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The *Longlife* AIDS-advocacy Intervention: An Exploration into ‘Public’ Disclosure

Abstract

This paper explores the Longlife AIDS-art advocacy intervention. This intervention was designed to support the AIDS treatment agenda by publicising the life narratives and art of a group of HIV positive people (all but one of whom was female). The research draws on in-depth interviews with twelve HIV-positive African women (known as the Bambanani Women’s Group) who were central to the intervention. Their experiences of public and personal disclosure highlight the complex relationship between their activist and private lives. In order to minimise the potential negative consequences of public disclosure, choice of audiences for their disclosure messages was mediated by a range of factors. These included social distance, type of media, activist ideologies, subjective constructions of community, and most importantly, perceptions and fear of AIDS-stigma. This paper reflects critically on the intervention by highlighting some of the social and individual problems experienced by people living with HIV when they disclose their HIV status publicly in their communities.

Introduction

South Africa is home to more HIV positive people than anywhere else in the world. It is thus unsurprising that many AIDS-related interventions are operational in South Africa including grassroots-mobilisation, prevention/education campaigns, anti-retroviral treatment, palliative care, psychosocial support, treatment education, income-generation, advocacy activities etc. This paper explores one such intervention, the *Longlife* AIDS-art advocacy intervention which was designed to support the AIDS treatment agenda by publicising the life narratives and art of a group of HIV positive people (all but one of whom was female). My research draws on in-depth interviews with twelve HIV-positive African women (known as the Bambanani Women’s Group) who were central to the intervention. The paper reflects critically on the intervention by highlighting some of the social and individual problems experienced by people living with HIV when they disclose their HIV status publicly in their communities.

When a person is diagnosed HIV positive, they are confronted with the knowledge that HIV is a life-threatening illness as well as the negative stereotypes attached to HIV/AIDS. At some stage of the illness, the individual will inevitably confront the issue of disclosure – whether they should reveal their HIV status or not, to whom, and for what purpose. Disclosure of HIV status is first and foremost a very difficult and complex decision, and the decision to disclose is made for a variety of reasons and is context-specific (Bharat and Aggleton 1999; Petronio 2002, Greene *et al* 2003, Chandra *et al* 2003; Serovich *et al* 1998; Petrak *et al* 2001).

Disclosure of HIV status is a contentious issue in many fields relating to HIV/AIDS. Studies have looked at HIV status disclosure in the household, to family members, to husbands or wives, to sexual partners, to friends, to medical and health-care workers, to employees and other work colleagues, and for insurance purposes etc (*ibid*.). Disclosure decisions are most often motivated by the need to access medical, financial, material, emotional, spiritual or social support. At the same time, disclosure can serve a psychological function through alleviating stress and helping individuals cope with their HIV positive diagnosis (Schmidt and Goggin 2002; Kalichman *et al* 2003). However, accessing this support may come at a cost with potential exposure to stigmatising attitudes, ideas, beliefs and actions (Greene *et al* 2003, Petronio 2002).

In the case of public disclosure of one's positive HIV status, rather different motivations are evident. The rationale for disclosure behind the *Longlife* AIDS-art advocacy intervention was the belief that it contributed to a public health agenda by putting a "human face" on the AIDS statistics. Participants thus believed (and were encouraged to believe) that by telling "their stories" publicly, they would be supporting prevention, education, treatment and care efforts. However, the private cost of public disclosure is increased vulnerability to stigmatising attitudes, as they are not just dealing with significant others, but the wider community. This paper examines the under-researched issue of public disclosure and its relationship to personal lived experience.

HIV/AIDS stigma and public disclosure

The AIDS-related stigma literature in South Africa often cites anecdotal accounts of people who have disclosed their HIV-positive status publicly and have consequently experienced some form of HIV/AIDS stigma. The most prominent of these stories are: Gugu Dlamini who was stoned to death by her community for disclosing publicly (*Sunday Times* South Africa, December 27, 1998), Nkosi Johnson who was not allowed to attend a specific school (*Mail & Guardian*, June

2, 2001), Lorna Mlofane who was gang-raped and then murdered when she disclosed her status to her attackers, and Mpho Motloung who was murdered with her family by her husband who then placed a sign on her that read “HIV Positive Aids”. The stories are broadcast publicly through the media and they highlight some of the very negative social contexts faced by people living with HIV in South Africa. Even though many people infected with HIV live in supportive environments, such stories are likely to instil fear when being diagnosed HIV positive. This fear is one of the more important reasons limiting people’s willingness to disclose publicly and privately (Greene *et al* 2003, Paxton 2002). These stories are especially relevant for this research as they are stories about ‘public’ disclosure. People choosing to disclose publicly have to consider not only the potential risks in their personal lives such as rejection or ostracism, but also possibly fatal consequences.

Why then is public disclosure deemed desirable?

The answer lies in the widespread acceptance that there needs to be a **G**reater **I**nvolvement of **P**eople **L**iving with or **A**ffected by **A**IDS (GIPA) in their own struggle for human rights, treatment, care and support (UNAIDS 1999). GIPA is a concept that refers to the recognition that people infected or affected by HIV/AIDS make important contributions in the response to the epidemic, and involves creating a space in society for their participation in all spheres of that response (*ibid.*).

The difficulty of disclosure is a serious potential barrier to the greater involvement of people living with AIDS due to the consequent social risks. Hence, the implication is that if public disclosure by the rare few results in more people disclosing their status to others, more progress with a GIPA agenda will be achieved.

A more in-depth look at HIV/AIDS stigma sheds some light on the problems associated with disclosure. Four types of stigma can be identified from the HIV-positive person’s perspective:

1. self-stigma,
2. perceived stigma,
3. courtesy-stigma,
4. expressed-stigma (Deacon 2004, Maughn-Brown 2004).

Self-stigma manifests as self-blame and self-depreciation. Perceived-stigma manifests in the fear of being identified as being HIV positive due to the possible negative consequences. Courtesy-stigma is directed towards family members and other affected individuals. Expressed stigma manifests in actual stigmatising attitudes, ideas and beliefs that might translate into actions (expressed stigma is sometimes known as enacted stigma) (*ibid.*). In many studies of disclosure, the anticipation of negative reactions (perceived stigma) prevents disclosure (Chandra *et al* 2003, Greene *et al* 2003, Schmidt and Goggin 2002).

There are two large-scale quantitative studies that look at HIV/AIDS stigma in South Africa, that is, the Nelson Mandela/HSRC national survey and the Cape Area Panel Study (CAPS). Both of these surveys show low levels of stigma in the general population towards people living with HIV/AIDS (PLWHA) (Shisana and Simbayi 2002, Stein 2003, Maughn-Brown 2004). The low to moderate levels of stigma documented in the survey findings do not correlate with extremely high levels of stigma experienced by persons such as Gugu Dlamini, Nkosi Johnson and Lorna Mlofane. Is this because these stories are unrepresentative, or is it because quantitative surveys fail to identify stigma properly? If the latter is the case, then is the greater involvement of people living with AIDS possible in the current social context of HIV/AIDS in sub-Saharan Africa?

Preliminary evidence from an AIDS and Society Research Unit (ASRU) survey on the long-term impact of antiretroviral (ARV) treatment suggests that the picture may be more complex. People are disclosing to their households and are receiving support. Approximately 73% of respondents agreed or strongly agreed that their family members were willing to take care of them when HIV made them sick (n = 79). Furthermore, 72% of respondents disagreed or strongly disagreed with the statement "Family members and friends have treated me badly because I am HIV positive". Yet, 61% of respondents agreed with the statement "People with HIV often get treated unfairly or badly by others." Even though the respondents are not experiencing high levels of stigma, they nevertheless perceive that other people living with HIV are experiencing stigmatising attitudes. The contrast between expressed stigma in the general population and the fearful perceptions about possible stigma on the part of PLWHA is evident also in India (Bharat and Aggleton 1999; Chandra *et al* 2003). Perceived negative reactions discouraged people from being open about their HIV status. The perceptions are fuelled by the potential risk of being identified and labelled as HIV positive when either accessing treatment and support, or providing public-health messages as is the case with GIPA initiatives and the *Longlife* intervention. Similarly, in a five-country diagnostic study, the International HIV/AIDS Alliance reported that one of the main barriers to the involvement of people living with HIV in community based organisations (CBOs) was the fear of stigma and discrimination. However, they noted that those who did become involved had not experienced negative reactions (HIV/AIDS Alliance News 1999).

Methodology

I have been working very closely with the Bambanani Women's Group (BWG) for over two years, first as a working fellow and then as a researcher and coordinator of *Mapping our Lives* outreach project. The BWG work as peer-educators and workshop facilitators in this project. I have been able to observe these women in multiple contexts; from professional related activities, *Mapping our Lives* workshops, in other qualitative and quantitative research projects, as colleagues and as friends. It is important to point out that I have been their supervisor for a substantial period of time, in which I have observed the dynamics of the group as well as the individuals themselves. It is through this position that I have been able to see the effects of the HIV/AIDS 'professional' environment better than most.

My study draws on a series of qualitative interviews and focus group discussions that took place in 2003 and 2004 with the BWG as well as their personal narratives published in *Longlife*. Some of the in-depth interviews and focus group discussions were conducted by Jo Stein[1] and Talia Soskolne[2].

To analyse the qualitative data, I use a combination of thematic analysis, stigma theory and Communication Privacy Management theory (CPM). CPM theory provides us with a core set of concepts through which we can better understand the determinants and consequences of HIV status disclosure (Greene *et al* 2003; Petronio 2002). In terms of public disclosure, CPM theory provides us with an interesting metaphor known as boundary turbulence. Boundary turbulence occurs when there is a loss of control over who has access to the individual's private information. Disclosure in the public domain is a factor that ultimately leads to vulnerability. This vulnerability can be empowering or disempowering. The narratives of the women of the BWG will shed light on these issues.

Longlife: an opportunity for advocacy, research and outreach

In 2002, the AIDS and Society Research Unit (ASRU) at the University of Cape Town (UCT) in conjunction with Medecins Sans Frontiers (MSF) initiated the

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[1] Jo Stein, a research psychologist, was the Principal Scientific Officer at ASRU in 2003.

[2] Talia Soskolne was a post-graduate psychology student employed by ASRU in 2003.

Longlife art and book advocacy intervention. The *Longlife* advocacy[3] project culminated in a book, *Longlife: Positive HIV stories* (2003)[4] by Jonathan Morgan and The Bambanani Women's Group (BWG). The book was launched in December 2003 at an exhibition of "bodymaps", the set of 14 life-size body paintings that are the central artistic theme of the book. Since then, the BWG have presented their bodymaps at lectures, conferences, on radio, in the print media, universities and exhibitions. The bodymaps have been on exhibition in four continents.

From an advocacy perspective, the stories told by these women illustrate the life-changing benefits of ARV treatment. These narratives have the ability to shift the ARV debate out of the economic, structural and clinical spheres, and into the personal sphere of lived experience. The use of narrative combines the fields of psychology and sociology where neither the social nor the individual is given preference. In some ways, the narratives transform a clear advocacy agenda into a story-like form with characters and plots and gives voice to a marginalised group such as the Bambanani Women's Group. Through the use of narrative, these women were able to mount some form of resistance against the dominant discourse of the South African government on ARVs (i.e. that they were unaffordable and possible undesirable).

Such sensitive and intimate narratives are too often over-looked due to 'more pressing' macro socio-economic discussions. This in turn might limit the ability of grass-roots research to provide guidance to interventions. For practitioners in the field of HIV/AIDS, the positive 'survivor' narratives of the BWG show the "potential of the stigmatised person to actively construct a positive identity … as a strength on which public health interventions can be developed" (Soskolne *et al* 2003: 1). In addition, the use of narrative provides a core set of concepts from which new ways of approaching HIV/AIDS can emerge. AIDS activist strategies such as *Longlife* build on these empowering positive identities in order to change the public perception of HIV/AIDS (*ibid*: 1).

Apart from the broader advocacy agenda, the *Longlife* advocacy project created valuable socio-economic benefits for the BWG, including income-generating opportunities, capacity-building and psychosocial support. Income-generating activities have ranged from directly linked initiatives such as profits generated from the sale of the book, profits from the sales of the original artworks for AIDS

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[3] Advocacy can be defined as "A process to bring about change in the attitudes, practices, policies and laws of influential individuals, groups and institutions, carried out by people proposing improvements on behalf of themselves or others" (Cornu and Attawell 2003:8).

[4] Morgan, J. and the Bambanani Women's Group (2003). *Longlife: Positive HIV Stories*, Double Storey Books, Cape Town.

awareness purposes; and payments for exhibition presentations. In terms of capacity-building, the group have received counselling training, training in memory work, treatment literacy and HIV education. Indirectly, the BWG assisted with other research projects looking at different aspects of HIV/AIDS, some have received transcription and translation training, and they have all become full-time fieldworkers in the Centre for Social Science Research at UCT.

However, a qualitative exploration of the processes underpinning their disclosure experiences paints a far more complex picture. This is due to the fact that public HIV-status disclosure is central to the success of an advocacy intervention such as *Longlife* – and public disclosure comes with many risks. These risks include personal, individual and social risks posed by the stigmatisation of people living with HIV/AIDS (Greene *et al* 2003; Petrak *et al* 2001; Chandra *et al* 2003; Arend & Morgan 2003; Petronio 2002; Paxton 2002). The risks are compounded when the disclosure process is undertaken not only for personal reasons, but also in the interests of advocacy and public-health, as in the *Longlife* case.

Longlife AIDS-art Advocacy Project: A History

Early in 2001, Jonathan Morgan and Kylie Thomas (both working in ASRU at the time) facilitated a series of Memory Box workshops in HIV support groups in Khayelitsha. These support groups were coordinated by Red Cross, *Mothers to Mothers to Be* and MSF at the Site C clinic in Khayelitsha. The Memory Box workshops were based on a combination of narrative[5] and art therapy. Workshop participants were taken through a series of exercises through which they made memory books and memory boxes. They were then encouraged to share their life narratives through painting and writing in the memory book, and decorating and preparing their memory box into which they could store valuable objects, photos, messages and historical recollections. Once the books and boxes were completed, the group shared their stories and experiences. These creative products acted as symbolic spaces in which the support-group participants could feel comfortable sharing their life stories and experiences of HIV.

The Memory Box concept was taken from a group of HIV positive mothers in Uganda who used memory boxes and books to disclose their positive status to their families and children. These women were members of the National Community of Women Living with HIV/AIDS in Uganda (NACWOLA) and were at the forefront of mitigating the effects of HIV/AIDS in their country. They

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[5] Narrative therapy was pioneered by Michael White and David Epston. See www.narrativeapproaches.com

made memory boxes in order to create a legacy for their children once they died from AIDS. In the boxes, they put stories about the family, traditions and heritage, audio recordings, birth certificates and other sentimental items. Memory work in the Ugandan context focussed on dealing with loss, bereavement work and succession planning.

This Ugandan approach was and still is very pertinent to many social issues posed by the HIV pandemic and is used by other interventions around Africa such as the Sinomlando Project in Kwazulu-Natal and WOFAK (Women Fighting AIDS in Kenya). However, this approach was developed in an environment where anti-retroviral treatment was just a fantasy, something that people living with HIV could not imagine in the foreseeable future. At the time of writing, the social context of the HIV pandemic is quite different as ARV treatment is now available in the public health-care system.

Even though logistical problems continue to affect the roll-out of ARV treatment, more and more people *are* getting treatment every day especially in Cape Town where ARVs have been available in hospitals since 2001. For this reason, the outreach project changed its strategy and name from Memory Box Project (which signified death) to *Mapping our Lives* (which aims to signify hope) in 2004.

After the initial workshops, Morgan and Thomas selected a group of six HIV-positive, Xhosa speaking African women from the workshops in Khayelitsha and they were trained in Memory Box techniques. Morgan named the group the ‘A-team’. The training aimed to empower the women with relevant workshop facilitation and counselling skills. In a broader light, ASRU aimed to make the Memory Box Project participatory. Prevention, education and support messages hold far more weight when they come from peers (Campbell, 2003; Paxton, 2002).

After five months of training, the A-team began facilitating workshops in support groups. The workshops were funded by each organisation that requested the workshops, and the A-team was paid for their facilitation services. This was in addition to being paid a monthly stipend while training.

The Memory Box Project’s initial aim was to fund the development of self-sustaining collectives who would provide psychosocial support and research services in their respective communities: an interesting mix of capacity-building, empowerment, psychosocial support and income-generation. ASRU envisaged a group of women living with HIV who would function as role-models for ‘positive living’, successful Mother-To-Child Transmission Prevention (MTCTP) treatment and Highly Active Anti-Retroviral Treatment (HAART), and disclosure within their own communities. Approximately half of the A-team: Neliswa, Pumla, Zamela, Nomawabo, Neliswa, Sylvia and Landiswa had already been through the MTCTP programme[6]. The rest of the group, Nosiseko, Zoleka, Monica, Nobantu, Evelyn, Portia and Tandiwe were on HAART.

At that time, in 2001/2002, the South African government and the Treatment Action Campaign (TAC) were in the throes of a larger struggle against the multi-national pharmaceutical companies over access to cheaper generic medicines. The pharmaceutical companies consequently dropped their law suit. However TAC then began fighting *against* the South African government to provide Nevirapine or AZT to pregnant women and rape victims. It was certainly an appropriate time for people living with HIV to be involved in their own struggle for dignity and human rights.

The A-team supported by ASRU was encouraged to share their stories of MTCTP and ARV treatment with other people living with HIV. Evelyn's first baby died from AIDS because she was diagnosed incorrectly; Landiswa's two children are both HIV-negative; Nosiseko was AIDS-sick but went on ARVs and is now healthy and fully employed; Portia's son was born HIV-positive (because she did not receive MTCTP) and died in 2004 when he was 8 years old; Neliswa's little boy is HIV-negative. These are just a few of the sad and uplifting stories of these women (Morgan and the BWG, 2004). These women know what it is like to have the knowledge that you might transmit HIV to your new-born baby. They know what it is like to lose a child because of HIV/AIDS. They have experienced gender violence and powerlessness in their relationships. Their experiences resonate with and give hope to thousands of other women in South Africa.

Practically and conceptually, ASRU's policy was in line with international HIV/AIDS prevention and support models. These models emphasised community empowerment and mobilisation as well as GIPA initiatives (UNAIDS, 1999, Stephens, 2004; Parker, 1996).

ASRU was motivated by the global GIPA trend and the alarming AIDS statistics, and a second A-team was selected from support groups in 2002. They were given the same training as the first group which included counselling and Memory Box workshop facilitation skills. Both the new A-team and the first A-team formed a tight unit comparable to a support group. At this stage in 2002, they gave themselves a name, the BWG, translated as 'holding hands together'. To this day they are extremely close and supportive of each other.

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[6] In 2001, the Western Cape was the only province in South Africa that offered Nevirapine or AZT to decrease the possibility of transmitting HIV to their new born babies through vertical transmission.

From May to July 2002, Jane Solomon, an artist, initiated a body map workshop with the group. The body maps were created over ten morning workshops held at the MSF clinic at the Khayelitsha day hospital in Site B. The participants worked in pairs and traced their bodies onto life-sized sheets of cardboard. According to Solomon, "Body Mapping investigates the world of symbols, self-portraits, anatomical diagrams, colour, decoration, beauty, health, emotions, experience and identity" (*Longlife* exhibition abstract, 2003). The BWG worked as individuals, in pairs and as a group. Sharing, discussion and reflection were integral parts of the workshops. The women painted representations of HIV, the battle between ARVs and HIV, personal symbols of power, scars, stories, and other areas of emotional and physical significance (Vasquez, 2004, Subotsky, 2004).

The bodymaps and memory books acted as psychosocial support tools to elicit narratives of the women's experiences of life and HIV. The narratives were sad, moving and emotional. However, they were also triumphant and hopeful. One listens to such stories and can only marvel at the journey these women have survived: extreme poverty, bereavement, loss, hopelessness, sickness, disease and struggle; then a movement towards survival, hope, 'positive-living', strength and a desire to help others living with HIV.

The bodymaps became the basis for further story-telling, and Morgan and Thomas recorded the narratives. When the documentation was complete, the women were invited to participate in a collaborative AIDS-art advocacy project that was funded by MSF and ASRU. This advocacy project (*Longlife*) aimed to:

1. increase the involvement and inclusion of PLWHA;
2. provide psychosocial support to a group of HIV-positive African women;
3. publicise their successful stories with HAART and MTCTP programmes;
4. contribute to the debate concerning the efficacy of ARV treatment;
5. put a 'human face' to the disastrous AIDS statistics;
6. provide income-generation, capacity building and skills development.

The entire group had experienced some form of ARV treatment by this time. Six had been through MTCTP and seven were on ARV therapy through MSF's pilot ARV programme. In the South African context this group was unique. The vast majority of people living with HIV in South Africa did not have access to treatment. South Africa was in the midst of intense public debate and activism over the provision of ARVs to pregnant women as well as the universal roll-out of ARVs to all who need them in South Africa[7]. The government was arguing that the drugs were toxic and unaffordable. MSF, TAC, ASRU and many other

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[7] See Nattrass 2001, Nattrass and Skordis 2001, Kuhn 2002, Nattrass 2002, Sparks, 2003.

organisations argued that ARVs could save millions of lives, serve AIDS prevention purposes, and mitigate some of the socio-economic effects of the pandemic (Nattrass 2004). The Bambanani Women's Group's success stories needed to be heard to change the perceptions of HIV/AIDS and ARV treatment in South Africa.

ASRU made numerous contributions to the public debates. Professor Nicoli Nattrass, the director of ASRU, was the chief witness in the Treatment Action Campaign's litigation against the South African government to provide ARVs to pregnant women. Numerous researchers have published working papers on ARVs, MTCTP, infant feeding, youth and sexuality etc. Nattrass (2004) published a book advocating for treatment and care from political, ethical and socio-economic perspectives, and ASRU initiated the *Longlife* art and book project and a creative writing competition that resulted in a book by Rasebotsa *et al.* (2004)[8].

The changing dynamics of disclosure as a result of the *Longlife* project

All of the women in the BWG agreed to take part in the *Longlife* project and to make their stories "public". However, the concept of "public" embodies different meanings for different stakeholders involved in this intervention. Each individual in the BWG constructs his/her own meaning of 'public' according to the risks and benefits of disclosing to a particular individual or group. ASRU and MSF have different constructions of 'public' and so do the authors and publishers. The following sections of the paper will focus on the divergent and convergent constructions of 'public' through the words of Bambanani Women's Group.

From the reader's perspective, *Longlife* has a clear advocacy agenda. This is evident from the introduction written by the authors.

> "We **Bambanani women** are making this book because we want to teach people living with HIV. And to also teach those who are not living with it how to survive. And to let people know that we positive people are getting a treatment to help us live longer. We want to tell the whole world that we are many and we are working. We are healthy. Also we want our stories to be published to the other countries. For those who are positive not to lose hope, maybe someday we will get a

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[8] Rasebotsa, N. Samuelson, M. Thomas, K. (Eds). 2004. *Nobody Ever Said AIDS*. Kwela Books, Cape Town.

> cure. We want people outside to know that it is not the end of the world. You can live as many years as you want." (Morgan and the BWG 2003:3)

'Public' seems to be all inclusive according to this introduction. If we unpack their words, it is quite clear that their words form part of an advocacy and activist discourse. However they subscribe not only to an advocacy discourse towards people or groups with more power than themselves as in some definitions of 'advocacy'. They include their HIV-positive peers and others. They want to "teach people living with HIV. And to those who are not living with it how to survive." They want to "tell the whole world" about their stories through publishing "to the other countries." These are *their* words, but they need to be put in context in terms of the *Longlife* project and explored according to their narratives.

The in-depth interviews illustrate that 'public' is in reality not as all inclusive as the entry to *Longlife*. This is as a result of numerous factors. Firstly, the experience of living with HIV is compounded by living in impoverished settings, as women they are expected to carry the burden of care for others, and they are on the receiving end of a patriarchal African society (Soskolne *et al* 2003). Secondly, there is a very real social risk associated with being HIV-positive, as HIV/AIDS is unlike most other diseases in the way that people living with HIV may be the target of discrimination (Herek 2002, Stein 2003, Maughan-Brown 2004, Deacon 2004). Therefore these women are constantly negotiating which 'public' they are disclosing to in order to minimise the associated risks (Greene *et al*. 2003).

Fear and gossip

According to the respondents, living with HIV is difficult whether their status is made public or not. In the focus group discussion, the women expressed their fears of disclosing in their 'community'. These fears were based on a range of experiences that illustrate the connection between their activist and private lives. They feel pressure to disclose as this is part of their professional responsibilities, yet their and others' experiences, present a dilemma: they realise the benefits of disclosure in the activist sense, but also realise the risk of disclosing where they reside.

In the focus group discussion, the question was posed: "Why is it difficult to disclose in the community?" Their responses were based on a loose interpretation of 'community' as referring to both large and small numbers of people e.g.

support groups, workshops, church gatherings, lectures, groups of friends etc. However, in general, ‘community’ was constructed as the particular ‘neighbourhood’ in which the respondents lived.

Interestingly, their interpretation of ‘community’ symbolised the dilemma between their activist and private lives. Because they interpreted ‘community’ as ‘neighbourhood’ rather than public gatherings, they offered personal stories relating to disclosure and the consequences thereof in the private domain rather than the professional. According to Neliswa and Nomawabo, this was justified as they attributed their identification as ‘HIV positive’ in the ‘community’ as a result of being identified through their work in support groups or by people who know others in the support groups.

> … It is very hard to disclose in the community because even though she has not told them anything, whenever she passes to her neighbours or somebody like that […] she gets like consciousness, guilty consciousness that maybe they are talking about her. (Zamela translated by Neliswa)
>
> So I told myself to that area where I am staying now, I am not going to disclose to them because they are very curious. They want to know what is going on in your house so that they can talk bad things outside about yourself. (Neliswa)
>
> The other reason why it is hard to disclose to the community ….Maybe you will decide to disclose to the neighbours, ne. There are big mamas there that know your mama. They gossip … they are witches; they practice witchcraft and all this things, ne. And you just go and say this, I am HIV positive …. They say bad things and all things like you are sleeping around and all those things, you know. I think the best thing for you to disclose is like to disclose like maybe in a group of people like maybe say five. People like you think they will really need to know the information, you just tell them that. If they spread it, it is up to them. (Nosiseko)

The experiences resulting from being identified as HIV positive showed that ‘gossip’ is the most common and hurtful form of stigmatising behaviour. In a casual conversation with Neliswa and Nomawabo, I asked what ‘gossip’ meant to them as ‘gossip’ had been mentioned many times in the interviews. They explained enthusiastically that ‘gossip’ meant being spoken about behind their backs and being called prostitutes or “loose” women.

In addition to being stigmatised by HIV negative people in their communities, Neliswa and Nomawabo expressed the notion that other HIV positive people gossip about them. According to these women, other HIV positive people gossip in order to hide their own positive HIV status and therefore defend themselves against gossip. Because the BWG are “earning money” and “wearing nice clothes,” they think that this particular group are acting out jealousy rather than stigma according to the general discrimination-based definition.

Stigmatising attitudes and behaviour (such as those described above) need to be analysed carefully. Stigmatising attitudes come in many guises, and have a wide range of determinants (Maughan Brown 2004). In a survey conducted by the CSSR, AIDS-related stigma was identified and probed from four different angles: stigmatising behaviour, symbolic stigma (stigma based on moral judgements), instrumental stigma (stigma based on fear of infection/contagion), and resource-related stigma (stigma due to resource constraints). This survey found that symbolic stigma was the most common form of stigmatising attitude (Maughan Brown 2004).

Similarly, the personal stories from the BWG correlate with the forms of stigma described above as well as the survey findings. Their personal stories often contain references to the connection between being HIV-positive and being called promiscuous or “loose women” by people in their neighbourhoods. This is clearly a form of symbolic stigma (stigma based on moral judgements). In addition, they refer to jealousy as a determinate of stigmatising attitudes (resource-based stigma).

Avoiding stigmatising attitudes and behaviour such as gossip, while still being able to contribute to the ‘struggle’, is an integral part of the life strategies of the BWG. As mentioned previously, Neliswa and Nomawabo pointed out that they and the other women from the BWG are identified as ‘HIV positive’ from their work in support groups. This is an example of private boundary turbulence resulting from professional actions. Stories such as this seem to lead the women to employ strategies that limit possible negative consequences caused by public disclosure.

> But I disclose to the other [people] like in Gugulethu, Nyanga, Eastern Cape, those people they don’t know me and uh the other day, the exhibition day, I was on the TV, on ETV. But the people didn’t realise that I was HIV positive because I was talking [as] the counsellor …. Yes, like a counsellor. (Neliswa)

Neliswa reconciles the fact that she has not disclosed in her neighbourhood, by contributing to the struggle against HIV/AIDS in other ways. She uses her knowledge of HIV/AIDS, not only as an HIV positive person but also as a counsellor. By acting as a counsellor, she is able to decrease the possibility of gossip and other negative repercussions in her private life. Neliswa is able to devise solutions which determine her identity in a particular situation

Creating barriers to identification

The *Longlife* project team were sensitive to the risks involved in disclosure and were therefore willing to ensure that the needs of the different members of the BWG were met as well as possible. Each person in the group was at different stages of disclosure throughout the project[9]. At the time of the book launch and exhibition, the majority of the women requested that ASRU tape over their surnames on their body maps, or digitally removed the surnames from the prints. Four of the thirteen have first-names and surnames, while nine have only a first name. Nosiseko, Landiswa, Zoleka and Portia did not mind having their surnames in the book or on their bodymaps as they were totally open with their status.

It was perfectly acceptable that some of the group members did not want their full names to be made public. Because of the public nature of the project, they did not have total control over who would see the bodymap exhibitions or who would read the book. Covering one's identity could be viewed as symbolic of the social context of HIV, in which stigma is seen to prevent people from disclosing as they risk the negative consequences stated previously (Greene *et al* 2003; Petrak *et al* 2001; Chandra *et al* 2003; Arend & Morgan 2003; Petronio 2002; Lee 2003; Serovich 2000; Schmidt and Goggin 2002). The individuals are not always willing to risk boundary turbulence where their private information about their HIV status is not in their control.

According to CPM theory, the tension regarding control over disclosure is caused by the individual's or group's need to decrease the probability of encountering boundary turbulence. They are not only concerned with themselves, but the effect of boundary turbulence on their loved ones (a fear of courtesy stigma).

> You know, if they can throw stones on you, you don't worry about that. But I can't disclose to them because I am worried about my family. I did disclose to them and they gave me a support. But I don't want the other people can throw stones to my family… (Sylvia)

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[9] There are 14 bodymaps in the *Longlife* exhibition set. Only 13 bodymaps and their corresponding narratives feature in the book as Nobantu found employment elsewhere while the book was developed.

This is understandable considering the fear of identification within their own communities that many of the group expressed in both individual interviews and focus groups.

> Uh the feeling of disclosing to the community (3), you give yourself a lot of stress. Because if you walk, come out of your gate and you walk out in the street, you see the people making some funny jokes. So that thing can hurt you because you disclosed to them now they got stigma on you now. (Neliswa)

The dynamics of this situation are valuable as they provide us with an insight of the kind of disjuncture between the different types of disclosure based on perceived definitions of community and family, and advocacy, spatial, racial and physical boundaries. Walker and Gilbert (2002) argue that race, gender and poverty are significant determinants of the vulnerability of African women to HIV/AIDS. *Longlife* embodies these issues. Sylvia tells her story of being attacked and stabbed for fifty cents by three men while walking from the taxi rank. Others speak of tremendous loss of family members to violence and poverty. These narratives provide us with a basis from which we can begin to understand how a group of South African black women living in an impoverished setting navigate between their everyday identity and their HIV-positive diagnoses.

By opting for only their first names and in some cases an alias for the book and bodymaps, the women were protecting their identity to some extent. Interestingly, the book and the bodymaps provided incredibly detailed information regarding the individual's life histories, families, dates and places of birth, education etc. If somebody really wanted to discover the owner of the bodymap or narrative, it would be possible.

However, all of the women feel relatively safe behind the barriers to their identities. Perhaps this reflects their confidence in the fact that they did not believe anybody they knew would actually read the book. As mentioned previously, four of the women did not mind having their surnames in the book or on their bodymaps, as they were more open with their status than the others. Since the launch of the book and exhibitions, many of the women have opted to take the tape covering their surnames off their bodymaps and reveal their full identity. This is as a result of their disclosure to certain significant others, as in the case of Neliswa who disclosed to her family for the first time in December 2003, four years after her diagnosis, and Sylvia who just felt that it was time that she did not mind who knew her status (she had just started ARVs). For others, it might be due to the fact that their social situations have improved and are therefore in a more empowered position in their personal lives.

Disjuncture between 'partial' and 'full' disclosure

The disjuncture between 'partial' and 'full' disclosure is an issue amongst the group. Although the group is generally pro-disclosure, they are divided according to their individual needs concerning disclosure and living with HIV in general. Landiswa is particularly opinionated with regards to the connection between access to ARVs and disclosure. This is one of the main reasons why Jonathan Morgan employed her to be the A-team coordinator in 2003. At a Memory book and photographic exhibition at the Oliver Thambo Recreation Hall in Khayelitsha, Landiswa told Morgan that she did not understand why the people in the photographs were hiding their faces. She said that they were the lucky ones who were accessing treatment and should therefore showcase the positive life-changing benefits of ARVs to all who denied this at the time.

> …. I hate when people hide, hiding themselves, because they are the ones who are fortunate. Very few people [who are HIV-positive and are on treatment] are getting treatment in Khayelitsha, more especially in Khayelitsha, because of the limited resources from MSF. But at least they are lucky enough to receive medication. So at least they should stand around to be an example to those who … are going to start treatment. Because I think they can be better counsellors for those who are starting treatment. But I don't know how they [the rest of the A-team and others on treatment] see it… Then say if I was taking for example ARVs, I will say that I am getting ARVs from MSF and I am healthy. They look to me and see that I am healthy; they will know for sure that the treatment is working, unlike what was being said for more than three years, the drugs were toxic. So at least people, even if they are not getting treatment, they will know that I can be HIV-positive, but I can not get treatment, but I can be healthy, if I look after myself. (Landiswa)

Landiswa's words resonate with only a small part of the group. Landiswa and Nosiseko feel that the majority of people living with HIV need to move from 'partial' to 'full' disclosure once they get access to treatment in order to show the life-changing benefits of treatment. Nosiseko explained to Susan Sontag that the ARV treatment "had given her wings to her future," and she is constantly promoting ARVs to people living with HIV and to those interested in the social challenges posed by HIV/AIDS. Landiswa is not on ARV treatment as her health does not require it, but she has been on MTCTP. These two women, specifically Landiswa, are the strongest activists in the group in terms of their willingness to disclose openly in most public gatherings. Landiswa's strong activism can be seen through her participation in the TAC's civil disobedience campaign that aimed to encourage and force the South African government to commit to and speed up the roll-out of ARVs to all South Africans who need them.

Landiswa and Nosiseko were chosen most often to speak about *Longlife* in the different media because of their 'openness' and activism. Even though some of the other women are not willing to take activism to such levels, the entire group agreed that this type of activism was necessary in the South African context. And all of the women are activists to some extent. They all wear MSF and TAC t-shirts, attend TAC and MSF rallies and meetings, give presentations about HIV/AIDS, and are all motivated to facilitate workshops.

A most interesting way of telling the story of the conflicts these women face, particularly in the context of the *Longlife* project, is through looking at to whom the women choose to disclose and their corresponding disclosure strategies. The recipients of their disclosure messages can be seen as the different types of audiences at the numerous presentations, exhibitions, lectures, in their household, at workshops and other gatherings. For example, Neliswa has no problem discussing her HIV status and her life story when talking to audiences from outside South Africa and outside Khayelitsha. She is an excellent facilitator of workshops, she has given numerous lectures at universities and conferences throughout South Africa and has disclosed to most of her family in the Eastern Cape. But, she has not disclosed to her long-term boyfriend, to certain other members of her household and she will not go on South African television. In terms of her household, she had only disclosed to her HIV-positive brother and her sister at the end of 2003, however when she visited the Eastern Cape in December 2003, she disclosed to the majority of her household that she thought would accept her status. Whenever Neliswa has disclosed in the past, she has always received positive support for her decision. Similarly, Landiswa has spoken about her HIV status to countless audiences, but had not disclosed her status to her boyfriend, and she did not feel that it was necessary considering she was using condoms, as is the case with some of the others in the group.

Different media as different publics

The group realises *Longlife*'s needs and mediates these needs with their own. For example, the group has presented their bodymaps at numerous exhibitions in Cape Town, Durban, Johannesburg, New York and London; some of the women gave presentations at the *Sex and Secrecy* conference in Johannesburg in 2003, at the *HIVAN Artists Action Around AIDS* workshop, at the *Women, Gender and HIV* conference at UCT, at multiple university undergraduate and postgraduate lectures, and of course in countless therapeutic workshops in HIV and non-HIV support groups. Radio and print media interview requests are accepted, as the risk of identification is low. According to Nomawabo:

> I am not worrying because to the radio, but I am worried to go to talk to the TV. Everybody must look at me on the TV. But if I am going to talk to the radio I am not worried because those people didn’t see me. (Nomawabo)

This feeling is generally shared by the group. Therefore requests for television appearances in South Africa are usually turned down, in order that the women do not create the opportunity to be recognised publicly. ASRU receives countless requests by filmmakers that want to make documentaries on the outreach intervention and the *Longlife* book. If the filmmaker can prove that the audience is exclusively foreign to South Africa, certain members of the group may accept an interview.

If we look at the risks and benefits of public disclosure, as in the different media discussed above, the benefits of this kind of disclosure relate to the professional aspect of the women’s lives, while the risks affect the personal lives of the women. However, locating where the particular risks and benefits are is complex, as benefits in the professional realm are essentially benefits in the personal realm too. Public discussions on the book and the bodymaps increase exposure to *Longlife* and therefore increase demand for the book and bodymap workshops. In some ways, public disclosure can be equated with advertising and marketing of the BWG as HIV/AIDS peer-education experts. From a purely financial perspective, the increased demand would mean increased financial returns for their peer-education and advocacy services. Neliswa, Landiswa and Nosiseko are examples of this, as demand for their expertise has meant that they have travelled around South Africa, to Europe and the USA, and many organisations have requested their participation in other HIV/AIDS interventions.

In some ways, the more risk they take by not being concerned with the disclosure audiences, the more return they will get. The more they disclose, the higher the chance will be of being identified as HIV positive in their communities. And clearly, these risks will only increase their employment opportunities within the HIV/AIDS field. This results in each member of the BWG having a personal strategy that minimises the risks and maximises potential benefits. The interviews highlighted one such strategy where ‘partial’ and ’full’ disclosure are mediated by out-group perceptions or social distance. Concerns over who to disclose to and when to disclose are determined to some extent by racial stereotypes.

> What I was saying is that our community, the black community is different from the white community and the coloured community. We will find it easier to disclose to white people, to a white community. It is easy, you don't feel afraid because those people they wont feel jealousy for you or get you down. They will always pick you up, saying good things about you. You must be strong, you know, those things. As well as coloured community. But if you come to the black community, if the people that know you, gossip and jealousy and like getting you down, you know. They not like giving you support, you understand. So sometimes it is easy to, maybe also if there is mixed, mixture of communities, like white, coloured and black together, that is also easy for you to disclose…. (Nosiseko)

Nosiseko mentions race as a determinant of the disclosure choice, although it may well be that social distance is the actual main determinant. Similarly, Neliswa stated previously that she did not mind disclosing in Nyanga, Gugulethu and Masiphumelele which are predominantly black areas. In a similar study of in Masiphumelele[10], respondents viewed Khayelitsha as a place of support and openness, where disclosure was easy and common-place (Kahn 2004). Interestingly, in terms of disclosure and physical location, it seems that many of the women believe that disclosure is easier in most other areas, regardless of where they actually live. The interviews show quite clearly that public disclosure can happen in any community other than their own community.

CPM theory can help unpack the mechanisms used by the women to minimise the risks at 'home'. According to CPM theory, individuals believe that all private information belongs to them (Greene *et al* 2003, Petronio 2002). They therefore want to control this information as revealing such information might make them vulnerable. The individual therefore sets up boundaries that control the flow of information to others, and they develop a set of rules that control their privacy boundaries. People that were previously included in their privacy boundaries such as community and household members are now placed outside their privacy boundaries as they pose the most immediate threat. The interview transcripts corroborate this theory. The disclosure experiences displayed well-planned and thought-out boundary management in both their private and professional lives. The group felt positive about disclosure to out-groups (outside their boundaries) and were weary of disclosure within their communities and households.

The majority of the BWG argue that non-black racial groups are more understanding and they therefore feel comfortable disclosing in other communities where the majority of the people are White or Coloured.

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[10] Masiphumelele is an urban, informal settlement on the outskirts of Cape Town.

Interestingly in both the HSRC/Nelson Mandela Study and the Cape Area Panel Study, the data showed that the Coloured population and White populations were more stigmatising than Africans (Shisana and Simbayi 2003, Maughn-Brown 2004). This may add to the argument that HIV/AIDS stigma is different from other forms of discrimination, not only in the theoretical sense, but in the way stigma is perceived and internalised by PLWA.

Disclosure as a performance: the professional, AIDS-advocate and activist

The successful marketing and promotion of the project as a research, outreach and advocacy intervention has relied on the type of ‘anonymous’ or ‘partial’ disclosure discussed previously. Even though most of the participants were only ‘partially’ public with their HIV status, the project was typically viewed as a success. The project team was convinced that ‘partial’ disclosure, within the context of a sympathetic and relatively safe environment, was empowering to the women involved, and moreover, that putting a human “face” (in the form of drawings and stories) to this pandemic would be extremely valuable. Clearly, the bodymaps and the *Longlife* book provide HIV positive people with a safe way to present themselves publicly thereby fulfilling both their needs to educate others and stand as role models to their peers, in addition to concretising ASRU’s advocacy role.

The A-team has succeeded in marketing themselves as activists, but equally importantly, as counsellors and care-givers. As the *Mapping our Lives* coordinator, I have been able to see them in action on many occasions. Workshop participants are encouraged by their enthusiasm and motivation. They are asked questions relating to ARVs, employment, nutrition, disclosure, opportunistic infections etc. Their treatment literacy knowledge and first-hand experiences have been particularly important, as at the time of writing this paper, many people are still waiting for ARV treatment. The workshop participants know that they will receive ARV treatment in the near future, and therefore want to know what benefits treatment will give. In other cases, people who are just beginning ARV treatment want to know what the future holds for them. Some questions that were asked are: Has the pain gone away? How long have you been on treatment? Why can you can you only start treatment when your CD4 is less than 200? These questions can only be answered meaningfully if the workshop facilitator is comfortable with disclosing their HIV status and in support groups, they are. Leaders in organisations that have benefited from *Mapping our Lives* workshops and presentations have reported that the A-team and their comfort with their HIV status were invaluable to their support groups and training sessions.

Zoleka described how it is easier to disclose now because she has known her HIV status for some time now (four years), and has been working in an HIV context. She acknowledges that disclosure is easier in support groups as *Mapping our Lives* workshops are run for people living with HIV.

> It is easier because you know … whenever you go to a support group to like run a workshop, you meet with the people who are HIV positive. So … it's easy because you are talking about this [HIV] every time, every time. So I am getting used to it. I mean, yes, it's easy. (Zoleka)

Zoleka discusses the ease of disclosure within the HIV context, although she omits the fact that running a successful workshop is to a degree dependant on the level of comfort with her HIV status. She touches on the frequency of discussions of HIV-related issues. Inevitably disclosure would become easier considering the frequency that they are talking about it in workshops, especially since one's 'professional' life consumes so much time. Disclosure in the support groups is essential for the success of the intervention as well as the individuals in the A-team as professionals. This would inevitably affect their views on disclosure specifically in this context.

As can be seen, the professional-private dialectic is most notably influenced by the work the group does for ASRU. The understanding of disclosure amongst this group of women in particular needs to be contextualised within the context of the women's outreach activities, and the broader political-economy of HIV/AIDS and South Africa in general. ASRU bases the majority of their outreach activities in the low-income areas of the Cape Flats. From a socio-economic perspective, ASRU is in a position of power in terms of being able to encourage individuals to become public HIV figures given the attraction of well-paid work of this type.

> I think for me last year it was because every time lets say they [ASRU] send these people to me, they will say but that's what we pay you, that's part of the reason why you are being paid this salary [to run workshops or do presentations]. So in a way I did not have a choice. And I don't really; I am not saying that was bad but sometimes … I really did not want to talk about like anything, like I didn't want to say anything about HIV, but like I felt the pressure. Even though nobody was serious about me because they assumed because I was [connected] to TAC, they assumed that I did not have a problem [to disclose]. But sometimes I had a problem. Sometimes talking about HIV, it's too much for me, and you don't really want to talk about it. But I did not have a choice, they were paying my salary. (Landiswa)

ASRU may be criticised for putting these women at risk through a public project such as *Longlife* with the attraction of a decent income. However, Meursing (1997) and Paxton (2002) argue that a reasonable wage is essential to recognise the important contributions people living with HIV can make to prevention, education and care interventions. This income may increase self-esteem for those with fragile income security and may contribute to household income as well as keeping these educators alive and healthy for longer so that they can remain positive and contributing members of their respective communities.

A few of the women consciously realise the need for the activist paradigm while they are unsure how ready they are to fulfil this role. Their professional and activist lives inevitably influence how they think and feel in their private lives. This must be a difficulty faced by all HIV positive people who work is this "industry".

> Sometimes the pressure you get, and we needed to promote the book, so I was there to do that. But at the end of the day I felt like that was not necessary for me. I was not the only one to disclose, I was not the only one to go there on public to the different newspapers and disclose and at the end of the day I ended up being angry but I dealt with it because at the end of the day you have to pass any stage in your life. (Landiswa)

In terms of disclosure, the group is divided along numerous lines. Many of the themes that were discussed in the individual interviews and especially the focus groups caused intense debate and argument amongst the group. As can be seen in the quote above, some of the women are more open regarding their HIV status than others. They therefore feel they are carrying the responsibility of the success of the intervention more than others. However, the issues run deeper than the success of the intervention. The group disagrees on major issues such as disclosure in sexual relationships, disclosure in the community and disclosure in the interests of public health.

Landiswa (in the quote above) touches on the problem of disclosure as an activist activity whereby it loses its personal meaning and becomes a performance. Disclosure in this way begins to interfere with the individual's identity, as their positive HIV status is the primary aspect of their shared life story. All other aspects of their identity become eclipsed. This particular woman indicates that the other members of the group, because of their unwillingness to disclose fully, are not living up to the expectations of the team as a whole, and she is carrying the burden of disclosure. In their professional capacity, the A-team is to a certain extent on parade and this might have an effect on the group dynamic.

Private disclosure in the interests of 'public' health: helping others

Despite differences in opinion amongst the group, the general consensus is that disclosure is beneficial not only for them as individuals, but also for their society as a whole. Some women use disclosure not necessarily to decrease transmission of HIV, but rather as a way of alleviating others' stress and helping people cope with their positive HIV diagnosis. They use their training as counsellors and peer-educators in conjunction with their personal HIV experience to educate others about voluntary counselling and testing (VCT) and other relevant issues.

> I want to help another people because outside in our communities there are so many people dying because of AIDS, because of HIV. Because they are hiding something. Then if you [are] hiding something then it is going to distress you everyday because you feel alone. Maybe its few who have got this virus ….outside there are so many people have got this virus. Maybe I can help you to go to support group because on Thursdays and Fridays I go to support group. (Nomawabo)

> … there was a young lady who was HIV positive, but she didn't want to come out with her status. Maybe this week she will come to this clinic in Site B, she will change names, next month she will go to Site C, that month she will go to Harare, changing names. But when Nobantu sit down with her and talk to her then she felt good, then she come out with her status. (Nobantu, translated by Neliswa)

In the cases above, disclosure takes on a very personal meaning. For particular individuals, these women are making a positive impact and it is empowering for all parties involved. It may be that this is actually having more of an impact on society than a book like *Longlife*. *Longlife* is written in English and is relatively expensive, while here the women are paying special attention to individuals and small groups of people. They are helping them cope with the stress of living with HIV through personal attention, which I am sure has a marked effect on the recipients of their advice.

Portia is generally more open with her status than the rest of the group. She claims not to care about who knows her HIV status. Due to this attitude, she aims to help others in her area that are living with the virus, and to stand as a positive role model, encouraging openness and being able to talk freely with those who need help because she is open with her status. Like other women in the group she talks about serving as a role model for the effectiveness of treatment.

> In my community I think they will be more supportive because they always see me as somebody who can help them within the community if they see somebody sick or if they know somebody who looks just like with HIV, they will want me to come talk to her. I think in a way I have helped because when I came there they already knew about my status so I became somebody that they can look after and they can relate to. Like if somebody is sick, they can relate that person to me, irrespective of the age. (Portia)

However, according to Landiswa, Portia’s attitude to disclosure is unique. Landiswa accuses the majority of the group of not disclosing in their own communities whilst being happy to disclose everywhere else. She has a problem with this because, due to the nature of their work, they would be better examples in the community if they disclosed. She looks at disclosure from a public health perspective, where disclosing to one’s household, friends or the community, is not only about one’s physical and psychological well-being, but rather intended to get loved ones to take precautions in the future so that they do not get infected. Her stance on many HIV-related issues, specifically ARV treatment and disclosure, is strongly influenced by her activist paradigm. She has been an activist for the TAC since before she was diagnosed with HIV, after which her involvement increased substantially.

Even though most of the women are pro-disclosure, there is a small group that is actually open with their status within and outside their areas. Amongst the group, they are unambiguous about their views regarding public disclosure from a public health perspective. Those who are most active believe that the women in the group should disclose in order to change the way the government has projected the ARV debate. If people are healthy and are lucky enough to get ARVs, they should show this, so everybody can see ARVs actually work and are not toxic. The geographical location of the women’s homes and the majority of their work, places Khayelitsha in focus. Accordingly, some of the BWG women believe it is important for people to disclose in Khayelitsha because MSF and South Africa’s first pilot ARV treatment project are in Khayelitsha.

Conclusion

This paper has highlighted many of the complex issues involved in the disclosure of one’s HIV positive diagnosis to the “public”. Disclosure is important for people living with HIV as it is the most necessary component of accessing adequate treatment and support. When somebody reaches the stage when they need do decide whether to disclose or not, and to whom, they are faced with the fear of negative reactions posed by the stigmatisation of people living with HIV. The complexity is exacerbated when the individual is disclosing not only for personal gain, but publicly in the interests of public-health, HIV-prevention, education, treatment and support.

Disclosure of a positive HIV diagnosis, especially in the public domain is mediated by the possible risks and benefits involved. The interviews from the BWG and data from many other studies show that perceived negative reactions or perceived stigma is potentially the most significant barrier to disclosure (Chandra *et al* 2003; Greene and Serovich 1996, Bharat and Aggleton 1999).

The BWG has made a significant contribution to the struggle of people living with HIV to get access to life-saving ARV treatment through the AIDS-art advocacy intervention entitled *Longlife*. They used their life narratives to show that treatment had changed their lives and that arguments regarding unaffordability and toxicity of ARV medicines were clouding the moral issue that all people including the poor have basic human rights and deserve access to health care. The project fed into the broader ARV advocacy agenda which already called on the government to rollout treatment. In addition to the public/political agenda, they were able to advise others living with HIV about ‘taking hold’ of their lives, and looking towards a ‘positive’ future.

Because of the activist and advocacy agenda of *Longlife*, the intervention’s marketing, exposure and main message were based on a need for some form of public disclosure. The women from the group defined ‘public’ subjectively and dynamically in order to minimise the risks on their personal lives. The in-depth interviews illustrated the way that specific ‘publics’ were perceived according to spatial and racial considerations. The women in general felt more comfortable disclosing outside their communities within Khayelitsha, and in other areas where the possibility of identification was minimal. This data highlighted the perceptions of social distance as mediating the public disclosure process. In this way, they could still be contributing to the struggle against HIV/AIDS, but live a normal life when they go home.

Their ‘public’ contributions were not only defined by disclosing and discussing their HIV status to large numbers of people. Through the training, capacity building and empowerment provided by ASRU at the University of Cape Town, they have become ‘experts’ on HIV and are able to give personal advice and counselling to many people in their communities. In this way, disclosure has become more meaningful now than the “performance” disclosure in front of TV cameras, art exhibitions etc. which occurred at the height of the *Longlife* project.

This paper has shown that careful consideration needs to go into interventions whose policy framework is based on the GIPA concept (HIV/AIDS Alliance, 1998; UNAIDS, 1999). Disclosure is incredibly complex and organisations that include people living with HIV need these individuals or groups to be constant contributors to processes and outcomes. People living with HIV should make their own choices where they want to disclose and who they want to disclose to. Interventions should use research stating careful guidelines for the inclusion and greater involvement of people living with HIV.

Interventions are not just a site for internal evaluation, but rather sites of rich data that can inform academic and intervention debate as well as future research directions. The narratives of the BWG provide researchers with an in-depth understanding of living and coping with the social and individual challenges posed by HIV/AIDS. If we are to address HIV/AIDS-stigma through the involvement of PLWHA, researchers need to use this understanding to determine the nature, perceptions and effects of HIV/AIDS-stigma and its resulting consequences for HIV-status disclosure.

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The CSSR is an umbrella organisation comprising five units:

The Aids and Society Research Unit (ASRU) supports quantitative and qualitative research into the social and economic impact of the HIV pandemic in Southern Africa. Focus areas include: the economics of reducing mother to child transmission of HIV, the impact of HIV on firms and households; and psychological aspects of HIV infection and prevention. ASRU operates an outreach programme in Khayelitsha (the Memory Box Project) which provides training and counselling for HIV positive people

The Data First Resource Unit ('Data First') provides training and resources for research. Its main functions are: 1) to provide access to digital data resources and specialised published material; 2) to facilitate the collection, exchange and use of data sets on a collaborative basis; 3) to provide basic and advanced training in data analysis; 4) the ongoing development of a web site to disseminate data and research output.

The Democracy in Africa Research Unit (DARU) supports students and scholars who conduct systematic research in the following three areas: 1) public opinion and political culture in Africa and its role in democratisation and consolidation; 2) elections and voting in Africa; and 3) the impact of the HIV/AIDS pandemic on democratisation in Southern Africa. DARU has developed close working relationships with projects such as the Afrobarometer (a cross national survey of public opinion in fifteen African countries), the Comparative National Elections Project, and the Health Economics and AIDS Research Unit at the University of Natal.

The Social Surveys Unit (SSU) promotes critical analysis of the methodology, ethics and results of South African social science research. One core activity is the Cape Area Panel Study of young adults in Cape Town. This study follows 4800 young people as they move from school into the labour market and adulthood. The SSU is also planning a survey for 2004 on aspects of social capital, crime, and attitudes toward inequality.

The Southern Africa Labour and Development Research Unit (SALDRU) was established in 1975 as part of the School of Economics and joined the CSSR in 2002. SALDRU conducted the first national household survey in 1993 (the Project for Statistics on Living Standards and Development). More recently, SALDRU ran the Langeberg Integrated Family survey (1999) and the Khayelitsha/Mitchell's Plain Survey (2000). Current projects include research on public works programmes, poverty and inequality.