is not a simple matter of labeling, or being labeled, although it includes these. Inequality and difference are always implicated. Lee & Loveridge (1987: 1, Preface) also notes: " Inequality… is a social construct supported by a complex process in which characteristics are attributed to the disadvantaged which then become the justification for that disadvantaged position in society. This stigmatization in turn further handicaps any attempts by the disadvantaged to alter or challenge this apparently normal set of hierarchical social relationships".

Perceptions that have come out from traditional rural communities have been that condoms are a western product and not African and therefore a

carrier of HIV/AIDS. At the XIV International AIDS Conference Nelson Mandela said,” Stigma, discrimination and ostracism are the real killers”. In his closing speech he said that AIDS is a war against humanity. Furthermore stigmatization has and continues to remain the main stumbling block for those wanting to disclose their status. For example, in Botswana, treatment for people living with HIV/AIDS is accessible, but people are not coming forward because of how society treats HIV positive people.

During the initial start up of the stigma project, we were given an individual assignment to visit any ARV or PLW site to interview someone living openly with HIV/AIDS about their experiences before and after disclosing their HIV status, and to pay particular attention to women’s experience and see whether do they differ with those of men. The interview was carried with a NAPWA (National Association of People Living with HIV/AIDS) activist, whom for the purposes of anonymity I refer to as Nohlanhla. From the interview one learnt that we still have to free men from denial.

Nohlanhla’s fiancee is one of those men who find it difficult to admit their infection for fear for being branded as ” not man enough”. This is a result of what society makes us to believe, that a man who succumbs to sickness is not man enough. When she told her fiancee about her status, he ran away. This explains why women are often seen as the axle around which HIV infection in Southern Africa revolves (Wassenaar & Richter, 2000: 6). The depth of stigma and discrimination cannot be in anyway underestimated in the African communities.

The Treatment Action Campaign (TAC) and the National Association of People living with HIV/AIDS (NAPWA) have shown that greater access to effective care, prevention and treatment is vital to breaking the cycle of stigma, discrimination and human rights abuses. 3. Aim of the study South Africa suffers one of the World’s highest HIV infection rates, but people deny the disease because HIV is linked with sex. Those people living with HIV/AIDS, it seems are labeled in South Africa and globally as living an immoral life. It seems that discourses on HIV/AIDS intersect powerfully with social taboos and stigmas related to sexuality and gender.

Over the years women have tended to be labeled or branded as the transmitters of the HIV/AIDS disease. A number of studies have focused on women and HIV/AIDS. However, most of these studies have also focused more on women’s vulnerability to the HIV/AIDS epidemic. Evidence presented has indicated that certain people are more vulnerable to infection than others. This has been seen in demographic characteristics, geographic distribution and access to resources of those infected (Strebel, 1993). The purpose of this study is to investigate the way in which gender identity intersects with constructions of HIV/AIDS, in particular the following: ?

Investigate whether HIV/AIDS is seen as a woman’s disease and why. ? Investigate if and why women are more stigmatized than men. ? Determine what socio-economic and cultural issues contribute to the stigmatization of women living with HIV/AIDS. ? Document community responses and perceptions to HIV/AIDS, in particular stigma attached to both men and women PLWHA. 4. Methodology of the study This study utilized qualitative

research methods. The data was collected through 6 (six) focus groups discussions and provides a narrative analysis of focus group discussions.

Different authors on qualitative research methods have had divergent views on which methodology is actually useful. They have also acknowledged the fact that each method has got its own limitations and strengths. According to Denzin & Lincoln, 1998: 3 qualitative research methodology encompasses the usage of multiple methods to collect data that informs an in-depth understanding of issues. Qualitative multiple methods include a study of empirical materials, case studies, interviews, personal experiences and other methods.

Socialist Feminist research methodology guided both the research methodology and the focus group discussion so as to encourage debates on gender and sexuality. Socialist feminists view patriarchy and capitalism as equally important forces in explaining the inequalities in society. They study how differences among men (in the access to power and other resources) help to explain the different ways in which men exploit women. They focus on the social relations of power (especially economic power) that enables men to control women.

It is for reason I felt that this view or method could help in understanding the social implications of HIV for women and men, and not in isolation from the position of both sexes economically and otherwise. A vignette was used in the focus groups to introduce the topic to the participants. The preferred methodologies used in general psychological stigma research tend to be vignettes followed by category based inventories where, for example,

alcoholism, mental illness, or people with cancer are rated on social distance Bogardus scales to provide quantitative measures of stigma.

Popular criterion measures are devaluation, avoidance and rejection, hierarchical comparisons of specific stigma categories; judgements of unpredictability and social discomfort have also been used (Levett, 1995: 6). The participants had a picture discussion. The discussion centred on what the participants think was happening in the picture. Why do they think this is happening? 5. The data collection process 5. 1 Population The target population of this study was the focus groups that included both men and women living within the vicinity of Khayelitsha Township in the Western Cape, who are between the ages of 18 and 55.

Each group included between 10-12 participants. Some groups were mixed and some had same sex group members. 5. 2 Focus group questions The focus groups questions were developed during the January 2004 Penn State/HSRC workshop at the University of the Western Cape. This was developed in conjunction with my mentor (See appendixes). During the workshop it was decided that questions could be direct, adapted, refined or adjusted depending on the flow of the discussions during focus group sessions. 5. 3 Focus groups

The 62 participants were recruited for the focus groups through a community member and a stigma project colleague. A letter of introduction to the community was made through the HSRC (Human Sciences Research Council). Most of the participants were unemployed and some came from the different sections of Khayelitsha. Khayelitsha can be classified as a poverty-

stricken township due to the number of shacks that have been erected within the vicinity and lately some residential areas. The dynamics of the area also includes the “ emerging” middle class, which have 4-roomed houses.

Khayelitsha can thus be classified as a working class area. During the focus groups, a vignette was read and used by the co-facilitator to introduce the topic. The vignette shows a protruding hand of a man pushing a critically ill woman away. The use of the vignette was to gauge people’s perceptions about HIV/AIDS stigma. The set-up and sitting arrangement for the focus groups was such that chairs were made in a round way, so that participants could see each other and that they could also maintain eye contact with both the researcher and the facilitator. 5. Co-Facilitator I used a co-facilitator in the data collection process, since there was the issue of language barrier. Though I’m able to communicate in Xhosa, I felt that I’m not quite fluent in the language and the concepts used at times might a bit confuse me. Another reason, to have the Co-Facilitator is that the presence of a woman researcher in groups of women is said to create a sense of shared experiences among the participants (Finch in Strebel, 1995). The co-facilitator is both a psychology lecturer and a stigma project member who stays in the community.

She was very helpful in translations when it was needed. Much meaning was not therefore lost, as I was also scribing or writing my notes to avoid as much as possible to lose meaning or the flow of the discussion. 5. 5 Procedure Each focus group lasted between 1 and 2 hours. At the beginning of sessions, the co-facilitator welcomed and thanked the participants for

volunteering and explained the purpose of the project. The participants were asked for permission to use the tape recorder. Participants were also told and given an explanation that they should not use their names during the discussions.

Each participant was given R50-00 as a token of appreciation for participating in the study and as a stipend as some of them were coming from the different sections of Khayelitsha. The fieldwork commenced in July 2004. The purpose of the fieldwork was to record community perceptions and responses to HIV/Aids and stigma. This involved a total of 62 participants who participated in 6 focus groups conducted in Khayelitsha. 6. Major findings The data transcriptions illustrated the problems that women living with HIV/AIDS face on a day-to-day basis.

In the whole 6 focus groups, the participants have shared their different reactions and experiences. In general, what could be picked up from the participants was that: ? Much of the stigma attached to HIV/Aids is that HIV positive women and men got infected due to their promiscuous behaviour. Whilst there is no truth in this view, there is still a need to educate people that promiscuity is a minor determinant of HIV risk. ? Unemployment among black people, “ the sugar daddies” and the socio-economic factors has been cited as factors that makes women more vulnerable or at risk of contracting HIV/AIDS. The concepts of ” Izibethi”, “ Ingangara” ” Indoda” or ” O fuze Tata wakhe” meaning he is like his father or like Father like son” particularly tends to mislead the youth and the elders in that a man who is having many girlfriends is seen as a “ boss” and this forms some kind of ” township masculinity” which encourages teenagers and young girls to go for, sleep, or

have unprotected sex with older men who have material possessions e. g. money and an expensive car. The combination of having money and an expensive car tends to put people at a high risk of infection.

Men's promiscuous behaviour, dominance and economic advantage is encourages and perpetuate patriarchy leading to the pervasive spread of HIV/AIDS. ? Sex has become a commodity in that women who are not having money tend to get a man who will assist or bring the grocery to the house. ? Young girls are particularly at high risk " They (young girls) are after money, clothes, fashion. ? People who are HIV positive become subject to gossip and ridiculing as one participant puts" They are seen as a curse, a shame and as carriers of the disease" ?

Family members are not honest about their feelings towards people living with HIV/AIDS as one participant puts it" Stigma also starts at home, for example, you won't wash dishes or at times you won't be told directly that you should not do this or that" ? Men are given comforting names" Izibethi", indoda etc whilst women are given denigrating names such as hoover, isifebe, Henyukazi etc. ? Churches or religious bodies also fuels stigma, as this participant puts it" They'll tell you that HIV/AIDS doesn't exist. ? Women are also or forms part of stigmatizing other women and in turn fuels stigmatization. Testing and disclosure recognised as difficult because of stigma, violence, and loss of income, blaming and being condemned. ? Traditional healers also fuels stigma according to one participant who said" Traditional healers point fingers if they can't diagnose your condition they'll say you are bewitched by so and so" ? Male power and promiscuity is endorsed and the males are often protected as some of the participants

have commented. ? Men who have money or income are at greater risk than men who don't have any income. This is evident in the construction of " izibethi" or " ingangara" etc. ho have money and material possessions and multiple girlfriends or partners. ? The effect of income on HIV stigma seems different for both men and women. ? Women are at times at higher risk of infection due to reliance on regular financial support, which they do for sexual favours. ? Clinics or health institutions and nurses aggravate or perpetuate stigma as one participant commented" Nurses and counselors should not sit in offices or clinics they must also go to the community, because the stigma also comes from nurses as well.

They gossip about patients and it becomes worse when this reaches the community" Another participant pointed that" when you enter the clinic, you'll find that nurses like to be in groups gossiping. This gossiping contributes to the stigmatisation of people. ? Males are not stigmatised, as this participant rightly put it " Because men have power or physical power, this serves as a threat to those who want to stigmatise men. ? Women who become infected may be seen as having been sex workers, promiscuous. Conceptions that a woman who doesn't breastfeed is HIV+ as this participant puts it" When I had my first child, I didn't breastfeed her and the second wasn't breastfed, whilst the third was breastfed, all because these children did not want to be breastfed anymore- so it ended up like people become suspicious, that you are HIV positive. ? Images of HIV/AIDS in the media- tends to suggest that it is' a gay disease', an American disease to wipe out Africans and a ' woman's disease- these stereotypes fuels stigma and reinforce beliefs (cultural) which are not true. Most women die from

HIV/AIDS, so it's a woman's disease. ? Men refuse to wear or condoms as illustrated in this view" I can't wear a raincoat- some men would say that they haven't seen their grandfathers and parents wearing a raincoat and they won't do it as well. ? Impact of stigma is mediated by gender and its impact is experienced more by women than by men. ? For many women who are infected or affected their position is characterized by financial dependence and their financial or social position cannot be examined in isolation from their position in society. Culture as a belief and practice of a community serves as a design for living and it is transmitted from one generation to the next and it is normally slow to change, as a result of this female participant put it " men don't want to use condoms, culture dictates that, if me as the wife request the use of a condom, he will call the elders". Others they will say that " o galela eplastiking" meaning you are ejaculating into a plastic. ? People with HIV/AIDS are subjected to gossip, ridicule, and rejection and for women it's worse in that they become subjected to violence once their partners know their status. . Conclusions and Recommendations This study focused particularly on one South African township, Khayelitsha. It would be ideal or important to have comparative study with other South African townships to find out, whether people hold similar beliefs and whether are there similarities with what has been learned in Khayelitsha. This study has revealed that women due to their social or economic status can at times put their health at risk. That though those who are in marriage cannot negotiate safer sex, the same goes for those who are unemployed who run the higher risk of contracting HIV/AIDS.

This is all about the “ buying power” that working men have, and those who have buying power tends to target women who are economically vulnerable and have to deal with their family’s welfare. Women are much blamed for their infections and they face different experiences, frustrations, negative responses etc. as a result of the stigma attached to HIV/AIDS. Culture tends to oppress women to a certain extent, as this woman puts it ” according to culture men are the ones who have power and control”. 8. Recommendations from participants The attitudes of health workers is cause for concern-The nurses should be educated on how to educated the public around HIV/AIDS. They current don’t have a good approach to patients and people. ? Support groups should go into the community. They should have roadshows and drama groups. It is important to have respected persons from the stigmatised community to share their life stories. ? In community projects, e. g. gardening HIV+ people should form part of community projects- they should be seen as productive people. We should have posters for example “ as big as ANC posters depicting President Thabo Mbeki, posters should be visible and should not only be in the clinic. ? People hide HIV/AIDS, you’ll hear that it is cancer, TB, diabetes that killed so and so. For as long as we are not open, people will continue to hide it. ? Parents should talk about HIV/AIDS to their kids or children. ? We must change the strategy in HIV/AIDS education; explain whether HIV causes AIDS, get celebrities who are infected to be part of the awareness programmes. Families & parents should be a platform where the issues of HIV/AIDS are raised to further reduced stigma. ? There should be a law enacted to deal with stigma and the law should be harsh and have a punishable offence- this could deter people from accusing each other, labeling each other etc. ? More and more

community workshops are needed. ? Put more messages about HIV/AIDS stigma on television in programmes like “ Asikhulume/Let’s talk” on TV, in radio to further educate people about stigma ? A need to have the Department of Health on board and the department should print T-shirts, tracksuits. Government should do something about the clinics and clinic staff, most are not working ? Treatment information should be shown on posters, ? We must challenge stigmatising statements such as “ People who sleep around deserve what they get or If I got HIV/AIDS I’ll kill myself” 9. Learning outcomes The participants in these focus groups were not asked their status. But one could pick up that there were those who are HIV positive and as a result they feared stigmatization from their respective communities.

It would be important as said earlier to look into the meaning underlying words such as hoover, ingangara, and izibethi because there might be different variations of these concepts in the different townships and rural areas of South Africa. But most important, it can be interesting perhaps to find out the meaning of these subtle, yet often at face value, deeply hidden concepts for us to redefine the masculinity and feminity in the face of the HIV/Aids epidemic. There is still a need to come up with new programmes to de-stigmatise HIV/AIDS.

People tend to think of HIV/AIDS as destructive, for them it represents some form of inactivity, exclusion from society. Throughout the sessions, one could pick up that people also tend to rely on the sum of knowledge and beliefs that exist in the community, place and society, without necessarily questioning it. So, here it becomes important to use indigenous knowledge

systems as a tool to educate people as well, since oral tradition tends to be a important aspect for the African community. Much of the information and knowledge, that was picked up has been shared with a number of stakeholders.

The recent ones being: ? The Men's Conference held on the 27 November 2004 at the Alexandra Township organised by ADAPT (Agisanang Domestic Abuse Prevention) ? The Gauteng Province Men's Summit held in Pretoria, Sammy Marks Square organised by the Gauteng Provincial Government Department of Social Development This was encourage men to take an active part in the prevention and elimination of violence against women and children particularly in the context of HIV/AIDS and for them to increase men and boy's responsibility and for the to adopt a safe and responsible sexual and reproductive behaviour.

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Shisana, O & Simbayi. L 2002. Nelson Mandela/HSRC study of HIV/AIDS: South African National HIV prevalence, behavioural risks and mass media, Household survey 2002. Cape Town, South Africa: Human Sciences Research Council Strebel. A (1993) Women and Aids: A study of issues in the prevention of HIV infection. Unpublished Masters thesis. Cape Town: University of Cape Town Sue. D, Sue, D & Sue, T (1994) Understanding Abnormal behaviour. 4th edition. Houghton Mifflin Company: Boston Van Dyk, A. 2001. HIV/AIDS care and counseling: a multidisciplinary approach. Pearson Education: South Africa Wassenaar, D.

R & Richter, L. M. 2000. Women, ethics & HIV vaccine trials in Southern Africa. AIDS Legal Quarterly, December 2000: 6-7 UNAIDS (2000). Report on the global HIV/AIDS epidemic. June 2000. Geneva UNAIDS (2002). Report on the global HIV/AIDS epidemic. Geneva, Switzerland: UNAIDS United Nations Declaration of Commitment on HIV/AIDS Appendix 1 1. What do you think about this story (after vignette on a woman with HIV/AIDS being thrown out of her home by her partner)? 2. Why do you think this happened? " The husband probably thinks about how will people look at him because her wife is HIV positive"- Male Participant The man thought about death before he

could reason”- Male participant Black people have a tendency to accuse a woman of bringing the virus”-Male participant ” The man thinks the wife has been misbehaving and that the woman will infect me as the husband”- Male participant. ” By just staying with this woman this man thinks that she will infect him”-Male participant. “ The man thinks that people will ridicule him since his wife is infected” Male participant. ” The shock that perhaps this woman has HIV/AIDS might have lead to her husband not accepting that she is HIV positive”- male participant. The Man thinks that the woman deserves to be beaten up for bringing the virus into the home- female participant. “ People will talk, the husband thinks about his status in the community and he doesn’t think about his sick wife. If it was a man who was HIV positive, the expectation is that the woman would have taken care of him”-Female participant “ The husband think that the woman is the one who bought the virus and that he will chuck her out of his house” “ People will think that this woman is the one who infected or brought the disease into the home”-Participant Probably the husband was shocked because he doesn’t know his status”. “ The husband didn’t accept that his wife is positive and therefore there is the issue of abuse- Female participant. ” He thinks she sleeps around”- Male participant. “ The husband is running away from reality, he should look good in the eyes of the community” Men are not aware of their status, they become aware of their status once their wives or women become sick- Female participant. 3. Why do you think community members treat PLHAs badly? ” People are generally afraid of death” . ” When you are sick, people don’t care about you.

They no longer have time for you- Female participant 4. Do you think HIV more easily infects women than men? If so, why do you think so? “ Men are stronger and they don’t normally go to the clinic like women do. Women go to the clinic every week”- Male participant “ Yes, men have strong blood, unlike women”-Male participant “ To most men the disease doesn’t show in the early stages, they can stay between 3-5 years whilst for women it is a different story- Male participant. ” Men sleep around, but the women’s biological make-up is different from that of men. “-Female participant. Women looks after children, they are home managers and they are weak biologically- Female participant 5. How do you think women living with HIV/AIDS acquire the virus? Unemployment- because you are not working at times you get a man who you think can be able to help or assist you at home and you end sleeping with him only to find out that he is HIV positive after a while- Female participant “ People normally blame witchcraft and say that one is bewitched. If a person like me is fat and decides to slim or reduce weight, the community already makes a judgment that you reducing weight means that you have AIDS- Female participant. It is a men’s problem, they (men) want to get recognition, status etc- Female participant” ” The sugar daddy/unemployment and socio-economic factors contribute to the acceleration of HIV/AIDS” Male participant ” Women normally think about kids, the family welfare and as a result for them to put bread or food on the table- they end up doing services or sleeping with other men just to make sure that she keeps the home-fires burning. “ It is men who propose to women, women don’t propose, it’s men and men are the ones responsible for bringing the virus and turning around to blame women! “-Female participant Men do not want to use condoms- Female participant. “ Women

wants to spread the virus, men wants to spread the virus, it’s the same”- Male participant” “ Prostitutes (Most prostitutes are women) and they are the ones who are spreading the virus”- male participant. 6. Do you think women LWHA are responsible for their illness? If so, why? Not answered…??? 7. How does your community respond to women living with HIV/AIDS? “ Women are always blamed, whilst it should be both men and women who are to blame” Female participant. ” People think that if you are HIV positive as a woman you have been promiscuous”-Female participant” The community abuses HIV positive people, whether it is the elderly or youth, female or male. The community cannot accept your status. There is no difference, they are treated the same”- Female participant ‘ If we see a HIV positive woman, we normally put it to be that she behaved immorally and she has been promiscuous” Female participant ” Women are to blame, because it is most women who die from HIV/AIDS”. ” Stigma is also fuelled by women themselves”- Female participant. ” They (women) are called Isifebe (Bitch) or Hoover (like a hooving machine), because a Hoover takes all the dust and everything it comes across” Male Participant. Women are given degrading names such as Isifebe or Henyukazi or Amahenyukazi” ” They are a Taxi”- Male participant. 8. How does the community respond to men living with HIV/AIDS? If there are differences, why do you think this is? “ If a man is HIV positive, he will not be stigmatized or called degrading names in the same way as a woman- Female participant “ Men are given names such positive names like: Izibethi or Ingangara (An Izibethi or Ingangara is a man who has many girlfriends, money, an expensive car etc.)- Male participant. Men are called “ Ncholongwane” (meaning virus)) whilst women are called “ Noncholongwane”. “ Men are called names like “ Player” and these names

are the ones that promote promiscuity among men because ” You are a boss”- Female participant. Men are called or given names that comforts them. They are called ” Indoda” or people will say ” O fuze Tata wakhe” meaning he is like his father or like Father like son”. Because of men have power or physical power, this serves as a threat to those who want to stigmatise men –Male participant 9.

What are the reasons that lead people to have negative responses to those living with HIV/AIDS? 10. What should be done to remove the negative perceptions in the community of those living with HIV/AIDS? ” In community projects- For example- gardening, HIV positive people should form part of the community projects- they should be seen as productive people”-Male participant. “ Support groups of people living with HIV/AIDS should go into the community. They should have road shows and drama groups. It is important to have respected persons from the stigmatised community to share their life stories”- female participant. Stigma starts from the home, if people at home are strong this can be reduced, health workers should go door to door to educated the community and the government should play a role- The solution for stigma is to arrest the perpetrators. Nurses and counselors should not sit in offices or clinics they must also go to the community, because the stigma also from nurses as well. They gossip about patients and it becomes worse when this reaches the community”- Female participant ” Parents should talk to their kids about HIV/AIDS though it is difficult to discuss issues of sex with kids” Female participant. We should have posters for example, as big as the African National Congress (ANC) posters depicting President Thabo Mbeki. These posters should be visible and

should not only be in the clinic. “- Female participant. “ By stopping or having to treat HIV positive people as if they are non-humans, perhaps this will reduce HIV/AIDS stigma and discrimination” Male participant. “ We must change the strategy in HIV/AIDS education, explain to people- Does HIV cause AIDS? This explanation has still not been explained to ordinary people.

Get celebrities who are infected to be part of the Awareness programmes, if they (celebrities) hide HIV/AIDS, then it’s a problem”- Male participant. ” We should intensify public awareness and education campaigns”- Female participant ” There should be a law enacted to deal with stigma and the law should be harsh and have a punishable offence- this could deter people from accusing each other, labeling each other etc”. – Female participant. The elderly should talk with their kids, furthermore the family should be a platform where these issues are raised as well- to further reduce the stigma- female participant

Parents should play a role in reducing stigma and they must be open to their children about educating them about HIV/AIDS- female participant 11. What is the community doing to remove prejudice and discrimination towards those living with HIV/AIDS? Question not answered 12. How are people (women & men) living with HIV and AIDS (PLHAs) treated by the community? “ People who are HIV positive are not seen as humans, the person is seen as an animal- he or she cannot live within the community rather the person can go and stay alone somewhere else- Female participant 13. What are the attitudes/feelings of the general public towards PLHAs? People respond differently some are rude and have their moods “. -Female participant” ” Our culture has not accepted that HIV/AIDS exists people don’t take diagnosis

from the Doctors, but will mostly take or go for the opinion of the traditional healers or doctors"-Female participant " They are seen as a curse, a shame and as carriers of the disease"-Male Participant. " When you are positive they say that you have struck the lotto (" o bambe ilotto"). " Stigma also starts at home, for example, you won't dishes or at times you won't be told directly that you should not do this or that" Male participant

Appendix 2: Research/ Focus Group Questions 1. What do you think about this story (after vignette on a woman with HIV/AIDS being thrown out of her home by her partner)? 2. Why do you think this happened? 3. Why do you think community members treat PLHAs badly? 4. Do you think HIV more easily infects women than men? If so, why do you think so? 5. How do you think women living with HIV/AIDS acquire the virus? 6. Do you think women LWHA are responsible for their illness? If so, why? 7. How does your community respond to women living HIV/AIDS? 8. How does the community respond to men living with HIV/AIDS?

If there are differences, why do you think this is? 9. What are the reasons that lead people to have negative responses to those living with HIV/AIDS? 10. What should be done to remove the negative perceptions in the community of those living with HIV/AIDS? 11. What is the community doing to remove prejudice and discrimination towards those living with HIV/AIDS? 12. How are people (women & men) living with HIV and AIDS (PLHAs) treated by the community? 13. What are the attitudes/feelings of the general public towards PLHAs? Appendix 3: Refined focus group questions 1. What do you think about this picture? . Why are women at risk? 3. Do you think women are easily infected than men? 4. What cultural issues contribute to the

stigmatization of women living with HIV/AIDS? 5. Why do you think women are treated differently than men? 6. Do you think women are more stigmatised than men. 7. How do you think HIV positive women acquired the virus? 8. What are people's fears about HIV/AIDS? 9. How do women (people) feel when they are treated badly? 10. What can be done to prevent stigmatization towards people living with HIV/AIDS? 11. What are the factors that contribute to women being more stigmatised than men?