Normative functions of HIV/AIDS support groups

Sandra Roberts
Doctoral candidate, Department of Sociology, University of Johannesburg
sandrar@mediamonitoring.org.za

Still a problem, HIV stigma necessitates strategies to deal with it. One such strategy is support group attendance. The role that support groups play in the lives of HIV+ people is multi-faceted, providing a range of different types of support that help deal with HIV stigma. Based on research which took place in a public hospital in Johannesburg at which a support group is run, this paper consolidates various previous contributions from a range of fields and explores a previously unexplored form of support – normative support. This form of support is particularly practical in dealing with stigma, particularly self-stigma.

Key words: Stigma, stigmatised identity, support groups, social representations, positive identity

Introduction

This paper argues that support groups provide a means for reforming stigmatising norms applied to PLHAs and building new social representations based on these reformed norms. Support groups are often advocated for, as they are easy to create, do not have to be linked to existing healthcare facilities and do not need professionals to run them. The paper is divided into three sections. The first considers stigma as experienced by respondents. The second examines the forms of support provided by support groups. And the third looks at social representations formed in the support group aimed at fixing social identities tainted by HIV.

Theoretically, the paper uses a combination of Goffman’s stigmatised identity and Moscovici’s understanding of social representations. The stigmatised identity, Goffman (1963:12-13) argues, is marked by “a special discrepancy” between the virtual (or expected) social identity and the actual (or the real) social identity, but the discrepancy must be discrediting in nature. Potentially stigmatising attributes are hidden by the person with the stigmatised identity, to protect the “self in various social environments that could lead to stigma”. The stigmatised are socialised by the ideologies of “normals”, regarding themselves as these “normals” regard them (Goffman, 1963:45). Social identities (including the stigmatised identity) are closely linked to social representations in that representations imply a “process of identity formation” (Duveen, 2001).

Social representations are “systems of values, ideas and practices” that help people orient themselves to the world, and provide a common understanding to facilitate communication (Moscovici, 1973). Moscovici defined three types of social representations (1988: 221, 222). Hegemonic representations are shared by all the members of a highly

---

1. This article stems from the author’s masters research funded by the National Research Foundation.
structured group, without them having being produced by the group. Emancipated representations are the outgrowth of the circulation of knowledge and ideas belonging to subgroups, such as people living with HIV/AIDS (PLHAs). These are “not yet incompatible with hegemonic representations” (Ben-Asher 2003: 5). Finally, polemic representations are generated in the course of social conflict or controversy.

The first section dealing with stigma, explores respondents’ experiences. Stigma can be broadly understood as associated with persons who are perceived as less than “fully human” (Goffman, 1963:15), that is to say, they have been socially discredited. Local and international research indicates that HIV stigma is a global phenomenon (Ogden & Nyblade, 2005), following similar patterns everywhere. Women are particularly vulnerable to stigma and the effects thereof (LeClerc-Madlala, 2001: 43; Haram, 2001: 54; Fox, 2003). Interventions against stigma seem to disguise it, rather than eradicate it (Stein, 2003), as stigma is rooted in social structure (Parker & Aggleton, 2003).

The second section deals with support in support groups. Support group attendance is a strategy to deal with the fallout of stigma on an individual level (Schopler & Galinsky, 1995: 4). Various forms of support are obtained from support groups: emotional support, as in comforting, informational support, practical information about ailment and instrumental support, practical assistance with daily living. These three types of support, according to Kalichman & Sikkema, can “directly alleviate psychological distress associated with chronic illness and can indirectly buffer the effects of stressful life events” (1996: 589). To this conceptualisation, this paper adds normative support. Normative support teaches PLHAs options for transforming stigmatising representations of HIV to enable a positive identity.

The third section looks at the potential for social representations to fix the social identity. Identity fixes refer to specific strategies employed to defer stigma from others and rebuild the social identity stigmatised by HIV. Despite the recent highlighting of the possibilities of social representations for health research (Howarth et al., 2004); social representation theory has yet to be applied to dynamics within HIV support groups. Social representations are critical to rebuilding social identities when faced with stigma. As such, collective social representations aimed at amending or “fixing” the stigmatised identity or “living positively” (explored by Whittaker, 1992; Stanley, 1999; Roberts, 2006) need to be included in the types of support supplied by support groups identified elsewhere.

All of the above are be investigated through the vehicle of the voices and experiences of Black women, who suffer most from the stigma associated with HIV/AIDS and have the least resources to challenge it.

Research design

To explore stigma and its impact on the social identity of PLHAs, the approach was explorative and included observation, in-depth interviews and group interviews. The three-pronged approach of this research was adopted in order to gain the most comprehensive view of the situation. Focus groups can generate uninhibited, lively discussions (Macun & Posel, 1998: 116). In addition, they had the effect of resembling interactions in the support group, with much advice being shared as respondents discussed their experiences. Individual interviews enabled respondents to discuss deeply personal issues,
avoided in group discussions because of the private nature of the content. Focus groups lend themselves to a methodological problem, in that responses do tend to be more homogeneous than individual interviews (Alexander & Uys, 2002: 303). By including individual interviews the effect of “focus group homogeneity” could be counter-balanced.

Before selecting the research site, four relevant experts where interviewed. Two of these respondents later acted as gatekeepers to the research site, a public hospital, where they were involved with the target population. These interviews led to participant observation of a HIV support group at a public hospital, three support group sessions were observed in total. The main research site, not where the participant observation had occurred, was then selected. Initial participants and research assistants were selected on the basis of recommendations from the head of the HIV clinic. Further participants were recruited from the weekly support group which took place immediately before the focus groups and interviews. Participants were recruited by the HIV+ research assistant and the study was then explained by the researcher, including its purpose and potential effects. Informed consent was obtained from respondents. Respondents were also offered anonymity, and assured of confidentiality. Out of concern to protect the respondents, the name of the research site was later withheld. Counselling was made available to respondents should the research be traumatic in any way.

In total, 47 people were interviewed for the purposes of the research, excluding various interviews with HIV/AIDS experts prior to and during the research. Participants were selected on the basis of cluster samples of people who had been participating in the support group. Of the 47, the majority were women (42) and the remaining five people were men. Of the 1477 patients in the clinic’s regular patient database (accessed March 2004, four months after research was conducted), 70% were female. From observation and expert interviews, it seemed that women were the more frequent and more numerous attendees of the clinic. The 89% female component in the sample means that females may be slightly overrepresented in the sample. In terms of race, the sample was almost wholly Black, with one Coloured respondent. Most of the respondents were unemployed, others underemployed, and only two who could be possibly described as middle-class.

Forty respondents were interviewed in groups and the remaining seven on a one-to-one, in-depth basis. The focus groups were made up of between four and six participants with four men in otherwise female-dominated groups. This may have resulted in a particularly feminine experience being more prominent than a masculine one. Both interviews and focus groups were semi-structured, with questions revolving around their sense of stigma and sources of support.

This level of analysis of this paper is broadly socio-psychological. The data was analysed using a form of thematic analysis. Braun & Clarke (2006) argue for thematic analysis as an approach in itself. This bottom-up approach looked first at the data itself and then to theories that would match the observations. In identifying themes, the researcher looked at a range of levels. The initial focus of the analysis was semantic or surface-level themes, such as stigma as a lived experience. The focus then shifted to look at latent themes not initially obvious, such as the “coaching” that happened in the observed support groups and in the focus groups, and what this meant, in terms of social identity. Keeping the experi-
ence of the respondents central, early analysis of the results was presented back to a group of respondents for further comments and reflections. Guided by the data, social identities are central to this analysis. Applicable theory explaining observations are used to examine the data. These are Goffman’s “stigmatised identity” (1963) and social representations by Moscovici (1988). Throughout the paper, quotations that captured the essence of what a number of respondents said are chosen.

**Stigma and the stigmatised identity**

The purpose of this section is not to prove the existence of stigma and the stigmatised identity, as it has been extensively explored elsewhere (Haram, 2001: 54; LeClerc-Madlala, 2001: 43; Fox, 2003; Stein, 2003; Ogden & Nyblade 2005), rather, there seems to be a link between the areas in which stigma is experienced and the fixes discussed. Similar experiences of stigma and support groups would explain the similar identity fixes employed by respondents.

Women are particularly vulnerable to stigma. From research conducted in five of South Africa’s nine provinces, Fox (2003: 15) concluded that: “the stigma attached to HIV/AIDS affects women in particularly adverse ways. Fear of violence, stigmatisation, exclusion and destitution dominates the lives of many women with HIV/AIDS in South Africa.” Rates of HIV infection are significantly higher among women than among men. The explanation for this is partly physical – related to the way the virus is transmitted – but largely social; a consequence of gender inequality (Lawson, 1999: 393). Research among Black women has highlighted the impact of economic reliance on men, generally lower levels of education, lack of sexual decision-making power, pressure to have sex at an early age and the formation of relationships marked by violence (Bujra, 2000: 8; Becker, 2001: 1; LeClerc-Madlala, 2001: 40; Walker & Gilbert, 2001: 9). Investigations by LeClerc-Madlala (2001: 43) and Haram (2001: 54) have shown that women tend to be blamed for HIV/AIDS, with their sexuality and promiscuity “demonised” as its cause. Men escape much of this stigma and are portrayed as innocent victims. The ultimate effect of stigma is that the stigmatised are denied life chances that they would otherwise experience (Goffman, 1963).

Respondents were asked about their experience of being HIV+ in terms of the reactions they felt they got from others. All respondents had experienced some form of stigma. Stigmatising reactions might follow disclosure, or they might result from suspicions of others. Stigma was experienced in three contexts of PLHAs’ lives. These are the community, the family (including partners), and in money-related matters. There is a difference between the stigma experienced from the community and that from more intimate relationships. From the community, voyeurism, gossip and taunting were encountered. At home, some PLHAs were subjected to neglect, abandonment and abuse. Money-related matters served to trigger stigma in the home and community. The quotations chosen capture the experiences of several respondents.

**Stigma from the community** was most commonly recognised as “stigma” or “discrimination”. Because relationships with community members are not necessarily close, stigma from the community could wax and wane together with symptoms. Taking the form of
voyeurism and gossip (also revealed in Odgen and Nyblade’s findings), stigmatisation from
the community involved the singling out of PHLAs, attempting to make them “other” from
the rest of the community via gossip and treating them like social pariahs.

Gossip may follow disclosure, or it may be based on symptoms, such as weight loss (or
thinner people in general), tuberculosis, skin rashes and baldness or hair loss. One
respondent reflected on the manner in which people gossiped about others based on her
previous experience of weight loss:

If you lose weight, they look at you, they can judge you, they say that
you’ve got AIDS, even if you didn’t tell them. If you lose weight you’ve got
AIDS.

If somebody did not die soon after the symptoms were noticed, the initial supposition that
they are HIV+ may be questioned. This doubt could lead to a decrease in stigma, as com-
munity members were no longer certain about whether the PLHA had HIV or not. This
woman knew that she could hide her status behind her healthy weight:

When you lose the weight you are afraid that everybody’s going to see, but
when you start gaining, like me, I’m gaining, even the one who said “this
one has got this [HIV]”, now she’s confused, she doesn’t understand.

Voyeurism may accompany gossip. Those who get sick and are confined to bed are often
suspected of having HIV/AIDS. Community members may even visit the invalid to ascer-
tain her condition in order to tell others. This respondent tells how she was stigmatised by
a community member:

I was very sick in 2001. They would like to come to my room and say
“how are you today?” I say: “I’m fine.” When they are coming outside, with
their other friends they say, “we must come and look at her. She’s got
Inculazi [AIDS]”.

Other respondents felt that members of the community watched them as they came to
and went from their homes.

Respondents felt that the stigma that PLHAs experienced was intense and disturbing
enough for PLHAs to avoid the community. Attempting to evade stigma from the commu-
nity may result in a lack of medical care and an earlier death. As one woman explained:

You know why many people die; it’s because of those people [in the com-
munity]. Because when they hear you have this virus, ei, the way they will
 treat you. That’s why many people are dying, because the person with this
virus, she will be or he will be afraid to go outside to the clinic to go [any]
where. The other people they are afraid to walk in the street until they
die.

Stigma at home, unlike stigmatisation from the community is difficult to avoid. Stigma from
the family and sexual partners can be deeply hurtful and pre-eminently stressful, but is
often a feature of PHLAs’ experience (Ogden & Nyblade, 2005). HIV stigma in intimate
relationships may compound existing family or relationship problems. As such, it may not
be recognised as HIV stigma, because the problems were present prior to HIV infection. It
is also likely that respondents would be unwilling to acknowledge or talk about stigma
experienced in intimate relationships, because of the emotional importance of these rela-

2. HIV/AIDS was frequently referred to as ‘this’ or ‘this thing’ by respondents
tionships and, as we shall see later, the use of family to demonstrate broader value to society. In fact, most of the respondents who discussed stigma in intimate relations spoke of past relationships. Two respondents, who were interviewed twice, had earlier used tactics of misdirection to avoid speaking about negative aspects of their home lives. One female respondent had spoken very highly of her relationship with her grandmother and the support she received from her. She was unable to live with her grandmother, however, and those at home were mistreating her. A male respondent shared what was happening:

She feels a little bit better while she’s getting her treatment from the hospital. At home [her family] neglect her; they are always fighting [with] her. Another respondent had her partner leave with their son, with her status mentioned as a contributing factor to the decision. She had earlier spoken at length of the affection her father-in-law had for her before she and her husband married and the lengths that her husband went to woo her.

In fact, sexual partners were known to cause stress. It is difficult to separate HIV stigma from normal relationship dynamics and unequal gender power relations in intimate sexual relationships. Many women reported arguments about their seropositivity. This woman was candid about the abuse she was suffering in her relationship:

When we are fighting he says that “You are HIV+ and you are going to die”, but when we are not fighting, it's fine, he says, “No, I love you” and all these things.

In addition, abandonment by partners was a realistic fear among female respondents. One respondent, abandoned by her partner, explained:

The father of my baby, when I told him that I was positive, he run away, you know. He said, “Hey, I don’t want to die with you, stay there and die alone”.

Stigma at home is particularly dangerous, as it may lead to loss of resources and valued relationships.

It seems that PLHAs may expect to be stigmatised to a certain extent at home. Respondents mentioned how they or other PLHAs washed the dishes after they have used them or expected to be handled with gloves. This interviewee expected to be stigmatised from her aunts, but was not:

Even if I drink something, I want to wash the glass ... and they say no, you are still the same person as we know. They just bring me this water and I drink it, but they don’t reject me.

Few respondents admitted to engaging in self-stigmatising behaviours, but rather mentioned them in other PLHAs.

A crosscutting issue appeared in both distant and intimate relationships. This was money, both in the lack of it and in the possible presence of it, if it is linked to HIV/AIDS. Stein argues that finances cause tension as PLHAs consume more than their fair share of resources in the resource-poor contexts (Stein, 2003: 8). HIV is likely to put further finan-
cial burdens on the family for which the PLHA may be blamed for and stigmatised. HIV is already associated with poverty, as those with the finances for private medical care can escape detection of their status. Lack of money could also expose PLHAs to stigma as they had to access health facilities which were close to their homes which could lead to their status being discovered.

The loss of a house due to a shortage of money caused arguments within the family of another (female) respondent:

Interviewer: “I heard that they lost the house because they are having financial troubles.”

Respondent: “I think that’s where the fight originated. I don’t know how these people are about money, really. I would conclude by saying that money is the root of evil. Really, where there is money there is devilish happenings.”

The female respondent was also checked out of the hospital and forced to fetch her disability grant by her mother, without the approval of the doctors and apparently without the consent of the patient. The male respondent quoted above was recruited to drive the female respondent and her mother around.

Real or perceived income from being HIV+ could also cause stigma. PLHAs were suspected of coming out openly about their status due to the financial and other rewards which may come with having HIV, such as attending conferences and educating people about HIV/AIDS (although this is often unpaid work and the suspicion is therefore unwarranted). This female respondent was accused of lying to school children because they thought she was being paid:

“I was like doing a presentation and sometimes kids will just look at me. "You know what, we know that the headmaster paid you to come tell us that, you don’t look anything like a person who is HIV+.”

The one possible financial benefit to being HIV+ is a disability grant. A disability grant is available for PLHAs as long as they remain too sick to work. This grant was, at the time of the research, an amount up to R750 a month. In families with very low incomes, this money can be a crucial source of income, but also a source of conflict. Even small amounts of money can amplify disagreements when there is little to live on. Stigmatising those who are suspected of gaining through the virus is understandable, then, as it seems that PLHAs gain through their “moral weakness”.

Parker & Aggleton’s (2003: 14) understanding of stigma makes stigma based on money easy to understand. They argue that stigma is more than an emotional reaction to difference in that it serves to emphasise and maintain structural inequalities. That is, stigmatisation of those with HIV/AIDS is, fundamentally, a sociological phenomenon: it is about unequal distribution of resources and power. There is also, however, a relationship between AIDS and material inequality, such as the fact that HIV is associated with poverty. It is more difficult for poor people to conceal their infection and escape the possibility of stigma. Those without resources, for instance, may be dependent on others and they may not be able to access treatment away from prying eyes of neighbours (Nyblade et al. 2003, p 30, 23). The structural disparity that underpins stigma is, then, directly related to illness and indirectly linked to poverty. As Parker & Aggleton (2003, 19) further explain, global
factors aggravate HIV/AIDS-related stigma. This epidemic occurs in an era of increasing inequality, and this exacerbates various types of exclusion, including informational segregation. This polarisation also tends to reinforce all forms of discrimination, including that based on "race", ethnicity and religion, but also HIV status. Support, discussed next, seems to moderate the effects of stigma, but may simultaneously cause further stigma.

Support groups and types of support

Respondents discussed various sources of support, such as family, friends and media, as well as support groups. This paper particularly examines support groups. Support groups are often advocated for HIV positive people (Krabbendam et al. 1998). They were also particularly alluded to in interviews when asked about support. This may have been due to the fact that respondents were drawn out of the support group which occurred immediately prior to the group interviews. Other support mechanisms ran in conjunction with the support group at this hospital. In particular, the wellness course provided information on topics such as nutrition, stress avoidance and alternative remedies. A monthly visit by members of the AIDS Law Project made legal advice available to PLHAs. This legal assistance gave certain respondents a sense of empowerment as they learned and empowered them to fight for their rights. Both the wellness course and legal project functioned to provide information which feed into the support group. Volunteer counsellors were also available to discuss problems with, although the counsellors were chiefly involved in pre- and post-test counselling. In addition, other complementary therapies were available for patients from time to time. The various forms of support are now discussed as they are found in the research.

Emotional support is perhaps the most obvious form of support provided by support groups. This type of support from other PLHAs was helpful for respondents because, being in the same position those who are also seropositive, they often understand the appropriate support needed. This is contrary to the home lives of PLHAs, where families and friends of PLHAs may, unknowingly, act in a stigmatising way. One woman explained her experiences: “It helps because at home you can’t talk to anyone, even those that understand [that you are HIV+].” It can thus also be a relief to PLHAs to know that others are having similar experiences. Another woman elaborated:

I was not handling it well, but when you come here and hear someone telling her story, you realise that yours is better than hers. It’s helped me.

Some emotional comfort, experienced in support groups, can be derived from the sense of not being alone.

Informational support occurs in the form of advice on how to live in order to increase the period of survival. It was provided by the wellness course, and also within the support group in the form of sharing personal experiences of what worked. This type of support included diet-related information, alternative treatments for symptoms and/or ways to boost the immune system, safe sex practices, legal assistance, shelter for the night and/or other services. Much of the information was based on expert knowledge or experience. The function of normative support is supported by accurate and unbiased information about HIV, which is often at odds with stigmatising notions of HIV. Information, such as
the fact that people can survive long with HIV, is important to contradict conceptions that people with HIV can expect a short life full of unsightly ailments. This in turn supports norms for HIV+ people not to be negative about the affects of HIV.

Instrumental support was not a function of the support group itself, but food packages for the very poor were made available by the clinic through donations from a nearby church. Staff would help those who qualified get a disability grant from the government and Antiretroviral treatment for those who qualified. Other support groups also run income generation projects. The form of material support made available by the HIV clinic was particularly for the most socio-economically marginalised. It is these people, whose diet is most compromised, who are likely to get sick and die earlier than others. A respondent explained her strategic use of support groups to access resources:

You don't want to be under pressure always because you don't have money, you don't have something, like if you come to a support group, you'll have some ideas, some help to survive.

Instrumental support from support groups is not needed by all PLHAs in all stages of infection, but rather particularly marginalised people.

Schopler & Galinsky's (1995) conceptualisation of three types of support (emotional, instrumental and information) leaves out a very important fourth source of support, which impacts the experience of support: that of normative support. This form of support draws on as necessary emotional, information and instrumental support. Brewer (2001: 307) notes the importance of group membership in transforming external social representations to identity:

Social identification entails an obligation to know and subscribe to the common symbols and norms ... It also entails an obligation to influence and be influenced by others within the group until shared meaning is achieved on any issue that impinges on the group's identity.

It is within the support group that members reinterpret societal norms to aid in the forming of social representations that defend the social identity. Social representations are a product of social construction, so, the teller of the fix is creating it through communication and the listeners are exposed to a fix they can use and adapt.

Normative support is, therefore, key to the understanding of support provided by support groups. Societal norms are used to judge PLHAs and find them wanting, impacting their view of themselves. In response, in order to maintain a positive self identity, PLHAs create or reform norms to challenge the stigma they experience. Thus, it is the normative support function that provides justification for not thinking poorly of themselves for the HIV infection. Normative support acts in transforming dominant discourses on a collective level to enable positive social identities, as Howarth et al. (2004: 18) argue occurs. These norms challenge stigmatising ideas that show PLHAs as immoral, a threat to their families and economically parasitic or idle. In counselling each other in these norms, the support group members coach themselves in social representations which offer defences against stigma. These "identity fixes" are covered in the next section. This type of support

4. Antiretrovirals were provided to patients only through foreign donors at the time of this research, the national rollout programme had not been initiated.
emphasised “positive living”, which entails trying to deal with the virus and symptoms and accessing healthcare. In this way, support groups encourage members to continue accessing health services.

The new norms developed in the support group are based on the norms of broader society and seem to be a reaction to the stigma experienced. The defences that PHLAs develop in support groups to protect their identities involve comparison between themselves and the “other” (those who deny their having an HIV infection and stigmatise PHLAs). In this way, there is a process of othering those who stigmatise them, as Joffe (1995: 81) writes:

In the face of a mass crisis, in which people perceive their world to be out of control, with their protection compromised, representations which contain an element of inter-group projection are most likely to arise.

This comparative function can be seen in some of the identity fixes that follow in the next section.

This support introduces PLHAs to an alternative representation in which they can be considered valuable despite being HIV+. However, the power in the support group to challenge broader social norms outside of a protected environment is likely to be limited as those who attend this support group have restricted social power. Joffe notes that the power to organise against the stigmatised/spoiled identity is important in resisting stigma (1999: 45). In the support group the PLHA learns to “fix” his/her identity, or manage the risk of being HIV+ (Green & Sobo, 2000). In other words, “make up” for their HIV+ status by being somehow better than others. However, as Soskolne et al. note, use of the “positive identities” in the support group make it difficult for PLHAs to access emotional support, as it is difficult to acknowledge and therefore deal with problems (2003).

While there are many benefits of support groups, attendance is not free from risk. A few people reported that support groups attracted voyeurs. A respondent noted how PLHAs were known to tell another’s status after attending support groups:

They come out of the support group and tell “ooh, so-and-so is also positive”. I think that is what makes it difficult for people to go to support groups and also for check-ups, like, at the clinics.

Another woman related that somebody from her community had told others about her status after finding out at the support group at the hospital. However, the fact that this clinic is located a distance away from where the majority of its attendees live, means that there is less chance of detection than at other clinics that are closer to the respondents’ homes. One woman explained:

Like here at [this hospital], most of the people come from Soweto and other places, so they run away from their communities because [if they attended a clinic in Soweto] everyone will know that they are positive.

There seems to be a little more chance to conceal attendance at this clinic, but the presence of others will always carry risks.

Identity fixes and the fixed identity

The normative function of support groups together with similar types of stigma (discussed
earlier) seemed to result in similar identity fixes. This is not to say that all respondents adopted identity fixes, indeed, some reflected much more of a "stigmatised" identity. In fact, the identity fixes seem to occur on a continuum between the stigmatised identity and the positive identity (Roberts 2006). There was also a level of coaching around these fixes, encouraging the adoption of these fixes along with disclosing the HIV status. These identity fixes form a social representation strategy "with which to subvert stigma and present affirmative versions of self" (Howarth et al., 2004: 17) and protect their identity (Joffe, 1999: 97). PLHAs use identity fixes to diffuse expected stigma and as a way of coping with social life in the wake of enacted stigma. In other words, this strategy is used before disclosure and with those who know their status (it is unnecessary to use it on strangers or individuals unlikely to discover their status). HIV infection is partially normalised by PLHAs, in effect, saying to others and themselves: "Yes, I am HIV+, but I'm a good and valuable person."

In terms of Moscovici's three types of social representations (hegemonic, emancipated and polemic), there are both polemic and emancipated representations in the identity fixes adopted by PLHAs. Hegemonic representations would be more associated with the stigmatised identity. The main fixes emphasise firstly, the moral or religious identity, secondly, the family identity, and thirdly, work identity. The possibility of categorising them in this way reflects both the common experiences that PLHAs have of stigma, and their discussions about how to respond to problems, reflecting the normative function of support groups. There are general categories embracing a number of specific approaches, and the list is not necessarily exhaustive. A PLHA may adopt more than one identity fix, sometimes simultaneously.

The moral or religious identity reasserts the morality of the PLHA. As Stanley (1999: 104, 116) showed, this may involve the view that AIDS is a "message from God" and "a blessing"; though contrariwise, it might also be regarded as a form of punishment from the Almighty (Stanley, 1999: 116). Either of these claims relieves the PLHA of a burden of guilt and shame. Both views were expressed in the interviews. This is not surprising because Christianity is very widespread in South Africa, and many respondents derived part of their identity from membership of a church. That HIV/AIDS acted as a form of redemption was a common theme. Many respondents said that the infection had made them realise the error of their ways or had given them reason to reassess their lives. Another common perception was that HIV was God's way of testing or judging society because people "do not live by God's ways". The respondents also spoke about coming closer to God through their seropositivity. As one respondent reflected:

What I know is that I'm not going to die any time soon. What I know is that God put me into this world to achieve many goals. And I'm not going to die until I've achieved what goals I must achieve.

HIV could function as a reminder of what was important. For some, it led to involvement in educating others about AIDS, or to participation in community work. Many affirmed how HIV had emotionally softened them, making them more compassionate. One female respondent said: "Sometimes I say, 'thank God I'm HIV+, because I want to feel how people with HIV feel'. Not that I was careless, but I wanted to be able to help people with
HIV." This fix acknowledges the hegemonic representation associating HIV with what is considered “wrong” and emphasises how they are now living morally.

The other moral or religious identity fix was to reject the hegemonic representation of associating HIV with what is considered “wrong” and to adopt a polemic representation. They did not consider their sexual behaviour to have been any different from that of others, so why should they be discriminated against? This approach questions the foundation of morality-based stigma. Related to this is the recognition of great numbers of those infected with HIV/AIDS. One female respondent argued: “But you think why, you know, what’s wrong with me? It’s in every house. Most of the times, they are both [HIV+], three, four, you know.” An alternative approach is to undermine the grounds of being “wrong” by claiming innocence in obtaining the infection. South Africa has one of the highest incidences of rape in the world, so it was not surprising to hear many of the women saying that they had probably been infected in this way. Others blamed their HIV infection on their husbands or past partners.

Family relationships were used by respondents to show their value. This representation can be expressed as “my family accepts me and finds me valuable”. There is an overlap between the moral/religious fix, for example by referring to oneself as a good mother, or valuable family member, the there is an implicit link to morality. In fact, Stanley (1999), groups references reflecting the worth of the person to the family, under morality. The use of the family identity fix shows that the PLHA is not sexually or otherwise deviant. Two respondents demonstrate their societal worth through their relationships to their families.

I don’t have any problem, I don’t mind, like, somebody knowing about my status. My family is important to me, so if they can accept me, I don’t mind what everybody else thinks.

[My family] don’t [discriminate against me], they know that it’s them only who knows and they support me.

Many respondents demonstrated the pivotal role of motherhood (men in the sample did not discuss fatherhood in the same manner). Sometimes the mother in question was the PLHA.

She told me “don’t worry about this thing, because if you worry you get sick.” Because my mother she supports me, my mother, she supports me.

On other occasions the mother was the PLHA, who used children to emphasise their importance:

Maybe they [my son and daughter] can pass matric. Then You [God] can do what you want to with me.

Another respondent explained how her son needed her, preferring living with her to her in-laws that he would otherwise have to live with.

The third identity fix was associated with work (in a broad sense of the term). Employment was regarded by PLHAs as an important way of demonstrating their worth to their family or wider community, and, even if the job was menial and underpaid, it provided a strong identity. Unfortunately, the majority of the participants were unemployed, and, whilst most of them had never been employed or had only been in short-term employment, two had lost jobs as a consequence of their seropositivity or poor health. The
employed and self-employed felt a sense of pride, and they also avoided the boredom associated with stigma-induced isolation. Many of the respondents were involved in helping others through volunteering or, in some cases, activism. For most, volunteer work was carried out in very personal ways, by spreading information and counselling those who were positive or suspected they might be. The men in the study tended to have paid employment out of necessity, to provide for their families, and they did not seem as proud of their work as the women did. In contrast, one woman was willing to labour for four days a week – thereby limiting her access to medical care – for R800 a month. In some cases an HIV+ diagnosis even provided the motivation to launch careers and businesses. Moreover, becoming a PLHA led to some of the women reducing their economic reliance on men. The following statements by two female respondents reflect the importance of the work identity:

I'm not starving, I can do business now. Now they are no longer looking at me like before, now they say: "This person is even better than us." Now that's what I'm realising now. "We are stupid, this one is clever, but she is sick."

So, we have to stand up. Like doing the beads [making beadwork ornamentation]; where I am, at the end of the day you bring the beads. You know that little bit [of income] is enough, because it is from your own hands. You are proud. I have R50, rather than wait for somebody else to give you R20.

Work prevents boredom, but income could also relieve some financial burdens of HIV on the family.

A limitation of the work identity, and to some extent the family identity, is that they are dependent upon the PLHA being in reasonably good health. Whilst each of the fixes helped the PLHAs to some degree, it is important to note that they could only mute stigma if the individual has admitted to being HIV+. In other words, it is only with those to whom the person has disclosed or otherwise knows that the PLHA can demonstrate their "fixed identity".

It seems that telling the stories which reflect identity fixes, such as those above, the PLHA is not only re-confirming their own positive identity, but also educating the others in the support group of the various fixes that can, where appropriate, be applied in their own lives. This process of peer-education and normative support assist the PLHA deal with the stigma experienced from the broader society. The use of identity fixes constitute an admission on the part of the PLHA that their social identity is damaged. In other words, it is a response to the "self-stigmatisation" which the infected adopt from the broader society. It is not surprising that PLHAs stigmatise themselves, as they are from the same community as their stigmatisers and, “while there is always the space and possibility for individuals and groups to take on, resist and transform representations, social [stigmatising] representations have something of an ‘irresistible force’” (Howarth, et al., 2004). Identity fixes do however indicate a break from the views of others in society which question the worth of those with HIV. In this way they mitigate the effects of stigmatisation on a person’s sense of self worth, while attempting to lessen the stigma experienced from stigmatisers. However, by using identity fixes in the support group, PLHAs can be avoid
talking about the struggles they face and access the needed emotional support needed from support groups.

Conclusion

In order to deal with the stigma and preserve a positive identity, PLHAs attending support groups reform societal norms for and through the use of social representations. In the support groups the PLHAs discuss what it means to be HIV+ and how HIV+ people could be equal, or otherwise, superior to those without HIV. It is this normative support which attempts to prepare PLHAs for the rigours of the stigmatising outside world. It does this through drawing on informational, emotional and instrumental support, whilst encouraging health-promoting behaviours. It is in this safe environment where PLHAs gain the resources to fix their identity to deal with, and it could be argued (Roberts, 2006: 171-188), challenge a hostile environment.

References


Kalichman, S.C. & Sikkema, K.J. 1996. People living with HIV infection who attend and do not attend support groups: A pilot study of needs, characteristics and experiences. AIDS Care, 8(5).


