Sero Positive Stigma: A Qualitative Study

Zareen Nishat Muslan-Beebejaun
Department of Mauritian Studies, Mahatma Gandhi Institute, Moka, Mauritius.

Abstract
This study explored the perceptions, emotions, feelings of stigma and discrimination experienced by sero-positive people in different settings. An interview guide was designed and in-depth face to face interviews were carried out with ten sero-positive males and females working in different organizations in Mauritius. An analysis of the data revealed that a stigmatised identity can considerably affect a productive member of the society. The data confirms that HIV related stigma and discrimination and perceived discrimination were experienced by all participants and was explained as a sense of loss that gave rise to feelings of fear and shame. These were often expressed through physical isolation and verbal insults. To cope with this, respondents were unwilling to disclose their status and when disclosed, they coped by physically and socially maintaining a barrier between themselves and others.

Key words: HIV-related stigma and discrimination, Sero-positive stigma, PLWHA (People living with HIV/AIDS).

Introduction
Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS) is currently one of the most devastating diseases affecting the world’s population. The AIDS epidemic now represents a pandemic touching all parts of the world and leaving behind extraordinary burdens on people living with the virus, their families, communities and the country at large (Yumiko et al., 2007). Entire populations, societies and countries are affected with drastic consequences at the national, community, family and individual level. HIV/AIDS is a severe threat to the overall productivity and profitability in countries with high infection rates as well as to the global economy. The impact of global HIV/AIDS epidemic has been felt at every facet of the society and the challenges lie in the development and the evolution of strategies for responding to the epidemic while thinking economically and from a global point of view (Kleinman, 1997).

HIV/AIDS related stigma and discrimination are major problems throughout the world, more so, in developing countries due to the existence of rich cultural, moral and religious values. The impact of stigma on the epidemic and on PLWHA has been widely discussed and analysed by researchers (Reid and Walker, 2003; Campbell et al., 2005, Steinberg, 2008). Since the beginning of the pandemic, stigma has been associated with AIDS mainly because of its association with behaviours which are believed to be deviant such as homosexuality, prostitution, promiscuity and injection drug use (Herek et al., 2002). According to UNAIDS, ‘HIV/AIDS related stigma and discrimination rank among the biggest and most pervasive barriers to effective responses to the AIDS epidemic’ Maluwa et al., 2003

Parker and Aggleton (2002) suggested that AIDS-related stigma and discrimination remains one of the most poorly understood aspects of the epidemic. People discredit others based on ‘differences’ and the ‘deviance’ so labelled results in ‘spoiled identity’ (Ragimana, 2006). Scrambler (1989) differentiated between forms of stigma by referring to enacted stigma (personal experiences of stigma) and felt stigma (perception of stigma), while Parker and Aggleton (2003) maintain that stigma must be understood in relation to the structural dimensions of ‘power’ and ‘domination’ in relation to inequalities. Some groups are devalued and excluded in comparison to those who are more valued and more privileged (Bharat, 2011). HIV-related stigma builds upon and adds to existing prejudices and inequalities of class (Parker and Aggleton 2003, Maluwa et al., 2003).

In addition, the metaphoric use of the word ‘AIDS’ also gives a powerful indication of the stigma attached to it (Sontag, 1978). Shame and social disgrace are associated with AIDS giving it a larger dimension in several situations and those who are infected are seen as bringing shame to the society (Bharat, 2011). AIDS stigma often results in the social and economic marginalisation and withholding...
of treatment or the denial of services to PLWHA (Maluwa et al., 2003). Around the world, HIV/AIDS related stigma is manifested in a variety of contexts within any given society. These contexts include law and politics, institutions such as employment, education, health, religious organizations, the family and the community (Synder et al., 1999, Surlis and Hyde, 2001, PANOS Institute, 2002). Both stigma and discrimination occur at family, community or at institutional levels (Bharat, 2011) while taking overt (visible) or covert (hidden) forms. Discrimination arising from HIV-related stigma is a response to the fears and prejudice of individuals and communities (White and Carr, 2005). The manifestation of stigma varies according to the time, place and contextual situations (Scambler and Poli, 2008). This is worsened along with fear, ignorance, anxiety, and lack of knowledge, denial, shame, taboo, and misleading metaphors like death, punishment, crime, war, horror and otherness (Ernesto et al., 2008).

One of the most poorly understood aspects of the epidemic is the HIV/AIDS related stigma and discrimination which is due to different cultural barriers and lack of theoretical framework in understanding its creation, manifestation and how it is maintained (Parker and Aggleton, 2003). Perceived-related stigma is associated with the endorsement of various reasons for not disclosing to friends, parents as they include concern about self-blame, fear of rejection, communication difficulties and the desire to protect the other person (Derloge et al., 2002). Disclosure of HIV status is a closely related construct which helps in reducing potential infections of sexual partners, thereby diminishing the spread of HIV (Charles, 2006). Many PLWHA resort to non disclosure, assuming that it can help in controlling the faced stigma and discrimination they face. The power of stigma which is associated with HIV overrides the need for support (Shelan et al., 2005).

Socio-economic status, relative financial and productive security can influence the stigmatising process (Parker and Aggleton, 2002). By enabling some families to ‘conceal’ the infected members either within the home or in private clinics, the PLWHA are prevented from being overtly stigmatised; as in wealthy families, it may be associated with shame and brings disgrace (Blunt, 2003). Furthermore, PLWHA continue to face marginalisation and discrimination as well as violations of many of their rights to health, education and social services. Prevention programs such as the screening blood donation and prevention campaigns, opening of day care centres, Anti Retroviral Therapy free of charge, psychological counselling, free testing, methadone substitution therapy, needle exchange program and the HIV/AIDS Act are amongst the measures taken by the Mauritian government to combat HIV/AIDS propagation and HIV-related stigma and discrimination. However, despite all these efforts, PLWHA continue to face a great deal of HIV-related stigma and discrimination in different situations in Mauritius.

The rapid socio-cultural changes taking place in Mauritius nowadays provides an appropriate environment where the AIDS pandemic can thrive and the challenge remains in keeping HIV prevalence low by initiating appropriate prevention measures (Bhowon and Ah Kion, 2004). In this era of globalization, cultural norms, values and beliefs are rapidly changing in Mauritius. People’s attitudes and practices are constantly evolving for instance, relationships between men and women, extra marital affairs, as well as sexual values and practices (Schensul et al., 1994). The absence of a vaccine to fight the disease and the lack of knowledge about the modes of transmission and cure makes it difficult for people to accept it. Thus, knowledge and positive attitudes such as empathy, tolerance and acceptance of AIDS and AIDS patients, can act as a motivator of individual behavioural change (Bhowon and Ah Kion, 2004).

Several studies concerning sexual behaviour of young people in Mauritius have been carried out such as a study of female EPZ workers (Schensul et al., 1994), the youth profile of the Republic of Mauritius (Mauritius Institute of Health, 1996), the KAPB study related to HIV/AIDS in the Republic of Mauritius (Ameerberg, 1998) and HIV-related behaviour among young people (Yumiko, 2007). The results generally show that about 33% of unmarried Mauritians aged between 18 to 25 years have had sexual intercourse and the mean age of first sexual intercourse was around 18 years. The study (Yumiko et al, 2007) also demonstrated that sexual activities among young unmarried Mauritians are relatively low as compared to other countries and this can be explained by their beliefs in traditional and ancestral values, family and religion.
In Mauritius, the HIV/AIDS Act of 2006 established legal provisions for the observance of a rights based approach to HIV and related issues, and, in particular to protect PLHWA against discrimination. It comprises of the different sections arranged under the following: HIV/AIDS not a disability, HIV testing facilities, pre-test counselling, confidentiality of information, discrimination and stigma against PLHWA, amongst others. The Act states “No person shall induce or cause another person to undergo an HIV test as a condition for employment, continued employment benefits and promotion or continued employment of the other person”\(^1\). That is no one can refuse or expel anybody detected with a positive status of HIV/AIDS from a job. In addition, recently the Government of Mauritius has implemented the Equal Opportunities Bill (EOB) with a view to ensure that each individual gets an equal opportunity to attain his objective, and that no person shall perceive himself at a disadvantage because of his status. In the context of this background, the aim of this study were to: 1) explore the respondents basic knowledge of HIV/AIDS, 2) understand the circumstances in which they were infected and their concerns related to disclosure, 3) understand their experiences of stigma and discrimination.

**Research Approach**

The aim of this study was to understand the perceptions, feelings about stigma and discrimination experienced by HIV positive people in different settings. Qualitative method was considered appropriate given the sensitivity of the topic. In-depth interviews were conducted. This method allows the opportunity of gaining insight into the world of participants in their own language and promotes self disclosure in a conducive environment. Ethical clearance certificate was obtained from the Ministry of Health and Quality of Life. Interviews were conducted with a convenience sample of ten respondents. Such sampling is normally used in exploratory research where the researcher is interested in getting inexpensive approximations of the truth. The sample had six males and four females. Questions and themes for the interviews were chosen after a review of the literature on stigma and considering the local context. This provided a structure for the interviews but also allowed for flexibility to pursue emergent topics. An informed consent form given to each participant before the interview and content of the form was read to them before their signing it. The participants were assured of confidentiality, particularly regarding their positive status and information that was to be obtained from them. Fictitious names were used in the study. The data was transcribed and sections where verbatim texts were taken were looked at in the context of the whole discussion. The transcriptions were read several times in order to highlight important words, phrases and sentences which were developed into codes which were grouped into larger categories. This process allowed for the eventual reduction of transcribed data into important themes which formed a picture that reflected the perceptions and experiences of all the participants in the study.

**Interpretation and Discussion**

The findings reported here are thematically arranged with a number of verbatim quotes to accurately present the people’s voices. Given the sensitive nature of HIV/AIDS and the stigma associated with it, the discussions started with some general questions related to knowledge of HIV/AIDS. The idea was not only to gauge their knowledge but also to put the participants at ease. All the participants in this study perceive AIDS as dreaded, mortal and incurable disease. It was referred to as, ‘Malad mortel; (deadly disease) It cannot be cured; no treatment exists for it’. As sero positive individuals, they were compelled to reflect on their past to identify specific behaviour that had put them at risk of acquiring the virus. This knowledge then led to a sense of regret as with correct knowledge they could have avoided the disease. As reported, ‘I left school because I had to help my parents sell vegetables in the market. I had never heard of this disease before. I was really shocked after learning that I have contracted such a disease’

All the participants had sound knowledge of the modes of transmission. However, for some of them, this knowledge was acquired after being infected leading to a sense of regret, one responden, ‘If I knew, I would have used a condom’. Three female respondent had contracted the disease from their husbands who frequently travel abroad regarding their work. One of them narrated with a deep sense
of betrayal, ‘Even if I had accurate knowledge I would never imagine that I would be infected by my husband’ as ‘I was never aware that he was visiting prostitutes’, This suggests that even with sound knowledge of the modes of transmission, married women are at risk because of the risky behaviour of their husbands. When questioned about the most common way in which people get infected, the unanimous response was injecting drug use and sexual behaviour, that is, sex with multiple partners, homosexuality. For the latter, many participants referred to betrayal on the part of their partners due to which they have been condemned for life. One urban female respondent stated, ‘I never thought that my husband would even think of betraying me since our marriage was a loved one’. The fact that AIDS is understood more as a social problem rather than a biomedical one (Bharat 2010) makes it a more fearful disease in the perceptions of the PLWHA. Some respondents when asked ‘what do you understand by the acronym AIDS?’ mentioned that they do not know the full meaning but this word makes them think of irresponsible behaviour and shame. As Bharat (2011) rightly mentioned that AIDS is contracted through sex with the ‘other’ such as with prostitutes and other ‘loose character’ women. Most of the PLWHA do not make a clear distinction about living with the virus and being an AIDS patient (Bantereya et al., 2004) and they cannot make the difference between HIV and AIDS. The most common beliefs of the origins of HIV are that it came from foreigners (Videesi), and that it is a punishment from God (Bharat, 2000). This common belief was echoed by one male respondent, ‘You see, this disease has been brought by foreigners in Mauritius, especially tourists’. Another male respondent claimed that the first thing he thought when he learnt about his HIV positive status was, ‘It’s time to pay for my deeds. I really do not know what is reserved for me ahead. I am so depressed these days’. As pointed out by Banteyerya et al., (2004), there is the perception that HIV/AIDS was sent by God to punish people for morally unacceptable behaviour.

Initial and delayed reactions
Bond (et al., 2002) mentioned that PLWHA are often judged to have brought the disease upon themselves by engaging in culturally prohibited behaviours and PLWHA are often faced with a moral concept of blame, responsibility and deservedness (Willig, 2001). Most participants had practically the same reactions when they first learnt that they contracted the disease. Some talked about feeling numbed, shocked, paralysed and traumatised. As Bharat (2000) rightly pointed out that AIDS is highly feared and it generates anxiety and concern for life. The initial reaction of most of the interviewees as soon as they heard about their sero positive status was the thought of death. One male respondent related that, ‘I thought my world has come to an end. I am going to die’. He added, ‘Others think that we caught HIV/AIDS because of our bad and immoral behaviour but they do not understand that sometimes destiny has decided otherwise for us’.

In addition to fear of death, people fear how AIDS can disfigure a person (Bantererya et al. 2004). As a rural female respondent explained, ‘I immediately thought that this disease will change my physical appearance and make me look ugly. I will become too thin, loose hair and appear pale. People will not look at me’. Given this fear and anxiety PLWHA face, they try to protect themselves by being in isolation or rather run away from stigmatising beliefs and attitudes. As another female participant expressed, ‘When a person is HIV infected, people run away from him/her. I will lose all my friends and close ones’.

Being concerned about family, friends, and wife, the interviewees confessed about their worries, fears and their future. For instance, a male respondent talked about his daughter’s education, ‘I realised that I should disclose my status to my wife since I need to protect her and my kids. My daughter will sit for the Certificate of Primary Education (CPE) this year and I have to sustain her’. Several studies provide evidence to show that AIDS is dirty, associated with promiscuity and prostitution (Sonywathana and Menderson, 1998). Nevertheless, there are multiple sources of information on HIV and AIDS which include family, friends, and community-based associations and so on (Bantererya et al., 2004). Shame and horror were the most enduring feelings that discourage the
PLWHA to disclose their status. HIV status disclosure forms an important theme in several stigma studies. Disclosure is about who knows or will come to know about one’s HIV positive status and the consequences, thus it is not only about the infected but also the close and dear ones of the PLWHA. Maintaining secrecy is one of the most protective behaviour adopted by respondents. It is associated with the forms of stigma namely felt and enacted.

One of the expected findings which have been reported in literature is the blame which is attributed to PLWHA and the feelings of shame associated to it (Bharat et al., 2001, Pallikadavath et al., 2000). All informants offered their opinion that HIV related stigma and discrimination is real and exists in the Mauritian workplace. There are some major contexts of stigma identified and experienced by the participants, for example the fear of reaction that they get from the society when they would reveal their status. A male respondent noted, ‘I feel like an outsider in my family, neighbourhood as well as at work. People think I am a bad person, promiscuous and have done things that I should be ashamed of’.

His feelings here are very much familiar to what authors like Mawar et al., (2001) and Crandall et al., (1991) found, that PLWHA are blamed for having violated social taboos, values and norms and they deserve to be like that. The informants revealed that living with such blame and shame makes them feel like they are not living their own lives fully and are subject to one of secrecy and shame they do not really deserve. Adil’s feelings of being an outsider was shared by other participants for instance another male respondent expressed, ‘It is as if I play hide and seek these days, I want to hide myself from others, but why? Why should I suffer like this?’

These feelings were also found in one study by Simbayi et al., (2007) which explained how internalised stigma was linked with signs of cognitive-affective depression and have a suffering effect on most PLWHA. Mawar et al., (2001) discussed that it is the fear of being stigmatised which causes PLWHA to isolate themselves and feel neglected. Gilbert and Walker (2009) also agree to this while saying that fear is the first reason for PLWHA to keep their status hidden. As Paul admit, ‘You see people will go away from me, my friends will reject me that is why I did not reveal my status. I would lose all my friends, colleagues and dignity at work’.

Blame and judgment involves PLWHA as seeing themselves either as ‘guilty’ or ‘innocent’ in terms of how they contracted HIV (Ragimana, 2006). Many respondents claimed, ‘Getting HIV is a punishment for our bad behaviour’ which they accept as deviant behaviour when for example the sharing of needles while taking drugs. PLWHA are ready to disclose their status to their partners for the sake of treatment support, but not really willing to disclose to family members and non family members due to their fear of being stigmatised (Shelan et al., 2005).

‘People talk bad about us once they know we have contracted HIV/AIDS. I had told my spouse of my disease because she will help and support me during my treatment’, ‘I also told her so that she does not get infected as well you know, since she is my wife and the mother of my two kids, I have to protect them’. The disclosure is also seen by some as a form of punishment for guilty persons, a curse from God or sinner’s disease (Aggleton and Parker, 2001) due to lack of knowledge. Another male respondent talks about the betrayal of his wife, ‘You know, people tend to tag PLWHA as immoral without really knowing the causes of the illness. In my case my wife has betrayed me by having an extra marital affair, so am I to be blamed if I have caught HIV?’

However, few respondents who have had any irresponsible behaviour nevertheless would judge and blame the partner, especially when the latter has been unfaithful, for instance in extra marital affairs. As a female respondent puts it, “Mo mari ine trompe moi, li habitué ale ar ban prostitués’ (my husband has been unfaithful to me, he frequently goes out with prostitutes).

Or sometimes it would be out of pity and anger on the partner as she relates, ‘Mo mari partage séringue kot line attrape sida ek zordi moi si mone infecté, si mo ti koné mo ti pou servi capot’ (My husband shares needles where he caught AIDS and today I got infected, if I knew I would have used condoms).

PLWHA experiences of prejudice and subjectivity in the society is quite common which leaves then with no other choice to cope with it thus setting the stage for silence and self stigma among them. The
majority of respondents noted that the disclosure of their HIV positive status has led to several changes in their relationships (both family and friends). They also reported that they feel even worse when these people who are close to them do not keep their sero positive status up to themselves but they go on telling to others thus the PLWHA are faced with more shame and blame.

**HIV-related stigma and discrimination**

Despite the fact that Mauritius has a well established legislation concerning PLWHA, their right to work and an egalitarian policy in the workplace for HIV/AIDS, the interviewees working in the private sector that is non-governmental and non para-statal bodies, experienced problems such as contracts not being renewed or could not get leave for treatment. The respondents admit that despite the legislation against discrimination of HIV infected people in Mauritius, certain companies especially private ones, discriminate against their sero positive staff. However, it is wise at this point to note that half of the participants cannot really make out the difference between stigma and discrimination as noted by previous researchers (UNAIDS, 2004). As Parker and Aggleton (2003) noted, the meaning of discrimination is almost taken for granted and leads it to be invisible. As a female respondent relates, ‘I often encounter problems in getting my leaves approved by my head of department who does not understand my problem. She said to one of my colleague the other day that I am sick and I should be dismissed from work’.

Such attitudes lead PLWHA to live and work in anxiety (WHO, 2008). This is not the only occasion where organisations have demonstrated a reluctance to invest in sero positive staff. One interviewee said that she does not have any clue about her contract being renewed or not since, each time she is told, ‘Ou bizin resign’ [you should resign].

Another case is also apparent where the respondent is not given enough assignments as his other colleagues. Working as assistant storekeeper, he would sometimes help in serving tea or coffee to senior staff of the organisation, but since disclosure of his HIV status, he is restricted to these types of assignments which did not give him satisfaction at the end of the day. As an outgoing person he related, ‘I would love to be the worker who accomplished two or three tasks, serving and at the same time socializing sharing my grief with friends but everything is completely different, I feel I am not up to my office expectations, they are not satisfied with my work’.

According to Dickinsson (2003), HIV/AIDS stigma impacts on the workplace by lowering the staff morale making the PLWA feel uncomfortable (Jugdeo, 2009). As Neha relates, ‘When I leave home in the morning heading towards office, I feel a deep sense of anxiety and my heart beats very rapidly as soon as my steps reaches the office doorstep.’ I think that my disease has really devastating consequences for my career’

A great deal of research showed that there are several forms of stigma namely verbal and physical stigma, social exclusion, loss of identity, rights and status and the loss of access to resources. The majority of respondents reported widespread gossip and rumours in both their neighbourhood and at the workplace. As Adeela narrated, ‘The other day I was passing by when I heard my neighbour telling my house tenant pointing his finger at me, she has the virus!’

This gives an indication of how PLWHA are treated due to their illness and the state in which they are living both in the society and their workplace.

**Physical stigma**

Physical forms of stigma include distancing and avoiding contact with people living with HIV and AIDS, physical isolation of the person and their belongings (for example through separate quarters, utensils and clothing and so on) and though it is rare, violence or threat of violence against someone with HIV or AIDS. Friends and neighbours distance themselves from a person who is suspected or confirmed to have AIDS. As one male respondent claimed, ‘One day while walking to the mosque I came across a friend and wanted to greet him, he told me “how can you think of greeting and shaking hands with me?” I was numb and really irritated by the words of the person who used to be my friend some time back’.

In addition to being avoided by friends and neighbours, participants described how people with HIV and AIDS are represented within the home so that contact is minimised. An urban male respondent described his brother’s reaction, ‘He is my elder brother and we live together, when I told him
that I am HIV positive, he left the house’. Along with physical exclusion comes social exclusion and a loss of one’s identity in the workplace. PLWHA are excluded from family and community life and experience a sense of social isolation. A male respondent noted, ‘You not only face the instances of social isolation at home and in the community but also in the workplace where everyone tries to avoid you. They always remain distant, even my best friend and business partner’.

Thus, PLWHA tend to lose their sense of inter-personal interaction having lost their social networks resulting in the loss of their identities and roles they usually played both in the community and in the workplace and when excluded, PLWHA are made to feel useless and hopeless.

**Enacted, perceived and internalised stigma**

Descriptive studies in the Indian context (Bharat et al., 2001, Pallikadavath et al., 2005, Thomas et al., 2005) report personal experiences of men and women who are isolated or dismissed from work, forced to use separate kitchen utensils and not allowed to cook and so on. Nevertheless PLWHA relating enacted stigma (personal experience of stigma and discrimination) in the workplace is less common than perceived and felt stigma. For instance, Subramanien (2009) and Thomas et al., (2005) showed that people experienced more perceived and felt stigma in the workplace. Qualitative studies support the presence of self or internalised stigma whereby those infected tend to accept stigmatisation from others, feel guilty and justify the discriminatory behaviour of others towards them (Bharat et al., 2001). For instance, one female respondent mentioned, ‘You see, they have always something to say about me, it can be for example a remark (usually a bad one) on my physique or clothes, perhaps it’s because they do not see me as a normal being’. Another male respondent stated, ‘My colleagues judge me by my appearance, making me feel even sick, ashamed which keeps me constantly blaming myself’.

HIV and AIDS is creating its own discourse as it is gaining centrality in the lives of people (Bantereyeya et al., 2004) however, as the majority of respondents revealed, HIV related stigma and discrimination is very much present in their lives and they suffer each and every day from different forms of stigma and discrimination. Settings such as health care, the home and the workplace as well play an important role in the manifestation of stigma and discrimination.

In the health care settings, the respondents reported that the medical system is insufficiently developed and cannot provide good quality care to all who need it, especially the PLWHA. A rural female participant Mary said, ‘People with money can go to private clinics and receive treatment but we are so badly treated at the day care centre, the health care assistants curse us for our plight, once a nurse wore five gloves to take my blood sample’.

Moreover, the home is also mentioned as a place where PLWHA experience stigma and discrimination. They face verbal stigma in terms of scolding and insulting, physical stigma through separation and the loss of identity (Bharat et al., 2001). As Anna, a female urban respondent, mentioned a form of physical exclusion in the family, ‘I am told to use my own things without mixing materials, eat or drink only from my own plate and glass’.

This is a form of exclusion within the family itself. Poverty is one of the main reasons that families act harshly towards a family member who has acquired HIV/AIDS. It makes the person feel useless and it becomes difficult to accommodate them. Paul, a male respondent related that one particular day he was very ill and asked his elder brother to take him to the hospital and the latter refused. Anna, a female respondent, also narrated that when she told her mother that she wants to continue her education, she heard the latter telling to her dad, ‘The family does not want to spend money on a PLWHA member since it does not bring any hope’.

People who live with HIV and AIDS reported on stigma related experiences they face from religious leaders. Sometimes the place of worship is simply a venue for forms of stigma commonly occurring in the community (Aggleton and Parker, 2001). As Mary, a female respondent noted, ‘Several times while going to the Church I have heard different people calling out names, pointing finger towards me and some even tell me not to enter this holy place as I am dirty, I have AIDS’.

Another place which leads to the marginalisation of PLWHA is their workplace. The incidents which the interviewees faced daily helped in tracing out the emotional and moral stigma into the ignorance of the facts of transmission and the myths about the disease. As Vickers (1997) mentioned, living with a
serious disease is usually a big sign of agony especially life at work becomes a passage of trauma, a perilous journey. As Mary relates, ‘Before I knew about my sero-positive status, I was a very ambitious person, with outgoing personality. Everyone would appreciate me at work, [pause] I would make them laugh all day, but now... You know... things have changed’.

A rural female respondent narrated that she used to go along with other colleagues for lunch in the nearby restaurant but once her status was known, however, she found herself in a state of isolation as they stopped having lunch with her; she felt emotionally rejected. As she related, ‘We were four friends of practically the same age group where we would go out for lunch sometimes eating our favourite dishes, but now things are different, they remain far from me, avoid me..., maybe they do not want to see me. They talk into idioms making me hear, for instance people are dying out of AIDS.

The stigma in this case is silent and she is suffering from painful rejection. A male respondent, a storekeeper, talked about his experience with colleagues who would every now and then ask for help, ‘Now you find them entering the storeroom taking out their things from the cupboard themselves without even greeting me, avoid from shaking hands (physical contact), as if I am invisible’. He considers himself as non-existent to his colleagues who do not feel necessary to take his service. He takes out a strong sense of emotional rejection from the stigma that he is facing in the workplace which made him feel worthless. Quoting his words, ‘I feel dirty through people’s eyes, I am infected with a virus which is sexually transmitted and this shows my immoral behaviour’. He continues after a slight pause ‘.... I heard a colleague talking about me and my illness while passing by the office the other day’.

The internalised stigma of the respondent is explained by Link and Phelan (2001) as occurring in the context of power where distinguishing and labelling differences associate human difference with negative attributes separating ‘us’ from ‘them’, and status loss and discrimination.

‘Sometimes they overreact, they are nice to you...overnice and sometimes they avoid me, while not trying to do so in the real sense. You know, they are ignorant of the disease thinking that it is the same as the virus we have just had that is AHINI flu; AIDS is not contagious through a cup of tea. They just think that by standing next to a person who is HIV positive you can be infected’. Stigma can lead to negative self-conceptions and life experiences (Link, 2002). The unsafe behaviour that produces AIDS is judged to be more than just weakness, it is indulgence, delinquency, addictions to chemicals that are illegal and to sex regarded as deviant (Bhattacharya, 2003). According to a respondent, ‘I am a confident parson, owning a company, having helped many staff who out of illness cannot come to work through counselling and granting them leaves, and in my turn, I feel isolated... like an alien’.

Dealing with stigma is so complicated for the interviewees and it has become a routine in their lives. People always understand the ‘other’ as ill (mainly due to bad behaviour) and give another connotation to the healthy. The need to separate the other physically from oneself is an urgent one (Ragimana, 2006). The public have a firm understanding and portray someone with HIV/AIDS as a dying person from the way it is depicted on television programs (Parker and Aggleton, 2004), which show very sick persons in their last stages of life, ‘It is this picture that they wish to see when they hear someone has AIDS’; ‘They tend to think that if I am HIV positive I should stay in bed, very ill’. The less knowledge individuals or communities have of HIV/AIDS, the more likely they are to be stigmatised (Herek et al., 2002). In this context, another male respondent relates that he feels ashamed and reduced in the wider society. Alzono and Reynolds (1995) rightly claimed that stigmatising ideas about HIV have a powerful hold on society because they are often being framed within a moral concept of blame, responsibility and deservedness. A female respondent related that her neighbour who works in the same office once told her, ‘You know, do not feel bad, but I truly believe that you should stop working or change occupation because your disease and your infected status leaves a bad impression on our locality in our workplace’.

Goffman’s (1963) concept about stigmatised persons are discounted and discredited, reduced in the minds of others from being whole and acceptable individual to those whose identities are spoiled or tainted show that they further internalize these feelings and their life opportunities and chances are
reduced. As a female respondent said, “I started to avoid people, ... I would not converse in the same way like before and I do not appreciate the way people treat me, thus I preferred to be alone’.

As Goffman and Jones et al., (1984) rightly point out PLWHA set them apart from the others, consider themselves to be inferior as if they represent a threat to the society. When asked if he has ‘ever been party to any discrimination either willingly or unwillingly’ a female respondent replied, ‘Yes... if you see a handicapped person on the road, it may happen or if you visit someone ill in the hospital you would be scared to touch his bed, clothes and approach the person’. Her response reflects that stigma is a social illness where the society emphasizes a negative label on a person or groups of people and this can be further explained by referring to the Mead and Cooley’s glass concept that is the ‘I’ and the ‘other’ separating ‘us’ from ‘them’ - attribution of illness.

The interviewees demonstrated that discrimination takes place at various levels such as in the workplace and other settings. It exists not only among employees and employers in work settings but also colleague’s avoidance from the stigmatised other, physically or emotionally. As a male respondent related, ‘My girlfriend who works in the same office has rejected me and has even resigned from the job when she learnt about my HIV positive status. Sometimes I think that my behaviour has led to so many losses in both my life and the lives of many people especially my dear ones.’

This clearly demonstrated that avoidance and ignorance of colleagues throws the person living with the virus into self blame. This result into what Mackoae (2009) refers to as ‘self-stigma’ a main reason due to which they isolate themselves from their families and communities. As mentioned in the literature review, people need to feel part of an ‘in-group’ (Branscombe et al., 1999). A person either fits in a group or if threatened, walks away and feels rejected. When someone successfully joins a group, it reduces stress and increases commitment to it. However, the process of fitting is not as easy for PLWHA as they are often labelled as the ‘other’ (Cooley self looking glass concept). The interviewees showed great interest in “belonging to their workplace” that shows their motivation to succeed in life and career. As Sunil stated, ‘As head of my organization, people used to respect me in the workplace but nowadays I feel as if I have left my respect and status at home, it is very hard sometimes you take it lightly but at other moments, you feel so rejected’.

As Atkinson (1999) puts it, the stigma increases as the symptoms of the disease becomes more visible. This leads the PLWHA in a state of trauma, a sense of self rejection where Goffman (1986) warned the marginalised person to a distained one. A female respondent relates, ‘My situation has become even worse since my health is deteriorating, I cannot be present at work all the time, and at home I do not have enough courage to look after my kids, I feel ill’.

There is a clear connection between morality and the nature of work assignments given to them, all directly linked to the possibility of PLWHA losing their lives due to illness. As another female respondent puts it, ‘During meetings I cannot talk about the strategic plan of the organisation which is planned for five years, since I do not know if I will be here or not.. [Pause] and then, you understand people would not believe me’.

The respondents noted that the stigma and discrimination they face, force them into silence about their status and disclosure becomes very difficult. The majority of respondents revealed that their level of disclosure is very low due to the stigma and discrimination they experience.

Gilbert and Walker (2009) listed moral judgment and blame, ostracism, relationship termination, verbal or physical abuse and discrimination as the factors discouraging disclosure among PLWHA.. As Greene and Serovich (1996) stated, most respondents prefer to disclose their status to their close family members as they are more likely to be accepted. ‘I told my mother about my HIV positive status since I knew that even though she will be very angry and shocked later, she will understand and accept me’. Another female respondent revealed, ‘My father cried and it was the first time I saw him cry in front of me, my mum was very angry, she yelled and yelled at me and said that they have failed to be good parents’.

All the respondents mentioned that after the disclosure of their HIV status at work, they have lost many friends and with time they are learning to socialise with only those who accept them and when
they met new people, they are very cautious about revealing their status especially to someone whom they want to impress. Moreover, the greatest consequence of stigma experienced by respondents is the level of social interaction that occurs at work for example during meals or travel. They revealed that they are subject to rumours and gossips at work which leads them to become socially isolated in the workplace. They mentioned that they feel socially isolated and ridiculed in the workplace. A male respondent said, ‘They tell you that they no longer need you as their friends and thus isolate you’.

During the course of discussions, several respondents came up with their explanations and understanding of factors that contributed to the stigma attached to HIV/AIDS and associated discrimination. Some respondents agree that PLWHA are subject to stigma and discrimination mainly since there is a general lack of knowledge and information about HIV irrespective of one’s level of education. As one female respondent pointed out, ‘We have learnt so much after contracting the disease and this makes a huge difference from what people think about the disease’.

In addition, Parker and Aggleton (2003) assert that stigma is partly responsible for producing and reproducing power and control. Jurgens et al., (2008) argue that the media’s emotional campaigns about HIV results into the belief that HIV infected people are doomed to die, failure due to irresponsible behavior, ‘You see, publicity on HIV infected people on television depict a picture of the dying one or a severely ill person, in very poor conditions’.

He was trying to explain here that the media show the HIV infected people through images of self destruction or helplessness that people (others) will either pity or blame them. As Parker and Aggleton (2003) assert, the media is partly responsible for producing and reproducing power relations and control by devaluing other groups while it elevates others.

Social exclusion and loss of identity

The majority of respondents expressed anxiety when they meet someone for the first time in the workplace especially in the presence of colleague who know about their status as this can affect their career opportunities. Anna, an urban female respondent revealed that, ‘When we have new clients who come in the office, I usually walk away since I am scared that others will spread the news of my HIV positive status to them’.

The respondents declared that although many of their family and friends rejected them, their close family members such as parents, spouse or even cohabiting partners supported them after disclosure of their positive status to them. As one rural male respondent noted, ‘My parents supported me in difficult times as they knew that I am their own blood and I have nowhere else to go’.

Respondents agree that social exclusion and loss of identity is a major feature that they experience in the workplace as well as in their respective community. The PLWHA are prevented from participating into projects, strategic plans for the future due to their illness.

The stigma relating to the HIV/AIDS disease is strongly related to the nature of its transmission that is sexually transmissible and the apparent physical symptoms that appear after the dominant phase as soon as the disease develops. These kinds of prejudice tend to make people think that PLWHA are suffering as a result of their deviant behaviour as Byon-Hee states, hence affecting their self esteem, psychologically harming them and at the same time tendency to isolate themselves, creating their own world’. Like a male respondent mentioned, ‘I am living with a virus, a deadly virus, I am the virus.’ PLWHA dislike the way people label them as being deviant and tagging them as unsocial. Given the fact that HIV/AIDS is still very taboo in Mauritius, they hide their status, refrain their activities such as joining clubs, leisure walk in health track and simply avoid being in the public. As he puts it, ‘I prefer to stay at home alone during weekends and watch a movie; this distracts me more that going out with friends bearing the poignant eyes of others’.

Coping strategies were a major focus for the majority of the respondents. Coping here means the processes PLWHA use to deal with stigma and discrimination. Crying is a main coping strategy for the respondents especially females. One female respondent, mentioned

‘Even if I am hot tempered and reply back to people, I cry when I go to bed at night thinking of my problems and fate’
Other respondents confront the people who stigmatise them directly. A frequently used way is to provide to the ‘other’ information in order to correct the misconceptions that lead to their stigmatising attitudes. As Mary point out, ‘I often explain to my colleagues about the disease, making them understand that PLWHA are not bed ridden patients, they can walk, work and live life like any other healthy person’.

Their work was for the majority of the interviewees a way of proving themselves, a reason to live, and a place where they could meet people and maintain contacts. As a female respondent says, ‘My work means a lot to me right now, I cannot see myself separating from my work for no obvious reason’. Moreover, many of the respondents have turned themselves to religion and faith. ‘You know I was very depressed when I heard the results from the doctor. I did not know what to do; I thought immediately that I would die. Then I went to the church, confessed and I got counselled by a preacher, telling me that I could defeat this by believing in God. I felt very relieved after talking to him and was the happiest person on earth. You know sometimes I felt so miserable, I think that I am good for nothing, and will not live long, but now everything is fine. I know God is with me. Religion has changed my whole life because I believe God is here to protect me during hard times’.

Stigmatized persons tend to internalise negative beliefs about groups or individuals leading to negative self-conceptions and life experiences (Link 1982).

Concerns for the future
As Aggleton and Chase (2001) discussed, AIDS is understood to imply death and the conflation of HIV with AIDS results in the belief that HIV, too causes imminent death. The eventual death with AIDS evokes anxiety and may lead PLWHA to believe that not enough time remains to weigh carefully the strengths and weaknesses of various alternative solutions to an AIDS related problem (Mawar et al., 2005). These beliefs are likely to foster a vigilant style that can further isolate the HIV-infected.

However, for some people living with the virus, the word ‘illness’ means a long and patient journey and all they wish is the possibility of having a long, healthy life ahead (Patient and Orr, 2004). The respondents expressed their concerns for the future, shared their views about what they feel can be done to ameliorate their lives and to combat HIV-related stigma and discrimination in the workplace. The majority of respondents, when asked ‘what does the future mean to you?’ they replied, ‘Life has come to an end now, I will die now’;
The illness also places a financial burden on the families which may affect their relationship ties. Half of the respondents were concerned about how they will lead their lives lonely without their closed ones if they are removed from their house since they now represent a financial burden for the family. For instance, one female respondent stated, ‘I am really concerned about my future, my survival, you know... [Pause], since I am fully dependent on my parents and I know I am a burden to them’. Also, the primary concern for most of the respondents who were working people and in many cases sustaining their households was that the plight of their families if something happens to them, ‘You see, we (my family) all depend on my salary for our living, I cannot afford losing my job right now..., otherwise we will be in deep trouble’

Much of the data presented in this chapter portray a vivid picture of the PLWHA and their experiences of stigma and discrimination. Indeed, it reveals that stigma is highly prevalent, affecting them in various places and in many forms, impacting on their personal and professional lives. Indeed, it reveals that stigma is highly prevalent, affecting them in various places and in many forms, impacting on their personal and professional lives. The participants noted that being HIV/AIDS infected people they find it very difficult and challenging to live in the society especially to adjust in the workplace. They had to alter their lifestyles in their surroundings and in different situations. In order to be able to live long and productive lives, they need to undergo frequent medical tests, visits to the doctor and under constant medication.
References


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