

**HIV/AIDS AND STIGMA IN NAMIBIA:
RESULTS OF A QUALITATIVE STUDY AMONG SUPPORT GROUP
MEMBERS**

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1. INTRODUCTION

Stigma is seen as an obstacle to the prevention, care and treatment of HIV and AIDS. “Labels matter” as they often evoke a wide range of reactions from individuals, groups, communities or even nations. These reactions can range from the benign (sympathy, empathy) to the malignant (anger, violence) and in some cases individuals have been killed for making their HIV status public.¹

Stigma is relational and ultimately about power and social control and its consequences are discrimination and neglect. In the words of one international HIV/AIDS charity²:

“Stigma is a powerful tool of social control. Stigma can be used to marginalize, exclude and exercise power over individuals who show certain characteristics. While the societal rejection of certain social groups (e.g. 'homosexuals, injecting drug users, sex workers') may predate HIV/AIDS, the disease has, in many cases, reinforced this stigma. By blaming certain individuals or groups, society can excuse itself from the responsibility of caring for and looking after such populations. This is seen not only in the manner in which 'outsider' groups are often blamed for bringing HIV into a country, but also in how such groups are denied access to the services and treatment they need.”

Stigma is furthermore important because it is considered a driver of new HIV infections. Rankin et.al. (2005) states that:

“Stigma is of utmost concern because it is both the cause and effect of secrecy and denial, which are both catalysts for HIV transmission.”

Given the consequences of stigma it is not surprising that various programs and projects have been instigated to combat stigma. In 2000 UNAIDS adopted a Protocol for the Identification of Discrimination Against People Living with HIV the aim of which was two-fold³:

1. *“The identification of different forms of arbitrary discrimination, with a view to eliminating them, helps to respect, fulfill and protect human rights. This is an important goal in its own right, as recognized by the ongoing attention and deep commitment to human rights across national and international communities.”*

¹ One such case occurred in 1998 outside Durban (South Africa) when Gugu Dlamini, an AIDS activist, was killed by members of her own community for openly disclosing her HIV status (Brown et.al. 2001:4)

² See Avert at <http://www.avert.org/aidsstigma.htm>

³ UNAIDS, 2000, Protocol for the Identification of Discrimination Against People Living with HIV, UNAIDS, Geneva.

2. *“Identification and elimination of arbitrary discrimination is an imperative in the control of HIV/AIDS. In this field, public health and human rights do not conflict with each other: instead, public health interests provide an additional and compelling justification for identifying and eliminating arbitrary discrimination on the grounds of HIV/AIDS status.”*

Further attempts to create an international political framework for addressing stigma were made in 2001 with the Declaration of Commitment on HIV/AIDS and in 2006 with the Political Declaration on HIV/AIDS.⁴ Locally a Namibian HIV/AIDS Charter of Rights was produced in 2000 after consultation with various stakeholders including the Namibian government. Various codes and policies apply to essential sectors of the Namibian economy including education and employment. It is unclear to what extent these measures have been effective in reducing stigma in their intended target areas and among their intended target populations. To date no impact measures exist.

It is estimated that 19.6% of Namibia’s national adult population is living with HIV⁵. Vast differences in infection rates occur within the country with Caprivi the region most affected with almost 43% of the region’s adult population living with HIV. At the same time, Namibia is one of only three African countries (Botswana and Uganda are the others) in which 50% or more of the infected population have access to antiretroviral (ARV) therapy (UNAIDS 2006). Both these statistics are important for stigma. First, high prevalence is associated with wide-spread, intense stigma and second, ARV’s as will be shown later, have proven to be an effective measure in combating HIV-related stigma.

HIV/AIDS related stigma has been around as long as the disease itself. However, the practice of associating epidemic illness with stigma is not new and in this sense HIV/AIDS stigma shows continuity with other epidemics (National Institute for Mental Health 1996). Yet compared to other illness-related stigma, HIV/ADS stigma is under-researched and it is only in recent times that the topic was given serious consideration. Although most work on the topic deals with HIV/AIDS stigma specifically, only a few have compared HIV/AIDS stigma with other illness related diseases such as cancer.⁶

This study draws extensively on a body of international literature dealing with illness-related stigma. The attempt to avoid a narrow HIV focus is thus deliberate in order to place HIV and AIDS stigma in context of all stigmatized illnesses and to look for the possible similarities among them. Secondly, the study also draws on a growing body of international study of HIV stigma in order to compare the dimensions and consequences of stigma in Namibia with those found elsewhere. In doing so, it looks for differences and similarities. Thirdly, the study aims to provide not only a description of the dimensions of HIV-related stigma, but also a scheme for understanding its origins, dimensions and manifestations in Namibia.

⁴ Piot (2006)

⁵ Ministry of Health and Social Services, 2005, Report of the 2004 National HIV Sentinel Survey, MOHSS, Windhoek

⁶ See for example Fife and Wright (2000) and Schulte (2002).

2. METHODOLOGY

Data was collected by means of eight focus groups. In Oshakati, Windhoek and Katima Mulilo groups consisted of male respondents and in Ekeke, Windhoek and Katima Mulilo respondents were female. The two groups conducted in Rundu were both mixed. All respondents are members of support groups and thus all are people living with HIV.

Group discussions were recorded and transcribed, and where needed translated. The audio recording of the male group in Katima Mulilo was damaged and could not be used for this report. Group discussions were conducted in respondents' language of choice. A standard set of questions were used to guide and prompt discussions (see Appendix 1). In addition to the focus groups, moderators conducted a number of face-to-face interviews with pre-selected key informants. These interviews were structured around a number of standard themes (see Appendix 2). These were also recorded and transcribed.

Respondents were required to describe key events, moments, experiences and actions with regard to HIV related stigma. In doing so they often presented their interpretations of these events, moments, experiences and actions as well. As one of the purposes of this project is to develop a theoretic understanding of HIV related stigma, descriptions are essential. Description, argue Strauss and Corbin (1998:19) is not theory but is basic to theorizing. The next step in the analytical process requires the descriptions to be sorted by means of conceptual ordering.⁷ These categories and their descriptions are presented in Section 6 below. The experiences of the various groups were compared during the conceptual ordering to ensure that these meet requirements for validity and reliability. The main purpose of the conceptual ordering in this study, is to sort respondents' descriptions of HIV related stigma into stages (or steps) and then to use the sorted data to describe these stages. The data was sorted and coded manually.

The report contains a large number of direct quotes from the focus groups. Although in some instances these might appear excessive, they do provide support to the broader conclusions reached, and they also capture the differences and similarities between the various localities and respondents.

⁷ Strauss A and J Corbin, (1998:19) define conceptual ordering as “[...] the organizations of data into discrete categories according to their properties and dimensions and then using description to elucidate those categories”.

3. CONCEPTUAL FRAMEWORK

Stigma refers to a *spoilt identity* (Goffman 1963).⁸ As such it is a process of social construction whereby specific people are assigned membership of a social group that is both discounted and discredited and as such they are reduced in the minds of others from being whole or acceptable. Fife and Wright (2000) argues that:

“persons become labeled as outsiders, and expectations and assumptions are associated with the individual from which patterns of response from others emerge during the interaction. As the individual internalizes this label, it becomes part of his/her identity, and thereby a part of the self that generates behavior”.

Much of the current research on stigma is still defined by the seminal work of Erving Goffmann published in 1963. Initially, stigma research by medical sociologists had a strong focus on patients with mental illness but over time new dreaded diseases were included: cancer, tuberculosis and leprosy. It is only during the last decade or so, that stigma among people living with HIV/AIDS (PWAs) attracted more frequent scholarly attention. Even more recently, stigma scholars started comparing HIV related to stigma to that associated with other diseases such as cancer.⁹ Over time stigma research progressed along two broad themes: 1) “who get labeled” and 2) “what are the consequences of labeling”. Where in the beginning the focus was on the mentally ill and their behavior as “grounds” for labeling, it has now shifted to include physical illness and the behavioral aspects associated with that.

Formal definitions of stigma have changed considerably over time to include not only the consequences but also the targets of this unfair and unjust treatment. Starting with Goffman’s work, the focus was primarily on the actual person with the attribute, i.e. those on the receiving end of stigma. Stigma was thus seen as:

“[...] an attribute that is deeply discrediting within particular social interaction”. Person with the attribute is “[...] reduced in our minds from a whole and usual person to a tainted, discounted one”. Stigma is a “spoilt identity”. (1963:3)

Much more recently UNAIDS¹⁰ published a definition of stigma that aims to draw attention to the discrimination that accompanies stigma. For them (HIV and AIDS) stigma is:

⁸ Goffman E, 1963, *Stigma: Notes on the Management of a Spoiled Identity*, Englewood Cliffs, NJ: Prentice Hall

⁹ See for example Fife B, and E Wright, 2000, **The Dimensionality of Stigma: A Comparison of its Impact on the Self of Persons with HIV/AIDS and Cancer**, *Journal of health and Social Behavior*, Vol. 41(1), p.50-67

¹⁰ UNAIDS (2002)

“[...] a ‘process of devaluation’ of people either living with or associated with HIV and AIDS. [...] Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Discrimination occurs when a distinction is made against a person that results in being treated unfairly and unjustly on the basis of belonging, or being perceived to belong, to a particular group”.

Brimlow, D et.al. (2003) offer an even more inclusive definition that includes not only those individuals with the attribute (i.e. HIV and AIDS), but also those groups and individuals that are closely associated with them that are also often the targets for stigma. For them (HIV and AIDS) stigma is:

“HIV-related stigma refers to all unfavourable attitudes, beliefs and policies directed toward people perceived to have HIV/AIDS as well as their significant others and loved ones, close associates, social groups and communities. Patterns of prejudice, which include devaluing, discounting, discrediting, and discriminating against these groups of people, play into and strengthen existing social inequalities – especially those of gender, sexuality, and race – that are at the root of HIV-related stigma”.

For the purposes of this report, we’ll follow the more inclusive definition of Brimlow et.al. (2003).

Goffman (1963) identifies at least three grounds for stigma: 1) Stigma based on *abominations of the body* (e.g. physical deformities); 2) Stigma based on *blemishes of individual character* (e.g. weak will, unnatural passions, and treacherous beliefs inferred from conditions such as mental disorder, imprisonment, addiction, alcoholism, homosexuality, and unemployment); and 3) *Tribal stigma* of race, nation and religion (i.e. beliefs transmitted through lineages and equally contaminate all members of the family, tribe or group).

According to Parsons, (quoted in Schulte 2002:83), ‘illness’ may be defined as ‘sin’ if the impairment is more global in its impact or if it is believed to be the result of individual choice. Illness is thus labeled as deviance if individuals fail to perform in obligatory role domains, and particularly if the illness is attributed to their own behaviors. Yet another view conceptualizes stigma as a social construction and illness may be linked to deviance if it can be attributed to behaviors that threaten particular moral standards of a dominant group (Schulte 2002:84).

The literature identifies a broad spectrum of stigmatized diseases that include diabetics, cancer, epilepsy, mental illness, leprosy and HIV and AIDS. These diseases are stigmatized because they combine two or more of Goffman’s three grounds for stigma. According to Fife and Wright (2000),

*“Illnesses are stigmatized because they represent potential or existing physical limitations, they are associated with particular negative images and myths, and therefore they take on **symbolic meaning**”* (emphasis added).

Whether or not a disease will become stigmatized depends very much on the nature of the disease. More specifically: 1) whether or not the individual can be blamed or held responsible for its occurrence; 2) whether or not the illness has potentially serious consequences for others; 3) whether or not there are outward manifestations of the illness; and 4) whether or not it results in decreased competence. (Fife and Wright, *ibid.*). HIV and AIDS as an illness conform to all the criteria of a stigmatized disease:

- ❖ The individual is blamed and held responsible for occurrence of disease;
- ❖ He or she is seen to have contracted the disease through immoral and deviant behaviour (extra-marital affairs, multiple partners, sex for commercial gain, drug abuse, homosexuality etc.);
- ❖ The disease is seen as progressive and incurable, also as ‘contagious’ and thus a great danger to the community and or public at large;
- ❖ The disease not well understood by the general public and knowledge of the disease is incomplete or inaccurate, and there is substantive fear of the disease;
- ❖ At some point the effects of the disease cannot be concealed and causes disfigurement;
- ❖ HIV and AIDS are associated with an ‘undesirable’ death.

Stigma is a highly complex, multi-dimensional social construction. Firstly, it is useful to distinguish between different types of stigma. One such distinction is between *internal* and *external* stigma¹¹. Internal stigma (felt or imagined) is based on shame and the fear for discrimination by the targets of stigma. External stigma refers to the actual experiences of stigma by the target. Research from other illness-based stigma projects, also shows that the type of illness determines the type of stigma. Cancer patients for example are often stigmatized with overly good intentions and are, hence, given an “extra break”. Link et.al. (1987)¹² have also shown that closeness to a “help seeker” (target of stigma) shapes the degree of stigma, and type of stigma send out. Those who are closely associated with targets of stigma, tend to show more understanding, and are less likely to stigmatize, than those further away from such targets. With regard to internal stigma, the form and degree of stigma is also explored by the type of disease. Fife and Wright (2000) showed that stigma is experienced by both HIV and Cancer patients and that stigma has a negative impact on perceptions of the self in both cases, but that HIV patients reported more stigma than cancer patients. Two factors shaped this: 1) the perceived severity of the disease; and 2) the functional health status of the patient. Internal stigma increased with an increase in perception of severity, and a decline in health functionality. They also

¹¹ Siyam’Kela, 2003. *Measuring HIV/AIDS Stigma: Literature Review*, p. 3; and Markowitz F, 1998, **The Effects of Stigma on the Psychological Well-being and Life Satisfaction of Persons with Mental Illness**, *Journal of Health and Social Behavior*, Vol. 39(4)

¹² Link B, Cullen F, Frank J, Wozniak J, 1987, **The Social Rejection of Formal Mental patients: Understanding Why Labels Matter**, *The American Journal of Sociology*, Vol. 92(6).

found that different dimensions of stigma have different consequences for perceptions of the self for both HIV and cancer patients. For example, being rejected by others and feeling socially isolated were instrumental for self-esteem, whereas, financial insecurity and social isolation were most consequential for understanding the sense of lack of personal control.

Another area of stigma that received substantive scholarly attention is the responses to stigma. These include: passing, covering, deviance disavowal, normalization, concealment, denial, social justification, secrecy and rationalization and a number of others. One relatively under-explored response is that of exploitation¹³. According to this set of responses, the targets of stigma are entering into exchange relations with others with the purpose of to alter the outcome of their exchanges (e.g. become more acceptable, gain access to resources etc.). Such exchange relations are characterized by the way the targets of stigma *exploit* their position to achieve their goals. Such strategies include: eliciting special consideration, evoking selected aspects of a stereotype, avoiding a more serious stigma, avoiding interaction, submissive manipulation, avoiding membership, and or gaining membership.

In research from the USA, PWA is stigmatized for their perceived homosexuality and IV drug use (Fife and Wright 2000:52). This is clearly not the case in Africa generally and Namibian specifically. Here, there are no real substantive differences, other than their medical status, between members of the in-group and the out-group, and in a great many cases, this difference is not even visible. Yet, locally, PWAs is stigmatized as HIV infection is associated with “loose or inappropriate moral values”, “deviant and inappropriate sexual behavior”, “the result of sin brought upon one self” and “being a danger to the community”. Labels and stereotypes are often used interactively: for example in Africa HIV is seen as a “black disease”. Thus, it is the interaction between one or more labels that often lies at the root of illness-based stigma.

In the case of HIV it is fear of casual transmission that is one key aspect that causes stigma among the general population. Another is the general belief that “bad people” (sex workers, drug users, homosexuals etc.) get the disease, and that they brought it onto themselves.

Stigma matters because it has serious consequences for the targets. These have been well documented over the years: negative image of the self, perceived loss of control over the personal, financial insecurity, social isolation, to name but a few¹⁴.

In addition to the negative consequences, Rosenfeld (1997) found that ‘labeling’ or stigma also has positive consequences, especially for subjective quality of life. Subjective quality of life is increasingly emphasized as an outcome of particular importance for

¹³ Gramling R and Forsyth C, 1987, **Exploiting Stigma**, *Sociological Forum*, Vol. 2(2)

¹⁴ Ogden and Nyblade (2005:26) provide an extensive list of the forms and consequences of stigma under four broad categories: physical, social, verbal and institutional. See, Ogden J & L Nyblade, 2005, Common at Its Core: HIV-Related Stigma Across Contexts, ICRW, Washington DC

people with serious chronic disease. As an important component of well-being it is at the same time: 1) damaged by stigma; and 2) improved by special services such as counseling, targeted medical treatment and inclusion in new social networks (such as support groups).

Some scholars have begun to question the conventional view that portrays HIV and AIDS related stigma as overly context-specific and defined by local specificities. Instead, Ogden and Nyblade (2005) argue:

“[...] HIV and AIDS-related stigma is far less varied and context-specific than may have been imagined. In fact, there are many more similarities than differences across the contexts in key causes of stigma, the forms stigma takes, and the consequences of stigma.”

4. FINDINGS

Socialization

Individuals who contract a stigmatized disease later in life, have been socialized¹⁵ to understand and internalize the stereotypes associated with their disease prior to contracting it themselves. They thus experience a shift in social power relations as they move from being a stigmatizer to being stigmatized. This puts them at special risk for low self-esteem.

It is likely that individuals acquire the communal values and norms that underpin HIV and AIDS related stigma at a young age during their primary stage of socialization.¹⁶ Agencies for primary socialization include: the family, peers, the church, schools and the media. During this stage individuals will be informed about important issues such as race, gender, religion and sex and sexuality, all of which make up part of the larger system moral values that are commonly used to define the boundaries between the socially acceptable and unacceptable.

Most respondents in this study were in their formative years when HIV first assumed pandemic status in Namibia in the latter part of the 1980's¹⁷. Others were born during the early stages of the pandemic. Either way, they were socialized in much the same way and with the same message: HIV is a disease brought onto oneself as a result of immoral behaviour. It was a disease found among 'prostitutes', 'homosexuals', 'returnees'¹⁸ and 'foreigners'¹⁹. All respondents reported a sharp, clear boundary between those like themselves (the moral) and the 'others' (the immoral). None included themselves as part of the group(s) perceived to be at risk for infection. The statements recorded below, highlights the close link between stigma and new infections.

"I thought it was an illness of homosexuals because that is what I heard from radio"

– Female, Eheke

¹⁵ Socialization refers to the process whereby an individual acquires social norms and values. It serves two purposes. "On the one hand, it prepares the individual for the roles he is to play, providing him with the necessary repertoire of habits, beliefs, and values, the appropriate patterns of emotional response and the modes of perception, the requisite skills and knowledge. On the other hand, by communicating the contents of culture from one generation to the other, it provides for its persistence and continuity." (Chinoy 1961: 75).

¹⁶ Primary socialization is the process whereby people learn the "appropriate" attitudes, values, and actions appropriate to individuals as members of a particular group, community or culture.

¹⁷ The first case of HIV infection was recorded in 1986 in the Caprivi region.

¹⁸ A term used to refer to the men and women returning to Namibia from life in exile at the time of Independence around 1989.

¹⁹ Most likely a reference to members of the UNTAG task force and the other foreign nationals seconded to the transition process.

“We heard it during Namibia’s first election that it was an illness from returnees”
– Female, Eheke

“I heard it from my father talking about an HIV positive relative from exile and that the disease came from monkeys”
– Female, Eheke

“It was also said that it was a disease for women who slept around”
– Female, Eheke

“I did not believe that HIV existed, those days, the people I heard were HIV positive looked healthy to me and it was said that HIV was an illness for homosexuals or promiscuous people and I was neither. I felt it was a consequence of their immoral behaviour. It is only years later that I saw someone showing the symptoms of AIDS that I paid some attention, but even then I did not use condoms because I felt I would not get infected. I think I was in denial”.
– Male, Oshakati

“I thought that people who were HIV positive were promiscuous or prostitutes in the case of women; and I had very little sympathy for them, but the strange thing is that when I was drunk I would have sex with some of those women who were HIV positive...sometimes without condoms, because I did not have condoms or I was too drunk to know what I was doing at the time”.
– Male, Oshakati

“I did not think that I would ever get that disease. I thought that it was not for me, it was for lesbians and for people who come from far away countries. It’s not for us. And these men in the army, it’s just for them, not for us. I thought it was a far away disease.”
– Female, Windhoek

“To me HIV was a reality but I never saw it as something close to me. I normally used to refer to a certain group of people like prostitutes, and never thought that I will get it some day. According to me it was only meant for promiscuous people. No, I never thought that it would happen to me some day.”
– Male, Windhoek

“We used to think that the infected people were prostitutes and were on death sentence. I didn’t believe that really the virus was there, until I was diagnosed with HIV. I couldn’t even eat with the infected people before I got it.”
– Female, Katima Mulilo

“I heard for the first time about HIV/AIDS when I was in Russia. We were thinking that the disease was just for Europeans. I came to know the seriousness

of it when I was in Angola with Unavem, or in DRC or in Cambodia. Even now I don't know where I got the virus, whether in Angola, or DRC or in Cambodia, I don't know, because I was a very handsome guy. When I am in my uniform, every girl or woman would run after me."

– Male, Rundu

"I was shocked to see a person suffering from this disease. I also thought they were prostitutes. I was not free to eat from the same plate with such a person. I was afraid that the disease will also affect me. I did not trust the company of such a person. I was afraid to share the same clothing or bath together with such a person. I also thought such a person was on the verge of dying. I doubted if such a person can live much longer"

– Female Katima Mulilo

During this stage knowledge about the disease and particularly transmission was sketchy, incomplete and inaccurate. In the minds of some respondents, especially those from the north-central part of the country, the disease is connected to Independence having been 'brought here' by Namibians returning from exile and foreigners involved with the transition period. High risk groups were identified on the basis of their perceived sexual deviant behaviour and not so much on religious grounds. Male and female respondents show similar degrees of stigma prior to contracting the disease. Individuals who do not recognize their own risk for HIV infection because they associate risk with stigmatized groups only, are unlikely to change their own behaviour or respond to public messages and campaigns. Thus, for these individuals, sexual contact with members of ones' own, non-stigmatized group constitute no risk for HIV infection for the stigmatizer, and sexual risks can be avoided or reduced by avoiding or limiting sexual contacts with members of the stigmatized group. In this way, stigma drives new infections.

"I first heard about HIV on radio in songs such as AIDS is the enemy. In those days we did not understand HIV and it frightened us. We did not really understand what was happening because there were so many false rumours. It was said that AIDS comes from monkeys or from foreigners. The community started to understand and become aware around 1997-1998."

– Pastor, Windhoek

"After Independence, I came to learn about HIV/AIDS, it is either brought into our country by UNTAG's or Defence Force that's how we heard it or may be the punishment with independence of the country from God."

– Traditional Leader, Windhoek

"There was also political machinery going on before Independence. So we took ...[it]... as people discouraging ...[Namibian]...people to mix with Swapo fighters because they were saying these ...[fighters]... will bring AIDS to the country and therefore don't associate with them. 'Reject them',... so we took it as plea to discourage us from accepting Swapo as freedom fighting group. But the fact that they

mentioned AIDS was true, it was real and we have seen this immediately after Independence. The disease began to spread like wild fire.”

– Politician, Windhoek

“I did not think I would get infected because we were told that it was an illness of returnees, people who came from exile were the ones that brought AIDS, so we did not take precautions because I had wrong information about the illness and how it spread”.

– Male, Oshakati

“There was also a notion that this was an illness for prostitutes, homosexuals, returnees from exile and UNTAG, so most people thought they were safe as long as they stayed away from these groups.”

– Male, Oshakati

“I thought I would not get infected because I had one sexual partner and my partner was not a returnee, since it only infected those who had sexual relations with returnees”.

– Female, Eheke

Female respondents much more often than male respondents linked their first actual experiences with HIV and AIDS to having to care for others. These experiences caused fear for contracting the disease and installed the notion that the disease is deadly and that death is immanent, and it is this fear that is often at the root of HIV and ADIS stigma.

“I really loved doing hospital visits. But whenever I walked in (there) I felt nauseous. I always had that attitude. But afterwards I thought – I am a child of God, so why am I acting like this? Then I would go back and visit people again. I always washed those who are bedridden. But sometimes people had to force me to go in there. Later on I got used to it. There was one sister who told me that I should always wear gloves. But I always refused and I thought why should we do that. Some or other time you will get the disease yourself and we don't know where it comes from. That is why I got used to it and I always visited the bedridden people. Even in the squatters, the DRC, I walked around there and did work there. This is where I got used to it (AIDS).”

– Female, Windhoek

“To me it was terrible because I did not want to come near those people. Because if I came near to them I would also get that disease. Because I used to work in the hospital. I was an assistant nurse. And before 1989 there was one man who was lying there who was from Katima Mulilo. Then we heard that that man had that disease. And right there in '89 I decided to leave this job. Because later I will just pick up this disease at the hospital. So I resigned and I left that job until today because I did not want to come near those people. And in our family, before that

time there was nobody who had the disease. We did not know those people. With me it was the first one in our family.”

– Female, Windhoek

“I always used to stay with people. There was a man who used to travel and then he visited girls. I thought he would get it but not me. But later on I used to wash those who are ill and I used to look after them and cook for them. I heard that it was this disease that is making all of us ill and that it is the disease that will kill everybody.”

–Female, Windhoek

“I saw the first person who was HIV positive in hospital when I went to visit a friend who was sick. It really frightened me but in those days we had unclear information about HIV and how it was spread and that it was indiscriminate, so we were ignorant and unprepared. It is because of these reasons that I did not think I would get infected”.

– Female, Eheke

Only one respondent linked HIV with the traditional practise of witchcraft.

“When I fell sick, I was first put on TB treatment, but did not believe that I had the virus. As such I consulted witchdoctors because I believed my husband died as a result of witchcraft. No one from the family knew what had killed my husband therefore; I concluded his death was caused by witchcraft. When my husband died, I was not sick, besides since he died I did not have any sexual relationship with anybody. Therefore, how could I get the virus? I was troubled all the time as I did not understand how I got this virus. However, my elder sister advised me not to blame myself because I did not know the behaviour of my late husband. In response to this advice I felt it was none of their business and told them I did not have the virus, but was only suffering from TB. With this denial I opted to visit witchdoctors where I was told I was troubled by my late husband’s ghost. I received treatment from witchdoctors, but I was not cured. Thereafter, I told my mother I was suffering too much and decided to continue with my TB treatment, but after two (2) months I fell ill again. It was during this time that I told her I was going to a New Start Center for testing.”

– Female, Katima Mulilo

Getting tested

The data shows that one of the effects of stigma is that it delays testing. Respondents, well knowing that they will be stigmatized in the same manner as they have stigmatized others, delay getting tested until such time as they can no longer hide their own physical symptoms, or withstand the pressures put on them by others close to them.

Getting tested for the first time is inspired by a number of factors including: chronic illness (oneself and/or others close to oneself such as children or a partner), having contracted a STD or some opportunistic infection, the death of a sexual partner, persistent physical symptoms (such as weight loss, shingles, headaches, and chronic coughs), the advice of a HIV councilor, and in the case of women, pregnancy.²⁰

All these suggest that testing takes place quite some time after infection and it is thus not surprising that most respondents tested positive first time round. Furthermore, since testing takes place once the physical symptoms are clear for all to see, some degree of external stigma might already be experienced at this point. At the very least, others suspect that the particular individual might be infected so rumors about possible infection are likely to be going around.

“I got sick. I vomited and I had diarrhoea and a headache. Then my father took me to the clinic. Then I went to the clinic and the sister said it was Malaria. Then I came back and told my father. Then he brought me to Windhoek and took me to the hospital. Then the doctor said he would take my blood and that I had to come back after two weeks. Then I came back after two weeks and he said that I was positive.”

– Female, Windhoek

“I just had headache. And I also got very thin and I got those warts, so I thought about having the test done.”

– Female, Windhoek

“I was pregnant and then the child died in my womb. And I was not ill that time. The pregnancy was not a problem. After that I decided to go to hospital because I am always getting children and my children don’t die. So what’s going on? So I went to the hospital and they asked me why I was there. So I said my child died in my stomach, what is that? That time I was fat so I did not worry, because I did not think I would be HIV positive.”

– Female, Windhoek

²⁰ These reasons might be specific to this sample because all respondents are living with HIV and hence, tested positive. Persons who tested negative will have reasons other than physical illness for getting tested. In their case, the behavior of the self or partners might be a key factor and exposure to campaigns or educational material might provide the main inspiration.

“I got tested because I had shingles (sores that looked like burn wounds). At the hospital the nurse advised me to have an HIV test, she said that the sores I had were rare in healthy people and that you found them in old people, and people with HIV.”

– Female, Eheke

“I went for an HIV test because I started to suspect I had a sexually transmitted disease. When I went to hospital I was advised to take an HIV test as well”.

– Female, Eheke

“I suspected that I might be infected, when an ex sexual partner got very ill and died. People said he was HIV positive.”

– Female, Eheke

“I suspected that I might be HIV positive, when I was diagnosed with TB. I knew that people who had TB in my area were also HIV positive sometimes, so I went to the New Start Centre.”

– Male, Oshakati

“Two of my girlfriends died and I thought it is possible that I might be HIV positive.”

– Male, Oshakati

“In the old days, the sexually transmitted diseases we knew of were Gonorrhoea and Syphilis, but as years passed, I realized that HIV was indiscriminate and in my village men from my generation were all dead, so I went for a test and found out that I was HIV positive.”

– Male, Oshakati

“I think that ... in most cases many people went for the HIV test when they were seriously sick. That is why you see many HIV positive people are dying, because we take a step to go for the test when we are very, very sick. I can say that 70% in most cases go for the test when they are seriously sick. If people could go for the test as early as possible before falling ill, I think they could not die so many like the situation now.”

– Female, Rundu

“I went for an HIV test after I got very sick. I got counselling and had a test but I did not go back to the hospital for the results because I was afraid; besides, I started feeling well again. After some time my wife got ill and then she died; that is when I thought I might be infected. So when I went for my second results I found out that I was positive.”

– Male, Oshakati

“It was my son who died after a long suffering of sickness, then my wife followed and I was also sick so I was encouraged by a friend and I was tested positive.”

- Male, Katima Mulilo

“I had a cough for a long time. Again, I had high blood pressure (BP). My father took me to the hospital several times without much help. Then a certain man from Malawi came along and said he could treat any kind of disease. I was taken to this man for a one-week treatment, but started vomiting which I did not do before. Thereafter, I decided not to continue with his treatment because I could not see any improvement. I decided to go for testing but did not know how to tell my parents about this decision. My father also had TB and I did not know how to approach and tell him what I had decided to do.”

- Female, Katima Mulilo

“Myself I knew that I might be having the virus, because I was with my husband who was always sick. People would always encourage him to go to hospital and have his blood tested, but he would refuse. His health condition deteriorated and he was taken away by his relatives to seek for treatment. That is why I knew that I might be infected with the virus, and decided to go for the test.”

- Male, Rundu

“As for me my husband had another girlfriend who suffered from HIV and died of AIDS. People told me that I would also die of AIDS. I did not believe them. Later on I started falling ill, but I was afraid of going for an HIV test. After many encouragements from friends and members of my family, I decided to go for the test. It was positive of course. I was hesitant to inform my husband, but later I informed him. He was furious with me. He decided to move to Nkurenkuru and leave me alone with the child.”

- Female, Rundu

“In my case, I came to know about my status after suffering for a long time. I was in pain and sleeping the whole day. People were even saying I have been sick for a long time and should therefore die. Others were laughing at me, but my mother told me to visit the New Start Center because I have suffered enough. I told my mother I was not a prostitute. I said people who suffer from such a disease are those who were sleeping around with members of the UNTAG. But my mother told me she was giving the same advice to all her children who are still alive to go the New Start Center to seek help. She urged me to go to the Center to get help because nowadays there is help for people suffering from HIV.”

- Female, Katima Mulilo

Dealing with being positive

Once test results are known respondents were faced with the challenge of telling others. Initially, respondents shared their status only with a small group of trusted confidants - siblings, colleagues, spouses, priests and clergymen. It is not uncommon for respondents to delay telling their parent(s) most likely due to feelings of shame and a fear that they too will be stigmatized. It is often siblings and/or other family members who inform parents. Some respondents reported living with their status for quite some time before telling anyone else despite persistent rumors about their status. Quite a few respondents mentioned that their decision to tell others was caused by the policy of having someone else present to collect ARV's. Others waited until they could no longer hide the fact that they were ill, i.e. they could no longer hide the physical symptoms.

"I was admitted in a hospital and I made an appointment with the nurse to inform my wife when she comes for her daily visits. That's the only way to go as the shock was unbearable for me. So I told my wife the same day I find out about my HIV status. My wife told her elderly sister and the story spread like a bush fire until it reached my parents and thereafter I was discharged from the hospital. And that was to our blessing as my parents provided us with accommodation."

– Male, Windhoek

"The day I got my result I threw away my medical card. And I did not tell anybody about my status for a very long time, but then some time later, my health started to deteriorate and I told my mother because I felt that, should I really get very ill, no one would know what do; or worse, they would take me to traditional doctors, because my mother is very traditional. So I told her that I was HIV positive and should I get very ill, she should take me to the hospital instead".

– Male, Oshakati

"I was obliged to go with someone to collect my medication and was forced to tell my friend, thereafter my family."

– Male, Windhoek

"The hospital advised me to bring along someone I trusted to come with me, so I went with my sister and I told her immediately."

– Male, Oshakati

"With me it took very long. I have known since 2000 that I am positive. But I did not tell anybody. Only during December of 2000 I got sick and then I went to hospital and the doctor said I should come with somebody else who can sign for the medicine. Who should I tell? That day I decided to tell someone. I told three people but lots of people only think of TB. That day I told someone that I am HIV positive and you should come with me otherwise I can't get my medicine if I am alone."

– Female, Windhoek

“Before I could tell anybody they already knew because of stories going round. I don’t know where they found out. I had an operation in the Roman Catholic Hospital. They removed my womb. The people in the hospital wrote on my card and then my family read it on the card but they did not tell me. They just spread the story but they told me not to worry. They can talk and talk but if it’s there it’s there...”

- Female, Windhoek

“I told my sister first. But I only told her after two days. Only my friend knew from the start. My sister told my mother and the other sisters.”

- Female, Windhoek

“When I found out that I was HIV positive, I told my sister but for many years I could not tell my mother. She is old and I did not think she could take such news. I lived with my mother and I realized that not telling her about my HIV status was not wise. What would happen should I get ill? I asked my sister to tell her about my status. My mother dealt with the news very well. She is my biggest source of love and support”.

- Female, Windhoek

“I did not tell my parents about my status immediately, but after I received my CD4 count I felt there was no need to hide my status from my parents. I felt if I hide my status there will be no one to assist me once I fell ill. Besides, my parents will continue taking me to witchdoctors for treatment. I felt it was better to inform everybody, my parents, sisters, brothers and those close to me so that when I fall sick they should know what to do.”

- Female, Katima Mulilo

“I took long to inform my parents because they were also patients. I decided to go back to the New Start Center for advice on how to approach this issue. At the Centre I was advised to bring my parents and they would know how to go about it. I took my parents to the New Start Center where they had a discussion with counselors alone, later I was called in too. During the discussion I told my parents I had known my status for a month and that was why I called them to the New Start Center to be informed. My father appreciated what I did.”

- Female, Katima Mulilo

Internal stigma

Having tested positive for HIV brings about internalized stigma based on strong feelings of guilt, shame, blame, judgment, fear of death, fatalism, and depression. Many respondents also reported feeling suicidal. These feelings are shaped by fear of stigma and this fear is based on respondents' initial HIV socialization. At this point in time respondents also realized that the contents of their initial beliefs around HIV and AIDS were false and that the disease is not limited to stigmatized groups. Given their prior socialization, respondents were well familiar with the contents and effects of (external) stigma, and would anticipate the effects of stigma on their family and others close to them. The most common strategy or coping with (external) stigma is self-imposed isolation. Other common strategies include drinking heavily and denial. Religion and religious agencies also assume a much more prominent role as coping mechanisms.

"I felt humiliated and far from God and wanted to put an end to everything. I asked the Lord why, why, should it happen to me."

– Male, Windhoek

"I felt ashamed and guilty. I was very much willing to tell my wife but I did not have the courage to tell others in the community because they will see me as someone who was sleeping around. For someone like me who is very active in the community they will say where is he coming from and that made me felt very bad. Because I used to link the virus to certain groups of people like prostitutes and promiscuous people, I thought of the eyes that will look at me and say was that he is also promiscuous. It was easy for me to tell my family but not the community."

– Male, Windhoek

"I blamed my girlfriend for my status and felt that my life was over, but at the same time, I was in denial...it was the only way I could cope with life"

– Male, Oshakati

"I was afraid; I was shaking and I did not eat for a week. I was hungry but I just could not eat. My family tried to find out what was wrong but I told them nothing...after some days I recovered somehow, but I was always afraid of dying all the time"

– Male, Oshakati

"I blamed myself and I was angry for bringing a disease to my wife...she was faithful to me, but I was not"

– Male, Oshakati

"When I found out the first time, and after I told that woman and the priest, I just felt that I could die any moment. That is how I felt. The woman dropped me off and said she would come back, then she went and bought shopping for me out of her own

money. I just locked myself up in the house for three months. When my husband came home from work he just slept in the children's room."

– Female, Windhoek

"I felt very bad. I decided that I would just drink until I died. I drank so much that people had to follow me like a child. Whenever I went out of the house I would go and drink. Until they had a meeting with me. My sister's husband said maybe we should just leave her alone so that she can realize for herself what she is doing. We must not follow her anymore. But I just kept on drinking. I drank so that I could die."

– Female, Windhoek

"I thought that from now on it is the day I die. I just drank. People say you can feel death coming. I thought that if I had to feel it I would strangle my child so that he would also die. If I had to die I wanted my child to die as well."

– Female, Windhoek

"I cried a lot, because I felt betrayed by my husband. I felt ashamed by the fact that HIV is a disease for much younger people. I am over 50 as well as the fact that my husband is of a much older generation"

– Female, Eheke

"I thought of killing myself with my child, because I felt worthless and would become a burden to my parent"

– Female, Eheke

"I became very suspicious of everyone. I thought everyone was talking about me. I became so paranoid that, if I saw people gathered and they were laughing. I assumed it was about me."

– Female, Eheke

"I distanced myself from everybody, if I met people in the road on my way to someplace; I turned back just to avoid them."

– Female, Eheke

Some respondents reported much more positive experiences in accepting their status. Almost without a fail, counselors and counseling played a most important role in reducing or limiting internal stigma. Doctors, volunteers, nursing staff, priests and support groups, and to a lesser extent, family and friends, all provide messages and information that challenge and counter the spurious beliefs around HIV and AIDS that were formed during the initial socialization stage. They help those who tested positive to better understand the disease and their own prognosis for a prolonged life. In doing so, they confront some of the key aspects of stigma (e.g. that death from the disease is inevitable, that only 'immoral people' contract the disease, and that becoming physically incapacitated is inevitable) and promote a positive self-concept based on the understanding that: "life does not end here and now". More accurate and detailed information about the disease as delivered as part of counseling assist in no

small way to ‘normalize’ the disease as it directly challenges the popular obsession with casual infection and immediate death. Rural respondents listed radio as a popular means of obtaining information about HIV and AIDS.

“I have to thank my counsellor at the hospital. Because she made me understand the fact that I was a carrier of the virus and I could have my health for many years before I got sick; and that should that happen; there was medication to prolong my life”.

– Female, Eheke

“I spoke to a lot of people and asked them what I should do. What should I do to look pretty? They said I should eat well and live healthy. My sister who went with me to the test told me a lot about it and said that people with AIDS can live healthy. This helped me to accept it.”

– Female, Windhoek

“I knew I had lots (of partners). I won’t know who gave me the disease. But when I found out I felt bad because I thought maybe I would die soon. I told my friend. She phoned her mother because she was also at New Start and I went and talked to her. She counselled me and everything.”

– Female, Windhoek

“I could not accept and could not even be with people. Luckily there are support groups, and someone positive came and discussed with me and we formed a support group.”

– Male, Windhoek

“Friends encouraged me. I am talking about people who have more information who took me to a place like Bernard Nordkamp to join the support groups. The Pastor prayed for me and took me to support groups to talk about my situation. I don’t blame anyone as I have accepted the situation.”

– Male, Windhoek

“Feelings I had to be ashamed drove me to depression and I stayed in bed. Of the volunteers from Catholic Aids Action came to me and said that I should join the support group meetings. I have received counselling and it has helped me a lot to get out of the depression. I joined the support groups and shared my problems with them. Every time I meet people who are positive, I started changing my way of thinking. I handed everything to God because that helps me to lighten the burden. Circumstances changed the more I prayed. That’s how I have overcome it.”

– Male, Windhoek

“While the people were always talking to me, and I could see that they stood by me, I just felt that this disease is actually just a normal one. And since then I just always told the people – I really love doing speeches for people – ‘we must remember one thing: first we were not allowed to talk about TB, then we were not allowed to talk

about cancer, and just like that, this disease is a normal one and maybe we will all get it one day. We don't know how it came but maybe we will all just get it."

– Female, Windhoek

"For me, I would say the counselling helped me a lot. I did not believe in the medicine, but I can say that the counselling that I got and the information I got out of that, that was my medicine. And how the people handled me and accepted me. How my sister looked after me was very important. It helped me a lot and it brought me back to life."

– Female, Windhoek

"I had counselling with a nurse after I found out and that helped me to accept my status. I started to listen to radio programs on radio that talk about HIV/AIDS."

– Female, Eheke

"I was given some booklets on information from the hospital and they had information of organizations to go to for assistance or more information".

– Female, Eheke

"The only people I interacted with were my immediate family, the people I lived with and I listened to radio a lot, you could say my only friend was my radio."

– Female, Eheke

"I joined a support group. I met people who understood what I was going through. Most of my friends are from my support group as well."

– Female, Eheke

"I talked a lot about my difficulties to my best friend and then I joined a support group where I got advice on how to deal with issues such as how to disclose my status and what to expect."

– Female, Eheke

External stigma

Stigma leads to discrimination, i.e. a sharpening of the boundaries of the “moral community”, where the distinction between “us” and “them” is converted into actions that are both discriminatory and unjust. HIV related external stigma is expressed in various forms that are near universal in all societies and communities with HIV prevalence. These include:

- ❖ Social rejection and isolation,
- ❖ Exclusion from existing social networks,
- ❖ Loss of employment and place of residence,
- ❖ Low and devalued self-esteem,
- ❖ Social ostracism and exclusion,
- ❖ Voyeurism,
- ❖ Name-calling.

External stigma seems to increase as the physical symptoms of the disease become more visible, as physical capacity is reduced or lost and specific physical conditions (e.g. weight loss) are observed. External stigma is driven by obsession with casual transmission: shaking hands, cooking food, shared linen, house visits and sharing eating utensils. Stigma is thus employed as a social strategy against those living with HIV to avoid possible infection. It is also clear that the fear for casual infection is based on inaccurate and incomplete knowledge of transmission, and as such external stigma is an ‘overreaction’ on the side of uninformed and inexperienced individuals. External stigma re-enforces internal stigma and thus drives pre-emptive self-isolation.

“I have lost my family - they rejected me - and even the people at church reject me and say bad things about me, where I thought I could speak openly about my virus with them. I was married in 1989 and divorced, and since then I don’t have a friend of a wife. I got infected in 2005, and in the environment where I used to live, people say bad things about me. That is why I am homeless and live in the park. Even when I did casual work at Pep Stores, people came there and say ‘...why are people with HIV employed and not our children with Grade 12’? They call me names and say that’s why I got infected.”

– Male, Windhoek

“It is the same with my sister’s two daughters; they are spreading my HIV status in the streets of Katutura. I went to report the case to Legal Assistance Centre and to the Police. Legal Assistance Centre came to talk to them and warned them, but they only stopped temporary and started again. They treat me like a dog.”

– Male, Windhoek

“My husband doesn’t talk to me since I told him that our child and I were HIV positive”.

– Female, Eheke

“In the early days when people found out about my status, I was called a prostitute by someone from my village”.

– Female, Eheke

“My in-laws are divided into two. The ones in Windhoek are Christians and accept my circumstances and support me, but the ones at the farm who are not even well informed reject me. When we go visit at the farm then they would say: ‘Did [he] come to give our daughter AIDS?’”

– Male, Windhoek

“I felt the stigma when I got ill and started showing physical symptoms, such as skin rashes and thinness. If you are at that stage and you are bedridden then you experience things such as your family isolating you and hiding you when they have visitors, but if you are looking healthy and you are still productive then people in the family or community are generally fine and comfortable with you”.

– Male, Oshakati

“People from the community stopped visiting our house, or if they did, I felt they did out of curiosity to see how sick I was”.

– Male, Oshakati

“I am only allowed to use specific utensils like my own cup, plates and so forth.”

– Female, Eheke

“If I cook food in our home, no one eats it, and the children are beaten for eating something I cooked.”

– Female, Eheke

“In my village, when I take my hand out to greet someone, they usually do not give their hand back to greet me, they are afraid that, they will get infected by shaking hands”.

– Female, Eheke

“When I go to visit my cousin in Wanaheda then I am not allowed to use their plates, but I am allowed to use my cousin’s dishes because he is not home at all time so I can’t infect him. But slowly but surely they are changing as my cousin’s wife is also HIV positive.”

– Male, Windhoek

“When I was very ill and thin I was embarrassed and avoided going out of the house, but when I went on medication this year and with my body improving I have confidence now and I go out with friends.”

– Male, Oshakati

“I avoided getting into discussions about issues in the community relating to HIV because I was afraid of someone bringing up my status. But when I became public about my status I became more vocal about the challenges that people living with HIV and AIDS face.”

- Male, Oshakati

“I became very depressed and suicidal. I stayed in my bedroom all the time. When my family came to my bedroom to find out if I was fine I chased them away. The only person I talked to was my mother; she really helped me out of my depression. And now when I am feeling down or I have a problem I come to my support group.”

- Male, Oshakati

Negative consequences of stigma

Stigma leads to actions that are both unfair and unjust. Victims of stigma reported a number of negative consequences they suffered as a result of their HIV status being known to the larger community within which they live and work. These include:

- ❖ Social isolation,
- ❖ Loss of social status,
- ❖ Breaking up of families,
- ❖ Loss of employment,
- ❖ Inability to find or maintain meaningful love relationships,
- ❖ Financial hardship, and
- ❖ Professional neglect.

These consequences invariably stems from actions taken to put sufficient distance between the HIV positive individual and those immediately around them who are not infected to avoid (casual) infection of the latter. In this respect respondents reported the difficulties in finding new partners in love relationships or being able to stay in existing relationships.

Some respondents reported deteriorating physical capacity leading to loss of employment, and the difficulties in finding new jobs even after their physical condition has improved, leading to financial hardships and insufficient food supplies.

Individuals living with HIV and AIDS are more socially and economically vulnerable than most others because they are often excluded from the existing social networks that normally provide an informal safety net for other vulnerable individuals. They often cannot count on the informal welfare systems present in the community to overcome times of financial hardship because of their stigmatized status. Social isolation from networks such as the extended family thus has severe economic and financial consequences.

Stigma sometimes also causes professional neglect. A few respondents mentioned being treated indifferently by hospital and clinic staff.²¹

“My children were taken away from me by my wife’s family when she died; I know that it is part of the tradition. But I think their life has changed, because they tell me that they are not happy where they are staying, but I can not stay with them right now because I can not afford to take care of them financially, like their mother’s family

²¹ Although respondents specifically identified stigma as the root cause of hospital staff ‘s indifferent treatment, it is possible that a number of other factors ply a role as well. Staff members often complain about long hours, staff shortages, and a huge workload. It is possible that indifferent service could be attributed to these rather than stigma.

can. I really miss my children, but I know it is for the best if they stay where they are and get a good education.”

– Male, Oshakati

“When I started to get ill my life was really difficult. I lost my job because I was always absent because of illness and people knew about my status but I feel that has changed once I started taking medication and my health improved. Now I found another job.”

– Female, Eheke

“It is really hard to find someone to have a serious relationship in this town when people know about your status. The only women I get are those I pay money to have sex with. It makes me sad because there is no love in that kind of relationship and that kind of relationship has no future, because it lasts as long as the money is there.”

– Male, Oshakati

“I have lost a lot of my friends from the past, because I can not participate in some of the social activities such as going to the shebeens and bars for drinks. Sometimes I feel very lonely.”

– Male, Oshakati

“When I lost my job I was not able to support myself and my family, so life is much more difficult, my health is also not good, so that has affected my ability to work in my mahangu field. Hunger is always knocking at the door of my family.”

– Male, Oshakati

“My life did change for the worse after my husband died. I felt that we did not get support from the extended family from my husband’s side. I have five children and it is getting very hard to pay for their education.”

– Female, Eheke

“The quality of my life has gotten worse due to the fact that I was always tired; my work performance deteriorated and I was asked to leave my job or get retrenched.”

– Male, Oshakati

“I started getting weak because I was always sick, so I was asked to leave work because I was no longer productive. The job that I was doing was very labour intensive. I was working in construction”.

– Male, Oshakati

“My partner left me a short time after I tested positive. I have been on my own since then. I find it much more difficult to have a long-term relationship now that I am open about my status. I think it will be hard to get married because women in my community do not want to be associated with a man who is HIV positive. I think they only do that if the man has a good job or if he is rich.”

– Male, Oshakati

“My quality has gone down as I used to drink a lot. But now I make sure I stay clean and neat. I stay on top of a roof in the park in Suiderhof. It has motivated me to be a strong person. Last year in December I went to see my brother and told him that I am hungry. He told his wife to give me food but that I should not enter his yard. She gave me food in a plastic bag - food like meat, salad and so on. It’s like giving it to a dog but I said to the Lord it is fine.”

– Male, Windhoek

“I accept and withdraw myself from those who are treating me bad. I stay on my own.”

– Male, Windhoek

“My brother discriminated against me at the shebeen. He said that I have AIDS and that I should actually bring my pills or medicine containers so that they can throw my wine in it. I was very sad, so sad that I ended up in hospital. Then the sister said to me that I can actually make a case against him. I thought about this for a long time and when I came out of hospital I thought: ‘You wait and see; his day will come too.’”

– Female, Windhoek

“My mother said that some of her friends talk about her and say she is a bad mother because she let me go to Windhoek and that is where I got AIDS.”

– Female, Eheke

“At the hospital I find that nurses are generally insensitive and the service is not good, there are long cues and sometimes they go for long lunches and you just have to wait for your medication even if it takes the whole day”.

- Male, Oshakati

“They don’t consider us... like those people at the hospital. When you go there in the morning, they would complain, why do you do not come during the day? They don’t care about you. They would just go to the other patients and leave you”.

- Respondent, Rundu

“Once I was admitted in hospital. I explained my situation to the nurse who was on duty, but the nurse ignored my information and kept on saying that I was nagging too much. That time I didn’t know much about stigma.”

Respondent, Rundu

Positive consequences of stigma

Studies on chronic mental illness by Rosenfield (1997) and Rosenfield and Wenzel (1997) found that stigma has positive consequences as well. These often come in the form of special services and benefits, new social networks and new opportunities for caring and empathy. In Namibia, those living with HIV and AIDS have access to free ARV treatments, special services such as counseling and new social networks such as support groups. None of these would have been in existence if not for HIV and AIDS related stigma, and all of these have a positive effect on reducing stigma. In the first instance, ARV medication improves physical health and promotes a health body image. Counseling counters the effects of inaccurate and incomplete knowledge about the disease and promotes a positive self-esteem, whilst the new social networks around support groups and other HIV related activities provide new opportunities for building a positive self-image, and access to new sources of empathy and care. Many respondents reported important positive lifestyle and attitudinal changes as a result of participation in these new social networks. In many instances, these new social networks have replaced the old ones that have become defunct as a result of stigma. Collectively these new networks have extensive experiences with and knowledge of HIV and AIDS and as a result have more empathy and are stigma free.

“The Lord has carried me thus far. Some organizations don’t allow HIV people, it’s a problem. Life has meaning now; I know that one day I will die so I make the best of each moment and each day to live happy and joyful. My heart’s desire is to help bedridden people and those who are dying.”

– Male, Windhoek

“My status changed me; I used to switch off the radio when they talk about HIV. Now I enjoy listening to the program. I became so angry when some one who does not even know his/her status talked about my status, now I tell them to go for a test themselves first. I have accepted my status and that’s that. I did not change, I remained the same.”

– Male, Windhoek

“When I was very ill and thin I was embarrassed and avoided going out of the house, but when I went on medication this year and with my body improving I have confidence now and I go out with friends.”

– Male, Oshakati

“I avoided getting into discussions about issues in the community relating to HIV because I was afraid of someone bringing up my status. But when I became public about my status I became more vocal about the challenges that people living with HIV and AIDS face.”

- Male, Oshakati

“I became very depressed and suicidal. I stayed in my bedroom all the time. When my family came to my bedroom to find out if I was fine I chased them away. The only person I talked to was my mother; she really helped me out of my depression. And now when I am feeling down or I have a problem I come to my support group.”

- Male, Oshakati

“Like my people. They haven’t changed. They are giving me a lot of love now. When they get paid they send the children with money. But then I was not so sick. They send me nice words like ‘you must always take your medicine nicely, or you are looking very well now, sister.’ They like me.”

- Female, Windhoek

“I am alone. I don’t have a sister or a brother. My mother likes me a lot and she does not mind that I am sick; she will just tell me to drink my pills. I did not tell her earlier but now that she knows she says that all the neighbours are drinking those pills as well.”

- Female, Windhoek

“Everyone in my family communicates with me. They ask me ‘have you taken your medicine?’ ‘What does the doctor say?’ ‘How are you feeling?’ ‘What do you want?’ They give me anything that I want.”

- Female, Windhoek

“I came out myself. I speak to my friends and I talk about AIDS. It’s positive, because if we sit together and its eight o’clock then they say to me ‘Hey, it’s time for you to take your pills.’ So they help me in this way.”

- Male, Windhoek

“If possible such a person should join a support group. As a result he/she will not feel bad or lonely because he/she will be with people with similar problems and concerns. In addition, in a support group a person would not get many things to think about and will also get a new family.”

- Female, Katima Mulilo

“Families and friends had come to witness the help that was being given to people infected with the virus. Today people are being advised to go to the hospital and people who were very ill have miraculously recovered and are alive. This indeed changed how they viewed us. Also the medicines given to us help to revitalize our energies and we do not feel that we are suffering from AIDS. We do not have any fear anymore, we are free!”

- Female, Katima Mulilo

Decline in stigma?

There are at least four reasons why stigma appears to be less prevalent today than when the disease first appeared.

- ***Better information and more accurate knowledge.*** This is due mainly because of the various workplace and public campaigns and the presence of HIV organizations, support and faith based groups, as well as, government and donor support programs in many more local communities.
- ***The availability of ARV's and counseling.*** ARV therapy have gone a long way to restore self-esteem by limiting and reducing the physical effects of HIV and AIDS, restoring productivity, and redressing the image of HIV as a deadly disease leading to early death. The positive effects of ARV's reduce external stigma based on physical appearances. Counseling further contributes by addressing internal stigma and promoting a positive self-esteem.
- ***Increased personal experience with HIV.*** As more people got infected, the moral boundaries between infected and non-infected members of the community became continuously more blurred and difficult to maintain. As a result, it became more difficult to reduce those infected, who are now also in a close relationship to oneself, to a morally unacceptable minority. Experience also promotes better understanding, more empathy and overall contributes to the 'normalization' of the disease. Experience challenge the inaccurate and incomplete knowledge acquired during the early stages of the pandemic, and in doing so it removes some of the public obsession with casual transmission.
- ***Making status public.*** As more people publicly declare their status, the more people have to accept and deal with the effects of the disease. This leads to more public dialog, greater awareness and more accurate knowledge.

“People got very little sympathy and they did not get any support, I think a lot of people in the early years died because they did not get support and their families rejected them. The attitudes are changing; most of the community understands that people with HIV are just like us. The provision of medication for HIV has helped a lot of people. In the early days, you see someone come to the hospital and they are very weak, cannot even walk sometimes and no one ever visits and they die alone.”

– Nurse, Oshakati

“There are many groups in this town that provide people living with HIV with support, such as Lironga Eparu, Yelula, Catholic Aids Action and many more. Yes I think they are successful. We have really gone a long way in terms of changing attitudes around stigma and discrimination. There are a lot of changes in the way that people living with HIV and their families are treated - the shame that is connected to the disease has decreased. Even the churches have stopped saying that HIV is a curse from God.”

– Nurse, Oshakati

“Yes, there a change in the way partners and family members of people living with HIV are treated, because the community has better understanding of the illness and it has affected most of our community members in one way or another.”

– Councillor, Eheke

“In the early days partners and family of people living with HIV were discriminated against. These attitudes are changing because of programmes with the support of the government, NGO’s and faith based organizations. In the early days I remember cases of people living with HIV chased out of their families when they got ill. These kinds of cases have become very rare.”

– Councillor, Oshakati

“In the early days before the community had information and understanding of HIV and AIDS, it was looked upon as in that clan, there is HIV and death, but now things are changing because the disease has infected or affected most families and people understand that it is indiscriminate. There is change because of information that the community is getting; and having people who are HIV positive to disclose their status in the community has changed perceptions. Even if there are those who discriminate they do so discreetly because they know that discrimination is somehow a wrong thing to do.”

– Nurse, Eheke

“I find my life to have improved because today we have HIV and AIDS counselors in hospitals. Patients are not allowed to be mistreated. It is different from past days when there were no people who were caring for those who were infected with HIV and AIDS in work places. For example, in 1994-1999 there was a girl from Nakabolelwa who was living in the squatters. When she fell ill she did not get any help or treatment. She later died, but her body was wrapped in a plastic bag and buried. This is very painful to treat a human being like that. However, today such practices are not happening.”

– Female, Katima Mulilo

“My family saw that I rapidly recovered after being very sick for a long time. Therefore, after many of my family members died from HIV and AIDS, my family could now see hope in life because of me. Now my family is encouraging others to follow in my footsteps.”

– Female, Katima Mulilo

“For me it was very difficult. The friends I had started to run away from me, because of my status. I came to accept the situation when I realised that it was not me alone, but the disease affected people globally. It is a matter of getting the right information. Education is enlightening many people about the disease.”

– Female, Rundu

“I want to add a bit: We have changed because now that we are on ARV’s, our bodies are well looked after, we are no longer thin. Now we know, and we can tell people that if a member of your family is becoming thin, don’t take him to the traditional healers, rather take him to New Start Centres, have him tested and start receiving better treatment.”

– Female, Rundu

“You know in the past we were very much discriminated against by the members of our own family. When visiting room number 7 at Rundu State Hospital, we felt ashamed and would even hide our health passports in our trouser pockets. But now things have changed. I can even take my medicine publicly without feeling ashamed.”

– Female, Rundu

“If you have TB or cancer you do not get stigmatized, but if you have HIV you get mocked. There is a big difference because HIV is connected to a lot of shame. Even if you have a sister who is infected with HIV you feel ashamed and you do not want to be associated with her. Stigma is not an issue anymore, things have changed, and there is a big difference in attitude compared to the early years. The campaigns that advocate for the rights of people living with HIV have helped to reduce stigma and have encouraged the community to support people living with HIV. The other thing is that with treatment, people are living longer and this has changed the face of HIV - it is not a death sentence like it was in the old days.”

– Councillor, Oshakati

“Changes are beginning to show up in the way community treat HIV positive people. They are now being accepted. Compared to say 2003. HIV people now are freer to speak about their status.”

– Female, Rundu

Many respondents reported important changes in personal relationships with spouses, friends, peers and family. As some respondents’ status became known, their already positive relationships deepened further. Some also reported positive changes in relationships that were previously “spoiled” due to stigma. Very often such changes are attributed to ‘stigmatizers’ becoming HIV positive themselves or that they gained much more personal experiences (hence also knowledge) with the disease as someone close to them also became infected. In other cases the relationships changed for the positive simply because respondent’s shared their status with others. Generally in all these cases, irrespective of the cause of changes, stigma was replaced with more empathy.

“The community and my husband are very good to me. My school friends who know that I have the problem are still the same as those years at school. Other friends that I got later on in life are also still with me. And they love me a lot. Especially youth because they always come to my house and they say ‘... that lady likes talking. And she talks about a lot of things!’”

– Female, Windhoek

“I feel that the quality of my life has improved because once people knew about my status I became involved with issues relating to HIV/AIDS and this has given me a position of respect in my community. Most families come to me for advice when they suspect that someone in their family is ill.”

– Female, Eheke

“My mother-in-law and I never really used to communicate but now that the problem is there we are much closer.”

– Female, Windhoek

“I have a friend who cares a lot for me. He will send me SMS’s almost every day which encourages me. He did not like me very much in the past; I think he changed because he went in deeper to analyze the situation.”

– Male, Windhoek

“My brother’s wife has changed completely as she is also HIV positive. Her HIV positive status has changed her a lot and she is very friendly with me but she was very hard when she was HIV negative.”

– Male, Windhoek

“There is a difference in my view because, for example if I have two patients, one with a disease like TB and another with HIV, I would pay more attention to the patient with HIV, because I know that people with HIV need moral support because they have to overcome stigma.”

– Nurse, Oshakati

“I also told my elder brother about my HIV status. He scorned and despised me. Later on he came to his senses and tendered his apology. Now I live better and he accepts me the way I am.”

– Respondent, Rundu

“I know of somebody, a soldier, who was laughing at people with HIV positive. When he himself tested positive for the virus, he totally changed his behaviour. Unfortunately he is no more, he passed away.”

– Respondent, Rundu

“At first, my step-mother sided with my father and she also did not speak to me. But later, she changed her mind and encouraged me to come home and visit. The change of heart possibly came about because she found out that there was someone in her own family who was suffering from HIV and AIDS.”

– Female, Katima Mulilo

“Most people change once they find themselves HIV positive too, or if they find out that someone close to them is infected as well. In my village many people have

experienced HIV on a personal level and have experienced stigma so there is more understanding and acceptance”

– Male, Oshakati

“My father was afraid of touching me, but I later realized that it was because he was misinformed, lacked information and understanding of how HIV is spread”.

– Female, Eheke

“In most cases I think stigma comes from ignorance, fear and lack of information especially in the villages, but that is changing, because most of the community has had an experience of having someone close, who is HIV positive.”

– Female, Eheke

“I am alone. I don't have a sister or a brother. My mother likes me a lot and she does not mind that I am sick; she will just tell me to drink my pills. I did not tell her earlier but now that she knows she says that all the neighbours are drinking those pills as well.”

– Female, Windhoek

“Everyone in my family communicates with me. They ask me ‘have you taken your medicine?’ ‘What does the doctor say?’ ‘How are you feeling?’ ‘What do you want?’ They give me anything that I want.”

– Female, Windhoek

“I came out myself. I speak to my friends and I talk about AIDS. It's positive, because if we sit together and its eight o'clock then they say to me ‘Hey, it's time for you to take your pills.’ So they help me in this way.”

– Male, Windhoek

5. CONCLUSIONS

The fact that our respondents reported wide-spread instances of HIV-related stigma within their families, friendships and communities is hardly surprising. HIV-related stigma remains a problem in Namibia. Yet the study found evidence that it might be on the decline compared to ten or so years ago. Four main findings are presented from this study.

Firstly, the dimensions of HIV and AIDS-related stigma are largely similar to that found elsewhere. In this respect, we concur with Ogden and Nyblade (2005) that HIV-related stigma is “common at its core”. Stigma is caused by incomplete and inaccurate knowledge that drives fear of casual infection. Those in fear of being infected seem to be near obsessed with modes of transmission that carries very low or no risk at all: sharing eating utensils, sharing bedding, shaking hands, ordinary touching and sharing or preparing food. Also similar are the expressions of stigma -physical, verbal, institutional and social- and consequences of being stigmatized: shame, self-imposed isolation, name calling, loss of employment and financial hardships, destruction of close personal relationships, social isolation and neglect.

Secondly, important similarities exist between HIV and AIDS and other stigmatized diseases. Stigma appears to be at its worst once the physical symptoms of the disease become visible and a degree of physical imperfection or incapacitation can be observed. As is the case with cancer patients for example (Fife and Wright 2000) social isolation is a common response to external stigma by people living with HIV and AIDS. In the final instance, as is the case with other stigmatized diseases, people living with HIV and AIDS do benefit from their special HIV status. They have access to special medicine and services and new social networks are built around them in the form of support groups and counseling. These are supplied and supported by church and other faith-based groups, civic organizations, donors and the Government itself. The positive impact of these special medicines and services on HIV-related stigma has been substantive. Counseling reduces self-imposed isolation, promotes self-esteem and provides a positive outlook on the future. ARV treatment promotes a positive body image by removing the physical symptoms and incapacity as grounds for stigma. It also challenges the perception that with HIV death is immanent.

Thirdly, stigma starts long before an individual gets infected with the virus. People acquire their attitudes and beliefs on HIV and AIDS long before they get infected or have personal contact with someone living with HIV and AIDS. They are acquired as a part of the general socialization process during which social values, norms and attitudes are transmitted from one group (usually older) to the next (usually younger). During this stage moral boundaries are drawn and stigmatized groups are identified and tagged with an ‘immoral label’. Having been exposed to anti-HIV views prior to infection means that individuals can accurately predict and anticipate stigma after infection. This delays testing substantially, sometimes until the individual are physically ill or incapacitated.

This also delays the decision to share their status with others, especially those closest to the infected one.

Finally, there are clear signs that albeit still at high levels, stigma is on the decline. There are at least four reasons for this. Firstly, there is better and more accurate knowledge about the disease and specifically transmission as a result of various education and awareness programs and more personal experience with the disease and those living with it. A second factor reducing stigma is increased levels of personal experience with the disease. Those close to someone living with HIV and AIDS are less inclined to stigmatize and more prone to empathy and understanding. As the number of infected individuals increase, so does the number of those indirectly affected by it causing rising levels of empathy and declining levels of stigma. Personal experience also counter imperfect knowledge and redress the fear for casual transmission. A third factor that had a positive impact on stigma is ARV therapy coupled with counseling and other forms of support. It reduces external stigma because it reduces the visible physical effects of the disease and counter the common belief that there is no life with HIV. These positive effects have been further enhanced by the availability of counseling and support networks. Not only do these networks promote a more positive self-esteem and in doing so counter internal stigma, but they also replace social networks and relations that have become dysfunctional as a result of stigma. The final factor that have reduced stigma, is the growing number of people who declare their status publicly.

In Table 1 below we have summarized six stages of HIV-related stigma, starting with socialization as a first stage, and ending with having to live with HIV and AIDS. Each stage signals a progression in stigma as experienced by our respondents. It is clear that the progression in stigma is closely correlated with the progression of the disease from times prior to infection to having tested positively. Internal stigma is at its peak at the time between when an individual tests positive and prior to joining support groups and receiving counseling. External stigma peaks when physical symptoms are at their most visible and when someone's status is made public.

Given that this study is a heuristic one, a few *caveats* are in order. *Firstly*, this study is based on the experience of support group members only. It is thus quite possible that the experiences of those who do not belong to support groups might be different. For example, those who formed part of this study all seemed to delay testing until they'd become ill. Yet, these days it is not uncommon for individuals to undergo voluntary testing before showing physical symptoms and as such might have experiences quite different from what has been recorded here. Also, it would be worthwhile studying the stigma-related experiences of non-support group members to establish more accurately the impact of membership on dealing with stigma. Those who participated in this study have made a deliberate decision to make their status public and to confront stigma head-on and as a result have gained access to skills and resources to help them cope. Yet, not everyone living with HIV has access to or has joined support-groups and as a result might experience stigma differently, both in forms and intensity. This study, for example, cast no light on their coping strategies. Therefore, to understand the complexities of HIV-related stigma better, future studies have to include non-support group members.

Secondly, the finding that stigma has been reduced in more recent times has to be contextualized properly. To start with, this might be only true for support group members and those who like them have access to the skills and resources offered by these groups to combat stigma. Those outside these networks might actually experience quite the opposite. Furthermore, stigma should not be seen as a monolithic entity, it is complex, complicated and takes diverse forms. Hence, it is possible that an individual could experience a reduction of the intensity of stigma in one form (e.g. not being allowed to use common eating utensils) or by some agencies (e.g. family and friends) whilst at the same time experience an intensification in other forms (e.g. being deemed 'unemployable') or by other agencies (e.g. employer and co-workers). Change in attitudes and behaviour cannot be seen as a uniform, linear process and as a result change must be assessed in specific contexts and by comparing specific contexts. There is a need to study stigma in different contexts, and to compare the findings in these contexts with what is presented here.

Thirdly, this study identified six stages of stigma. Yet, it is quite possible that not all individuals go through all these stages, or that they follow the stages in the same chronological order in which they are presented here. In fact, one might even argue that with the appropriate interventions, it might be possible to shorten or even skip one or more of the stages. For example, it is conceivable that deliberate programme interventions aimed at changing experiences during Stage 1 (socialization), Stage 2 (first experiences) and Stage 5 (self-imposed isolation) could have a fundamental influence on an individual's experiences during Stage 4 (testing) and Stage 6 (Coping). In the same vein, individuals that go for testing (Stage 4) before falling ill (Stage 3) might be able to skip the experiences of Stage 3 and Stage 5 (self-imposed isolation) all together if they receive the appropriate support at the right time. Thus, should these program interventions become successful, some of the experiences during stages described here might change or even disappear over time.

Fourthly, the separation between stages might not be clear and exact as it is portrayed here. It is possible that these stages are 'fuzzy' and that individuals might, for a specific period in time, be caught in two consecutive stages as they are moving forward or slip backward. For example, an individual that decide to 'go public' (Stage 6) might experience more stigma causing a temporary resort to some form of self-imposed isolation (Stage 5) before making a re-embarking on a coping strategy (Stage 6). It is likely that individuals would be most vulnerable to temporary reversals soon after they enter a new stage. It is also likely that individuals might carry some of the features of the preceding stage with them into each new stage. Thus, it is likely that one stage does not replace the other immediately and completely.

All four these caveats emphasize the need for more research into HIV-related stigma. Future studies should expand on both the scope and focus of this study, and should make use of both qualitative and quantitative methods to carry our understanding of stigma forward. The propositions made here should be tested and re-tested in different contexts with different respondents and with different methods. More specifically, stigma should also be studied among those who are not living with HIV, i.e. those who are the 'sources'

of stigma. Past research²² identified a number of important issues that could only be addressed by including this group in future studies. They include:

- ❖ Are people conscious of the fact that their actions and attitudes are stigmatizing?
- ❖ In what ways do knowledge and fear interact and how does this allow for stigma to continue?
- ❖ To what extent does care and empathy co-exist with stigma and discrimination often in the same space?

In recent times a number of international organizations such as UNAIDS, USAID, ICRW and the Futures Group have allocated significant time, resources and effort to developing indicators for measuring HIV-related stigma. These need to be explored for use in Namibia. This would require much larger national surveys on a regular basis.

²² ICRW (2002)

6. TABLE 1: THE SIX STAGES OF STIGMA

<p style="text-align: center;"><u>STAGE 1: Socialization</u></p> <ul style="list-style-type: none"> - Introduction to disease. - Founding myths: disease for foreigners, returnees, sex workers, promiscuous people, and amoral people. - Extensive labeling of others, stigma-based actions taken against them. - Obsession with casual transmission. - Moral boundaries between ‘us’ and ‘them’ sharp and clear. - Own self excluded from any risk for infection. - Inaccurate and incomplete knowledge of disease especially transmission. - No change in sexual behavior 	<p style="text-align: center;"><u>STAGE 3: Falling Ill</u></p> <ul style="list-style-type: none"> - Deterioration of own health - Physical symptoms become chronic and visible - Personal exposure to infections and deaths of others (e.g. children, partners, spouse, family). - Increasing fear of being stigmatized. - Initial experiences with stigma against own self. - Low and declining self esteem and/or low body image. - Fear for stigma of family and others. - Suspect own infection. 	<p style="text-align: center;"><u>STAGE 5: Self-Imposed Isolation</u></p> <ul style="list-style-type: none"> - Test results positive. - Strong feelings of guilt, shame and fear. - ‘Forced’ to share results with someone. - Postpone telling parents –fear of stigma. - Frequent experiences with external stigma. - Reinforced internal stigma. - Low self-esteem, body image and low mastery of own destiny. - Suicidal - Self imposed isolation, and anti-social behavior. - Initial exposure to counseling.
<p style="text-align: center;"><u>STAGE 2: First Personal Experience</u></p> <ul style="list-style-type: none"> - Greater awareness of the disease - Personal contact with someone who tested positive. - Recognize the disease as “real”, “serious” and “deadly”. - Fearful for casual infection and dying. - Sharp distinction between ‘us’ and ‘them’. - Extensive labeling and stigma-based action against others. - Denial of own personal risk for infection. - Inaccurate and incomplete knowledge of disease especially transmission. - No change in sexual behavior 	<p style="text-align: center;"><u>STAGE 4: Testing</u></p> <ul style="list-style-type: none"> - More serious physical symptoms - Decision to get tests made with or without others’ inputs. - More fear of stigma against own self and others. - Initial attempts to find empathy. - Experience intense internal stigma. - Experience some degree of external stigma. - Low self-esteem and body image. 	<p style="text-align: center;"><u>STAGE 6: Coping</u></p> <ul style="list-style-type: none"> - Decision to ‘go public’. - Prolonged counseling. - Increased access to and integration into new social networks (e.g. support groups, church programs, other HIV+ people). - Access to ARV medicine. - More empathy from some. - Better knowledge. - Life style changes. - Better self-esteem and body image. - Much less internal stigma. - Reduction in external stigma.

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8. APPENDIX 1: FOCUS GROUP DISCUSSION GUIDELINES

FINAL STIGMA FOCUS GROUP GUIDELINES

6 FEBRUARY 2007

ENGLISH VERSION

INTRODUCTION

- Welcome participants and thank them for taking the time to take part in the focus group discussion.
- Explain that we are going to talk about the differences in their lives since finding out about their HIV status.
- *Focus group discussions are helpful in understanding how people feel about certain issues in a creative way. It helps us to understand the feelings and motivations of those who take part in it.*
- *For this particular study, we are interested in understanding how people living positively feel about **HIV AIDS and THE POSSIBLE EXISTENCE OF STIGMA**. This will enable programmers to develop improved information campaigns. For example, if we were interested in misconceptions of transmission of HIV AIDS, we would talk to a group of people who know about it and use their responses to develop better information campaigns regarding this specific issue.*
- Tell the group that we are interested in their personal opinions. It is therefore also important to inform the group that opinions may differ, as long as the discussion can continue in an orderly fashion.
- Also assure the group that there are no wrong answers.
- Assure participants that all comments and responses are confidential. Tell the group that the responses of today will not be linked to their names in any way.
- Participants who feel more comfortable using another name are welcome to do so.
- Explain the rules pertaining to the focus group discussion:
 - Kindly ask all participants to switch off their cell phones for the duration of the group if at all possible.

- Remind participants to speak one person at a time so that we can record the discussion clearly.
- Also request participants to speak as loud and clearly as they feel comfortable with.
- Also inform the group that the session will be video-taped. Explain that it assists us with report writing. If we feel that we have missed something in the notes, we can refer back to the video tape.
- Put the snacks and drinks on the table and tell the group to help themselves to it during the course of the discussion.
- Ask participants to introduce themselves to the group in any way they feel comfortable and tell the other members a little bit about themselves.

SECTION 1 PRE-DISPOSITION TOWARD HIV AIDS PRIOR TO DISCOVERY OF OWN STATUS

1. Firstly, we are going to talk about the views that you had regarding HIV and AIDS before you found out about your own status. We would like to know how you felt towards *People Living With AIDS* (PLWA) before you tested positive for HIV. Try to explain how you acted toward them or how you talked about them.
2. Before you knew that you were infected, how likely did you think it was that you would get HIV AIDS? (Try and build a profile of how they saw HIV positive people before they got infected themselves).
3. Did you ever test negative before you tested positive for HIV?

SECTION 2 EXPERIENCES

Now we would like to ask you about the experiences you have had since it became known that you tested positive for HIV.

a) INITIAL FACTS

4. Why did you go for an HIV test?
5. How did you know or suspect that you might be HIV positive?
(Ask participants to give as much detail as they feel comfortable with. Ask: *Can you tell us a bit more about it?* See whether they mention any of the following, BUT DO NOT PROBE FOR THESE IF NOT MENTIONED SPONTANEOUSLY: VCT/Blood screening/Partner getting tested).
6. When did you let others know about your status? How long was this after you tested positive? Please also tell us why you only chose to let others know then?

b) INTERNAL STIGMA

Here, the key is to talk of a period when you knew about your status but no one else or very few knew.

7. How would you describe the way you felt when you first found out about your status? Why did you feel this way?

(Ask participants to give as much detail as they feel comfortable with. Ask: *Can you tell us a bit more about it?* See whether they mention any of the following, BUT DO NOT PROBE FOR THESE IF NOT MENTIONED SPONTANEOUSLY: Blame/Shame/Avoidance/Hopelessness/Worthlessness).

8. How did you deal/cope with this at the time?

(Ask: *Can you tell us a bit more about it?* DO NOT PROBE FOR THESE IF NOT MENTIONED SPONTANEOUSLY, but see whether they tell you about places they visited, information booklets they read, people they spoke to)

9. What advice would you give to others in this position?

c) EXTERNAL STIGMA

Let us talk of a time when your status was more widely known.

10. What, if anything has changed with regard to the way the following groups of people **talk or communicate** to you after they found out that you have tested positive for HIV? (Ask participants to give as much detail as they feel comfortable with. Ask: *Can you tell us a bit more about it?* See whether they mention any of the following, BUT DO NOT PROBE FOR THESE IF NOT MENTIONED SPONTANEOUSLY: Mocking/Name calling/Offensive phrases).

Personally: Partner/Immediate family

Socially: Community/Other family and Friends

Institutional: Workplace/Hospitals/Others

11. What, if anything has changed with regard to the way following groups of people **acted** towards you after they found out that you have tested positive for HIV? (Ask participants to give as much detail as they feel comfortable with. Ask: *Can you tell us a bit more about it?* See whether they mention any of the following, BUT DO NOT PROBE FOR THESE IF NOT MENTIONED SPONTANEOUSLY: Keeping a distance/Ignoring/Hand shaking/Sharing).

Personally: Partner/Immediate family

Socially: Community/Other family and Friends

Institutional: Workplace/Hospitals/Others

12. Are you aware of anyone who underwent a change of heart (from stigmatiser to non-stigmatiser)? Why did the person change? How did the person change? How can more people be helped to change?

d) INTERNAL STIGMA

The way people talked or acted towards you after your status was known must have affected you. Let's talk about this.

13. Did you change because of the way people talked or acted towards you? How did you change?

(Ask participants to give as much detail as they feel comfortable with. Ask: *Can you tell us a bit more about it?* See whether they mention any of the following, BUT DO NOT PROBE FOR THESE IF NOT MENTIONED SPONTANEOUSLY: Became Stronger/Downhearted/Hopeless/Depressed).

14. How did you deal/cope with this at the time?

(Ask: *Can you tell us a bit more about it?* DO NOT PROBE FOR THESE IF NOT MENTIONED SPONTANEOUSLY, but see whether they tell you about places they visited, information booklets they read, people they spoke to)

15. What advice would you give to others that find themselves in this position?

SECTION 3 CONSEQUENCES OF STIGMA

Consequences of stigma for self (personally) and others (Socially/Institutional)

16. Would you say your quality of life has improved and/or has gotten worse in the following areas as a result of others changing their behaviour toward you? Please tell us why you feel this way? (Probe and explore every area in detail.)

Personally: Partner/Immediate family

Socially: Community/Other family and Friends

Institutional: Workplace/Hospitals/Others

17. Would you say your life now is more difficult from life before it in became known that you had HIV in the following areas? Why do you feel this way? (Probe and explore every area in detail.)

Personally: Partner/Immediate family

Socially: Community/Other family and Friends

Institutional: Workplace/Hospitals/Others

18. Do you feel that the life has changed for your family and others close to you since it became known that you were HIV positive? Please tell us why you feel this way.

SECTION 4 NEEDS OF PEOPLE LIVING WITH HIV AIDS (PLWHA)

Let's talk about ways that stigma can be 'tackled'!

19. What do you think can be done to reduce stigma? Why do think this would work?

20. What can specific programmes do to reduce stigma?

21. What changes in your environment can help to reduce stigma? (Ask: *Can you tell us a bit more about it?* DO NOT PROBE FOR THESE IF NOT MENTIONED SPONTANEOUSLY: Legal ways/Nature of services/Organisations)

22. What about TUSANO? Do you think that they are helping to reduce stigma?
23. Do you think they are effective?
24. In your opinion, is there anything that they can improve on?
25. Is there anything that you would like to tell us that we did not discuss in the session already?

CLOSING

- Inform the group that they will be requested to fill out a short questionnaire before they leave.
- Hand out the questionnaires and pencils and assist participants in the filling in thereof.
- Again, assure participants that their names will not be linked to any of the answers that are given, since they do not write their names on the questionnaire.
- Wait for the group to finish and collect the questionnaires and pencils.
- Hand out the participant gifts and ask each person to sign the attendance list. This signature will also serve as proof that each participant has received his or her gift.
- Thank all participants for attending the focus group discussion.

9. APPENDIX 2: KEY INFORMANT INTERVIEW GUIDELINES

KEY INFORMANT INTERVIEW

We would like to talk to you about some matters relating to People Living With HIV/AIDS (PLWHA) in your community. We would like you to provide us with as much details as possible. Your views are important to us and will be treated as anonymous and with confidentiality. You will not be personally linked to any opinions in the final report. Thank you for your time and for speaking to us.

- 1) In your view, how seriously is your community effected by HIV and AIDS?
- 2) When did you and your community first learn about HIV and AIDS in your community?
- 3) What was the general reaction at the time?
- 4) In your view: 1) PLWHA are different from people with other serious infectious diseases and people are right to treat them differently from others; or 2) PLWHA are no different from people living with other serious infectious diseases and people have no right to treat them differently. Please explain your answer.
- 5) Some people feel that PLWHA have done something wrong or bad and that they are being punished for that. In your experience how dominant is this view in your community? Are there any specific groups that are associated with this view?
- 6) Could you describe how members of this community treat and act toward PLWHA? Why do you think they act this way?
- 7) In your experience, how are the partners and family members of those PLWHA treated by the rest of the community?
- 8) In your view, were there any changes in the way PLWHA and their partners and families are treated from when the community first learned about HIV and AIDS? If so, in what way?
- 9) Are you aware of any groups or programs that provide PLWHA with support? What do they do? Are they successful?
- 10) Are you aware of any special groups, organizations or programs that work to change the views and actions of the community toward those living with HIV and AIDS? Have

you observed any changes in the way PLWHA are being treated as a result of these programs? What could be done to make them more successful?

11) In your view, who are the key leaders in this community that could shape people's views toward PLWHA? How would they be able to help?

12) In your view, what are the most serious challenges facing PLWHA in your community? What could be done to address these?

13) How well informed do think your community is with regard to HIV and AIDS? Is there any need for interventions in this regard? Who should be targeted for these interventions?

14) Is there anything related to these issues you would like to discuss before we end this interview?

Thank you very much indeed for your time.