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**BODY PERCEPTIONS OF HIV AND
AIDS: THE MEMORY BOX PROJECT**

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AIDS: THE MEMORY BOX PROJECT**

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Body Perceptions of HIV and AIDS: The Memory Box Project

Abstract

In South Africa, nearly fifteen per cent of the population is HIV positive and its impacts go beyond the disease itself. Biomedical treatment can be effective in reducing the physical effects of the disease, but does not deal with these wider issues, or with the body perceptions of the clients. This leads to their disempowerment, which is evident in the dealings that clients have with medical practitioners and the high levels of non-adherence to treatment. Re-appropriation of their bodies - through the use of tools, including body mapping and personal narratives – can offer a way of empowering those who have been stigmatised and isolated. This paper explores these issues through the body perceptions of and responses to HIV and AIDS of a group of women from Khayelitsha, near Cape Town. This work is based mainly on testimonies of participants in the Memory Box Project run by the AIDS and Society Research Unit at the University of Cape Town. These testimonies were collected by Jonathan Morgan (the Director of the Memory Box Project) and Kylie Thomas. A group of poor HIV positive women show how this process can work but also, how the effects may in the long run, be ambiguous.

Introduction

‘The whole has broken up into numerous parts whose interrelation in whole can no longer be ascertained. This is the essence of alienation, whether the part under examination is man, his activity, his product or his ideas. The same separation and distortion is evident in each’. Ollman interpreting Marx (in Martin 1987: 18).

South Africa has a population of 39.8 million people. Of these, 4.2 million are living with HIV in a context of poverty or extreme poverty¹. South Africa, a country with a traumatic past of injustice and violence and still working on a social reconciliation process, has to face yet another dramatic challenge, AIDS.

However, for many South Africans, HIV and AIDS is just another problem that, together with poverty, discrimination and violence, is endured on a daily basis.

¹ Population Resource Centre (2001).

People who can afford it, go to hospital regularly to be tested, but do not stop living in constant fear of infection. Others just do not want to know or have more immediate things to worry about, such as hunger and violence.

Biomedical approaches to dealing with HIV and AIDS in South Africa rarely take this complexity into account. Furthermore, the philosophy and power relations that underlie the biomedical approach can often lead to disempowerment and undermine the effectiveness of the treatment itself. This is compounded by the complexity of the medical information available, the many apparent contradictions and the confusion that this generates. Therefore, it is important to analyse and understand how methods that enable those affected to make sense of the disease and treatment offered can improve its effectiveness and empower them in a way that allows taking control of their bodies and their response to their situation.

In this paper, I look at women's perceptions of HIV and AIDS, how they understand and interpret the disease in their bodies, how society influences these perceptions and how people both deal with and respond to them. I base this analysis on the testimonies of those involved with the Memory Box Project in Khayelitsha, South Africa and consider how this project has influenced the participants' behaviour and enhanced their empowerment. I analyse the process undertaken by those involved in the project and how an understanding of the disease and its impacts can enable people to have greater control over the illness and improve both their physical and psychological recovery, and their reintegration into society.

The testimonies are the result of interviews, presentations of the women's body maps, transcripts of meetings, anecdotes and the reflections of the people involved in the project. This material was put together by the Memory Box Project team for dissemination purposes and documentation of the pandemic, in a book published under the title *Long Life: Positive HIV Stories* and in the document *Hope Zones and the Pandemic's Lullaby* by Morgan (2002).

For the purposes of my analysis, I have selected twelve narratives to analyse in detail. In the account that follows, I draw directly on the women's narratives², preserving their voices as personal fingerprints in this work to give credit to their knowledge and participation, but changing their names to protect their right to confidentiality.

² I have used the transcript in their original form without changing any apparent spelling or grammatical errors.

In Section 1, I provide an overview of the Memory Box Project and its participants with the aim of providing context to the testimonies and analysis that follows. In Section 2, I look at how these participants have been treated by medical practitioners, the philosophy underlying this treatment and its impact. In particular, I emphasise the disempowerment and sense of fragmentation that occurs as a result of the unidirectional flow of information and prescription from doctor to client³. Nevertheless, this flow is not entirely one-way and many clients do not follow the prescriptions of medical practitioners, reinterpreting the often confusing and inadequate information provided, in order to understand it in their own terms as highlighted in Section 3.

This reinterpretation, however, does not necessarily enable these women to gain control over the disease and its treatment as it cannot overcome the sense of fragmentation, isolation and stigmatisation caused by HIV and AIDS, poverty and the attitudes of health workers towards people with HIV and AIDS, especially poor women. Nor can it address the wider aspects of inequality that prevail in society and, as a result, a more comprehensive and multi-faceted form of empowerment is necessary. In Section 4, I look at how reaffirming people's perceptions of their bodies and disease can offer this possibility and I assess how the use of techniques such as body mapping and personal narratives used in the Memory Box has enabled this process to take place for the project participants. Finally, in Section 5, I attempt to draw some lessons from this experience, looking in particular at the implications for the effectiveness of biomedical approaches to treatment, the potential for scaling-up and replication and the wider impacts on the lives of the participants. I conclude by identifying some key areas for further research that can build on the initial results presented here.

1. The Memory Box Project

Khayelitsha, which means “our new home”, is the country's second largest township after Soweto and one of the fastest growing, created in 1983 by the apartheid government. It is estimated that between 600,000 and 1.5 million people live in Khayelitsha (Dyantyi and Frater 1996).

There are no street names in Khayelitsha; they are known only as Site B, Site C and so on. The huge area is divided into 26 districts. The outskirts of the town are covered with tiny shacks made of timber and sheet metal and generally in

³ I use the term client in the general sense as an alternative to the term ‘patient’, to refer to the people who use the medical services and have an illness.

pitiful condition. Some parts of the town lack basic services including electricity and/or water. Half the population is unemployed⁴.

Although all children are given primary education at local schools, secondary and university level education are extremely expensive. In both cases, the conditions of schools and the facilities available are poor: while attendance rates are reasonably high the quality of education is deficient and many women, in particular, drop out due to pregnancy and/or illness (Dyantyi and Frater 1996).

Khayelitsha is part of a pilot project – jointly operated by the Provincial Government of the Western Cape, Municipal Health Services of Khayelitsha and Medecins Sans Frontieres (MSF) - offering access to antiretroviral treatment (Morgan, n.d.: 16). The *Treatment Action Campaign* (TAC), a grassroots social movement, which advocates for access to treatment for all, has also played a major role in Khayelitsha. Led by Zackie Achmat, the campaign focuses on multi-national pharmaceutical corporations and the South African government. By working in partnership, MSF and TAC have gained access to generic Anti-retroviral (ARVs) and other drugs,⁵ cutting the cost of treatment from \$4.55 per-patient per-day to \$1.55 (MSF 2003). Even though this is a significant reduction, for poor people – and poor women in particular – treatment is still often unaffordable.

Medecins Sans Frontieres (MSF) runs two major projects: treating HIV positive adults with anti-retroviral therapy (ARVs); and prevention of Mother-To-Child-Transmission. The government clinics also run a *Mother-To-Child-Transmission Prevention Programme*, where women are tested for HIV, receive the AZT drug to prevent transmission to their babies during birth, and are given free formula milk for their children. The women who joined the Memory Box Project came from these programmes.

In April 2001, the University of Cape Town set up the Memory Box Project, as part of its Aids and Society Research Unit. The core team is made up of a multidisciplinary group whose objective has been to use memory boxes⁶ as a therapeutic intervention. They assist people living with HIV and AIDS in narrating their life-stories in transformative ways. Their work is based on participatory action research driven by the needs and hopes of HIV affected communities and, in conjunction with Medicins Sans Frontieres and the

⁴ Statistics South Africa, October Household Survey, 1999. in Dyantyi and Frater (1996).

⁵ MSF began to import generic ARVs from Brazil in late 2001 and more recently from India.

⁶ They have developed a Memory Box manual that shows how to make a box or a book out of recycled and other materials, how to open comfortable spaces for creative story telling and other techniques for support (http://web.uct.ac.za/depts/cssr/asru_pubs.html).

Treatment Action Campaign, has attempted to work with people living with HIV and AIDS in a collaborative and integrated manner.

The idea of creating memory boxes was initially applied in Uganda, where a group of HIV positive women filled boxes with pictures, photographs and their own intimate stories about their lives and memories. With these materials, children with HIV positive parents had the opportunity to have and keep details about their parents' and their own lives. This has shown to be a caring and sensitive way to help them deal with fear and confusion as well as the grief at the death of their parents (Morgan 2002), in particular because it is transmitted in a language that is meaningful to those affected.

The project team started by developing links with HIV affected communities around Cape Town and piloting a basic working model for memory box workshops in the area of Khayelitsha. Memory books and boxes were offered to people in the final stages of the disease, as a way of supporting and counselling to help them come to terms with the psychological and practical issues surrounding death. One of the tools they used was the preparation of personal legacies for their families and close relatives. Another was the creation of 'body maps' by participants to explore their experiences of HIV and how they understand and cope with living with the virus.

The technique of body mapping was introduced to the Memory Box Project in 2001 with the Khayelitsha group. The women not only drew their bodies, but also embarked on a journey of empowerment with a group identity and re-appropriation of their selves through the understanding of their status.

For Cornwall, the technique of drawing body maps, offers a way of "opening up and entering people's experiences of living in their bodies. Bridging gaps between knowledge, experiences and expectations, between the biological and the social..." (In: Cornwall and Welbourn 2002:230). She also explores the way biomedical messages are translated into local languages and how these messages can change the sense and the way in which the body is perceived. She explains how local health practitioners replicate biomedical knowledge and in the translation can treat local knowledge as ignorance. Body mapping and similar tools open up the possibilities for local people to understand biomedical messages and also make sense of how they perceive their bodies. As such, they enable people to reclaim their own bodies from under the 'gaze' and intervention of medical science, fill them with their own understandings and make them their own again.

The women taking part in the Memory Box Project are or were in stage 4 of HIV⁷ and receive antiretroviral treatment and disability grants of R620⁸. They come from harsh backgrounds where domestic and social violence are common. Some dropped out of school as a result of their early pregnancies and/or illnesses. They generally got pregnant by their boyfriends who also infected them with HIV. For example, Hasana who is now 31 years was 4 years when her father died and lived with her uncle. When she was 18 years she got pregnant. The same year her boyfriend was stabbed and died. At the end of the year 2000, she was diagnosed first with TB and then with HIV.

Sara's life has been surrounded by tragedy. Brought up in Cross Roads in the middle of the anti-apartheid protests, at 5 she found herself running for her life when white soldiers opened fire on a bunch of school children, one hitting her 7/8-year-old cousin and killing him. At 17, she was stabbed by a group of men who tried to steal her family's money. In 1998, her sister killed herself by drinking paraffin and setting herself alight. In 2000, she also got pregnant and tested HIV positive.

Lindiwe lived with an abusive uncle and an alcoholic mother. She had to look after her mother who was very ill because of her HIV positive status; she soon passed away due to opportunistic diseases. When Lindiwe found out that she was HIV positive, her 27-year-old boyfriend was already dying of HIV-related illnesses at the hospital.

Nwabisa lived with her grandmother and aunt and as a girl, had to work hard for her living. She moved to Cape Town with her mother and stepfather, who used to beat her and tried to rape her. This situation forced her to move in with her boyfriend. She married another man and, when she got pregnant, discovered she was HIV positive.

Mondisa, Siyabonga, Fezeke, Nombeko, Issa, Nobonzi, Sipliwo and the others share similar stories of child abuse, domestic violence, poverty, young

⁷ The World Health Organisation (WHO) has a method of describing people with HIV as being in different stages of infection. This is known as the WHO staging system for HIV infection and disease and is based on the different clinical symptoms the client may present. A person is considered to be in Stage 4 when the immune system is so damaged that the illnesses that he/she presents are very severe, leading to a diagnosis of AIDS. However, there is great controversy surrounding this diagnosis, as people can be very ill but not be diagnosed as having AIDS.

⁸ MSF were instrumental in extending general disability grants to people living with AIDS. They also helped people in Khayelitsha gain access to these grants, although the government now refuses to pay the poverty grant of R100 per person (Morgan, n.d.: 52).

pregnancies and the shocking news that they are one more person infected with HIV.

1.1 Working with personal narratives

One of the innovations of the Memory Box Project has been the introduction of body maps, drawing and painting in workshops with the women. The workshops consist of participants drawing their body maps on large pieces of cardboard. On these maps, people are asked to mark sites on their bodies showing wounds, marks or special memories as a part of their bodies' records through which they are able to narrate their personal stories. Each body map is drawn with the help of one or more participants, and then each person works on their own picture. When the pictures are finished, they present their work to the others and explain the meaning of what they have drawn. These tools have helped participants to express emotions and represent perceptions of the virus in an alternative way and have been particularly valuable for the information they have generated.

According to Skultans (2000), through personal narratives, the individual creates both self-awareness and awareness of others, recognising and identifying vulnerabilities and strengths in each other: "...the point of narratives is not to mirror the world but to enable human beings to achieve an identity" (2000:9). The project aims to reaffirm the knowledge of people living with HIV and AIDS by recording and disseminating their testimonies and stories, a process in which people become the researchers and story tellers of their own lives and thereby achieve a positive identity. These narratives of HIV and AIDS contribute to the documentation of the pandemic from the client's perspective, opening fresh ways of understanding the disease.

The project also involves what is known as the A Team, which is formed by HIV positive community-based trainers⁹ who represent a vivid example of successful reintegration into society. Their main job is to relate their stories and experiences of living with the virus how they got access to treatment and adhere to it, the importance of testing and counselling, and how this vital information can save their lives, to the community and other groups.

Before assessing the role and contribution of the Memory Box Project and in order to recognise the impact it has had on the women participating in it, it is necessary to understand the prevailing methods and conventional knowledge

⁹ The A Team train the community in Memory Box work and offer other services such as group therapy, group facilitation, education and prevention, etc.

used in dealing with AIDS in South Africa and, in particular, in Khayelitsha. It is to this that we now turn.

2. HIV and AIDS, biomedicine and fragmented bodies

No one can but applaud the success of the TAC and MSF in their struggle to get treatment for all. It is clear that increasing access to treatment and medicine saves lives and improves the quality of life. It also contributes to the empowerment of the population and reinforces their human rights. However, an approach focussed on macro-level biomedical interventions alone¹⁰ can risk ignoring and dismissing the client's personal perceptions, and reinforcing existing social inequalities. This is the way in which biomedicine is generally practised (Synnott, 1993).

Biomedicine has traditionally dealt with disease in a scientific/logical way, following a positivist tradition of cause and effect, not only looking at the individual as separate from society but also treating the illnesses in isolation from the rest of the body. The Cartesian tradition that regards the body as a machine that can be fixed by mechanical manipulation also leads to the idea of the body being fragmented. This allows the body to be divided into organs and illness that can be treated separately from each other and the body as a whole (Martin, 1987; Synnott, 1993). This constrains open interaction between the client and the doctor and the client's active role in treating the illness, leaving almost all decisions to be taken by the doctor or other health workers, especially in medical institutions such as hospitals, clinics and health centres. A power relation is established in which the health workers seem to control all decision making over the life and even death of the individual (Kleinman 1988; Martin 1987).

In the following testimony¹¹, Mandisa a 28-year-old woman describes her early experience with doctors and nurses when she went to hospital:

‘I went to... a private doctor and he told me my blood was dirty. There were signs of TB and he checked my chest and I kept going there but I was not getting better. The pills Dr Patel gave me to clean my blood and for my chest didn't help me and they cost a lot. If I walked for just five

¹⁰ This is not the case with MSF or TAC but more general in health care systems.

¹¹ The testimonies used in this paper are the original unedited texts drawn from the source material of Morgan and the Bambanani Women's Group (2003).

minutes, I would get so tired. I was scared I was going to get these discharges and get sick and be in pain. The problem was that at the clinic they never tested me for HIV but they told me my blood is clean and they were giving me treatment only for the STD. I went back to the clinic all the time because it didn't go away. Then I just gave up going to the clinic and I just stayed at home with that sickness in me...'

Mandisa is scared of the pain she can feel because of the symptoms she is getting. Health workers gave her no explanation of the disease or of the side effects the medicines can cause. In other words, they did not give her an informed response that would allow her to understand her status and therefore make a decision about her treatment. Mandisa's psychological state is ignored and her shame and fears are feelings she has to deal with on her own, leaving her with a sense of inadequacy and frustration. As a result, she stops going to the clinic. A similar experience of uninformed response is narrated in Sara's testimony:

'They test me the results came out HIV positive but I didn't understand. I just take it easy. The counsellor didn't say what she means by positive. Then she asked me lots of questions and explained some more. Then I understand. It was a bad day. I got a shock. I say to her I've got only one boyfriend. Why I've got so much HIV? That day I was thinking about death for a long time'.

The little information Sara has about HIV makes her wonder why she is so ill. She has heard that having lots of partners is risky, but though she had only one partner, she got infected and became very ill.

Nwabisa is HIV positive. When she was pregnant she was told about the risk of transmitting the virus to her baby by breastfeeding. When the baby was born, however, she had little control over her choice not to breastfeed him.

'...it was not so easy for me not to breastfeed ... When I went to Site B clinic to get my baby, maybe they saw to my folder that I'm HIV positive then the nurses forced me to get out of the bed then they forced me to breastfeed my child. I was confused because when they diagnosed my status they told me at the clinic that I will get the free formulas and I mustn't breastfeed my child because I can then give my child my HIV. It was very sad to me but I listened to those nurses and just did that'.

These testimonies are of situations where the client cannot make sense of the information they are given. These situations result in feelings of frustration and hopelessness for these women. For example, for Mandisa, her encounters with

doctors made her feel confused and scared, she reacted by not going back to the clinic, a place where she was not receiving any help. Similarly for Sara, confusion due to lack of information about the disease and how it affects the client end in insecurity and depression, when she starts thinking about death. Finally for Nwabisa, the advice she was given was not easy for her to understand or make sense of. She is scared of affecting her child's health, but feels she is not in control of the situation.

Biomedicine is based upon a long accumulated tradition of knowledge and power, which is maintained by the scientific community through the development and use of an exclusive language (Foucault, 1997; Kleinman, 1995). Biomedical language and technology can only be understood after years of study and practice. This serves to reinforce and perpetuate the power of the practitioner and attenuate and diminish the active role of the client. This means that the client has to trust the practitioner's knowledge and submit to his/her expertise. This also means that the client who does not have access to specialised biomedical language may feel alienated and fragmented, both psychologically and physically. This adds more insecurity and fear to the already difficult situation the client is experiencing with the illness itself.

Mandisa describes how she felt when she became very ill, and her testimony shows that even if the treatment she is receiving may be curing her TB, she still needs to come to terms with her new situation:

‘...When I got very sick, sick, sick. I had things like ringworms in my skin – it looked like a brown map. My skin was very light before but it slowly started to get a grey colour, then it went darker and darker. The doctors never told me why it happened. I thought maybe it's the HIV but I don't know how it works. It's all over my body. It started to itch when I was eating the TB tablets and I told the nurses... They said it was nothing. I finished the pills and my skin started to go dry and I started to itch and then my skin started to peel and peel like a snake. Then as I scratched, it turned dark. It was terrible and I felt like going underground. When *I looked at myself in the mirror I felt it's not me*. I couldn't go outside. If I went to the clinic I just took an early taxi and came back again and went inside the house and stayed in bed and watched TV. I thought to myself there's no future, I'm going to die. I have done nothing. No children. My family is still poor. The only things I want to get rid of are these marks. I don't know where can I go to just be me. The ARVs have helped a lot but this skin is taking time to get better’.

Mandisa is living in a physical body she does not recognise as hers; she cannot identify with it any longer. In other words, she feels separated from her body:

her person and body have been fragmented by the physical symptoms of the disease and by the approach to treatment taken by the practitioners she has seen. The physical changes are so dramatic that her idea of dying becomes overwhelming and affects her self-esteem. As a result, she feels shame and isolates herself by hiding from society.

With chronic diseases such as HIV and AIDS, the person's perceptions of self as well as of time and space change. For example actions we take for granted such as getting dressed, brushing our teeth, showering, or moving from A to B take longer due to weakness or pain. Sense of space also changes, since very ill people can hardly move from their beds. For Kleinman (1988), the possibility of bodily deterioration follows from the loss of control over the body and its natural functions; emotionally the self is also disintegrated. This makes them more dependent and therefore vulnerable to others. In this interview with a neighbour (Nonhlanhla) of a woman with AIDS called Nomble, her attitude of concern gets confused with a tint of blame:

'The first problem with this family is that no one is working. There are three children who must go to school but there is no one to pay their fees and uniform. There is no food and no clothes, her mum is not working and there is no father.' "She is sick, she has no power, if she takes food she vomits, her leg is not able to travel, she has AIDS" "Yes, she has HIV," she says laughing'.

'She always say that she is going to die of hunger and is angry that her children are going to become orphans. Because of her weakness Nomble always need members of family to carry her from the house to the toilet. She always vomits and cries for pain and says that it can be better if she can die now. There is confusion. She acts as if she is mad and is always short tempered. It will be better Mpho [her daughter] doesn't know about her mother's sickness'.

According to Martin (1989), dividing the 'self' can sometimes serve as a defence mechanism for the individual; presenting one's whole self to society can increase vulnerability. Nomble, for instance, acts in a confused manner as a way of rejecting reality and relinquishing responsibility for her situation. "When external circumstances deny dignity to a person, letting only a proportion of the self outside to be degraded is a form of self preservation" (1989:18). For example, one of the ways of coping with tragedy is laughter; as Alice Welbourn, Chair of *The International Community of Women with HIV/AIDS* (ICW) has

stated, we have to understand and accept laughter as a legitimate way to cope with daily tragedy¹².

An approach to treating HIV and AIDS based on biomedicine alone can reinforce existing power structures, in particular the hierarchical relationship between health practitioners and their clients. Much of the power of the practitioner resides in his/her use of specialised medical language and the fact that clients feel disempowered if they cannot communicate in this language. While clients may have confidence in health workers, their lack of understanding of the messages delivered often causes confusion about whether to follow the practitioner's advice or not. Together with the ravages of the disease itself, this increases the sense of isolation and fragmentation in the client and the likelihood that they will not adhere to the treatment.

People's perceptions of self are altered, their senses of time and space change and their view of and relationship with society are modified, both as way of making sense of their situation and as a form of self-protection. These changes in perceptions are fundamental to understanding people's responses to HIV and AIDS, in particular how they interpret and reinterpret the disease and the treatment prescribed. In Section 3, we analyse these responses in more detail.

3. Living with AIDS: Biomedical Control and people's responses

Lawton (2000) argues that rather than being passive recipients of medical assistance, clients actively shape their own social reality and influence their environment. Foucault (1997), in turn, regards medical science as one of the fundamental elements in producing knowledge for the control and regulation of the individual in society. He also opens a window for understanding power relations; all power creates its own counter-power. Returning to the doctor-client relationship, no matter how powerless the client, s/he will find his/her own ways of understanding and interpreting biomedical language. While clients often try to understand their complaints and cures by explaining them in their own words, acts or attitudes, this reinterpretation could also sometimes be an expression of resistance. Illustrating this, in the following testimony Mandisa is confused by the health practitioner's questions and then makes her own interpretation, when her lungs are being cleaned, by using her local word for medicine, "*muti*":

¹² This was a comment by Alice Welbourn after a meeting in May 2003 in which an African health worker said that probably 99% of the people she knew got AIDS laughed, and then she apologised for it.

‘I went to the hospital and they asked me a lot of questions in connection with HIV and AIDS. I was tired and I felt like saying, “get away from me, you’re making me crazy.” They said they wanted to check my blood but I kept saying no. “We must know what is wrong with you,” they said so I said ok.

They took three bottles and they drew blood from between my ribs and said my lungs were full of water. So they poured some brown muti inside. They then sent a lady to tell me I am HIV positive. I don’t know if she was a counsellor or what, but she gave me a book of stories of people living with HIV. I didn’t read the book. I just put it there. I thought, soeka, I’m not going to read this. This lady asked me who I was going to tell. I told her I was going to tell my parents but I didn’t’.

She takes an attitude of disinterest in the information she is given and tells the counsellor that she is going to disclose her status to her parents, although she did not. The assumption that the client accepts the doctors’ decisions without question has been contested in many studies (Abel and Browner 1998; Cornwall and Welbourn 2002; Csordas 1994; Farmer 1992; Kleinman 1998; Lock and Kaufert 1998; Martin 1987, 1994). Individuals have their own way of interpreting their complaints as well as how to deal with them. For example, Abel and Browner (1998) explain how pregnant women negotiate a variety of different ‘knowledge’, including knowledge based on experience and biomedicine. Intuition, personal experiences and physical sensations are strong determinants in women’s decisions, beyond what the doctor suggests.

Women follow their instincts and what they have learnt from experience. This gives them enough information and knowledge to feel confident in using other forms of treatment, knowing for themselves rather than being told by doctor. In the following testimony, Siyabonga visits the doctor at the clinic, but she also decides to visit her traditional doctor to complement her treatment:

‘When I look at this picture I can see what I am and what I’m not and what I believe in and what I don’t. I can see that my finger is missing and that I have HIV but also that I’m strong, very strong. See that aloe. Aloe is a medicine. It is bitter but it helps a lot. It chase things out, even HIV things it can settle down. I find aloes growing near Langa station and I go there sometimes to pick them. I just squeeze out the green water and dry out the leaf in the sun and then cook it and drink the water again. This was taught to me by Dr Mwamba who is a Venda doctor as well as a western doctor. I believe in both medicines because sometimes the pills don’t help you so I use aloes and garlic and African potato’.

Following Landy (1977), conventional medicine is here combined with traditional practices in a translation and reinterpretation of illness and cures in society. However, he continues, people are not only looking for cures or prevention to their illnesses, but also for sense in their lives and their place in society. This can be expressed through the language that is used to portray bodily experiences. In the extract from Hasana's testimony below, her choice of words and images is evocative:

‘Lamacokoza

These big dots on my painting represent the rash that I had. These small dots the blue ones and these red lines represent how is HIV in me. It's when again I started to be sick. HIV it's like one word but lots of sickness. I represent HIV like a storm. If a storm comes there is heavy rain, thunder, storms, lightning and wind. I represent HIV like that. I did have rash, thrush, falling of hair, coughing and headaches...’

‘The blue dots represent the thrush that comes all the way from my throat. Small red lines is the way I feel my body pains and the big red one is the mark where I have a caesarian for my baby... Kule ndawondaye ndasinkwa nrandi fumana umntwana... This place is where they cut me when I give birth to my baby’.

By using metaphors that are closely related to her life experience, those of others and a shared language, Hasana is trying to establish her place in society. She uses her own words to make sense of her situation because biomedical language and the power relations in the health system can be an obstacle for her.

3.1 The social aspect of disease

The hierarchical doctor-client relation, however, is not only the result of the biomedical construction but is also influenced by other power structures - economic, political and social - that add other complex and interdependent elements to the interactions of individuals and how they negotiate these interactions (Farmer, 1992; Kleinman, 1995) Therefore focussing on the biomedical side of the HIV treatment alone is too narrow. All the women's stories share the fear, blame, shame and frustration that HIV and AIDS cause, but also the hunger, insecurity, and unemployment caused by poverty.

Living with HIV is not just hard because of the attitudes of health workers and the power of biomedicine to discriminate and neglect clients, it is hard because many of those living with the virus in South Africa are also black and poor and

discriminated against in other areas of their lives. This makes the suffering associated with AIDS that much harder to bear, let alone the difficulties of affording medicines, healthy food and the other things that the biomedical establishment might suggest that people with the virus need in order to be able to survive.

In the following testimony¹³, a grandmother is bringing up her grandchildren in extremely difficult conditions. She has to cope not only with the anguish of seeing her family getting ill and dying of HIV and AIDS- related illnesses but also with the pain of witnessing her grandchildren's hunger. The burden of extreme poverty and social neglect did not allow her to look after her ill, now dead, family members. This situation frustrates and scares her, especially when she thinks about her grandchildren. Sipliwo lives in a corrugated iron shack with sixteen other members of her family:

‘Six are my own grandchildren,... three are my children, four are relatives, this one with the white face is my aunt's daughter she came to see those who are sick. Not only my son Hlanhla is in hospital, also my other child. I have no money to visit them. Life here is very painful. Before Hlanhla went to hospital, he had spots on his body and holes on his other thigh. When he feels the pain he screams so loud and sometimes cry. I don't know what is killing my son. He never talks to me about his ways. Clinics must have helping medicine for those who are sick. Doctors must please tell us as parents about our children's health. We gave birth to these children and suddenly we have no right of knowing why they are so sick...the parents [of her grandchildren]... died of this disease because the doctors said there is no drug for it. I am suffering and starving because of this disease. Where did this animal (AIDS) come from? The nation is finished now about this animal’.

Although there are government programmes to subsidise food, not everybody qualifies to receive them. For this family, the result is simply hunger and misery. These feelings are entangled with those of sadness and frustration at disease and death that come out as a desperate but vain call for help to the authorities, either government or doctors. Sipliwo is a poor old woman, yet it is remarkable to observe how much she knows. She develops strategies for obtaining everything to which she is legally entitled, but when this is insufficient she resorts to other means:

¹³ Note that this testimony is extracted from Morgan (2002).

‘The electricity we take for nothing. The Home Based Care gives us food parcel but it is not enough for this big family. When I cook I boil the water with no mielie meal till the children fall asleep. They just listen to the water [boiling] and wait and they fall asleep’.

Due to our natural survival instinct, it is not easy for any human being to deal with issues related to death, especially that of people close to us. In South Africa, this is a reality people face every day¹⁴. Vuyi is Phemba’s mother; the frustration and anger she feels comes out as putting blame on the ill, which seems to be a frequent response of those who look after the chronically ill in difficult conditions:

‘I am Vuyi. Phemba, my son has been sick for twelve months and he can’t do anything, I have to take him to the toilet, even wash him... He don't have a wife or children, his wife left him because of cheating, she was looking after someone else. When it looked to her like he had HIV she vanished with their three children... The hospital is too far and even if they admit him he comes back sick. His brother found him lying in the bed full of sores. He coughs blood that makes him difficult to eat and we have to force him to eat or he will die. The government give him no disability. What will be the benefits of this research? ... How are we going to receive these benefits by post or you will it come physically? It would have been better if Phemba was working before he got sick. I have never benefited from this child. I remember when he was young I make it a point I did everything for him as he was the first son but now its over I have to do it again’.

(“Through the wall I hear Phemba crying...”) (Morgan: 17, 18.)

However, it is notable that her response goes beyond the biological and encompasses both her experience of disease and of poverty; in other words, the biomedical is merged with the social perception. People affected by HIV and AIDS can suffer from low self esteem as well as feelings of loss of control over their bodies, particularly when treatment and counselling are not available. This adds to the disintegration and loss of perceptions of the self that lead to feelings of self-stigma, isolation and dependency. For Kleinman (1988), this is the direct result of how society perceives the disease and the individual. In a clinic or hospital environment, there is little or no decision power over treatment or how their bodies will be managed. The result of this practitioner/client power

¹⁴ “In 2001, 2.3 million Sub-Saharan Africans died of AIDS-related causes, compared with 2.2 million deaths in 1999. This was 80 percent of all the AIDS-related deaths in the world. AIDS is by far the leading cause of death in Africa, causing one of every five deaths on the sub-continent. In South Africa, it is estimated that in 2000, HIV/AIDS was the cause of 40 percent of adult deaths aged 15-49 and 25 percent of all deaths. Projections show that without treatment to prevent AIDS, the number of AIDS-related deaths will increase to more than double the number of deaths from all other causes within the next ten years.” (Population Resource Centre 2001).

relationship will create and/or reinforce meanings about HIV and AIDS. These meanings are closely related to social perceptions of the subject and how this relates to the rest of society.

In the following case, a woman named Busi relates her experience and we can see the similarities in the language to that used by Fezeke when referring to personal pain and suffering, and how the opportunity is taken to make demands to the government. In this case, when she describes her husband and son's disease, she seems to know more about the symptoms, perhaps due to her experience of caring for them at home:

‘Both my husband and my son have died, they were both breadwinners. My son was sick and now he's dead. How can we find some help in our situation from the government? I am also ill, my chest, shoulders, back. I am very poor because no one is taking care of me. My son left me his daughter. I applied for a grant of R100 and I am getting it now. I want to build house, this is a shack, not a house... Zuzu my son who died, his chest, was very sick and thin, his eyes and his hair changed, his hair became like yours and his feet were very painful, his skin was woma woma bumpa, when you touch it, it becomes painful dry and thin, if you touch him you hear the bones...Zuzu's wife, she died vomiting. Their daughter is five years now’.

The cause of her son's death on his death certificate was respiratory failure due to TB, and her husband's *lobere pneumonia*. For Busi, showing her suffering in an open way gives her the right to demand from the government. Her priority is her grandchild and obtaining as much help as she can from the government is one of her strategies for reintegration into society. Furthermore, the losses of her husband and son also have double meaning; not only the loss of loved ones but also of the household's main breadwinners.

The combination of HIV and AIDS and the disempowerment caused by the power relations inherent in conventional biomedical practice, inconsistent messages and specialised medical language leaves many women confused and with a feeling of powerlessness. This is echoed in the words of Sara on receiving the news that she was HIV-positive in Section 2 - “They test me the results came out HIV positive but I didn't understand. I just take it easy. The counsellor didn't say what she means by positive.” – and in the fragmentation felt by Nwabisa and Mandisa. This is exacerbated by the desperate social conditions and power inequalities experienced by poor black women in South Africa.

Indeed, as we have seen, these conditions are not merely a context but an integral part of the women's situations, without which their response to HIV and

AIDS and its treatment cannot be properly addressed. With such pressures and the social power of the biomedical approach, it becomes extremely difficult for them to find their own voices and their own ways of dealing with their dilemmas.

4. Memory Box: The Journey to Empowerment

Before becoming involved in the Memory Box Project, many of the women whose testimonies we have seen felt confused and isolated. This was the consequence of the disempowerment resulting from their relationship with healthcare professionals, of poorly explained treatment, of experiencing HIV and AIDS and of the wider context of inequality, poverty and social violence. This affected their bodily perceptions of HIV, their understanding and interpretation of their situation.

The tools used in the Memory Box Project have helped these women to recover their sense of self and thus respond more positively to the disease. In this Section, I look at this process and its effects on the participants, drawing particular attention to the importance of making sense of body perceptions. In so doing, we see how the women re-appropriated their bodies. In order to understand this, however, we first consider the importance of the body and its different meanings in the literature, focusing in particular on the role of personal narratives and body mapping.

4.1 Bodies, body perception and narratives of the body

There have been many reflections on the body and its meanings in the social sciences. Douglas (1999), for example, distinguishes two bodies - the physical and the social - to explain how the social body constrains the way the physical body is perceived. Scheper-Hughes and Lock (1987) differentiate three bodies: 1) the individual body-self; 2) the body-social and how it relates to society and culture; and 3) the body politic as the instrument of social and political control. O'Neill 1985 (in Synnott 1993) refers to five bodies: the body in relation to the cosmos, the social body, the body politic, the consumer body and the medical body. In each case the body is divided in order to analyse its different roles and meanings.

Borrowing from Bourdieu, Lawton (2000) argues that we are embodied - the way in which people happen to “inhabit” their bodies so that they become

habituated - in multiple ways simultaneously and only from this perspective can we talk about the body as “inhabited”. The notion of multiplicity of bodies, interacting in complex multifaceted societies, influencing one another has affected the way we perceive and inhabit our bodies.

The individual is bombarded with images and messages of healthy, young, beautiful, active bodies, in other words, perfect bodies. The pressure to achieve this ‘perfect body’ is translated into an urge to meet these social demands. At the biomedical level, a healthy body is a perfect body, a body that is kept under control, in the Foucaultian sense (a body that has been completely submitted to the control of the doctor¹⁵). To retain this authority, doctors and medical researchers have to control disease and illness, but also the production of their social meanings. Following Kleinman (1995), socially normative processes are mediated with the biologically normal; these mediations are the epistemological and ontological grounds for understanding health and disease. At a micro level, people suffering from diseases use personal narratives to dialogue between the inner and outer voice, the individual with the social sphere.

Therefore, illness narratives can offer a greater understanding of social values and meanings. Since their narratives originate in the experience, illness narratives represent the perspective and interpretation of that particular individual, although it is also mixed up with other stories and beliefs. Nevertheless, with personal narratives the individual is in charge of the story. For Rapport (2000), personal narratives become the technique through which HIV positive people make sense of experience through symbolic reflection, such as spoken or written language. However, there are experiences that cannot be simply translated into these languages. These experiences are sensed in different ways, for example they can be visual or simply felt, and therefore difficult to express. In these cases, other techniques of communication such as drawing, dancing and music become equally valid forms of expression and cognition. Body mapping has become an alternative way to communicate and express experiences through the development of innovative symbols and abstractions in which reality is perceived and known.

In the Memory Box Project, narratives were used in a range of ways to enable people to express their experiences. Some of the most powerful narratives emerged as women talked about their body maps, drawn to represent their bodily experiences of living with HIV. In the following section, I explore how the Memory Box Project’s workshops worked to create spaces for women to

¹⁵ As Foucault put it himself: “[I]t was no longer the gaze of any observer, but that of a doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention.” In: Shawver, L, 1998.

share and gain confidence in their own knowledge, by sharing images of the body and narratives from their experience.

4.2 Creating a safe space

Memory Box workshops “often begin as a very private and introspective journey but develop into a more public performance of a liberating account of one’s life. The first step in this direction happens within a safe space where participants begin to explore how it feels to have their lives witnessed by considerate, understanding and caring others.” (Morgan, 2000: 28) The group discussions, workshops, exhibitions and other activities are carried out in a ceremonial way. The intention is to create new meanings through powerful rituals so HIV positive people can have a sense of identification and mutual support. For example, when one of the members of the project died, the group overcame their fear by sharing their thoughts and expressing their feelings thus:

‘We sit in a circle, many of us are crying. Lindiwe expresses it’s good to cry and to release the pain and we all cry until Nwabisa says,
“Don’t cry people
God is taking Xoliswa
Xoliswa is not getting any pain
Xoliswa is sleeping
Xoliswa who came to us
Not us who came to Xoliswa.”
Xoliswa always brave, strong and very kind’.

‘We light candles each person a flickering flame burning bright. Kibibi starts to sing from the belly a deep sound moving through the layers and layers of pain and loss, bringing all of us with her towards the freedom of joy. All of a sudden Issa says “ OK Jane let’s start.” and we begin the workshop using visualization to remember ourselves as eight year old girls, holding, sharing, caring, memories of children with so much courage simply to be alive’.

All the participants were asked to trace out their bodies on a huge piece of brown cardboard. On each map, people then marked sites on their bodies where actual wounds and marks held feelings and recorded their stories. Each picture represents a powerful life story and each person becomes a ‘self’ in an ongoing story told to and shared with others. Through the abstraction of their experiences and translation of their perceptions into this symbolic form, they open a window into their intimate selves revealing not only their experiences of a medical condition but also of a social situation.

Lawton (2000) argues that places - such as those where the workshops are carried out - become alternative social spaces in which clients are able to realise and sustain a comparatively stable sense of self and form '*communitas*' (in Stockl, 2002:190). The Memory Box workshops provide this space, where participants can find and identify a comfortable sense of self from which they are able to express their emotions without fear or shame. Here the rehabilitation and reintegration of the person into society becomes possible.

As we remember, Sara has had a traumatic life, brought up in a violent environment at the height of the anti-apartheid protests and running for her life. She witnessed the murder of her young cousin, shot by white soldiers, faced her sister's horrific suicide and experienced the insecurity of everyday violence. All these painful experiences were drawn on her picture in a cathartic recovery process. She painted the HIV in her body and metaphorically compared the disease with a killer animal:

'On my painting I have written, Try to be faithful of course HIV is a killer. I put the light blue color and the white dots (dots) it means now I'm sometimes feeling well because I'm going to the doctor and the doctor looks after me fortunately. White dots means I'm healthy and when I'm standing I look like I'm so happy with my hands up and my feet on the snake'.

'In my opinion the virus look like a snake. You can't see it and it's moving in the secret ways and the dark ways. I make the virus look like that because with AIDS many people are dying and you can't point to the people who have the virus. It's a destroyer like a hurricane that destroys everything on the earth. With the snake if there is a strong wind or storms people wake up to see houses fall down. Inkanyamba, a big snake that lives in the water is moving them [referring to the wind and storm] so our mother's told us. It destroys me but you see I am standing on the snake. This virus is a destroyer but I destroy this virus too... I didn't know I was going to see myself like this'.

Sara's "self" comes into "being" through her explanation of how she perceives the virus. She is surprised by her own strength and the possibility of destroying the disease herself. Her explanations are a mix of her beliefs, her experiences and what she knows about the virus. Now she has a position, she acknowledges the destroying power of the virus but confronts it and feels she can destroy it.

In the next statement, Hasana, by bringing her experience into language in the explanation of her body map, opens up the possibility of self-understanding and

repossessing her body from a stronger, more confident position. It is important to notice how she not only makes sense of the virus and its symptoms, but also of other medical experiences, such as her caesarean. She explains her drawings as follows:

‘These big dots on my painting represent the rash that I had. These small dots the blue ones and these red lines represent how is HIV in me. It’s when again I started to be sick. HIV it’s like one word but lots of sickness. I represent HIV like a storm. If a storm comes there is heavy rain, thunder, storms, lightning and wind. I represent HIV like that. I did have rash, thrush, falling of hair, coughing and headaches... The blue dots represent the thrush that comes all the way from my throat. Small red lines is the way I feel my body pains and the big red one is the mark where I have a caesarian for my baby... My baby didn’t come the right way out, they say it was upside-down. It was in 1990 before there was too much HIV. I didn’t tell my child about my status.’

At this stage, the women express their experiences of the virus openly and use concepts and language that make sense in their own circumstances. At the same time, this information is understood and shared with the group in a non-judgemental way. The women adapt their discourse with what they hear from other women but also from the people working with them in the project. This can be seen in the way Hasana expresses her wishes in a positive possible way. Her attitude towards the disease and towards life in general has changed.

‘About the pot symbol I like to cook. In that pot is the food. I want to dish for everyone who want food. And fire represents me. The way I like people and I have that warmth in my body. My symbol of power I put in my head because the first thing I must do is think before I do anything’.

The safe space they have created in this project allows them to talk openly about intimate issues, although for some women it takes longer to get to this stage. The women who feel more confident find themselves able to disclose their status outside the group, to their families, at work, with friends, and so on. Siyabonga expresses her views in a very powerful and confident way, using a language internalised during the project.

To be given the space to reflect on our own stories is an opportunity to go on a very private journey and create positive change. It is also an opportunity to slowly begin to share our experiences with others.

These personal narratives have emerged from a process in which these women have come to terms with HIV and transformed their relationship with health

workers and with society in general. This new framework is based on their personal ways of arranging and expressing their feelings, reinterpreting them in meaningful ways so they can communicate to others through explanations and sharing. In addition, as part of this process, women share interpretations and meanings associated with the virus and with the treatment they've been receiving, reinterpreting the information which has been given to them not as passive patients but as active participants engaged in making sense of their bodies and their lives. The same process we see in the following testimony where Mandisa explains:

‘On my picture I drew the virus – it’s the small blue dot. The red circles are the ARV’s eating the virus and the virus is going down. The white is my blood. The ARV’s are strong. I have been on ARV’s for five months now. It’s changed a lot since the first month when I took them until now. First I was always getting sick, sick, sick. I went twice in a week to the doctor. Now that I’ve got the ARV’s, the whole month I’m fine. I’m just ok and I only go to the clinic for medication. When I had flu it would stay a long time, but now when I get flu, it goes away quickly. I take a long walk to my clinic every time I go there so I say the ARV’s are working and I’m starting to feel OK now’.

Mandisa’s earlier experiences with health workers were scary, confusing and ultimately alienating. Now she feels in control of her disease and understands how it works; therefore she is confident in her recovery. She knows she can live with the virus and she is feeling better, not only about the disease, but because she is back as a member of society.

The recognition of the importance of both patients’ self-esteem and social empowerment – particularly in decisions over treatment and adherence - is reflected in the approach taken by the three organisations (Memory Box, MSF and TAC) that support these women. For, example, Doctor Herman Reuter, the director of one of the MSF clinics in Khayelitsha, underlines the importance of empowering the clients by providing adequate information and giving them the space to make their own decisions. The doctor becomes an advisor and the client is in control of the situation:

‘We had put the patients in charge of their own health. Most patients know their cell number, or their ID number. But most clinics do not expect their patients to participate in any decisions that are taken at the clinic. To treat people living with HIV successfully we have to provide them with enough information that they can take decisions about their own health’.

However, as mentioned previously, making sense of the physical body, and re-appropriating and inhabiting the body, is not a one-way process. The importance of the social context is fundamental to the empowerment of the self and the two cannot be separated. For the women, the Memory Box Project not only offers them the possibility of understanding and coping with the HIV virus, but has also given them jobs and access to grants, solving the other major problem they suffer, poverty.

The following is a fragment of a discussion about the disability grants the government pays to people infected with stage 4 HIV and how this affects the group:

‘Issa:

-I get the disability grant of R620 per month because I’m HIV positive

Mandisa:

-In order for the AZT to work, we need some good enough nutrition...that is how MSF chose us to get the grant, if you had the grant it meant that you had been very sick but also that you had enough money to afford the right nutrition so the ARVs could work. Now what if they stop the grant, the ARVs won’t work.

Jonathan:

-...a woman I met in Bloemfontein,...said she loves HIV because she and her HIV positive child receive over R1300 a month in grants whereas before she was HIV positive she was unemployed for years and years with no grants and no income.

Mandisa:

- I also love this HIV, before I was sitting at home, no job, no nothing, now everything is lekker. Is that shocking to you Jonathan? Now at least I’m hoping.”

Siyabonga:

- Me also, I was thin. Thin-Thin-Thin and not from HIV, it was before I became infected, ... I was just thin from no job. Now I’m fat because of my grant and my job which is all about HIV.

Sara :

- I can feel I can go everywhere I want to go with this HIV...I can fly and go to the sea and climb a mountain...I mean I can now do the things I used to be afraid of. It help me to see life is precious and how you can’t just live it, you got to plan.

Nobonzi:

- HIV is my friend. With this grant I can now have something. Before only my husband was the only breadwinner, now we combine it and buy some foods and medicines and herbs to boost my immune system. And if

there is some change at the end of the month we build on our home. I feel good that I can contribute also.

Siyabonga:

- Yes HIV do a lot to me, I meet a lot of people, white people who I was scared of, black people from America, not like before, even after Apartheid end, we were living separate, and now we talk about this thing in my blood and also about other things.

Nombeko:

- HIV change my life, it help me see how I can limit some of the things, the wrongdoings, like now I'm sick I'm afraid to go to jail...Before I was a criminal ...[now] I get R1240...R620 for me and another R620 for my son who is also HIV positive...[with that money] I am building my mother's home...'

These women seem empowered by the language they use, particularly when they say things like: "I can go anywhere, I can do everything, I can now do the things I used to be afraid of, seeing that life is precious, everything is lekker". Now that they have access to treatment, they have hope and can plan for the future, they feel they can live with HIV. However, living with HIV needs to be placed in a social context, and for these women in particular, in a social context of poverty and hardship, the disability grants they receive have transformed their lives. For people without the virus, the idea of being infected with HIV is one of the worst things that could happen to them; these women's testimonies, however, put this into sharp relief, and underline that extreme poverty is as much if not more of an ordeal.

Access to ARVs and their experience with the Memory Box has given the women the space to empower themselves not only in a physical but also in a material way by getting greater agency in their relationship with their husbands in the case of Nobonzi, and contributing to the well-being of other family members as in the case of Nombeko. Some who were permanently unemployed are working as part of the A team. Odd as it may seem, being HIV positive has in a way become the means of their empowerment and offered them the opportunity to live in hope rather than despair.

5. Conclusions

Biomedicine is based on a long tradition of treating illness in isolation and, through this process, health workers also end up isolating the client from the rest of society. Biomedical practices produce and reproduce hierarchical relationships - through exclusive language and technological practices - in which

the clients' knowledge and experiences are diminished. Clients, on the other hand, produce their own mechanisms to interpret and appropriate biomedical language. One of the ways they do this is by producing their own language and ways of communicating and explaining their experiences. However, the power of biomedicine and of health workers, and the situations in which people with the virus are in, makes it difficult for them to find their own voices and their own ways of dealing with their dilemmas.

By allowing their voices to be heard and their experiences to be legitimated and given importance in the process of curing an illness, biomedicine can receive an essential input to understanding disease that has been ignored for too long. Clients have an active role, although rarely validated, in the construction of meaning through their personal experiences of pain and disease. This is a basic element that needs to be readdressed in the general politics of how disease, and HIV in particular, is treated and perceived. As Cornwall puts it: "providing this information in ways that make sense of women's own knowledge of their bodies requires an approach that can bridge the gap between biomedical messages, popular knowledge and lived experiences" (Cornwall in Cornwall and Welbourn 2002: 229).

Furthermore, by reclaiming their own bodies through specific facilitating tools, such as body mapping, and filling the pictures they create with their own language and meaning, women were able to gain a sense of greater control over their lives. It is important to recognise the place that people's own bodily knowledge plays in the process of dealing with sickness and other personal experiences. The Memory Box Project made this possible by opening a space for women to express themselves rather than being treated as ignorant patients or with a similar stigmatising label.

My hypothesis is that people with the virus can empower themselves by expressing their emotions through alternative 'languages', such as drawing, writing and painting, and the sharing of these experiences in a safe environment. This allows them re-appropriate their bodies and their self and to understand their situation. They are empowered through the recognition and re-appropriation of their bodies through the control over and understanding of the virus. Awakening memories of their bodies makes people remember who they are as well as what their potentials and abilities are. For people living with HIV and AIDS, sharing life experiences through personal narratives allows them to overcome the feelings often associated with the disease, in particular isolation, fragmentation, denial and fear, and take a more proactive role – individually and communally – in overcoming them.

Body mapping has resulted in a far more effective way of promoting therapy and healing than just the 'expert' talking. There are two main reasons for this: a) participants can express their emotions in other ways than speaking, which allows more space for participation; and b) sometimes the 'expert' talk is charged with judgement, interpretation and analysis that does not necessarily reflect or represent that of the participants.

By explaining their body map pictures through personal narratives, the participants in the Memory Box Project are able to empower themselves and create a new identity. Not only by making sense of their own discourse through personal narratives, but also coping and learning to live with the virus, they can face society from a powerful and safe position that this new identity offers them both as individuals and as a group. The key message is to keep reminding people that HIV is a chronic but manageable condition that does not necessarily lead to AIDS and should not be seen as a death sentence.

Projects like the Memory Box have a lot to offer in enabling people to take charge of their own treatments, thus enhancing treatment adherence and the effectiveness of ARVs in tackling AIDS-related sickness. They also help to ensure that supportive social policies, such as giving grants to people living with HIV and AIDS, can make a real difference in people's lives. The Memory Box has proved effective and it is important to find ways in which it can be replicated and scaled up at an affordable cost. Similarly, research on how the lessons of this project can be incorporated into the general biomedical treatment of HIV and AIDS is essential.

It is also important to remember that disease has a social context and that, for many of those living with the virus that are poor, black and female, it is difficult to cope. The positive stories of empowerment these women tell portray a positive aspect of the possibility of transforming situations. What is ironic is that at the same time being HIV positive becomes the means by which these women get access to income and back to society in an empowered position.

I am fully aware that the ideal way to do this kind of analysis would be through constructing and analysing mini-ethnographies of each person, in order to obtain a deeper insight into these women's lives and the context in which they are immersed, as Kleinman (1988) has suggested. This would be a fascinating future direction to take for this work. Although the Memory Box Project has started exploring these fields, they recognise it is only a scratch on the surface of all the issues the work involves. The need for more research is evident; however, the project also acknowledges that the urgency and desperation of the situation demands immediate action.

References

- Abel, E and Browner, C. (1998) 'Selective compliance with biomedical authority and the uses of experiential knowledge' In: Lock, M. and Kaufert, P. *Pragmatic Women and the Body Politics*. Cambridge University Press. UK.
- BBC News (2000) Mbeki digs in on Aids. Wednesday, 20 September, UK <http://news.bbc.co.uk/1/hi/world/africa/934435.stm>
- Cornwall, A. and Welbourn, A (2002) *Realizing Rights. Transforming Approaches to Sexual & Productive Well-being*. Zed Books, London, NY
- Csordas, T. Ed. (1994) *Embodiment and experience. The existential ground of culture and self*. Cambridge University Press. UK
- Dyanty, R. and Frater, W. (1996) Local Economic Development Initiatives in Khayelitsha. Foundation for Contemporary Research <http://www.local.gov.za/DCD/ledsummary/khayelitsha/introduction.html> [21st July 2003]
- Douglas, M (1999) *Implicit Meanings. Selected essays in anthropology*. 2nd edition. Routledge. USA
- Farmer Paul (1992) *AIDS and ACCUSATION*. Haiti and the Geography of Blame. University of California Press, Berkeley.
- Foucault, M. (1997) *The Archaeology of Knowledge*. Routledge, London. <http://www.thefoucauldian.co.uk/archaeology.htm> [1st August 2003]
- Hancock, P et al (2000) *The body, culture and society*. An Introduction. Open University Press. USA
- Kleinman, A. (1988) *The Illness Narratives. Suffering, Healing & the Human Condition*. Basic Books. USA.
- Kleinman, A. (1995) *Writing at the Margin. Discourse between Anthropology and Medicine*. University of California Press. USA
- Landy David (Ed) (1977) *Culture, Disease and Healing: Studies in Medical Anthropology*. Macmillan Publishing Co., Inc. NY, London.

Lawton, J. (2000) 'The Dying Process: patients' experiences of palliative care'. In: Stockl, A. (2002) Book Review. *Anthropology & Medicine* 9(2): 189-191.

Le Monde Diplomaque (2002) In Denial About A Deadly Future. South Africa's Aids Apartheid. August. <http://mondediplo.com/2002/08/04aids> [21st July 2003]

Lock, M. and Kaufert, P (1998) *Pragmatic Women and the Body Politics*. Cambridge University Press. UK.

Martin, E. (1987) *The Woman in the Body. A Cultural Analysis of Reproduction*. Open University Press. UK.

Martin, E. (1994) *Flexible Bodies. The role of immunity in American culture from the days of Polio to the age of AIDS*. Beacon Press Books. USA

MSF (2003) HIV/AIDS treatment in South Africa proves success in the poorest conditions. <http://www.msf.org/countries/page.cfm?articleid=86A7962A-0B5B-4A47-88E1D917BB081C04> [21st July 2003]

Morgan, J. (2000) 'Boxes and remembering in the time of AIDS'. In: Living Positive Lives, Dulwich Centre Journal, no. 4.

Morgan J. (2002) *Hope Zones and the Pandemic's Lullaby*. Centre for Social Science Research. University of Cape Town. South Africa.

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

Population Resource Centre (2001) Sources include UNAIDS, WHO, USAID, Population Reference Bureau, UN Population Division, and the South African Medical Research. <http://www.prcdc.org/summaries/aidsinafrica/aidsinafrica.html> [11th August 2003]

Rapport, N. (2000) 'Writing on the body: The poetic life-story of Philip Larkin'. *Anthropology & Medicine*. 7(1): 39-62. University of St. Andrew Scotland.

Scheper-Hughes, N and Lock, M. (1987) The Mindful Body: A Prolegomenon to Work in Medical Anthropology. *Medical Anthropology Quarterly* 1,1: 6-41.

Shawver, L (1998) *Notes on reading the Birth of the Clinic*. <http://www.california.com/~rathbone/foucabc.htm> [4th May 2004].

Skultans, V. (2000) 'Narrative, illness and the body'. Editorial, *Anthropology and Medicine*, 7(1): 5-13.

Sontag, S. (1989) *AIDS and its metaphors*. Allen Lane, London.

Synnott, A. (1993) *The Body Social. Symbolism, Self and Society*. Routledge, London and New York.

Turner, B. (1996) *The Body & Society*. Sage Publications, London, California, New Delhi.

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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.
