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AN EVALUATION OF BODY
MAPPING AS A POTENTIAL HIV/AIDS
EDUCATIONAL TOOL

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Abstract

Since antiretroviral treatment was first made available in the public health care sector in 2004, there has been an urgent need to train people working in the field and increase biomedical knowledge about HIV/AIDS within the South African population. This paper aims to assess the potential of further developing the technique of body mapping as an HIV/AIDS educational tool for adults in HIV-positive support groups. It will involve an evaluation of the Longlife Project, the body mapping workshop process and individual body maps. While the over-arching intention of the Longlife Project was advocacy in the face of government resistance to providing antiretroviral treatment at the time, its proposed advocacy could not take place without education. Building on this premise, together with an analysis of the body maps and interview transcripts found in the book Longlife: Positive HIV Stories it is suggested the creation of body maps increased biomedical understanding of HIV/AIDS and to some extent health-enhancing behaviour. Apart from gaining factual knowledge about their health, the women involved in the project also engaged in conversation that provided a rich opportunity for discussing the personal, emotional, cultural and socio-economic challenges of being HIV-positive in South Africa. Both the body mapping and conversation processes will be situated within adult education theory and discussed in relation to 'transformational learning', 'critical consciousness', community art-based learning, peer education and Participatory Research practice. By assessing the strengths and failures of these concepts within an African context the potential for body mapping to be employed as an HIV/AIDS education tool will be further developed.

Introduction

Twelve years after gaining independence, South Africa remains a young democracy with all the challenges, successes and failures any new nation can expect. However, one unprecedented crisis has come to shape not only the present, but also the future of the country. National adult HIV prevalence in

South Africa measured less than 1% in 1990. It now approaches close on 25% (UNAIDS/WHO, 2005). With the South African government's long-awaited announcement in 2003 that it would provide antiretroviral treatment in the public health care sector, it became vital to train more people in the field, including doctors, nurses, counselors and Community Adherence Workers.

This paper identifies counselors who facilitate support groups for HIV-positive adults as a particular group in need, since they can often lack adequate training and knowledge to provide accurate information about HIV/AIDS and antiretroviral treatment (*Mail & Guardian*, January 20-26, 2006, p.28). Through the development of a 'train-the-trainer' type workshop, this research aims to address this gap. It is built on the premise that with a greater understanding of HIV/AIDS, individuals will be able to take greater responsibility for their health, including nutrition, controlling opportunistic infections and the uptake of and adherence to antiretroviral treatment. The development of a workshop to increase biomedical and practical knowledge about HIV/AIDS supports recommendations made by the *South African HIV Prevalence, HIV Incidence, Behaviour and Communication Survey* published by the Human Sciences Research Council (HSRC, 2005).

Past education interventions using media, such as public announcement style billboards, have received criticism in South African studies and media articles revealing their inefficacy in changing behaviour (Makgela, 2005, Clark, 2006, Taylor, 1995). Increasingly research emphasises the need for face-to-face programmes using clinics, youth and community centres (Groenewald, 2005). Clearly what is being called for are community-based programmes that employ participatory strategies to increase understanding about HIV/AIDS. This paper looks at the art-based *Longlife Project* that took place in the Khayelitsha township outside Cape Town, South Africa between 2002 and 2003. The project resulted in the creation of detailed, life-size drawings that became known as body maps and explored the physical, emotional and social impact of HIV/AIDS. This paper will assess the potential use of body mapping as a workshop-based education tool in South Africa where there are high levels of illiteracy, inadequate understanding about HIV/AIDS and the urgent need to communicate with people in a way that takes into account their lived socio-economic reality and cultural understandings of health.

History of the *Longlife Project*

The *Longlife Project* was developed and facilitated by the AIDS and Society Research Unit (ASRU) based at the University of Cape Town between 2001 and 2003. It was primarily an advocacy project that aimed to raise awareness about

the life-saving potential of antiretroviral treatment by showcasing the lives of thirteen HIV-positive women. This involvement in advocacy work marked an important development in ASRU with increased involvement with non-governmental and civil society groups such as Médecins Sans Frontières and the Treatment Action Campaign. To better understand the nature of the *Longlife Project*, some background knowledge is essential.

ASRU was established in 2001 under the umbrella of the Centre for Social Science Research (CSSR). The centre was based at the University of Cape Town to undertake interdisciplinary research on topics relating to Southern Africa, its politics, economics and social issues including the AIDS pandemic. Academics working in different disciplines including economics, anthropology, psychology and historical studies were brought together to conduct research on HIV/AIDS and ultimately contribute to informed public policy-making.

The Memory Box Project

ASRU's original 'outreach programme' was the Memory Box Project created to assist people to come to terms with their HIV-positive status and encourage disclosure to their children and family. Jonathan Morgan joined ASRU as director of the Memory Box Project. Apart from his training as a clinical psychologist, Morgan had used narrative therapy as a group therapy tool suitable for low resource environments. Narrative therapy focuses on individuals retelling stories of events that have shaped their lives. This process is similar to conversations within the group therapy context.

The memory box concept was conceived prior to antiretroviral treatment being provided through public health care systems in Southern Africa, and was initially a tool to enable HIV-positive parents plan for the future with their children. Within this context the project sought to assist with succession planning, grieving and also providing children with a sense of their roots and family history. Parents, in particular mothers, would decorate boxes, baskets or tins, and place objects of sentimental or historical value within them, as well as important documents, such as birth certificates.

The original idea of memory boxes has its roots in Britain in the early 1990s where a group of HIV-positive parents of African descent devised a way of communicating their status to their children through the writing of memory books. Working together with the children's organisation *Bernardos*, the writing of these personal stories provided both adults and children with the opportunity to discuss not only the past, but also the future. By 1999 Ugandan NGOs had developed the idea and adapted it to specific African needs. Beatrice Were and the Community of Women Living with HIV/AIDS in Uganda

(NACWOLA)¹ pioneered the technique of memory boxes, which were better suited to illiterate or rural communities.

Drawing inspiration from the model of memory boxes used in Uganda, as well as narrative therapy, Morgan and Thomas² facilitated a series of workshops with support groups for HIV-positive people in Khayelitsha township in 2001. After the initial workshops, ASRU offered to train participants to facilitate the process themselves. Six women were selected from the initial support groups and named 'the A-team'. After five months of training in memory work and counseling skills, the group went on to facilitate workshops of their own.

In exchange for their facilitation, the women were paid by the organisations affiliated with the support groups, as well as being given a stipend by ASRU. In this way, the women were able to generate income from the skills they had acquired. This was in line with the Memory Box Project's greater aim of developing self-sustaining groups of HIV-positive individuals who would provide 'psychosocial support and research services in their respective communities: an interesting mix of capacity-building, empowerment, psychosocial support and income generation' (Almeleh, 2004, p.8). The success of the A-team model led to the selection of a second A-team from support groups in 2002. These two groups formed the Bambanani Women's Group, which roughly translates as 'holding hands together'.

Living Positively

With the formation of the Bambanani Women's Group, the project developed further in terms of outreach and capacity building. Much of the success of the women facilitating workshops rested on the fact they were HIV-positive and so shared the experiences of the other people in the support groups. They had experienced the loss of children whom they had unwittingly infected in the absence of treatment. They too knew the fears associated with disclosure, as well as the tough economic realities of their communities. They gave hope to others through sharing stories of survival and resilience at a time when most South Africans still saw HIV/AIDS as certain death (Almeleh, 2004).

At the time the South African National Government was resisting a nationwide rollout of treatment on the grounds that it was too expensive and insufficient research had been done on the side effects of such treatment (Nattrass, 2004).

¹Africa: Memory boxes to help say goodbye. (2003). Integrated Regional Information Networks. UN Office for the Coordination of Humanitarian Affairs. Retrieved August, 8, 2006 from http://www.irinnews.org/report.asp?ReportID=37492&SelectRegion=Southern_Africa&SelectCountry=AFRICA

² Kylie Thomas was a doctoral student in oral history working at ASRU at the time.

The Bambanani women provided compelling evidence refuting the argument that the medication was potentially toxic and poor, uneducated people were incapable of adhering to the strict treatment regimen. Having witnessed the recovered health and the impact it had on the women and their families, ASRU decided to record their stories to promote access to antiretroviral treatment.

Medécins Sans Frontières were also eager to showcase the successes of their pilot antiretroviral treatment project and actively supported ASRU's move to document the women's stories with the view to advocating treatment through providing real faces, as opposed to more numbing statistics. Up until this point the Memory Box Project had focused on running workshops to enable participants to create memory books and boxes. With the decision to record the women's life stories the project's focus shifted to advocacy. While memory books and boxes had provided an important therapeutic tool for many HIV-positive people, they concentrated on preparations for death. With the advent of treatment and advocacy, the project was renamed the *Longlife Project* with new attention on ensuring a longer and healthier life.

As the project developed, publishing a book seemed the best medium to reach both a local and international audience. Cape Town artist Jane Solomon was invited to join with the intention of generating further visual material and using art creation as a talking point for discussing further issues.³ In response to the needs of the *Longlife Project* and its advocacy function, Solomon devised a workshop using a traced outline of the body as a starting point for exploring the social, emotional and physical aspects of living with HIV/AIDS. The workshops ran from May to July 2002 and were held at the MSF clinic at the Khayelitsha day hospital in Site B (Almeleh, 2004).

These detailed life-size paintings became known as body maps, and went on to form the basis of the book *Longlife: Positive HIV Stories*. Apart from providing rich visual material for the book, the body maps also provided the women with a chance to tell their life histories and explore their physical and emotional experiences of being HIV-positive. The book was launched at the opening of the exhibition of the original body maps at the South African National Gallery on 29 November 2003. It also marked a new era for South African AIDS activism with the government announcement of a programme to provide antiretroviral treatment on a national scale. Interest in the body maps themselves did not end with the sale of the original works to the NGO Absolute Return for Kids. Art dealer David Krut launched a limited edition of Fine Art prints of the body maps. These reproductions continue to be exhibited and sold both locally and internationally.

³ From personal communication with the artist in 2005.

Theoretical Framework

Having provided an overview of the history of the *Longlife Project* and how the body maps came to be created, the body mapping workshops will now be discussed with reference to key adult education theories. The intention is to highlight ways in which body mapping is in keeping with much of the conceptual framework of participatory adult education practice. By discussing the workshop process and drawing on examples found in the body maps, the aim is to illustrate the extent to which the women's knowledge about HIV/AIDS increased, as well as their ability to take action and transform their life situations. Ideas as to how the technique might be further developed as an education tool will also be explored.

Adult Education Theory

The *Longlife Project* exhibited a number of features closely linked to key concepts found in the adult education literature. Among others, Freire's idea of 'critical consciousness' and Mezirow's 'transformational learning' are both appropriate for engaging with participatory adult education theory. While for Freire 'Liberating education consists of acts of cognition, not transfers of information.' (Freire, 1997, p.60), Mezirow defines the goal of adult education as

...the process of helping learners become more aware of the context of their problematic understandings and beliefs, more critically reflective on their assumptions and those of others, more fully and freely engaged in discourse, and more effective in taking action on their reflective judgments. (Mezirow & Associates, 2000, p.31)

Both these concepts will be discussed in relation to body mapping and ways in which the *Longlife* workshop supported aspects of these ideas. Both Freire and Mezirow's approaches to adult education raise interesting questions regarding participatory education practices, peer education and the creation of social identity. While acknowledging the enormous influence both have had on educational theory and practice, possible limitations of their approaches encountered in past projects will also be discussed. These concerns will be addressed by looking critically at the adoption of the concepts of critical consciousness and transformational learning in HIV/AIDS education in the African context.

Consulting Communities

The last twenty years has seen the adoption of the Freirian notion of ‘critical consciousness’ by a number of projects working within the domains of social justice, adult education, grassroots mobilisation, participatory action research and health (Minkler & Cox, 1980; Campbell & MacPhail, 2002; Campbell, 2003; Cornwall & Jewkes, 1995). This has coincided with a shift from ‘top down’ approaches to addressing social issues to more community based and participatory interventions. This is evident not only in academic literature, but also in a number of international declarations promoted by the World Health Organisation, including the Ottawa Charter and the Jakarta Declaration (Campbell, 2000). Participation has become the buzzword on everyone’s lips from NGO workers, governments, business CEOs and academics, but the extent to which it has been adopted and implemented in practice is uncertain. While the world has become increasingly politically correct and sensitive to those marginalised by society, it has also increasingly become a place where the gap between rich and poor, north and south, the haves and have-nots has widened. This is no more clearly illustrated in the way the AIDS pandemic continues to play itself out.

Emphasising Socio-economic and Political Contexts

A deep concern for the oppressed in society was the driving force behind Freire’s education and social theories. It is perhaps the fact there remain so many marginalised people in the world more than twenty years after he wrote his defining text (Freire, 1973) that it is still seen as relevant. The link between greater individual and community participation and developing critical consciousness is central to understanding why Freire has dominated the field of adult education and also been adapted to other areas.

Freire argued the perceived ignorance and lethargy of the poor is a direct product of an entire economic, social and political situation depriving them of critical awareness and the ability to act. This strongly echoes critical theory and its emphasis on the need to identify, challenge and change the processes of our unequal society and the dominant ideology supporting it (Brookfield, 2005). Counter arguments to this suggest that far from lacking agency, poor people are able to resist economic, social and political practices that disadvantage them by engaging in forms of resistance such as boycotts, and other forms of in-group solidarity (Scott, 1985). According to Freire education is seen as the key to empowering people and giving them the skills to engage critically and creatively with their life situations and develop a course of action. This marks a shift from seeing oppression as an unchanging state, to a present limitation that has the potential to change (Freire, 1997). This utopian ideal will be discussed with

direct relation to HIV/AIDS, body mapping, peer education and the role of networks of support.

While acknowledging the power of socio-economic and political contexts have over individuals, it is important not to view poor people as a homogenous group. Within the group there are not only levels of economic deprivation, but also multiple influences on people's perception of personal agency and their ability to initiate change. This is where social networks and the concept of social identity can be seen to play a role. Both social networking and social identity attach importance to belonging to groups (such as church choirs, support groups or sports teams) that provide a space where opinions, skills or knowledge can be shared and acknowledged. This process is believed to increase self-confidence and be the foundation for engaging critically with their situation.

Freire argues when people have been oppressed they adapt to a structure of domination, and that even once the political or social situation no longer exists they remain unable to reject that way of thinking. By developing critical consciousness they are able to reflect on their life situation and ultimately take steps to change it. This is very similar to Mezirow's idea of 'critical reflection' that enables adult learners to question their assumptions and arrive at new ways of directing their actions based on a revised interpretation (Taylor, 2000).

Societal norms and expectations

In terms of approaches to HIV/AIDS education, developing critical consciousness is in keeping with the move away from purely information-based programmes to looking at ways of developing health-enabling communities (Taylor, 1995; Campbell, 2000). This shift marks the acknowledgement that individuals do not operate in isolation, but rather their behaviour is largely shaped by societal norms and expectations. Many studies have revealed the limitations imposed on women in the African context, even once they have the relevant knowledge of how to protect themselves from HIV infection (Preece & Ntseane, 2004; Campbell & MacPhail, 2003; Campbell, 2003).

It has been suggested 'Women are generally more vulnerable to sexual risk than men because their sexuality is usually controlled by others. Patterns of sexual activity and numbers and types of relationships are influenced by cultural, social and economic factors, as well as personal attributes.' (Taylor, 1995, p.183). This also demands an honest assessment of how effective developing the critical consciousness of individuals really is in terms of enabling them to take action and change their life situations.

The extent to which women are capable of protecting themselves from HIV infection raises the issue of gender inequality in many African societies. In order to increase the potential success of HIV/AIDS education programmes, it is vital that gender issues, as well as economic and political contexts, are considered in relation to social identity and individual behaviour. The failure of adult education arguments for empowerment to take into account the existing dominant male position in many African societies has been critiqued in past studies (Preece & Ntseane, 2004). It is argued the application of adult education principles 'are embedded in critical, postmodern, feminist pedagogical approaches that take account of difference, the social situation of gender power relations...within a particular cultural and historical context.' (Preece & Ntseane, 2004, p.16). These approaches and theories are essentially the product of a western culture and therefore cannot be applied to African social contexts without serious reworking or at least the acknowledgement of differences between cultural, social, historical and political contexts and how these differences might be addressed.

Apart from theoretical considerations, there are also more practical issues needing attention to ensure the involvement of men in HIV/AIDS education programmes. There has been an unfortunate and damaging tendency within HIV/AIDS education discourse to cast men as the major problem and reason why education programmes fail. It is vital that facilities such as clinics and Voluntary Counseling and Testing (VCT) sites become more male-friendly both in terms of opening hours and the demographics and attitudes of the staff (Dlamini, 2006). Increasingly there has been an attempt to reach out to male partners through prevention of mother-to-child transmission programmes. A project in Swaziland recorded lower transmission rates to the infant when the male partner participated in support groups (Smart & Sherriff, 2006). Another example in Tanzania initially showed couple counseling accounted for less than 5% of all HIV testing at the clinic. This changed after clinic staff decided to hand-deliver letters inviting male partners to attend the antenatal clinic visit which resulted in an overall 30% increase in male partner testing. Both these examples reinforce the importance of greater male involvement in HIV/AIDS interventions (*ibid*).

Having emphasised this point, it can be argued it is pointless increasing knowledge and developing the critical consciousness of women when they will be unable to act on their new understanding because they are in relationships that inhibit behaviour change. This acknowledgement of the involvement of men as being central to any HIV/AIDS education programme is based on research that suggests

Generally speaking men are more likely to engage in sexual activity before marriage and to have extra-marital relations after marriage than are the married

women who receive HIV-prevention education at family-planning and MCH clinics. Work with groups of boys and men, particularly those who are single, or spend time away from their stable partners may have a greater impact on the sexual health of men and women. (Taylor, 1995, p. 188)

Bringing together ‘outsider’ and ‘insider’ knowledge

Freire argues both educational and political programmes that fail to respect the particular worldview of the people they are working with run the risk of being ineffective. He suggests a person’s worldview is manifested in their actions and reflects their life situation (Freire, 1997). This can be interpreted in two ways in relation to HIV/AIDS education. Firstly, socio-economic realities, including gender relations, should always be kept in mind, as well as cultural beliefs and values. Secondly, while respecting these shaping influences, it could also be argued a person’s worldview can negatively impact them through limiting their ability to act in ways that benefit them more. In this case, developing critical consciousness based on accurate biomedical information is important in getting people to review the assumptions driving their behaviour.

The transition from naïve to critical consciousness is built on seeing reality from a new place of understanding or distance. Viewed in this way it can be said critical consciousness is the product of a ‘tension between two modes of *distantiation*: that produced by the ‘knowledge’ contributed by ‘outsiders’ (experts, intellectuals) and that latent in the experience of ‘insiders’ (participants)’ (Freire, 1997, p.46). This links to Mezirow’s idea of ‘perspective transformation’ when adults interrogate their assimilated values or ‘meaning schemes’ driving their decisions and develop a new worldview. Through this type of discourse people are able to test the validity of their ideas within a learning environment that should ideally mirror the outside world.

The Power of Group Dialogue

This idea of recreating real life situations within learning practice is one of the key arguments in support of peer education and support group environments. Mezirow stresses the optimal conditions for ‘rational discourse’ to take place include having accurate information and participants being able to fully participate and challenge each other (Mezirow, 1991). The *Longlife* workshops in many ways reflected this kind of space where the women were able to express themselves, ask questions and receive correct information. This process is supported by the idea that

Groups can provide mutual support for behaviour change...As people become more aware of sexual needs and potential choices, and ways in which their

environment limits their sexual health, they may become motivated to work towards change. (Taylor, 1995, p.186)

This supports the idea of group dialogue proposed by Freire and Mezirow in order to develop critical consciousness and engage in perspective transformation. This type of dialogue is not simply conversation, but built on the foundation of an equal relationship (subject-subject) where people reflect on their experience and behaviour and develop potential new ways of living that would benefit them more. This is explained as follows:

The thinking Subject cannot think alone. In the act of thinking ...s/he cannot think without the co-participation of another Subject. There is no longer an 'I think' but 'we think'. It is the 'we think' that establishes the 'I think' and not the contrary. This co-participation of the Subjects in the act of thinking is communication. (Freire, 1973, p.137)

The importance of an equal relationship underpinning this process is based on the understanding that all human communication is challenged by power relations between groups and individuals. This includes the teacher/student, facilitator/learner and researcher/participant relationship. It does not imply facilitators and researchers should not share their expertise and knowledge, but rather the relationship works in both directions. The student/participant is equally capable of contributing to the learning process. This principle underpins Participatory Research, which will be discussed in detail later. It also returns to the tension between the knowledge of expert 'outsiders' and latent wisdom found in 'insider' participants.

Negotiating Biomedicine and Indigenous Knowledge

The concept of negotiating local knowledge is central to engaging in constructive HIV/AIDS education in the South African context. It is built on an understanding that 'The values and customs associated with ill-health are part of the wider culture, and cannot really be studied in isolation from it.' (Helman, 1990, p.7). This would suggest the importance of presenting Western biomedical and scientific information, while acknowledging local/indigenous understandings of health and illness. The *Longlife* body mapping workshops operated in a similar way. An example of this is the women's engagement with anatomical diagrams before drawing their pregnancies or internal organs, as well as referring to indigenous medical practices and plant remedies. By allowing both approaches to understanding health and illness, the workshops acknowledged 'To the members of all societies, the human body is more than just a physical organism, fluctuating between health and illness. It is also the focus of a set of beliefs about its social and psychological significance, its structure and function.' (Helman, 1990, p.11).

The process of engaging with biomedical understandings of the human body in the *Longlife* body mapping workshops could be further developed in a future workshop with an increased emphasis on visual presentation of biomedical knowledge using the Visual Body Map. The Visual Body Map is an educational tool developed by ASRU. It is a visual representation of the systems in the human body on layers of acetate that can be overlaid to build up a coherent understanding of the inter-related nature of the body and how HIV/AIDS affects it. It is also important to discuss the possible dangers inherent in taking traditional medicines while on antiretroviral or western medication and find ways of negotiating the two different approaches. Freire emphasises the importance of scientific knowledge, despite his stress on knowledge being constructed subjectively through dialogue. This can be seen when he writes 'For dialogue to be a method of true knowledge, the knowing subjects must approach reality scientifically in order to seek the dialectical connections which explain the form of reality' (Freire, 1970 quoted in Morrow & Torres, 2002, p.115).

In future body mapping workshops, participants would not only engage in dialogue arising from the visuals, but would also take what is relevant to their health and understanding and draw it on their personal body map. In this way participants engage in verbal dialogue within the support group context, as well as a visual dialogue exploring medical concepts relating to HIV/AIDS and so increase their knowledge through actively engaging with the material through drawing. This is supported by the idea that literacy is not confined to language.

In the broadest political sense, literacy is best understood as a myriad of discursive forms and cultural competencies that construct and make available the various relations and experiences that exist between learners and the world. (Giroux, H. quoted in Morrow & Torres, 2002, p.119)

Given the limited education of many support group participants in the South African context, the use of visual tools to enhance learning about HIV/AIDS is particularly important. In this way participants can engage with biomedical information without the need to necessarily read or write, or to have studied biology. Visual tools (such as the Visual Body Map) provide clear illustrations of the internal workings of the human body. Obviously it is not enough simply to show participants drawings and diagrams. Discussion and participatory exercises (such as body mapping) need to engage participants with the material so that they can come to understand the direct relevance of the science of HIV/AIDS has to ensuring them better health and longer and more productive lives.

Limitations of Adult Education Theory

Some of the dangers inherent in simply transferring Western adult education ideas of empowerment and learning to the African context have already been discussed. This is particularly true in the case of understanding ways existing gender relations can affect the potential efficacy of HIV/AIDS education interventions in enabling behaviour change. The need to acknowledge local understandings of health and illness while providing accurate biomedical information about HIV/AIDS has also been emphasised. Both gender and lay perceptions of HIV/AIDS need to be discussed in relation to social identity and ways behavioural norms are developed within communities. Given the sensitive and difficult nature of these types of conversations, participatory exercises such as body mapping provide alternative learning contexts where participants can start interacting with and addressing these issues.

Criticism of Mezirow's theory of transformational learning suggests that it decontextualises learning and over-emphasises rationality. This is linked to what is seen as a failure to account for the impact of societal inequalities and the tension between individual and social change (Clark & Wilson, 1991; Taylor, 1998; Collard and Law, 1989; Tennant, 1993 in Baumgartner, 2000 pp. 75-78). These issues have been addressed in prior discussions surrounding the importance of understanding people's ability to take action within their socio-economic and cultural contexts. Body mapping situates the learning process firmly within individualised experience of HIV/AIDS and stresses the impact of socio-economic contexts in shaping people's vulnerability to HIV/AIDS, as well as impacting on their ability to protect themselves.

An additional criticism leveled at projects using transformational learning as a framework for engaging with HIV-positive adults (Baumgartner, 2002; Courtenay *et al*, 1998, 2000) is their failure to acknowledge the individualistic tendencies apparent in Mezirow's theory. Rather than perspective transformation occurring "in the head" of individuals, it is suggested human learning is an inter-personal process arrived through engaging in communities of practice (Plumb & Berringer, 2003). While Mezirow acknowledges personal meaning is acquired and developed through human interaction and communication, he essentially views meaning as existing within individuals. This is not in keeping with the powerful learning that took place in the supportive community evidenced in the *Longlife Project* and other participatory interventions. In these instances meaning is developed from shared experiences and discussion of possible options and solutions available to individuals. The importance of this type of dialogue process is found in arguments supporting peer education and the role it plays in negotiating behavioural norms.

With regard to Freire's theory in relation to HIV/AIDS education in South Africa, it has been argued developing critical consciousness is not enough to enable people to initiate change. As previously argued, social norms informed by cultural and gender relations, as well as socio-economic context largely control the degree to which individuals can take control of their sexual health. However, critical dialogue within learning contexts such as support groups and peer education settings is a vital tool for encouraging participants to see how these social norms and socio-economic situations impact on their lives. This is echoed in the following statement.

Critical consciousness is a precondition for the collective renegotiation of sexual and social identities in ways that are less damaging to sexual health, as well as for the development of confidence and empowerment to be able to engage in safer sexual behaviour. (Campbell, 2003, p.133).

In the case of HIV/AIDS education in South Africa, developing critical consciousness is not an end in itself, but rather a step in the process of increasing awareness within people as to what inhibits them from engaging in safe sex, disclosing their HIV status, eating a nutritious diet or adhering to antiretroviral treatment. In this way it can be used to enhance understanding and ultimately develop people's capacity to engage in health-enhancing behaviour. Starting with individuals attending support groups and being exposed to accurate biomedical knowledge about HIV/AIDS, together with access to practical advice, it is hoped this information will be discussed with their families and friends and filter slowly into the greater community.

Participatory Research

Various forms of mapping as a visualisation technique have long been employed in different disciplines including psychology, geography, sociology and anthropology to record information such as natural and urban environments, local resources and social structures. Participatory Research practitioners were particularly drawn to mapping as a tool for accessing local knowledge because of their emphasis on using knowledge to stimulate social action. Mapping supported the Participatory Research focus on a 'bottom-up' approach based on locally defined priorities and perspectives, as well as acknowledging indigenous expertise and knowledge (Cornwall & Jewkes, 1995). This was especially powerful in developing countries where language barriers and illiteracy stood in the way of researchers accessing knowledge and working with local communities.

Of special significance in relation to the body maps created in the *Longlife Project* is a study that employed drawing as a tool for rural Zimbabwean women

to communicate their knowledge of their bodies. The study investigated the differences between the women's knowledge and western biomedicine with the aim of improving their sexual and reproductive health (Cornwall, 1992). Central to the drawing process was an acknowledgement and affirmation of the women's knowledge. Apart from avoiding potential communication misunderstandings, the use of drawing provided the women with a non-pressured way of presenting their knowledge within their own conceptual frameworks (Cornwall, 1992; Crawford, 1994). Furthermore, 'The process of constructing a visual representation is in itself an analytic act, revealing issues and connections that local people themselves may not have previously thought about.' (Cornwall & Jewkes, 1995, p.1671).

While visual literacy is a universal communication tool, visualisation is not a neutral process since it still relies on interpretation. This is particularly true when looking at symbols and the use of metaphor. For this reason the body maps have not been analysed as if they were works of art. Transcripts from interviews conducted with the women in the book *Longlife: Positive HIV Stories* have been used in this paper to discuss the body maps. The descriptions and stories told by the women who created the body maps emphasise the view that visualisation techniques facilitate, rather than replace discussion. In the *Longlife Project* the body maps served as catalysts for further story telling and sharing within both group discussions and interviews with each of the women.

Since the concept of Participatory Research was first explored, the exact nature of what constitutes 'participation' and the negotiation of the power dynamics between researcher and community have been much debated. What remains pertinent in the context of body mapping is the way methodologies that enhance participation in health issues provide individuals with not only new ways of learning, but also new ways in which to express indigenous knowledge and explore social and cultural aspects relating to health and illness. It has been suggested that affirming local knowledge and agency enables communities to analyse their situations and develop their own solutions (Cornwall & Jewkes, 1995). If one were to transfer this argument to HIV/AIDS education I would argue that education programmes have to encourage dialogue concerning traditional and biomedical approaches to health and illness. Problems arising from the use traditional medicine, such as purgatives, which negate the efficacy of antiretrovirals, need to be confronted head-on, rather than ignored. Body mapping within the support group context could serve as a potentially powerful participatory learning environment where adults can debate these issues and propose possible solutions. For this reason it is important that support group counselors have accurate knowledge concerning traditional medicine and biomedicine. Participatory approaches are particularly relevant in the context of

HIV/AIDS where other didactic or authoritarian approaches have failed (Campbell, 2003).

A number of academics have recently addressed the relationship between traditional medicine and western biomedicine in the context of HIV/AIDS. The role traditional medicine plays in peoples lives in South Africa has been investigated in an attempt to better understand what motivates people in their choices to seek either or both traditional and western practitioners. While figures on the number of people who visit *sangomas* vary, it has generally been agreed that patients move between traditional and western medical practitioners depending on the type of illness (Nattrass, 2005, Wreford, 2005, Mills, 2005). This movement between both approaches is summed up in the following statement.

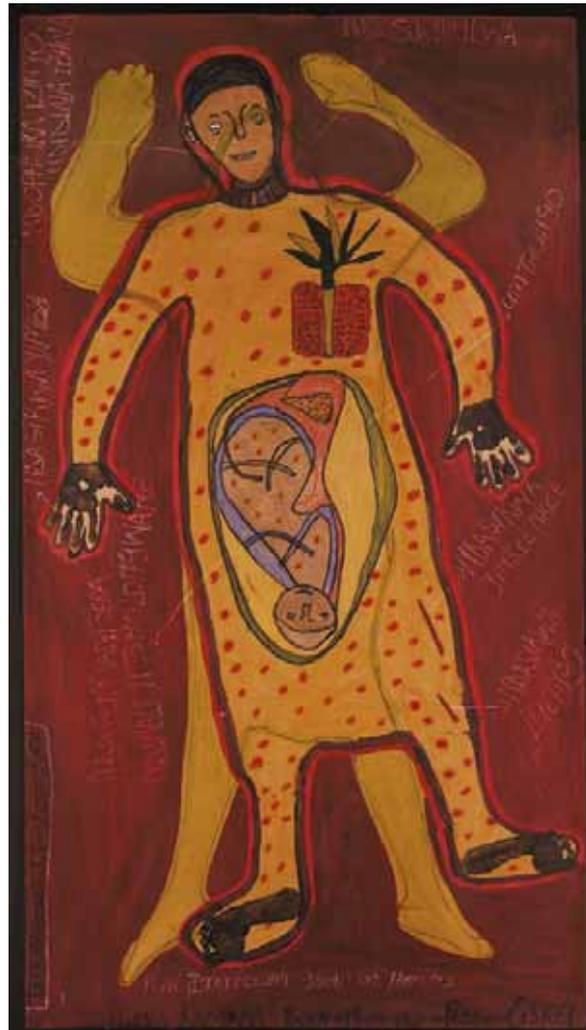
Many black South Africans will consult a traditional practitioner before, during or after receiving biomedical treatment. This is not out of stubbornness or ignorance, but because western biomedicine is unable and unwilling to offer explanations for the onset of illness, the ‘why me? why now?’ rationale which forms a crucial part of traditional understandings of health and healing. (Pretorius *et al*, 1993, p 18, quoted in Wreford, 2005, p. 68)

The need for understanding the underlying reasons for ill health is central to many black South Africans and is considered the main motivation driving people to consult *sangomas* and other healers. Given the fact there remains no cure for AIDS, it has been argued that this leads to denial and a search for alternative causes for ill health, such as bewitchment (Wreford, 2005). Furthermore, there remain some illnesses that are considered ‘natural’ (as part of the natural world), while others are believed to be driven by human agency and are associated with bewitchment (Ashforth, 2005). An additional problem facing the promotion of biomedical approaches to HIV/AIDS is that many of the illnesses (such as wasting, diarrhea, stomach ailments) associated with bewitchment are also symptoms of AIDS illnesses.

Other resistance to western biomedicine is largely due to its history and being seen as a colonial tool with *apartheid* era experiments proving particularly sinister in South Africa. For all these reasons, it is important that HIV/AIDS education programmes encourage discussion of traditional approaches to health, while providing accurate information regarding antiretroviral treatment, how to access it and steps to ensure adherence and support during treatment. It has also been argued that ‘...collaboration does not infer the mapping of traditional healing onto biomedical practices, or vice versa, but should allow for the places of divergence where each can offer relative and different resources to HIV-positive clients (Mills, 2005, p. 155). Body mapping workshops could potentially provide a space where both approaches can be discussed. In the

body maps produced by the *Longlife Project* there is evidence that traditional medicine was discussed. This can be seen in the example of the aloe drawn in Victoria's body map.

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 the 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... (Morgan and the Bamabanani Women's Group, 2003, p.56).



Maria's body map records alternative knowledge on how to treat certain illnesses.

Maria's explanation of the pineapple that she drew in her body map is a further example.

In the case of HIV, pineapple is also a cure. It can help you when you have a running tummy; you must eat the hard block inside. The block is fighting with the

virus inside your tummy (Morgan and the Bambanani Women's Group, 2003, p. 129).

In this way the Bambanani women recorded alternative understandings of health and illness in their body maps. This process recognised traditional and lay systems of knowledge on treating or healing the body. Rather than ignoring or censoring traditional medicine, it is vital to acknowledge and discuss it in relation to Western biomedicine. A good example of how this might be done can be found in the TAC treatment literacy fact sheet 'Talk about Antiretrovirals' (Ashforth & Natrass, 2006). In this example a traditional healer warns about potential interaction between traditional medicine and antiretroviral drugs and stresses the importance of the patient telling both traditional healers and medical doctors if they are taking alternative medication.

Community Art-based Education

Another approach to adult education built on the principles of participation is the use of community art-based projects. The *Longlife Project* naturally falls within this field with the creation of body mapping, as well as photography to document the lived realities of the women in the project and their communities. Collaborative artistic production has long been acknowledged as a powerful vehicle for experiential learning, as well as therapy. The creation of the body maps within the *Longlife Project* encompasses both these aspects. Central to enabling both learning and healing is the withdrawal of any aesthetic or artistic value judgments of what constitutes 'good' art. By making the level of skill irrelevant, greater social inclusion and engagement in the process is achieved (Karkou & Glasman, 2004).

This was accomplished in the *Longlife Project* body mapping workshops in a number of ways. Artist/facilitator Solomon wanted the women to feel at ease within the creative process and so devised a series of interactive exercises involving the whole body as a tool for mark making. Examples include tracing the outline of the body while lying down on a piece of card and also painting and then stamping hands and feet directly onto the body maps. These exercises immediately involved the women in process of art-making and built their confidence as they could see their body maps taking shape. Solomon states these intentions clearly near the beginning of the book *'Longlife: Positive HIV Stories'*.

Letting them work with their own bodies, which they know best, helped the group not to fear making 'wrong' marks. Also, because the body holds memory, I was hoping the artworks would turn out not merely as illustrations of the powerful stories I expected to encounter, but as something more primal and primary that

could precede and even inform the stories (Morgan and the Bambanani Women's Group, 2003, p.15).

The use of prompts not only guided the women through the creative process, but also encouraged the group to engage in exercises that facilitated reflection and group discussion about issues related to the women's general life experiences, including their discovery of their HIV-positive status. Often before the women commenced working on their body maps, the group would gather in a circle round the pile of body maps and discuss events that had taken place, concerns they might have or to raise questions that needed answering.

Creating a Supportive Environment

Another important aspect of art-based learning is the provision of a safe space where the participants not only feel emotionally safe, but also free from judgment. This was particularly pertinent in the case of the *Longlife Project* since the participants were HIV-positive and there was the additional fear of disclosure. By the time the women engaged in the body mapping process they had formed a close-knit group called the Bambanani Women's Group. The importance of a supportive environment is central to using the visual arts as both psychosocial support and educational tools for HIV/AIDS. For this reason future educational body map workshops will take place within already established support groups for HIV-positive people. By operating within the 'train the trainer' model, counselors will be equipped to run the workshops within groups where they have already developed a relationship with the participants. This is believed to be a favourable and sustainable option, as opposed to employing new facilitators who do not have any relationship with the people within the support group. The use of support groups also ensures ongoing support will be available following the completion of the body map workshops.

Non-verbal Communication

While the creation of the body maps worked as a catalyst for discussion within the *Longlife* workshops, it should also be emphasised that the act of drawing and painting is itself a form of communication. One of the most powerful aspects of engaging in art production is the way visual forms can operate as an alternative, non-verbal language. Body mapping is a powerful example of how people with limited formal schooling and literacy can engage with and learn material that would otherwise be inaccessible. When educating people about HIV/AIDS in the South African context, there is not only the issue of which of eleven official languages to use, but there is the additional consideration of Western biomedical language and how it can potentially alienate people. For this reason the use of

visual teaching aids that do not rely on language as a means of communication is particularly useful. An example of one such tool is the Visual Body Map developed by ASRU and currently being used by the TAC in their HIV literacy workshops.

Art production ‘involves the person as a whole, including sensor motor, perceptual, cognitive, emotional, social and spiritual aspects’ (Karkou & Glasman, 2004, p 61). This multifaceted way of engaging with issues using a visual art is exemplified in the body map process where participants lay down and had their bodies traced as a starting point for documenting their life stories. From the first exercise, the women were engaged and challenged to probe their understanding of issues of health and illness, their personal histories and the ways they inform each other. The autobiographical and sensitive nature of this process once again emphasises the need for a safe and supportive environment.

Symbolism and Metaphor

The use of symbols and metaphors in the creation of the body maps provided the women with an alternative language and means of expressing themselves. In particular the exercises of developing a symbol of personal power and rendering HIV/AIDS metaphorically in the body maps gave rise to some interesting and alternative insights. By communicating ideas using metaphor and symbol, multiple meanings can be explored. It has been argued, ‘As a result of this, symbolism and metaphor offer many more possibilities for creative solutions compared with solutions found from direct articulation of problems’ (Karkou & Glasman, 2004, p 62).

Apart from providing possible insights and solutions into problems, the use of metaphor in the body maps often captured information revealing how learning had taken place. It is difficult to gauge whether or not the participant was aware of how she had assimilated the new knowledge. An example of this can be found in Bulelwa’s body map where her symbol of power is a plant filling her torso. She describes the reason for her choice. ‘This is a tree and it gives me shade on hot days...trees make a country beautiful. My home is also surrounded by trees. Some trees give us fruit which makes us strong and healthy’ (Morgan and the Bambanani Women’s Group, 2003, p. 87).

Her description reveals details about both her present life, as well as her past. Her description of her home being surrounded by trees, suggests a reference to her traditional home in the Transkei, since there are very few trees in Khayelitsha township. Her relationship to a tree is primarily defined by the provision of shade emphasising protection and care, as well as the nutritional value of fruit. By drawing attention to the importance of fruit as a source of

vitamins in her diet, Bulelwa links safeguarding her health to her symbol of power. It is likely she was first exposed to information about nutrition during the pilot anti-retroviral treatment project and the body mapping workshop. It is difficult to ascertain whether she was aware of demonstrating this newly acquired knowledge in her choice of symbol of personal power.



In Bulelwa's body map, her symbol of power is a plant filling her torso.

Like Bulelwa, Noloyiso's symbol of power also potentially demonstrates the extent to which new knowledge has now become an integral part of her understanding. In Noloyiso's body map, her symbol of power is not immediately apparent since it is a simple line drawing of a cooking pot drawn in her head. In her own words, Noloyiso describes what the cooking pot means to her.

About the pot symbol on my painting. I like to cook. In that pot is the food, the veg, the green, me and healthy 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. (Morgan and the Bambanani Women's Group, 2003, p. 69)



Noloyiso's symbol of power potentially demonstrates the extent to which new knowledge has become an integral part of her understanding.

The potential of metaphor to explain complex or foreign biomedical concepts has been explored in a number of HIV/AIDS educational programmes. This approach is also often promoted as a way of communicating sensitive material, given the fact HIV is primarily a sexually transmitted disease in the South African context. The use of the red AIDS ribbon and the condom are perhaps the best-known symbols to represent AIDS and the safe sex message. Despite the usefulness of metaphor in some contexts, they do not always carry clear messages. This is particularly true when encountering different cultures. This can be found in even in the most simplistic example of white being favoured in Western style weddings where it symbolizes purity. In other cultures white is the colour of death and so red might be preferred since it promises the newly weds good luck. It soon becomes clear metaphor and symbols should be used with caution in educational settings. Furthermore, it is patronising to assume people with limited formal education cannot understand biomedical explanations of HIV/AIDS and need metaphor to replace science.

Another worrying aspect associated with metaphor in relation to health and illness is the way these metaphors often alienate, villainise or judge people who suffer from the illness. An example of this is the analogy of the immune system as an army of soldiers. In this case questions surrounding who is going to war, who is victorious and the assumption of a just victor present all sorts of problems for a person living with AIDS. It is argued that ‘...the effect of the military imagery on thinking about sickness and health is far from inconsequential. It overmobilises, it overdescribes, and it powerfully contributes to the excommunicating and stigmatizing of the ill.’ (Sontag, 1989, p.94). The way certain illnesses and diseases have been linked to specific metaphors has been explored by a number of contemporary writers (Ashforth & Natrass, 2006) and artists (Churchill Madikiwe) who investigate the dangers inherent in using metaphor to describe illness.

Having brought to the fore the potentially negative aspects of the use of metaphor, it is equally important to look at ways metaphor can give people a tool for expressing concepts in their own language. It is in this context that metaphor was used within the body mapping process. Rather than prescribing metaphor to the group, the women were encouraged to think of creative ways of expressing their understanding and experience of HIV/AIDS.

Depictions of Personal Experience of HIV

When Solomon asked the women to draw how they experienced or saw HIV in relation to their bodies, the exercise focused on their personal experience of illness. By emphasising a metaphoric way of visualising HIV/AIDS, the women were given the creative freedom of expressing themselves in whatever way they wanted. The depiction of HIV in each of the body maps served to record the emotional, as well as the physical aspects of illness. This can be seen in the next example.

In my picture the HIV looks like fire because I felt that it was like something was burning inside because I had lots of pains in my body. But now I cannot feel it because now I’m healthy. (Morgan and the Bambanani Women’s Group, 2003, p. 107)

Bongiwe’s choice of a cooking fire to represent HIV is closely linked to her world and the things that fill it. A cooking fire is something she would have grown up with in her rural home and perhaps it was something she still used despite being in an urban setting. It is a powerful symbol in the way it captures the sensation of pain and links her experience of illness and health to something most people can relate to, especially those within her community.

Apart from using a visual language built on their life experiences, the use of metaphor also captured accurate understanding of HIV/AIDS and how they affect the body. Nloyiso's depiction of HIV as a storm is a good example of how metaphor reveals a sound underlying biomedical understanding of HIV/AIDS.

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, lightening and wind. I represent HIV like that. I did have rash, thrush, falling of hair, coughing and headaches (Morgan and the Bambanani Women's Group, 2003, p. 67).

She compares HIV to a storm because of the many different illnesses and opportunistic infections the virus makes her susceptible to. The concept of AIDS as a syndrome, as opposed to a single illness or disease is often confusing for patients. This often relates to questions about the links between TB and HIV, and reasons why one can be cured but not the other. Nloyiso appears to have understood and internalized the complex nature of how HIV affects the body. This suggests accurate comprehension can be gained through visually recording the body using personal imagery and metaphor.

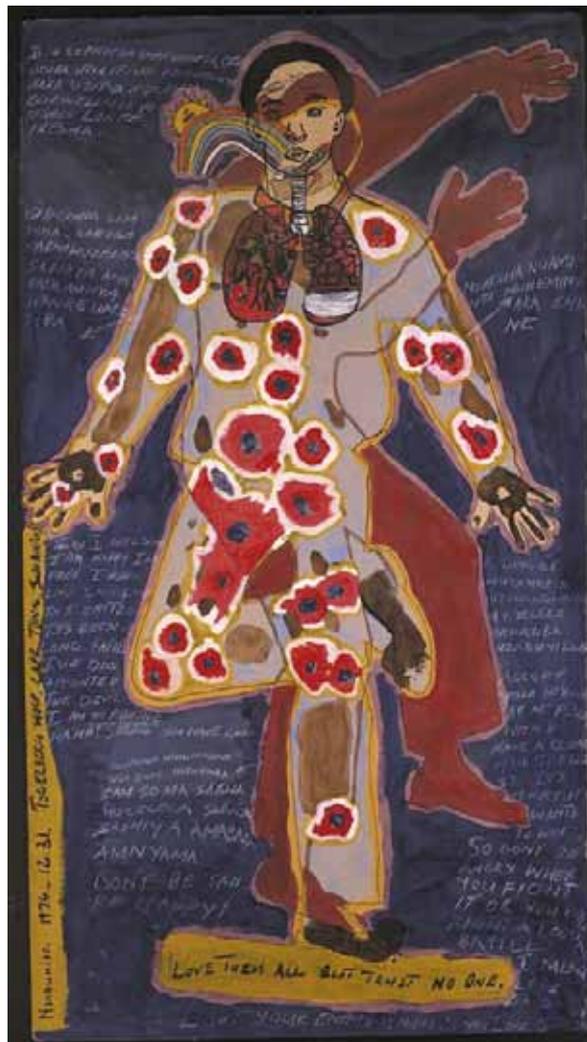
Illustrating understandings of Antiretroviral Treatment

Some of the women also illustrated their understanding of how antiretroviral treatment works by drawing it in their body maps and discussing their recovery since being on treatment. In the course of the workshop, Solomon brought anatomy textbooks, encyclopedias and drawings of the body by artists such as Leonardo da Vinci.⁴ This was in response to questions asked by the women and their desire to know more about what lay within their bodies. For some of the women it was the first time they had seen such illustrations. The impact medical knowledge about their bodies and HIV/AIDS had on the women is apparent even in those women not on antiretroviral treatment. In Nomawethu's body map, she depicts her HIV-positive status by painting a blue line on the contour of her body outline with white dots on it. She explains this in her own words.

I am lucky because I know that when my CD4 count goes lower than 200, I can get ARVs from the MSF clinic. I put the light blue colour and the white 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 happy with my hands up... (Morgan and the Bambanani Women's Group, 2003, p. 23).

⁴ Personal communication with Jane Solomon in March 2006.

Nomawethu's sense of hope and health is closely connected to her knowledge of how to monitor the HI virus and how it affects her immune system. While she is not on antiretroviral treatment, she knows what to do in order to access it when the need arises. Her understanding of a CD4 count⁵ and how it can be used to measure the HI virus's effect on her immune system is accurate. This would suggest that through painting her body map, she learnt and retained a great deal about HIV and how to manage her health.



Nondumiso's description of the virus 'going down' is a reference to the reduction in her viral load.

⁵ CD4 cells are vital to the functioning of the immune system. HIV targets CD4 cells in order to reproduce and ultimately kills them. CD4 cells are reduced as the HI viruses increase. A CD4 count is calculated by taking a blood sample and counting the number of CD4 cells in a cubic millimeter of blood. A healthy person's CD4 count is in the region of 750. When a person's CD4 count drops below 200 they are considered to be experiencing Stage 4 AIDS and should consider going onto antiretroviral treatment.

Another example can be found in Nondumiso's body map and her description of drawing antiretroviral treatment in her body.

On my picture I drew the virus – it's the small blue dot. The white is my blood. The red circles are the ARVs eating the virus, and the virus is going down. The ARVs are strong. I have been on ARVs for five months now. It's changed a lot since the first month when I was always getting sick, sick, sick. I went twice a week to the doctor. Now that I've got ARVs, the whole month I'm fine. I don't complain about anything now. 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 (Morgan and the Bambanani Women's Group, 2003, p. 41).

Nondumiso's description of the virus 'going down' is a reference to a reduction in her viral load or the number of HI viruses in her blood stream. This demonstrates an understanding of how HIV operates within the body. She also draws attention to a quicker recovery time from opportunistic infections now that she is on antiretroviral treatment.

The previous examples of how visual language can potentially enhance learning in relation to HIV/AIDS all support the concept of community art-based projects with the emphasis on actively engaging participants in their learning experience. The use of prompts and exercises illustrate ways of breaking down people's fear of art-making and gives participants the courage to create. These exercises also lead participants to new places of understanding with regards to HIV/AIDS and how it impacts on the body. As previously mentioned, drawing and painting the body maps also operated as a catalyst for group discussion and the opportunity for further healing and learning.

Conclusion

The potential use of body mapping as an HIV/AIDS education tool has been explored in the evaluation of the *Longlife Project* and the ways it supported and operated within the framework of adult education theory and practice. Key points include the importance of providing accurate biomedical information while acknowledging indigenous knowledge and beliefs about health. This should work together with developing critical insights into how socio-economic pressures and social identity inhibit individual health decisions. Such insights are the product of dialogue taking place within learning environments such as support groups and peer education settings. This type of group dialogue should encourage participants to stop seeing their HIV-positive status and life situation as something they have no control over and encourage them to take on greater responsibility for their health. This would include knowing how to manage opportunistic infections, attending the clinic regularly, accessing antiretroviral

treatment when necessary and steps to ensuring adherence. In this way, the proposed future body mapping workshops aims to not only increase the knowledge of participants through drawing-based activities, but also increase personal agency in affecting behaviour change.

References

- Almeleh, C. (2004). The Longlife AIDS-Advocacy Intervention: An exploration into Public Disclosure. *CSSR Working Paper No. 96*. Cape Town: Centre for Social Science Research. University of Cape Town.
- Ashforth, A. & Nattrass, N. (2006). Ambiguities of 'Culture' and the Antiretroviral rollout in South Africa. *CSSR Working Paper No. 156*. Cape Town: Centre for Social Science Research. University of Cape Town
- Baumgartner, L.M. (2000). *The Incorporation of HIV/AIDS into Identity over Time*. Doctor of Education. University of Georgia. Michigan: Bell & Howell Information and Learning Company
- Baumgartner, L.M. (2001). *The Incorporation of HIV/AIDS into Identity over Time: Transformational Tales Continued*. Paper presented at the Annual Meeting of the Adult Education Research Conference
- Belenky, M., Bond, L.A. & Weinstock, J.S. (1997). 'A Tradition that has no name'. *Nurturing the development of People, Families and Communities*. New York: Basic Books
- Brookfield, S.D. (2005). *The Power of Critical Theory: Liberating Adult Learning and Teaching*. San Francisco: Jossey-Bass
- Campbell, C. (2000). Social Capital and Health: Contextualising Health Promotion within Local Community Networks. In Baron, S., Field, J. & Schuller, T. (Eds). *Social Capital: Critical Perspectives*. Great Britain: Oxford University Press. Pp. 182-196
- Campbell, C. & MacPhail, C. (2002). Peer Education, gender and the development of critical consciousness: participatory HIV prevention by South African Youth. *Social Science & Medicine*, 55, 331-345.
- Campbell, C. (2003). 'Letting them Die': Why HIV/AIDS prevention programmes often fail. South Africa: Double Storey Books
- Clark, C. & Wilson, A. (1991). Context and Rationality in Mezirow's theory of transformational learning. *Adult Education Quarterly*. 41(2), 75-91

- Clark, S. (2006). Aids NGOs must show their worth. *Mail & Guardian*. Retrieved July 20, 2006, from http://www.mg.co.za/articlePage.aspx?articleid=261928&area=/insight/in_sight__comment_and_analysis/
- Collard, S. & Law, M. (1989). The Limits of perspective transformation: a critique of Mezirow's theory. *Adult Education Quarterly*. 39, 99-107
- Cornwall, A. (1992). Body mapping in Health RRA/PRA. *RRA Notes*. 16, 27-30. London: International Institute for Environment and Development.
- Cornwall, A. & Jewkes, R. (1995). What is Participatory Research? *Social Science Medicine*. 41 (12), 1667-1674.
- Courtenay, B., Merriam, S., Reeves, P. (1998). The centrality of meaning making in transformational learning: how HIV-Positive adults make sense of their lives. *Adult Education Quarterly*. 48(2), 65-84.
- Craig, G. & Mayo, M. (Eds). (1995). *Community Empowerment: A Reader in Participation and Development*. London: Zed Books
- Dlamini, P. (2006). 'Men-friendly' HIV/Aids facilities needed in SA. *Cape Times Review*, Tuesday February 28.
- Freire, P. (1997). *Pedagogy of the Oppressed*. New York: Continuum Publishing.
- Groenewald, Y. (2005). Why South Africa needs to hear more about AIDS. *Mail & Guardian*. Retrieved July 20, 2006, from http://www.mg.co.za/articlePage.aspx?articleid=259531&area=/insight/in_sight__africa/
- Helman, C.G. (2nd ed.). (1990). *Culture, Health and Illness*. Great Britain: Wright
- Human Sciences Research Council. (2005). *South African HIV Prevalence, HIV Incidence, Behaviour and Communication Survey*. Cape Town: HSRC Press.
- Integrated Regional Information Networks. UN Office for the Coordination of Humanitarian Affairs. (2003) *Memory Boxes help to say goodbye*. Retrieved August, 8, 2006 from

http://www.irinnews.org/report.asp?ReportID=37492&SelectRegion=Southern_Africa&SelectCountry=AFRICA

- Karkou, V. & Glasman, J. (2004). Arts, education and society: the role of the arts in promoting the emotional wellbeing and social inclusion of young people. *Support for Learning*. 19(2), 57-65.
- Liddell, C., Barrett, L. & Bydawell, M. (2005). Indigenous representations of illness and AIDS in Sub-Saharan Africa. *Social Science & Medicine*. 60, 691-700
- Madikida, C. (2005). Exhibition 'Status' at Michael Stevenson Gallery, Cape Town, South Africa. Retrieved August, 22, 2006 from <http://www.michaelstevenson.com/contemporary/exhibitions/churchill/status.htm>
- Makgela, N. (2005). Lovelife's solo MO. *Mail & Guardian*. Retrieved July 20, 2006, from http://www.mg.co.za/articlePage.aspx?articleid=258015&area=/aids_report/aids_rep_insight/
- McDonald, M. Antunez, G. & Gottemoeller, M. (1999). Using the Arts and Literature in Health Education. *International Quarterly of Community Health Education*. 18(3), 269-282.
- Mezirow, J. (1991). *Transformative Dimensions of Adult Learning*. San Francisco: Jossey-Bass.
- Mezirow, J. & Associates. (2000). *Learning as Transformation: Critical Perspectives on a theory in Progress*. San Francisco: Jossey-Bass.
- Minkler, M & Cox, K. (1980). Creating Critical Consciousness in Health: Applications of Freire's Philosophy and Methods to the Health Care Setting. *International Journal of Health Services*. 10 (2), 311-322
- Minkler, M. & Wallerstein, (Eds). (2003). *Community-based Participatory Research for Health*. San Francisco: Jossey-Bass.
- Morgan, J & the Bambanani Women's Group. (2003). *Longlife: Positive HIV Stories*. South Africa: Double Storey Press

- Morrow, R.A. & Torres, C.A. (2002). *Reading Freire and Habermas: Critical Pedagogy and Transformative Social Change*. New York: Teachers College Press
- Nattrass, N. (2004). *The Moral Economy of AIDS in South Africa*. Cambridge: Cambridge University Press
- Nattrass, N. (2005). Who consults *sangomas* in Khayelitsha? *Social Dynamics*. 31(2), 161-182
- Plumb, D. & Berringer, B. (2003). *Sharing AIDS: Cultural Learning in Communities of Practice*. Canadian Association for the Study of Adult Education. Online Proceedings 2003.
- Preece, J. & Ntseane, G. (2004). Using adult education principles for HIV/AIDS awareness intervention strategies in Botswana. *International Journal of Lifelong Education*. Vol. 23. No 1.pp 5-22
- Scott, J.C. (1985). *Weapons of the Weak: Everyday Forms of Peasant Resistance*. USA: Yale University Press
- Smart, T. & Sherriff, L. (2006). Getting the most prevention and care out of programmes for the prevention of mother-to-child transmission. *HIV & AIDS Treatment in Practice*, 70, 14th July 2006. Retrieved July 19, 2006, from <http://www.aidsmap.com/en/docs/9680F328-82CC-48D8-8A32-440CB7786733.asp>
- Sontag, S. (1989). *Aids and its Metaphors*. New York: Farrar, Straus, Giroux
- Taylor, E.W. (2000). Analyzing Research on Transformative Learning Theory. In Mezirow, J. & Associates, *Learning as Transformation: Critical Perspectives on a theory in Progress* (pp. 287-348). San Francisco: Jossey-Bass.
- Taylor, E.W. (1998). *The Theory and Practice of Transformative Learning: A Critical Review*. ERIC Clearinghouse on Adult Career and Vocational Education. Columbus: Ohio State University
- Taylor, V. (1995). Social Reconstruction and Community Development in the Transition to Democracy in South Africa. In Craig, G. & Mayo, M. (Eds.), *Community Empowerment: A Reader in Participation and Development*. London: Zed Books. pp168-180.

UNAIDS/WHO. (2005). *AIDS Epidemic Update, December 2005*. Joint United Nations Programme on HIV/AIDS and World Health Organisation. UNAIDS/05.19E

Wreford, J. (2005). Missing Each Other: Problems and Potentials for Collaborative Efforts between Biomedicine and Traditional Healers in South Africa in the Time of AIDS. *Social Dynamics*. 31(2), 55-89