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# The Potential of Visual and Participatory approaches to HIV literacy in South Africa



Annabelle Wienand

Supervisor: Professor Michael Godby

Faculty of the Humanities

University of Cape Town

2007

# **The Potential of Visual and Participatory approaches to HIV literacy in South Africa**

Annabelle Wienand

WNNANN001

A dissertation submitted in fulfillment of the requirements for the award of  
the degree of Master in Historical Studies

Faculty of the Humanities

University of Cape Town

2007

## **COMPULSORY DECLARATION**

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signed by candidate

This study is dedicated to my parents - thank you for showing me that ideas matter.

University of Cape Town

## Abstract

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An estimated 18.8 % of South African adults aged 15-49 are currently living with HIV. While HIV literacy campaigns and other strategies have aimed to reduce HIV incidence, there remains a general lack of knowledge of the biomedical nature of the disease. This not only inhibits attempts to reduce HIV transmission, but also discourages voluntary counseling and testing (VCT), accessing clinic care and the uptake of antiretroviral therapy. This dissertation identifies the essential role played by community health workers and treatment activists who offer 'HIV literacy' in their communities and assist the formal health care system. The aim of this study was to complement these initiatives with the development and analysis of a visual and participatory HIV literacy workshop.

The central focus of the workshop was the creation of life-size drawings based on tracing around a human body. These 'body map' drawings enabled the participants to develop their knowledge of human biology and discuss social issues related to HIV in a series of participatory exercises. The 'train-the-trainer' approach to the workshop served the dual purpose of increasing the participants' knowledge and enabling them to replicate exercises in their daily work. The workshop was conducted with a sample of forty participants from three separate groups (community health workers, treatment literacy educators/trainers and HIV-positive mothers). It was evaluated using a mixed method, but relied on a predominantly qualitative approach including multiple-choice questionnaires, participant observation, analysis of the body map drawings and semi-structured in-depth interviews. This data assessed the participants' responses to the biosocial content of the workshop, as well as the efficacy of visual and participatory training methods.

While most of the participants had been previously exposed to the biomedical content of the workshop, the use of visual and participatory tools and techniques was something new and received positive appraisal. A visual and collaborative learning style was found

to be effective because it presented the material in a practical and straightforward way that people could readily apply to their lives and work environments. The significance of this finding is that visual and participatory approaches to HIV literacy are shown to have the potential to help facilitate a better and more in-depth understanding of HIV prevention and treatment. Given the small size of the sample group, further research is needed into the value of visual and participatory learning methods in the field of HIV in order to verify and extend the findings to South Africa's general population.

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## Acknowledgements

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This dissertation never would have happened without the support of Professor Nicoli Nattrass and funding from the AIDS and Society Research Unit (ASRU) in the Centre for Social Science Research. I am hugely indebted to Professor Nattrass for taking me on as a 'wild card' Fine Art student and welcoming me into the social science fold. The last two years have been very happy – thanks for giving me the opportunity to grow academically and to see the world in new ways. Thank you to Professor Godby for the clarity and structure he brought to the process of writing, for supporting me through the different phases of the project and for encouraging me to return to academia.

I would also like to thank Libbi Downes and Kathy Forbes for guiding me through the intricacies of red tape and for being so kind and generous with their time. Thanks to my colleagues and friends at ASRU for their laughter and energy – especially Brendan Maughan-Brown, Colin Almeleh and Elizabeth Mills for helping me think more clearly. Thank you also to Nondumiso Hlwele who has been there always with a smile and answered so many questions - *hamba kakuhle mhlobo wam*.

I am also indebted to Pauline Jooste and Dr. Madri Carstens from HOPE Cape Town for giving me the go-ahead to facilitate the body map drawing workshop. The same applies to Ntombi Mfiki from TAC – especially for her encouragement and for inviting me to join the regional training week in 2007. This dissertation never would have reached this stage without the participation and enthusiasm of the workshop participants – I cannot thank them enough for the energy they brought to the process, the time they generously spent on interviews and the insights they gave me. I am humbled by the hard work they continuously do in very difficult circumstances and which often goes unrecognised.

Thank you to my friends and family who have listened to me, even when it wasn't clear to them what I was consumed with. Special thanks to Lucy Kemp for being my 'sister in arms', enlarging my ethnic fabric collection, feeding me red wine and for keeping me on track. Finally, I thank David Mercer for taking me into the mountains and up rock faces, making me laugh and for being there constantly.

## **Abbreviations**

<b>AIDS</b>	<b>Acquired immunodeficiency syndrome</b>
<b>ARK</b>	<b>Absolute Return for Kids</b>
<b>DOH</b>	<b>Department of Health</b>
<b>HAART</b>	<b>Highly Active Antiretroviral therapy</b>
<b>HIV</b>	<b>Human immunodeficiency virus</b>
<b>HOPE</b>	<b>HIV Outreach Programme and Education</b>
<b>MSF</b>	<b>Medécins Sans Frontières</b>
<b>MTCTP</b>	<b>Mother-to-child-transmission-prevention</b>
<b>NGO</b>	<b>Non governmental organisation</b>
<b>NSP</b>	<b>National Strategic Plan for HIV/AIDS and Sexually Transmitted Infections 2007-2011</b>
<b>PEPFAR</b>	<b>United States President's Emergency Plan for AIDS Relief</b>
<b>STI</b>	<b>Sexually transmitted infection</b>
<b>TAC</b>	<b>Treatment Action Campaign</b>
<b>VCT</b>	<b>Voluntary Counselling and Testing</b>
<b>WHO</b>	<b>World Health Organisation</b>
<b>UNAIDS</b>	<b>The Joint United Nations Programme on HIV/AIDS</b>
<b>UNFPA</b>	<b>United Nations Population Fund</b>
<b>UNISA</b>	<b>University of South Africa</b>

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# Chapter 1

## South Africa's AIDS epidemic

In 1994 South Africa celebrated its new democracy after decades of struggle against the apartheid regime. As South African citizens enjoyed the freedoms so long denied them an unprecedented, but not entirely unexpected, crisis began to take hold of the country. While HIV prevalence measured less than 1% in 1990, according to the ASSA2003 model, by 2007 11% of the population (and 20% of adults) was HIV positive (DOH, 2001; ASSA, 2003). Some have argued that AIDS was an 'epidemic waiting to happen' in South Africa due to the coexistence of poverty, rapid urbanization, migrant labour (both internal and from the rest of Africa), conflict, gender inequality and the breakdown of social norms (Marks, 2002; Delius & Glaser, 2002; Stillwaggon, 2002; Iliffe, 2006). Nearly two decades ago 'high risk situations', including political, economic and social factors, were identified as being responsible for placing particular groups of people at high risk of HIV infection (Zwi & Cabral, 1991).

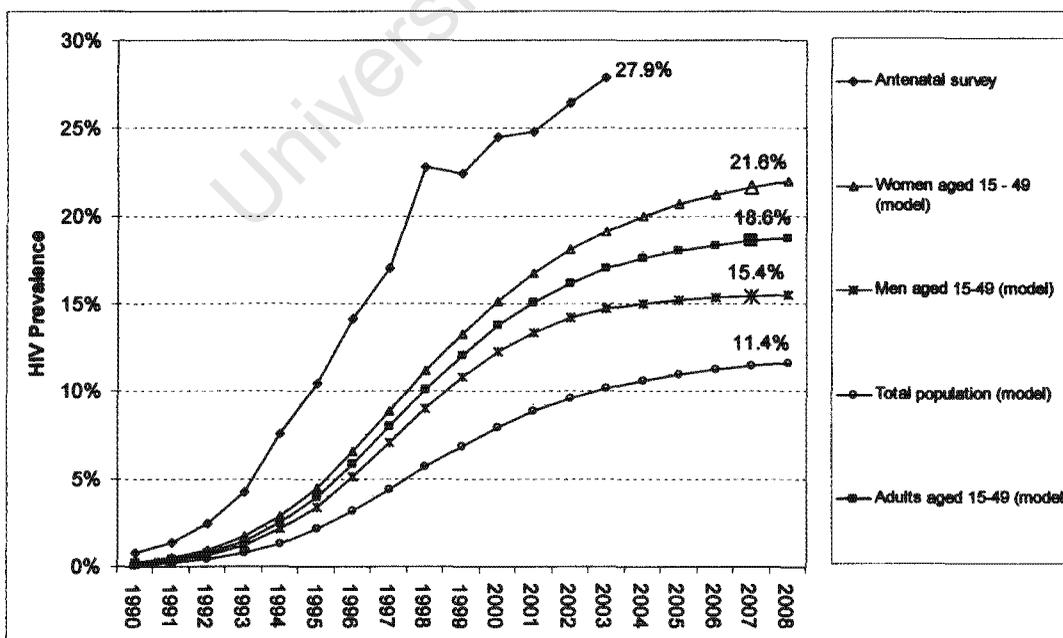


Figure 1.1 HIV prevalence in South Africa (Data obtained using the ASSA 2003 model)

The continued demand for effective HIV interventions in South Africa is testimony to the enormity of the challenge of readdressing the inequalities of the past, as well as current socio-economic and political obstacles. This chapter will discuss key factors that have shaped HIV/AIDS<sup>1</sup> in the country. It will also contextualize the HIV literacy workshop described in this dissertation within South Africa's AIDS epidemic.

## **Legacy of colonial and apartheid rule**

It is impossible to grasp present day social problems in South Africa, including the AIDS epidemic, without looking at the history of the country and its people. Particular laws, policies and structures such as migrant labour, segregation, forced removals, inferior education for 'non-whites' and institutionalized violence have had a lasting and devastating effect on South African society. Racially discriminatory policies of the past probably contributed to the spread of HIV within the impoverished, unemployed and predominantly black underclass of the country.

### **Homelands and migrant labour**

Among the most damaging aspects of colonial and apartheid rule was the destruction of social structures of indigenous cultures through the processes of Christianization, land dispossession and discrimination. The allocation of 13% of the land to the black South African population, while the remainder was reserved for white ownership was one of the principal ways that African society was undermined. The creation of so called 'homelands' modelled as tribally grouped reservations within the country sought to keep black South Africans from settling permanently in 'white' South Africa. The homelands were overcrowded, poorly resourced and the land soon became depleted and overgrazed. The lack of industrial development within the homelands also ensured that they served primarily as labour reservoirs for the industrialized cities of 'white' South Africa.

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<sup>1</sup> It has been suggested that using the term 'HIV/AIDS' is problematic because it links the two conditions and suggests an automatic and speedy progression from being HIV-positive to AIDS-related illness and death. This is not necessarily true, especially with the provision of antiretroviral therapy. Where possible I have avoided using the term 'HIV/AIDS' in the course of this dissertation, however this is not always practical.

While migrant labour was responsible for industrializing South Africa and developing its mineral wealth, the destructive side to this system was the erosion of African family and traditional life. It also created the ideal environment for the spread of infectious diseases, including sexually transmitted infections and HIV (Marks, 2002; Stillwaggon, 2002). Movement to urban areas became increasingly controlled with the implementation of pass laws, which served to enforce the institution of migrant labour where men would leave their families to work on the mines and in other industrial settings. Gone for most of the year, migrant workers would seek the companionship of casual sex partners or take on second wives in the urban areas, sometimes not returning at all.

Land dispossession resulted in a situation where agrarian incomes were no longer able to support families and rural livelihoods increasingly relied on money sent home (Hunter, 2007). The dependence on income from migrant work also put rural women at risk as they would take on casual relationships to put food on the table and to fill the place of absent partners (Parker, Easton & Klein, 2000). While only a relatively small number of black women originally moved to urban areas in the early part of the twentieth century, migration increased from the 1920s, and especially in the 1940s, as conditions in the rural areas deteriorated (Delius & Glaser, 2002; Seekings and Nattrass, 2005). Influx control and the pass laws controlled this movement to some extent, but could not prevent the growth of a large black urban working class by the 1970s (Seekings and Nattrass, 2005).

Recent studies have looked more critically at the effects of migration on the spread of HIV in South Africa. In particular, emphasis has been placed on looking beyond the stereotyped scenario of male migrants infecting their rural wives (Hunter, 2007; Lurie *et al*, 2003). Hunter (2007) cautions against over-simplifying a causal link between apartheid, the breakdown of African families and increased vulnerability to HIV infection. He argues that these factors were exacerbated by the political and economic crisis of the 1970s that marked an increasingly rapid rise in unemployment. He also draws attention to the adoption of a market-led economic policy by the post-apartheid government that has accentuated social inequalities. Large scale migration driven by economic needs continues to this day with the movement of both men and women to urban centres in search of employment.

The legacy of apartheid homelands, pass laws and influx control undeniably underlies current patterns of circular migration in South Africa, but it is the absence of both rural and urban livelihoods that has kept this process in action and has dramatically impacted on marriage, household formation, sexuality and the spread of HIV (Hunter 2007). Marriage has become less of a viable option for poor South African men who are increasingly unable to pay bride wealth (*ilobolo*) and be material providers. It is interesting to note that historically most young men initially engaged in migrant labour as a short-term way of accumulating bride wealth (Delius & Glaser, 2002). With over 40% unemployment, marriage has currently become a predominantly middle class institution with less than 30% of black South Africans in either civil or customary marriage (Hunter, 2007).

### Abandonment of culturally proscribed sexual norms

The decrease in marriage is indicative of a larger social transformation and the abandonment of traditional family norms and gender roles. Among these is the 'sexual socialization' for young people which used to take place in most South African cultural groups. Traditionally, most cultures strongly prohibited pre-marital pregnancy, but allowed forms of non-penetrative adolescent sex prior to initiation and marriage (Carton, 2006; Delius & Glaser, 2002; Iliffe, 2006). In some cases this was enforced with virginity testing and public humiliation and punishment for those youth who transgressed the norms. These forms of peer and inter-generational control began to lose currency during colonial times and were completely abandoned during the apartheid era. Furthermore, it has also been suggested that there was increasingly little incentive to respect parents who were degraded by racial discrimination and poverty and unable to offer inheritance of land and cattle or material security (Delius & Glaser, 2002). The humiliation experienced by the black adult population, as a result of apartheid policies and the racism and superiority it engendered in the white population, eroded individual self-worth as well as family structures.

Increased urbanization resulted in exposure to global urban youth culture which promoted fun-loving lifestyles dominated by music, fashion and freedom from parental control and censure. Unemployment and the limits of Bantu education also encouraged the formation of township gangs with a culture of violence, coercion and disregard for older generations. The

*tsotsi* gang culture awarded status to multiple sexual conquests, many of which were forced. This marked a growing culture of unequal gender relations where women were unable to protect themselves from unwanted sexual advances (Delius & Glaser, 2002). While gang culture was the one extreme of urban youth culture, increasingly permissive sexuality became the norm among other urban youth as they no longer subscribed to traditional norms. With this came increased pre-marital pregnancy and of course increased risk of sexual disease.

### Bantu education and 'liberation before education'

The Bantu Education system was inferior in many ways with over-crowding, poor teacher to student ratios, limited resources and low pass rates (Fedderke *et al*, 2000). But the most damaging aspect was its intention of stunting the educational development of black South Africans and preventing them from entering into the professional job market. In 1953 Bantu Education was instituted with the intention to provide the homelands with administrators, but it also set a clear limit on further academic development. The limits of the Bantu education system are perhaps most transparent in the allocation of funds where in 1976 R41 was spent per black school child, R177 per coloured child, R231 per Asian child and R621 on each white child (Johnson, 1979). While it has been argued that up until the mid-1970's an ethos of learning still prevailed in township schools, student frustrations were mounting (Delius & Glaser, 2004). The implementation of Afrikaans as a medium of instruction was strongly resisted, but knowledge of the inferior status of the education they were receiving and the limitations they would face once they left school also fuelled student protest (Johnson, 1979).

The 1976 uprising marked the beginning of a new era that resulted in the abandonment of education for many and increased political action built on the idea of 'liberation before education'. As young men and women curtailed their schooling and joined the political struggle, almost a generation of South African youth traded education for freedom from white, minority rule. A further blow to township schools was that many of the older teachers who were trained prior to the implementation of Bantu education left the profession after the Soweto uprising because of the shame of being associated with the apartheid system (Delius & Glaser, 2002).

While South Africa is indebted to the 'struggle' youth for bringing an end to apartheid, it now carries the burden of a large, uneducated and unemployed section of the adult population (Seekings & Nattrass, 2005). The 1994 elections heralded the end of the 'struggle' culture and in many respects marginalized the politicized youth (Delius & Glaser, 2002). Massive unemployment, even for those who completed high school, further alienated this group of South Africans with no prospect of improving their situation beyond unskilled, poorly paid jobs as manual labourers and domestic workers. Despite achieving political freedom, for millions of poor South Africans there has been little material or economic gain in the past fourteen years. It is this portion of South African society that carries the triple burden of poverty, unemployment and high rates of HIV infection.

### Unemployment, poverty and poor nutrition

Poverty impacts on individual and community health in two ways. Firstly, the physical environment, including poor nutrition, increased exposure to disease and inferior living and working conditions, makes people more prone to ill health (Stillwaggon, 2002). Poor nutrition compromises the body's immune system and makes it vulnerable to infection and illness. Protein and micronutrient deficiency dramatically increases vulnerability to all types of infection and disease, including sexually transmitted infections and HIV (Stillwaggon, 2002). Damp, crowded and unsanitary living conditions commonly experienced in South African informal settlements further limit the health of the urban poor by creating an environment where opportunistic infections, such as tuberculosis and pneumonia, are easily spread.

Secondly, individuals living in disadvantaged communities are under pressure to meet basic needs, such as food and shelter. Short term survival strategies seldom facilitate long term planning and limit the ability of individuals to make decisions advantageous to their health (Tawil *et al*, 1995, Campbell, 2003). This is particularly marked with a disease, such as HIV/AIDS, where there is a gap between infection and exhibiting signs of illness. Within these settings, HIV and AIDS are often perceived as less of a threat than other problems such as crime, hunger and unemployment which require immediate attention (Fenton, 2004).

Prior to the AIDS epidemic dominating global health issues, studies in different parts of the world have recorded a causal relationship between low-income and ill health and high death rates (Marmont, 2005). Within the context of HIV, the relationship between poverty and poor health and increased mortality is exaggerated. The fact that HIV prevalence in informal settlements has been recorded as nearly double the national norm emphasizes the link between impoverished communities, ill health and the spread of HIV (Shisana *et al*, 2002, 2005). Some scholars have argued that this suggests that sexual behaviour can only partly explain the discrepancies in HIV prevalence between different communities, because factors such as nutrition, sanitation and health care services also play an important role in increased vulnerability to HIV infection (Hunter, 2007, Stillwaggon, 2002; Furin, Walton & Farmer, 2005).

The rural poor are not exempt from facing similar health challenges to those in informal settlements. Unlike some of its poorer neighbours in Southern Africa, South Africa's epidemic was not restricted to the big cities and main transport routes, but quickly spread to the rural areas due to the mobility of people (Ilfie, 2006). The impact of migrant work on rural relationships has been previously discussed. Limited health care services available in rural areas, including voluntary testing and counselling and the provision of HAART, also negatively impact on rural health. A recent study in the Free State province of South Africa revealed that both urban and rural households affected by HIV were poorer to start with when compared to their unaffected neighbours (Bachmann & Booyesen, 2003). Households carrying the burden of illness related to HIV also experienced a substantial decline in income as they struggled to cover medical and funeral costs. This illustrates how poverty predisposes individuals and communities to illness and how ill health further impoverishes these households (Wagstaff, 2002).

In the course of this dissertation, health is framed not only with reference to individual well-being and the absence of disease, but also pertains to the kind of environment that individuals live in and how free they are to make decisions regarding their health. This is particularly important when looking at HIV and AIDS because of its inextricable link to sexual behaviour. The complexity of sexuality and the way that sex intersects with other social

issues, such as food security, poverty, education, gender inequality and violence all shape the way that HIV and AIDS affect different communities. This is clearly demonstrated by global HIV prevalence figures where certain parts of the world population, such as Southern Africa, are disproportionately affected by the AIDS epidemic (UNAIDS, 2006).

The unequal distribution of HIV prevalence has also resulted in growing consensus that any attempts to reduce HIV transmission need to go beyond the biomedical prevention paradigm and include social and economic empowerment (Green, 2003; Farmer, 2003; Eaton *et al*, 2003; Fenton, 2004; Campbell, 2003). The development of health enabling communities where individuals, particularly women, are free to make decisions about their sexual and reproductive health is essential to both HIV prevention and treatment (Campbell, 2003, Tawil *et al*, 1995).

### Women at risk: economics, culture and gender inequality

Throughout the world, women have been identified as being particularly at risk of HIV infection for a number of reasons, including their physiology and a host of socioeconomic and cultural factors (Pettifor *et al*, 2004; Hunter, 2002; Dunkle *et al*, 2004). Physiologically, women are at least twice as likely as men to be infected by HIV during unprotected sex (UNFPA, 2005). Women are at increased risk of contracting HIV as a result of circumstances including financial dependency on male partners, unemployment, transactional sex, violence, forced sex and rape. In sub-Saharan Africa an estimated 60-80% of HIV-positive women are infected by their husbands and sole partners (UNFPA, 2005). In South Africa, women are four times more likely to be infected with HIV than men. In 2005, HIV prevalence among young women was 17%, while among young men it measured 4.8% (UNAIDS, 2006).

Gender inequality has been identified as one of the key factors contributing to the spread of HIV (Zwi & Cabral, 1991; Delius & Glaser, 2002; Tawil *et al*, 1995). Unequal relations between men and women are most often accompanied by imbalanced access to economic and material security. Globally women represent 70% of people living in poverty, are less educated than men, work longer hours and have lower life expectancy (Gilbert & Walker,

2002). In South Africa, where unemployment rates are already exceedingly high approaching 40%, women are more likely to be without a job than men. The way economic dependence impacts on unequal gender relations is particularly marked among women living in poverty where money or gifts are the driving force behind many sexual relationships (Hunter, 2002; Dunkle *et al*, 2004; MacPhail & Campbell, 2001).

Increasingly, studies have looked at the transactional nature of sexual relationships between South African women and men (Hunter, 2002; Pettifor *et al*, 2004; Dunkle *et al*, 2004; Jewkes *et al*, 2001). These studies have distinguished prostitution from other sexual relationships where women have sex with men in exchange for rent, food, commodities (such as clothes and cellular phones) and also cash. In these instances both casual and long standing relationships are framed within the discourse of a love affair, as opposed to a business agreement. Many contradictory issues emerge when discussing transactional sex. For instance, women often view themselves as possessing agency in that they choose their sexual partners, but at the same time seem blind to the fact that they relinquish their ability to protect themselves from HIV infection and abuse (Hunter, 2002).

Another contradictory factor that influences heterosexual relationships is the construction of masculinity in a way that favours multiple sexual partners. In contrast to this, women are censured from having more than one boyfriend. This is despite both men and women acknowledging that in all likelihood, a woman will have more than one partner to meet her material needs. The paradoxes of unequal gender relations are further demonstrated in the violent ways that men 'discipline' girlfriends who are rumoured to have other partners (Hunter, 2002; Dunkle *et al*, 2004).

Transactional sex for subsistence purposes has tended to dominate the perceptions of why women enter into these kinds of relationships (Dunkle *et al*, 2004). This is most profoundly obvious in informal settlements, as opposed to more established and relatively wealthier townships where young women engage in relationships with 'sugar daddies' in order to access desirable consumer goods (Hunter, 2002). Hunter (2002) revealed that style, fashion and other examples of consumerism among township youth was a driving force behind sexual

relations. The tragedy and incongruity of this situation is that young women put themselves at risk of HIV infection by engaging in sexual partnerships in exchange for consumer items that make them more desirable for future partners.

Apart from transactional sex, another dominant aspect of gender inequality is the way both men and women frame relationships in largely patriarchal terms. The view of masculinity being affirmed by multiple sexual partners is often justified in terms of a polygamous cultural tradition, but in doing so fails to account for the material and economic forces that have undermined other forms of manhood, such as paying *ilobolo* when entering into marriage (Hunter, 2002, 2005). Furthermore, in calling on cultural traditions that supposedly demand that men have more than one partner, these justifications tread very close to other racist perceptions of an innate promiscuous African sexuality. Despite the fact that African men do not report more lifetime sexual partners than men in other parts of the world, the practice of having multiple and concurrent sexual partners has been isolated as one of the main reasons why HIV prevalence in Southern Africa is so high, (Halperin & Epstein, 2004). High levels of HIV prevalence among women reporting one lifetime sexual partner underscores the consequences of their partners' actions (Pettifor *et al*, 2007).

Many studies have revealed the extent that violence and forced sex dominate sexual relationships in South Africa (Pettifor *et al*, 2004; Gilbert & Walker, 2002; Wood *et al*, 1998; Jewkes *et al*, 2001; Varga, 1997). A decade ago, Varga (1997) recorded that over half the women in her study had refused sexual advances in their most recent relationship, but 71% reported their attempts had failed due to physical coercion, abuse or threats. Jewkes and colleagues (2001) reaffirm the high number of women, especially young women, who report coercion, forced sex and rape. The way that violence has been normalized in heterosexual relationships (Jewkes *et al*, 2001; Wood *et al*, 1998) marks the extreme nature of unequal gender relations in South Africa. The very existence of a term such as 'forced sex', which is differentiated from rape, demonstrates the extent to which unconsensual sex with a regular partner has been normalised.

Another factor contributing to unequal gender relations in South Africa is that historical and economic reasons have limited the majority of women's education opportunities. In 1995, 23% of black South African women had no formal education and 31% reported pregnancy to be the chief reason they stopped school (Gilbert & Walker, 2002). Sexual harassment of girls at school is also a problem. Thirty-one percent of children reported that boys harass girls at school, while 8% claimed that male teachers made sexual advances on girls (Shisana *et al*, 2005). Higher education increases women's ability to be economically independent, which often enables them to enter into more egalitarian relationships. Jewkes (2002) suggests that better educated women experience less domestic violence, but conversely such empowerment can also expose women to violence since their partners may not approve of their increased liberal attitudes towards gender roles.

Parents play a major role in shaping their children's ideas of gender roles and relationships. The disruption of black South African families due to the systems of migrant labour and the institution of homelands has been previously discussed. The forced removal of 'non-whites' as a result of the Group Areas Act also contributed to mass upheaval and dislocation. The absence of fathers in the rural areas resulted in young people, especially sons, growing up without a paternal role model. While it is important not to transfer ideas of a 'Western' nuclear family onto African family structures, the disruption of African families also isolated extended family and grandparents who traditionally assisted in child rearing. The current predominance of mother headed households in both rural and urban areas is further indication of how traditional household structures have been abandoned due to socioeconomic and political pressures (Hunter, 2007).

## Conclusion

This section has focused on some of the key links between the history of South Africa and current socioeconomic conditions that continue to make poor, black South Africans vulnerable to HIV infection. In this way the structures of apartheid are seen to have set in motion a continuum of disadvantage that is difficult to reverse given the entrenched nature of some of the social problems, such as massive unemployment and wide spread poverty. In short, there are few post-apartheid options for South Africa's poor who lack the skills and

means to change their life circumstances. The lasting legacy of apartheid and colonial rule, combined with more recent economic, political and social developments assert the spread of HIV infection as a systemic social problem. This argument does not deny the relationship between sexual behaviour and the spread of HIV. Rather it encourages situating this relationship within the breakdown of social networks and cultural norms in the face of economic survival strategies.

### **The problem of leadership**

As the liberation movement took over the governance of the country it inherited a host of social challenges including poverty, unemployment, housing shortages and large discrepancies between the privileged and the poor. South Africa also needed to address its recent violent political past. The tenets of the Truth and Reconciliation Commission pointed to a new style of political leadership and in many ways shaped the identity of the new South Africa. However, by the time Mbeki was voted in as South Africa's second democratic president, the effects of HIV/AIDS were also shaping the country and demanded immediate attention.

Despite numerous reports that highlighted the urgency of the situation with figures revealing rising levels of HIV prevalence within the country, the government continued to stall implementing a national strategy to address the AIDS epidemic. The 2002 Nelson Mandela/HSRC Study of HIV/AIDS (Shisana *et al*, 2002) was the country's first nationally representative household HIV survey. Up until this point estimates had been calculated using data collected at pre-natal clinics. The study provided conclusive evidence that HIV infection was on the rise, with some urban areas recording 28% prevalence (Shisana *et al*, 2002). Equally alarming was the doubling of the number of deaths among South Africans aged 25-44 years between 1997 and 2002 (Marais, 2005). Following the HSRC study, Statistics South Africa's mortality report reaffirmed the astonishing rise in deaths. The main causes of death included those diseases and conditions most commonly associated with poverty, including tuberculosis, HIV/AIDS, diarrhoea and malnutrition. All this had occurred within a period of increased economic growth and service provision.

Up until this point the government's position on HIV/AIDS had been characterized by prevention education. While neighbouring countries, such as Botswana, implemented antiretroviral programmes to prevent mother-to-child HIV transmission, the South African Department of Health argued that antiretroviral therapy was too expensive (Nattrass, 2007). Concerns were also raised about the ability of people in resource-poor environments being able to adhere to highly active antiretroviral therapy (HAART) and thus developing resistance to first line regimens<sup>2</sup>. A major factor contributing to the delay to providing antiretroviral therapy was the alignment of top government leadership with dissident AIDS scientists and denialists who questioned, among other things, the link between HIV and AIDS and the efficacy of HAART (Nattrass, 2007). The emphasis on poverty as the cause of AIDS-related illnesses, as opposed to framing it as a key contributing factor, challenged mainstream science that argued AIDS was the result of a retro-virus. Debate raged as better nutrition and poverty alleviation were posited as the best way of approaching the HIV/AIDS crisis.

While the HSRC and Statistics South Africa reports clearly documented the relationship between poverty and mortality, they also highlighted the increase in AIDS-related deaths. The severity of the AIDS epidemic in South Africa could no longer be questioned. President Mbeki 'withdrew' from the public debate on AIDS in October 2000, yet his Health Minister continued to resist the introduction of antiretrovirals. In 2002, a constitutional court ruling forced the government to provide antiretroviral treatment to pregnant mothers in order to prevent vertical HIV transmission to their infants. The court ruling on the implementation of a mother-to-child-transmission-prevention (MTCTP) programme in South Africa was the result of sustained action by civil society lead by the Treatment Action Campaign (TAC). The fact that MTCTP policy had to be resolved in court also is illustrative of the ideological differences over antiretrovirals that were being fought with regards to AIDS policy in South Africa.

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<sup>2</sup> Highly active antiretroviral therapy includes a combination of three different drugs. First line regimens include drugs such as D4T, 3TC, Efavirenz, AZT, Nevirapine, DDI and Kaletra. Many of these drugs have cheap generics available. Second line regimens are generally more expensive and offer fewer generic options.

While the reasons for President Mbeki's initial questioning of the science of HIV/AIDS are complex, what does become clear is '...how phenomena as traumatic as AIDS inevitably serve also as arenas for contests between rival systems of knowledge and rival claims to 'truth'. It has shown that these skirmishes are always also distillations of other political and ideological struggles' (Marais, 2005:21). The tussle between the AIDS denialist camp and those promoting conventional scientific explanations of HIV/AIDS perhaps demonstrated an unwillingness to accept 'Western' scientific solutions in an African context. Given the history of the nefarious misuse of biomedicine and science during colonial and apartheid rule, it is perhaps not surprising that an African leader should want to question this tradition. However, to position conventional AIDS science as a product of 'pharmaceutical company monopoly' and as 'un-African' is to deny the African lives that have been saved in other countries like Uganda, Botswana and Namibia where prevention and medical treatment, including HAART, go hand-in-hand. It is also to deny the fact that African people are comfortable using both 'biomedical' and 'traditional' medical systems in their eclectic search for health (Nattrass, 2005). According to Nattrass (2007), AIDS denialism delayed the use of antiretrovirals for both HIV prevention and AIDS treatment and was responsible for hundreds of thousands of unnecessary HIV infections and AIDS deaths.

The main challenge to the ideology that informed the Mbeki government's stance on HIV/AIDS came from grassroots and civil society activists, including groups such as the TAC, Médecins Sans Frontières (MSF), academics and scientists. These groups demanded a biomedical approach to HIV/AIDS in South Africa and in particular fought for the provision of antiretrovirals for both MTCTP and HAART as part of a comprehensive plan to combat the spread of the disease and provide care and treatment to those living with HIV. It was the TAC who filed the successful constitutional court application resulting in the government being ordered to provide the antiretroviral drug Nevirapine to pregnant mothers on a national scale in 2002. Following this success the TAC turned its focus on the human rights dimension to HIV and argued that the government had an obligation to provide antiretroviral treatment (in the form of HAART) to all its citizens and not just HIV-positive mothers. In November 2003, the government finally bowed to public pressure and announced its commitment to a national treatment provision plan.

Unfortunately, the subsequent public sector HAART rollout did not immediately end the debate on how best to treat and care for people living with HIV. Health Minister Tshabalala-Msimang continued to describe antiretrovirals as 'toxic' and to promote vitamin supplements and foods such as garlic, beetroot, olive oil and lemon as alternative ways of treating AIDS illnesses. Poor nutrition weakens the immune system and increases the likelihood of infection. In the context of HIV and AIDS, poor nutrition compromises immunity and increases the chance of acquiring opportunistic infections, which in turn leads to further deterioration in nutrient status (ASSAF, 2007). The same report (ASSAF, 2007) also reaffirms that nutritional approaches to ameliorating the affects of TB and other opportunistic infections associated with AIDS illness must be part of a comprehensive and integrated approach including public health care provision.

Tshabalala-Msimang's support of entrepreneurial business people (Matthias Rath, Tine can der Maas, Zeblon Gwala) selling vitamins and other products as alternative treatment for HIV and AIDS further confused public opinion on antiretroviral therapy (Nattrass, 2007). While it is true that HAART can have fatal side effects, these can be managed if and when they occur. A study in Khayelitsha township revealed that 8.4% of all patients who were on different triple therapy<sup>3</sup> combinations had to change their first regimen because of drug intolerance, mainly due to patients needing to start TB treatment (Coetzee *et al*, 2004a).

Furthermore, with 86.3% of the patients remaining alive after two years, the clinical outcomes of this study are comparable to first world settings in Canada and the USA where patients had similarly low CD4 counts<sup>4</sup> (Coetzee *et al*, 2004a). Over half the Khayelitsha patients had CD4 counts lower than 50. According to previous work in Cape Town, South Africa, the median survival rate of people with CD4 counts lower than 50 is less than twelve months (*ibid*). The study also reported adherence rates to HAART that are on a par with rich

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<sup>3</sup> When antiretroviral therapy first became available it consisted of a single drug type (mono therapy). HAART consists of a combination of three different drugs and is known as triple therapy.

<sup>4</sup> A CD4 count is used to measure how healthy a person's immune system is and determine the stage of AIDS-related disease progression. According to the WHO, Stage 1 and 2 are largely asymptomatic. During Stage 3 the patient's CD4 count drops as they experience increased opportunistic infections and illness. Stage 4 is defined as being AIDS-sick and the patient's CD4 count is usually below 200. Antiretroviral therapy is usually administered at this point.

countries of the North, revealing that antiretroviral therapy can be successfully provided and adhered to in resource-poor settings in the South. Another South African study investigating the effects of antiretroviral therapy concluded that even in resource-poor environments, HAART patients' health-related quality of life improved and side effects appeared to have a negligible impact on their well-being (Jelsma *et al*, 2005).

During this period, the TAC, MSF, ARK and other groups sought to provide the South African public with information about the biomedical nature of HIV/AIDS, as well as the benefits of HAART. The TAC in particular increased efforts to make the science of HIV available in communities worst hit by the epidemic by training volunteers as 'treatment literacy practitioners' to bring knowledge into clinics, support groups, municipal meetings and other settings. Activists also campaigned door-to-door to combat the confusion around HAART and provide accurate information on treatment options. Posters were used to answer commonly asked questions pertaining to the efficacy of antiretroviral treatment and address other issues such as the use of traditional medicine. Organizations providing antiretroviral therapy in partnership with government clinics, such as Médecins Sans Frontières (MSF), Absolute Return for Kids (ARK) and HIV Outreach Programme and Education (HOPE), also trained and employed lay people from communities to act as HIV educators and community health workers.

The 2006 16<sup>th</sup> International AIDS Conference in Toronto marked a low point for the country's efforts to addressing HIV/AIDS. The South African stall displayed a variety of fruit and vegetables and vitamin supplements with the marked exclusion of antiretroviral medication, which according to reports was later added after initial protests (Thom, 2006). The South African government's relatively poor performance with regard to rolling out HAART was sharply criticized at the conference. Despite protests by international and local lobby groups at the conference, Health Minister Tshabalala-Msimang continued to defend her promotion of vegetables and fruit by arguing that South Africans were free to choose their approach to treating AIDS-related illnesses. All the while South Africa's epidemic continued to grow. In 2006 an estimated 950 people died every day from AIDS-related diseases and a further 1400 were infected daily (Dorrington *et al*, 2006).

In the aftermath of the criticism received at the 16<sup>th</sup> International AIDS conference, a shift in South African AIDS policy was noted with the appointment of Deputy President Mlambo-Ncguka in September 2006 to lead the development of a plan to combat HIV/AIDS in South Africa. Mlambo-Ncguka was praised for her revival of the South African National AIDS Council, which had become largely defunct, as well as for forging new relationships with civil society. This coincided with the absence of Health Minister Tshabalala-Msimang from office due to health reasons. Deputy Health Minister Madlala-Routledge together with Deputy President Mlambo-Ncguka and the health department worked in collaboration with civil society, doctors, HIV specialists and other interest groups on the new National Strategic Plan for HIV and AIDS and Sexually Transmitted Infection 2007-2011.

The National Strategic Plan was approved by Cabinet in May 2007. Its broad aims are to cut the number of new HIV infections in half and to extend HAART coverage to 80% of those who need it by 2011 whilst also reducing the impact of HIV and AIDS on individuals, families, communities and society. The main challenges to its execution are the completion of the costing of implementation, together with continued monitoring and evaluation in order to achieve its goals of universal access to prevention, treatment, care and support (UNAIDS, 2007). Simply put, while the development of the new National Strategic Plan has been successful, the real challenge is the implementation of this policy.

Despite the promise of a new era for South African AIDS leadership exhibited in the writing of the National Strategic Plan (NSP), the firing of Deputy Health Minister Madlala-Routledge in August 2007 has cast serious doubt on the government's commitment to addressing the AIDS crisis, especially as far as antiretrovirals are concerned. For example, while Tshabalala-Msimang was on sick leave, the government agreed to rollout antiretrovirals in prisons. This agreement with the TAC was reneged upon when she returned to take up her post. Madlala-Routledge's dismissal resulted in protest both locally and internationally and re-inflamed civil society groups, such as the TAC, who were involved in drafting the NSP.

Aside from fears that the targets set by the National Strategic Plan will now be side-lined, many other serious challenges remain with regards to South African public health in general.

Recent investigation into the level of care available at public hospitals and clinics across the country have revealed cases of serious mismanagement, lack of funding and gross understaffing (Cullinan *et al*, 2006). Medical privatization has grown to such an extent that over two-thirds of South African doctors work full-time in the private sector serving less than 20% of the population who have health insurance (Benatar, 2005). The challenges of implementing the National Strategic Plan and providing treatment, care and support for people living with HIV are coupled with the urgent need to upgrade general health provision.

### Activism and education

From the start organizations such as the Treatment Action Campaign (TAC) and Médecins Sans Frontières (MSF) challenged the government's position on not providing antiretroviral therapy with protests and advocacy campaigns. These organizations mobilized both HIV-positive and HIV-negative people as they increased awareness of HIV/AIDS as a chronic, but treatable disease. A rights-based and biomedical approach to health and managing HIV/AIDS dominated the discourse of these members of civil society and was shared by other groups such as the media, medical practitioners, scientists and academics.

While the TAC's 'Defiance Campaign' of 2003 was characterised by 'sit-ins', marches and the signing of petitions during this period, their advocacy work also took on other forms. These included academic studies, the recording of the clinical outcomes of pilot antiretroviral programmes and also arts-based projects. The *Longlife* advocacy project was born out of collaboration between the MSF Khayelitsha clinic and the AIDS and Society Research Unit<sup>5</sup> (ASRU) from 2001-2003. It was this MSF clinic that was piloting HAART in order to test its efficacy in a resource-poor setting with high HIV prevalence. The Khayelitsha pilot study was chosen by the World Health Organisation (WHO) as a case study to illustrate how antiretroviral therapy can be successfully implemented in a primary health care setting (WHO, 2003).

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<sup>5</sup> The AIDS and Society Research Unit falls under the umbrella of the Centre for Social Science Research based at the University of Cape Town, South Africa.

The *Longlife* project aimed to raise awareness of the life-saving potential of antiretrovirals by documenting the life stories of thirteen HIV-positive women enrolled in the MSF pilot project. Their stories were unique because HAART was not generally available in the public health care sector at this time. The women were all Khayelitsha residents at the time and were either part of a mother-to-child-transmission-prevention programme or were themselves taking HAART therapy. Their testimonies disputed the argument that poor, uneducated people were unable to adhere to HAART by providing compelling evidence of how antiretrovirals had saved their lives and those of their children. Their stories recorded their return to good health, as well as the socio-economic conditions that had predisposed them to HIV infection in the first place.

Apart from interviews with the group, the *Longlife Project* was instrumental in the creation of life size paintings that came to be known as 'body maps' (Figure 1.2). These paintings were produced over a three month period assisted by the facilitation of Cape Town-based artist Jane Solomon and other counsellors and researchers based in ASRU. The body maps started with a tracing around the bodies of the women and were filled with detail pertaining to their lives, including understandings and experiences of health and illness. Using a series of exercises and prompts the women were encouraged to visualize their emotional and physical experiences of HIV and AIDS-related illnesses. The inclusion of metaphor and symbolism, alongside accurate renditions of pregnancy and organs in the human body served to capture a blend of biomedical and alternative understanding of health and illness. Some of the paintings recorded traditional medicine and home remedies, while others depicted antiretroviral treatment attacking the HI virus. The stories of the women ultimately took on the form of a book entitled *Longlife: Positive HIV Stories* (Morgan & Bambanani Women's Group, 2003) that made use of a blend of interview transcripts, the body maps created by the women and autobiographical photographs taken by the women.

Apart from serving a powerful advocacy function that promoted HAART in resource-poor settings, the body maps were testament to the demand of people living with HIV to understand their bodies and the nature of the virus that had infected them.



Figure 1.2 Four examples of body maps produced during the *Longlife Project*.

According to Jane Solomon, the women requested drawings of the anatomy and biology of the human body so that they could see what lay beneath their skin<sup>6</sup>. In response she provided material such as *Grey's Anatomy* and anatomical drawings by Leonardo da Vinci. Most of the women on the mother-to-child-transmission-prevention programme drew their pregnancies. Four of the women chose to draw their lungs after having experienced tuberculosis. Many of the women included some reference to the presence of the HI virus in their systems, sometimes accompanied with blood cells and antiretroviral treatment. Further evidence of understanding the nature of HIV and how it compromises the immune system was evident in the interview transcripts (Morgan & Bambanani Women's Group, 2003).

While the main intention of the *Longlife* project was advocacy and the provision of psychosocial support, I was intrigued by the potential of visual methods to communicate biomedical concepts to people living with HIV. This dissertation grew from my observation of the way the women involved in the *Longlife* project seemed to develop their understanding of their bodies and HIV/AIDS through drawing and seeing visual representations of human biology. I thus set out to explore this possibly more systematically through action-oriented research based on developing and running workshops.

### **Aims of the study**

The development and implementation of the workshop project described in this dissertation is built on the premise that ordinary people can, and more importantly want to, learn the science of HIV. One of the lasting legacies of colonial and *apartheid* rule is that a large number of South Africans lack basic education, including knowledge of human biology. Without knowledge of a circulation system, how can a person understand the existence of a virus? And without knowledge of viruses and other pathogens, how can a person make informed decisions with regards to their general health, and in particular the treatment and prevention of HIV?

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<sup>6</sup> Personal communication with Jane Solomon, 2005.

The project thus aimed to increase biomedical knowledge of the human body and HIV/AIDS so that people living with HIV could have a deeper appreciation of the health options available to them. This promotion of a biomedical understanding of the human body did not aim to discount the existence and importance of indigenous models of approaching health and illness. Rather, it aimed to make available information on human biology and other social issues related to HIV/AIDS so that people could make more informed decisions about their health. The workshop was designed to be used to train people working as treatment literacy educators and community health workers in existing organizations that provide HIV education, treatment literacy and care and support for people living with HIV. It aimed to serve the dual purpose of increasing the participants' biosocial understanding of HIV/AIDS whilst enabling them to use the workshop in contexts such as support groups, schools and clinics. By using participatory learning techniques and visual tools the workshop intended to encourage group learning, dialogue and creative thought as a way of promoting HIV literacy.

## **Chapter contents**

Chapter one has described key historical and contemporary factors that have shaped South Africa's experience of the AIDS epidemic as a way of contextualising the HIV literacy workshop described in this dissertation. Chapter two engages with the relevant literature that has informed the development of the visual and participatory workshop described in this project. Chapter three then provides the reader with an account of how the workshop was developed, implemented and evaluated. It gives a report of the workshop content and techniques, as well as a description of the workshop participants. Chapter four draws on interview data as a means of assessing and evaluating the workshop from the perspective of the community health workers, treatment literacy practitioners and HIV-positive mothers. In conclusion, chapter five addresses the limitations of my HIV literacy workshop. It also provides recommendations and looks to the possible future implementation of visual and participatory approaches to HIV literacy in South Africa.

## Chapter 2

# Approaches to HIV Literacy

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This dissertation evaluates an HIV literacy workshop based on visual and collaborative learning techniques. The workshop aimed to increase knowledge of human biology and HIV/AIDS, while taking into account some of the social aspects of disease in the South African context. The intention of the workshop was to enable ordinary people to make better informed health decisions by increasing their understanding of human biology and health. It did not seek to deny the role of other approaches to healing, such as indigenous traditions, but suggests that increased knowledge of the science of HIV empowers people and provides information that has been denied due to poor education. It is useful to situate this workshop project within past and current experiences of other AIDS interventions. This chapter thus reviews the relevant literature that informed the study in order to develop a new understanding of the dynamic relationships between HIV literacy, adult education and health management in the South African context.

The chapter begins with an assessment of some of the challenges facing different approaches to HIV literacy interventions. This is followed with a look at how the provision of HAART not only saves lives, but also empowers people living with HIV by increasing their knowledge and agency. In this way it is argued that the provision of HAART contributes to increasing HIV literacy in communities worst hit by the epidemic. The necessity of situating HIV interventions within existing cultural understandings and socio-economic conditions is also examined. This is followed by an evaluation of participatory approaches to HIV literacy. Finally, the advantages and limitations of visual tools and techniques used to increase knowledge about HIV/AIDS are assessed.

## The challenges of HIV Literacy

HIV literacy encompasses a wide range of approaches to increasing public knowledge about HIV and AIDS in an effort to curb new infections and provide care for HIV-positive people. In the past, campaigns have typically chosen to focus on a particular aspect of HIV literacy, such as prevention of HIV transmission or how to access antiretroviral therapy. This chapter argues that these various aspects to HIV literacy are inextricably linked and should rather be approached simultaneously. This is supported by studies that reveal the separation of prevention and care has severely limited effective responses to reducing the impact of HIV/AIDS (UNAIDS, 2003; Furin, Walton & Farmer, 2005).

Uganda's successful reduction of HIV prevalence from about 17% in the 1990s to 6.4% in 2006 has been both lauded and heavily debated (Wakabi, 2006). While many attribute the decrease in new infections to Uganda's ABC (Abstain, Be Faithful, Use a Condom) campaign, others suggest that the successful reduction is much more complex and was affected by the impact of conflict, dying off, migration and increased access to medical care (Farmer, 2003). Cohen (2003) also cautions that what happened in Uganda took place at a specific time and place and the ability to replicate it may not be successful. Furthermore, in addition to the 'ABC' campaign, there were also multiple other programmes taking place in Uganda at the time including efforts to reduce HIV related stigma, increase public awareness through education and the provision of voluntary counselling and testing (VCT) services (Cohen, 2003). Furthermore, it is worth noting that despite the initial 'success' at combating AIDS in Uganda, new HIV infections have been rising once again in recent years (Murphy *et al*, 2006).

The ABC approach to preventing the spread of HIV is built on three central tenets - abstain, be faithful and use a condom. It does not take treatment and care of people living with HIV into consideration. The rational argument that abstinence is the only sure way of protecting individuals from HIV infection is disrupted by the reality that in the African context women in particular have relatively limited control over their sexual relationships (Morah, 2007; Ntseane & Preece, 2005, Dunkle *et al*, 2004; Buvé *et al*, 2002, Wood *et al*, 1998). There is

extensive literature on women's subordinate status in many societies, but this is particularly evident in poor countries where institutionalized inequalities make women financially dependent on men and less able to negotiate partner fidelity or condom usage (Murphy *et al*, 2006; Dunkle *et al*, 2004). It is also in these very countries that HIV prevalence is highest. Farmer (2003) argues that risk of HIV transmission is inextricably linked to poverty. Another way of thinking about the relationship between high HIV prevalence and disadvantage is to regard the poor as the 'global risk group' (Farmer, 2003).

This calls into consideration the socio-economic factors that impact on people's sexual decision making, which are often closely tied to survival strategies. Farmer (1996) writes extensively on the ways in which vulnerability to HIV infection is the result of economic, social, political and cultural forces that over-power individual agency. This is summed up in the following argument that addresses people living with HIV and AIDS.

Their sickness may be thought of as a result of 'structural violence', because it is neither nature nor pure individual will that is at fault, but rather historically given (and often economically driven) processes and forces that conspire to constrain individual agency. Structural violence is visited upon all those whose social status denies them access to the fruits of scientific and social advances. (Farmer, 1996:23)

Farmer (1996) goes on to suggest that there is 'nothing wrong' with emphasizing the importance of personal agency in the fight against HIV and AIDS but argues that it is both unjust and unreasonable to apportion blame on those who are unable to protect themselves from HIV infection. He also notes that it makes little sense to compare strategies for decreasing HIV incidence to health campaigns in the developed world that address issues such as cigarette smoking and middle-class heart disease (Farmer, 1996). In order to develop meaningful HIV interventions, it is vital to look beyond the individual to the society they live in and take into account the socio-economic, cultural and political factors that shape their lives. Chapter one accordingly described how historical political, economic and social forces have shaped current conditions that continue to expose poor South Africans to increased risk of HIV infection.

The promotion of condom usage as an HIV intervention strategy has been challenged by both cultural and moral-based objections In Southern Africa. The call for abstinence until marriage has been promoted by faith-based organizations, traditionally-minded groups and projects funded by the United States President's Emergency Plan for AIDS Relief (PEPFAR) (Cohen, 2003). Multiple studies have revealed that condom usage within marriage or a 'love relationship' (as opposed to a casual sexual partner or client) is neither acceptable nor practiced (Morah, 2007; Bracher *et al*, 2004; Campbell, 2003). In these cases condom usage is believed to imply lack of trust between partners, promote promiscuous behaviour and deny an important aspect of traditional marriage, which is to have children. There is also evidence of increased violence against women partners, including wives, when they have suggested condom usage within a relationship (Dunkle *et al*, 2004; Jewkes *et al*, 2001; Varga, 1997).

The emergence of AIDS at a similar time to the promotion of family planning programmes in Africa contributed to a mistrust of condoms and gave rise to the belief that condoms were responsible for the spread of the virus (Kaler, 2004; Ntseane & Preece, 2005). The fact that available condoms are usually made from latex which is naturally pale in colour and predominantly imported has further emphasised the idea that they are a European invention and not in keeping with African bodies, beliefs or practices (Preece & Ntseane, 2004; Ntseane & Preece, 2005).

Green (2003) identifies the emphasis on risk-reduction (condoms, treating STIs) rather than risk avoidance through behaviour change (monogamy, abstinence, delayed onset of sexual activity) as the main cause of the failure of prevention campaigns in Southern Africa. He argues that the model of approaching AIDS as a medical problem needing medical solutions was essentially developed for high-risk groups in North American cities, such as intravenous drug users and men who have sex with men. In an attempt to be open-minded and limit discrimination towards these groups, this prevention paradigm did not address sexual behaviour. Green (2003) asserts that this approach cannot be applied to Africa where the experience of the epidemic is not limited to specific groups and is found in the general heterosexual population.

However, talking about and initiating changes in sexual behaviour has been both controversial and complex in the Southern African context. This has been particularly obvious in South Africa where the sexual link between HIV and AIDS has been questioned in order to resist racist perceptions of African sexuality (Marais, 2005). Given the history of colonial preoccupation with racialising sexual difference, epitomized in the case of Saartjie Baartman<sup>7</sup>, it is perhaps unsurprising that African leaders have wanted to put an end to depictions of African sexuality as over-active, primal and even violent (Robins, 2004). But it is equally important to speak frankly about current social problems, such as forced sex and rape, which not only weaken efforts to prevent the spread of HIV, but also undermine the very structure of society. Once again it is important to relate these behaviours to disrupted traditional family and social structures.

While the merits of addressing primary prevention as advocated by Green (2003) in the Southern African context are obvious, it also has to be acknowledged that behaviour change is dependent not only on the choices made by individuals, but also cultural and societal norms that to a large extent over-shadow individual decision making (Campbell, 2003). Farmer (2003) argues that it is perhaps more useful to see AIDS as a social problem with social solutions, as opposed to isolating sexual behaviour change. This is supported by the argument that individual behaviour change can only take place within 'health-enabling communities' (Campbell, 2003, Tawil *et al*, 1995). Such communities would have to address a range of factors that have an adverse effect on safer sexual practice. This is summed up in the statement that 'social conditions, rather than ignorance about HIV and its modes of transmission, are the primary determinants of risk in many of the poorest parts of the world.' (Furin, Walton & Farmer, 2005:294)

Given the link between social inequality and risk of HIV transmission, the validity of increasing knowledge of HIV as a key HIV intervention strategy in isolation of other socio-economic interventions may well be questioned. However, HIV literacy has to be the

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<sup>7</sup> Saartjie Baartman (1789-1816) was a woman of Khoisan origin who was taken to England where she was put under anatomical scrutiny and made to parade in shows as a sexual freak because of her enlarged buttocks and elongated labia. On her death she was further denigrated by being dissected, a cast made of her body and her brain and genitalia preserved for exhibit in the Musee L'Homme in Paris.

foundation of any effort to address prevention of HIV transmission and the provision of care and treatment for HIV-positive people – and besides, long-term social change on the required scale is beyond the scope, of this or any other individual project. While acknowledging the socio-economic limitations to health, it is vital that ordinary people are equipped with accurate knowledge about HIV/AIDS. It is a necessary, albeit not necessarily sufficient condition for, combating the AIDS epidemic. By enabling people to understand the science of disease, it is hoped that people will base their decisions on understanding the options available to them, and not simply because they have been told to behave in such a way or take a particular medication. They will thus have a stronger basis upon which to develop safer and more supportive behaviours.

Despite socio-economic conditions and cultural norms that can limit individual and community health, it is important to recognise that behaviour change is nevertheless possible. Recent studies have shown behaviour change to be one of the key factors behind a decrease in HIV prevalence in Zimbabwe, urban Kenya and urban Haiti (Hallet *et al*, 2006; Gregson *et al*, 2006; Mahomva *et al*, 2006). This suggests that even in adverse conditions, individuals are making decisions that are advantageous to their sexual health and that decrease their chances of contracting HIV. These changes include delayed onset of sexual activity among young people, reduction in number of casual sexual partners and increased consistent condom usage. In the case of Zimbabwe, Gregson and colleagues (2006) suggest that a well-educated population, together with early control of sexually transmitted infections (STIs), social marketing of condoms, VCT services and HIV literacy radio and television campaigns have all possibly contributed to positive behaviour change. This supports the hypothesis that education and knowledge about HIV/AIDS is necessary in order for individuals to protect themselves from HIV infection – and under some circumstances may even be sufficient. It also emphasizes the necessity for HIV literacy to accompany treatment and service provision including VCT and HAART.

Developing and assessing ways of disseminating knowledge about HIV is one of the key concerns addressed in the course of this dissertation. HIV literacy should be context specific and driven by local needs and lived experience. Information-only campaigns have been

criticized for centring on individual behaviour change without adequately taking into account existing cultural values and social norms and economic limitations. This chapter promotes the argument that prevention messages need to go hand-in-hand with the provision of care, education and HAART for people living with HIV. The following section looks at the relationship between HIV literacy and treatment provision together with VCT.

### **The impact of HAART and VCT on HIV literacy**

Despite the development of improved antiretroviral treatment options in North America in the early 1990's, prior to 2000 it was generally proposed that 'prevention is the only cure' within Sub-Saharan Africa (Hardon, 2005). The promotion of prevention in the absence of universal access to HAART also gained some notoriety in the South African context where it was argued that the provision of HAART was not only a human rights issue, but would also curb the rate of new infections. This is supported by studies that show that with the provision of HAART people are more willing to come forward for VCT, whereas without treatment there is little incentive for doing so (Mukherjee *et al*, 2003; Farmer *et al*, 2001). Farmer and colleagues recorded a 300% increase in VCT in rural Haiti after the introduction of HAART therapy (Farmer *et al*, 2001).

VCT plays a vital role in alerting HIV-negative individuals to possible risks of HIV infection, as well as informing HIV-positive individuals of their status. A major barrier inhibiting individuals testing for HIV is the perception that they are not at risk (Hutchinson & Mahlalela, 2006). This is confirmed by a nationwide study of South African attitudes towards HIV that found 60% of respondents did not think they were at risk of HIV infection and 51% of respondents who tested positive said they would 'probably' or 'definitely not' get infected by HIV in their lifetimes (Shisana *et al*, 2005). This highlights an urgent need to raise peoples' awareness of their vulnerability to HIV infection. It also reveals the dangers inherent in people not being aware of their status and how this assists the spread of the virus.

VCT is accompanied by pre- and post-test counselling which includes information on how HIV is transmitted and how to manage one's health as an HIV-positive person. It also addresses the psychological and emotional impact of discovering that one is HIV-positive. The importance of individuals knowing their HIV status relates to both prevention and treatment efforts. A recent study revealed that people who go through VCT are less likely to get infected or infect others because of adopting safer sex practices (Sweat *et al*, 2000). This is supported by a Malawian study where Morah (2007) found that HIV-positive people who are aware of their status have better knowledge about HIV/AIDS and report substantially higher safer-sex practice than those who do not know their HIV status. In another study on the use of VCT services in South Africa, it was revealed that 79% of women and 77% of men reported that they would inform their sex partner if they tested HIV-positive (Hutchinson & Mahlalela, 2006). This confirms not only the importance of VCT, but also the vital role HIV literacy plays when linked to the provision of health care services.

Apart from prevention, VCT also serves as an entry point into public health care services. This is particularly advantageous for HIV-positive people because they are able to access prophylactic medication for opportunistic infections, as well as HAART if necessary, before their health deteriorates. It is better to commence HAART before a patient is seriously ill, because mortality rates of people on HAART are higher among those who commence treatment with very low CD4 counts (Coetzee *et al*, 2004a).

VCT enables people to learn their HIV status, and based on this knowledge, make decisions about their future. Once people know their HIV-positive status they are usually encouraged to join a support group. Mabunda (2004) reveals the important role played by support groups, not only with providing emotional and psychological support, but also increasing knowledge of HIV. In her study, all but one of the participants belonged to a support group. Prior to joining a support group, all of the women exhibited a severe lack of accurate knowledge about the basics of HIV and AIDS, including not knowing the difference between HIV and AIDS and being unsure of how the virus is transmitted (Mabunda, 2004). Low levels of knowledge of HIV/AIDS are found throughout South Africa with 18.7% of young people between the ages 12-14 not understanding the sexual transmission of HIV and the

same percentage disagreeing or unsure if HIV causes AIDS. In the age group 50 years or older, 28.6% disagreed or were unsure if AIDS is caused by HIV. Across all age groups a third of all respondents disagreed, or were unsure if HIV infection could be reduced by having fewer sexual partners (Shisana *et al*, 2005).

Sexual behaviour change to prevent the spread of HIV/AIDS begins with people understanding how HIV is transmitted and what steps can be taken to prevent getting either infected, or re-infected in the case of sero-concordant HIV-positive couples<sup>8</sup>. For those who are living with HIV, other lifestyle choices also have to be addressed, such as limiting alcohol intake, maintaining a balanced diet, regular clinic visits and taking precautions when delivering home-based care. This is usually the focus of support groups for HIV-positive people. The attendance of a support group should not only increase knowledge about HIV and AIDS, but also develop self agency and enable people to take better care of their health and adhere to their medication. Ideally, HIV-positive support groups also serve to increase knowledge about HIV/AIDS in the general community by giving attendees information that they can relay back to their families and friends. However, Mabunda (2004) revealed that despite the positive impact that HIV literacy had on her rural participants, none of them chose to disclose their status to their families because they feared jeopardising these important relationships.

The importance of increasing health-related knowledge among people living with HIV is emphasized in a study conducted by Kalichman and colleagues (2000). The study revealed that poor health literacy acts as a barrier to healing and adherence to medication. It was also discovered that when compared to HIV-positive people with good health-related knowledge, HIV-positive people with lower health literacy have lower CD4 counts, higher viral loads, were less likely to access HAART, were hospitalized more frequently and reported poorer health (Kalichman & Rompa, 2000). These findings highlight the role played by HIV literacy in order to ensure improved health for HIV-positive people. Adherence to medication is especially pertinent with regards to HAART where resistance treatment limits the patients'

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<sup>8</sup> An HIV-positive person can be re-infected with a different strain of HIV if they have unprotected sex with another HIV-positive person. This can adversely affect their immune systems and the efficacy of antiretroviral therapy.

chances of living a longer and more productive life. There are also economic implications to resistance, since people who develop resistance to first-line regimen HAART will need to access more expensive, second-line treatment where fewer generic options are available.

Booyesen and colleagues (2007) conducted a study in the Free State Province of South Africa that highlighted that it is not access to HAART alone that enhances quality of life. Rather it is the broader health and social benefits associated with treatment, such as a decrease in stigma and the ability to access support and care within and beyond the health care sector, that have the greatest effect on the lives of people living with HIV (Booyesen *et al*, 2007). The study looked at overall life satisfaction and happiness as measures of general quality of life before uptake of HAART and then again at different intervals during treatment. It revealed that patients receiving HAART are significantly more satisfied with regards to their personal life and socio-political issues when compared with those awaiting treatment. This suggests not only an improvement in physical health, but also a greater sense of agency and control over one's life.

This section has focused on the relationships between the provision of HAART, voluntary testing and counselling and HIV literacy. It has suggested that the provision of HAART and VCT helps increase levels of HIV literacy. It also argues that VCT plays a vital role in preventing the spread of HIV by making people aware of their status and initiating positive sexual behaviour change (Morah, 2007; Hutchinson & Mahlalela, 2006). Participating in VCT also encourages people to join support groups where they can learn more about living positively with HIV and potentially accessing care, support and HAART (Mabunda, 2004). The provision of HAART increases patients' health-related quality of life, even in resource-poor settings (Jelsma, *et al* 2005; Booyesen *et al*, 2007). Most importantly HAART saves lives and enables people to return to being productive individuals with improved quality of life (Coetzee *et al*, 2004a; Jelsma *et al*, 2005; Booyesen *et al*, 2007; Badri *et al*, 2004).

## **African context specific interventions**

Increasingly there have been calls for African context-specific approaches to HIV education and prevention strategies (Chilisa, 2005; Ntseane & Preece, 2005; Airhihenbuwa & De Witt Webster, 2004.) This is summed up by the argument that ‘...educational research which excludes indigenous ways of knowing is most likely to fail to speak to and come up with research results that can enhance the quality of life of the researched communities.’ (Chilisa, 2005).

It has been suggested that local understandings of illness and health built on specific indigenous worldviews should be used as the starting point for HIV interventions in Southern Africa (Chilisa, 2005; Preece & Ntseane, 2004). The assumption that an American HIV campaign will be effective in Africa is as short-sighted as the assumption that all countries in Southern Africa face exactly the same challenges. It is vital to take into account cultural diversity even within country borders where different groups of people have different understandings of health and illness and HIV/AIDS (Chilisa, 2005). This approach to HIV literacy demands not only culturally-specific approaches, but also community-specific interventions. While some communities may well share similar concerns and challenges, the specific needs of individual communities have to be accounted for and interventions adapted accordingly.

By demanding more culturally and community-specific HIV interventions, this approach critiques the power dynamics inherent in using Western or ‘first world’ approaches to address African experience of the AIDS epidemic. The term ‘Western’ has also proved contentious. Farmer (2003) suggests that while in development terms ‘western’ refers to the wealthy countries, it is often difficult to distinguish between something that is truly ‘home-grown’ and other instances where even traditional medicine has been informed by a long history of adaptation and adoption of different cultures. Other studies have shown that many South Africans move between allopathic and traditional healing practices, which suggests that in practice the dichotomy between ‘western’ and indigenous medicine may not be as clear-cut as academic debate suggests (Nattrass, 2005; Mills, 2005; Wreford, 2005).

Chilisa (2005) grapples directly with some of the reasons that interventions often fail to diminish the spread of HIV in Southern Africa. For example, biomedical explanations and language used for HIV and AIDS are presented as absolute truth and do not allow for indigenous definitions of HIV/AIDS that differ according to the context of the illness. In the case of Botswana the name given to AIDS-related illnesses depends on the age of the person and is defined by the expected cause of the illness, such as a result of having sexual intercourse with a widow or widower (*Boswagadi*) or wronging the ancestors (*Molelo wa Badimo*). Chilisa (2005) argues that without understanding this cause-effect relationship in relation to illness, it is not possible to communicate HIV prevention and treatment messages effectively.

The same is also true of South Africa where traditional healing practice describes some illnesses as 'natural' (caused by the natural world), while others are believed to be driven by human agency and are associated with bewitchment (Ashford, 2005). An additional challenge facing the promotion of biomedical approaches to HIV/AIDS is that many AIDS-defining illnesses (such as wasting, diarrhoea, stomach ailments) exhibit symptoms that are associated with bewitchment. It has also been argued that the failing of allopathic medicine to provide a cure for HIV/AIDS has resulted in patients seeking alternative causes for ill health. For example, attributing AIDS-related illnesses to bewitchment enables the patient to regain a degree of perceived agency whereby they can carry out steps towards recovering their health by visiting a traditional healer (Wreford, 2005).

This suggests that providing biomedical explanations of the causes and treatment of HIV/AIDS should be preceded by researching existing indigenous understandings of HIV and AIDS, as well as health and illness more generally. This approach calls for an engagement with local healing traditions in order to develop interventions that communicate meaningfully with the intended audience. This is pertinent to the South African context where it is generally agreed that patients move between indigenous and allopathic medical practitioners depending on the type of illness they are experiencing (Nattrass, 2005; Wreford, 2005; Mills, 2005).

The TAC treatment literacy project provides an example of encouraging dialogue between biomedical and traditional practice in their treatment literacy fact sheet 'Talk about Antiretrovirals' (Ashforth & Natrass, 2005). In this example an HIV-positive traditional healer who is taking HAART warns about potential interaction between traditional medicine and antiretroviral drugs and stresses the importance of the patient communicating with both their traditional healer and their medical doctor if they are taking additional medication. Other groups involved with the provision of antiretroviral therapy and the training of HIV literacy educators have also engaged with traditional healers. Another example is the Sangoma Pilot Project co-ordinated by the non-government organization HIV Outreach Programme and Education (HOPE Cape Town) that encouraged debate and shared learning between community health workers, medical practitioners and traditional healers (Wreford, Hippler & Esser, 2006).

Apart from the practicalities of how best to manage a patient's health, it is also important to understand other more emotive reasons why people seek out indigenous healers and the role they play in providing spiritual and psychological advice and healing. The need to uncover the root cause of ill health is central to indigenous understanding of health and illness in many Southern African cultures. It is also considered the main motivation behind the consultation of *sangomas* and other healers. Pretorius and colleagues (1993) explain the need to understand the various causes of illness, which are not addressed in the allopathic tradition. They also suggest the different approaches adopted by allopathic and traditional medicine practice can provide a more complete understanding of health and illness and that these two systems can co-exist.

The Western clinician places emphasis mainly on **what** is wrong and attempts to treat the symptoms. The traditional healer, on the other hand, rather focuses on the **why** and looks into the anxiety which accompanies the disease...From these insights one comes to the conclusion that Western and traditional medical systems can co-exist independently in a given society, as they throw light on different aspects of the process of disease. (1993: 18)

Resistance to allopathic medicine in South Africa can in part perhaps be explained by its long association with colonialism and subsequent exploitation, with *apartheid* era medical

experiments uncovered during the Truth and Reconciliation Commission proving particularly sinister. The inferior quality of health provision for black South Africans under *apartheid*, along with current crowding, long queues and the lack of facilities in rural areas has failed poor South Africans in particular (Bodibe, 2007). This has been confirmed by recent investigations into the level of health care available at South African public hospitals across the country where mismanagement, lack of funding and gross understaffing plague the public health care sector (Cullinan *et al*, 2006). In place of race, an economic *apartheid* in health care is now experienced where those who can afford private health care have access to more resources and superior services when compared to the poor who can only access the public sector.

The previous discussion highlights both the importance of developing understanding of indigenous healing paradigms and also the challenges to promoting allopathic approaches to explaining and treating HIV/AIDS. The vast majority (approximately 70%) of South Africans make use of the public health care sector (Shisana *et al*, 2005). The same study reports a very low number of Africans visiting traditional healers (1.1%), which contrasts with a general perception that the majority of black South Africans consult sangomas and other healers. This could partly be explained by a bias in reporting due to respondents not wanting to admit to visiting a traditional healer in a survey. However, regardless of the exact number of people who seek traditional healers, it must be acknowledged that different cultural understandings of illness inform patients' ideas of HIV/AIDS and how to treat it. In this way, it is important that HIV/AIDS education programmes encourage discussion of traditional approaches to health, while also providing accurate information regarding the viral nature of HIV, how it is transmitted, treatment options and care.

It is also useful to view allopathic and traditional doctors as being able to perform different roles for patients living with HIV, with the one being able to address purely medical concerns and the other offering spiritual and emotional guidance. Mills suggests that '...collaboration does not infer the mapping of traditional healing onto biomedical practices, or vice versa, but should allow for places of divergence where each can offer relative and different resources to HIV-positive clients.' (2005:155).

## **Participatory and collaborative approaches to adult learning**

From the outset it should be made clear that the use of the word 'participatory' in the context of the workshop described in this dissertation refers to collaborative approaches to adult learning. My workshop project was not a Participatory Action Research or Participatory Research project in the strict sense of communities initiating social change (De Koning & Martin, 1996). I approached organizations and offered the workshop training, as opposed to an organization or community approaching me. While the workshops focused on adult learners actively engaging in their own knowledge production, this process was perhaps influenced by the presence of a tool like the Visual Body Map. I presented the workshop material as a way of providing information and demonstrating innovative, visual approaches to HIV literacy. The participants 'took ownership' of the learning process by recording what they believed to be important and relevant to their needs. But I also acknowledge from the outset there was a potential limitation with the degree to which the workshop participants shaped the workshop content.

Given the interactive nature of the workshop, it is important to consider the influential work of adult educationalist Paulo Freire. The last twenty years have seen the adoption of Freire's notion of critical consciousness (Freire, 1997) by a number of projects working within the domains of social justice, adult education, health, grassroots mobilization and participatory action research (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 development 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).

Freire promoted participatory approaches to adult education as the key to empowering people and giving them the necessary skills to challenge current limitations in their lives. Freire resisted the traditional power hierarchy evident in the teacher/student relationship where the student was perceived as an 'empty vessel' needing to be filled with information. This model

sees the student largely as passive, while the teacher actively 'teaches'. Freire proposed that adult learners bring a wealth of lived experience and knowledge to the learning process and should ultimately drive their development of new knowledge and ways of understanding. In Freire's model the teacher acts as a facilitator and guide, while the learners are actively engaged in the learning process. This is built on the premise that 'liberating education consists of acts of cognition, not transferrals of information.' (1997:60).

Freire proposed that adult learners need to develop critical consciousness, which included skills of enquiry, problem solving and creative ways of challenging circumstances that currently limit their life situations. The learning process was not an academic exercise, but rather a way of equipping adults with skills to engage in social action and improve their lives. In a similar way, Mezirow's ideas of critical reflection and transformational learning (Mezirow, 1991; Mezirow *et al*, 2000) enable adult learners to question their assumptions about their life situations and make changes to improve their circumstances (Taylor, 2000). Both Freire and Mezirow identified group conversation as a tool for developing awareness and an increased sense of agency with adult learners. This was achieved by addressing real life situations within the learning environment and shares similar principles to peer education and support group environments.

The type of dialogue advocated by Mezirow and Freire is not simply conversation, but rather a mediated process where participants are provided with accurate information and guided by a facilitator while debating and developing potential solutions to existing challenges. This process is particularly relevant in relation to HIV literacy and 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. (Gordon, 1995:188)

This form of group conversation is built on the understanding that through sharing and reflecting on their past and present experience, adult learners are able to develop potentially new ways of behaving that would benefit them more. The importance of group learning links

powerfully to ideas of how social identity is formed and the potential impact this can have on individual behaviour.

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, 1997:137)

The transition from naïve to critical consciousness is the result of a tension between the learner's existing knowledge based on lived experience and new information provided by the facilitator. Freire describes these two different types of information as '...the 'knowledge' contributed by 'outsiders' (experts, intellectuals) and that latent in the experience of 'insiders' (participants).' (Freire, 1997:46). While acknowledging the role played by 'outsiders' as facilitators of the learning experience, Freire also warned that both educational and political programmes that fail to respect the worldview of the people they are working with run the risk of being ineffective.

Freire's emphasis on respecting peoples' worldview links with the previous discussion of the need to develop relevant HIV interventions based on existing indigenous knowledge systems. However, it could also be argued that at times a person's worldview, based on their experience of cultural, gender and socio-economic conditions, can negatively shape their decisions and behaviour. This is particularly true of the ways that cultural and social norms influence decisions around HIV and health and in many instances limit people's ability to act in ways that would benefit them. For example, socially sanctioned unequal gender relations limit many women's ability to protect themselves from HIV infection (Dunkle *et al*, 2004; Wood *et al*, 1998; Jewkes *et al*, 2001). In this case, it can be argued that culture should be approached as being more open to challenges to change in order to safeguard those who prescribe to its mores.

When considering Freire's theory of critical consciousness it is useful to see the development of critical consciousness not as an end in itself, but rather as a necessary skill for initiating social change. In the case of HIV literacy it can be seen as increasing awareness in people as

to the conditions and norms that inhibit them from making decisions that prevent them from becoming infected with HIV and also living productive lives as an HIV-positive person. Campbell (2003) echoes this sentiment in the following statement.

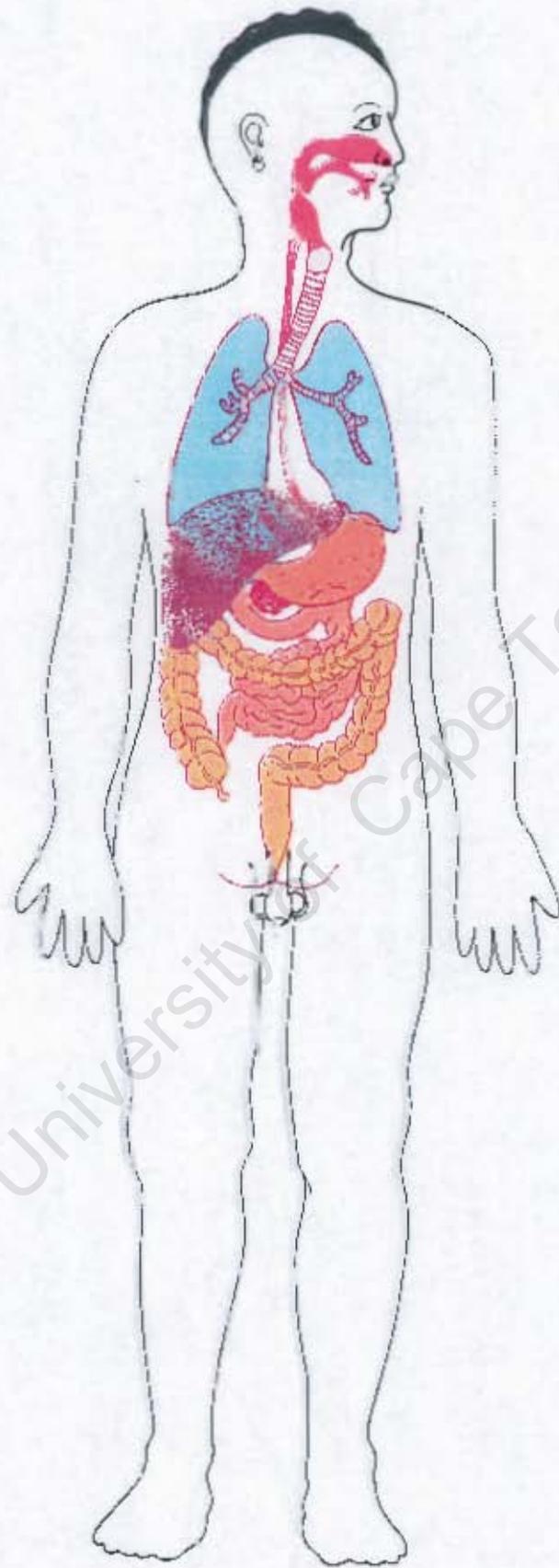
Critical consciousness is a precondition for the collective renegotiation of sexual and social identities in ways that are less damaging to sexual health, as well as for the development of confidence and empowerment to be able to engage in safer sexual behaviour. (Campbell, 2003:133).

Both Freire's theory of critical consciousness and Mezirow's transformational learning are participatory approaches to adult learning and support the idea that adult learning is an active process. They both view adult learning as an agent for social change that enables both individuals and their communities to develop solutions to existing challenges and limitations. This dissertation focuses on participatory learning approaches to HIV literacy as a way of initiating social change through the decisions people make about their health – either remaining HIV-negative or living a longer, productive life as an HIV-positive person.

### **The potential of visual approaches to HIV literacy**

Various visual forms of mapping and drawing 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. In particular, Participatory Research practitioners have made extensive use of mapping and drawing as a tool for accessing local knowledge and stimulating social action. In this way mapping and drawing techniques support a 'bottom-up' approach based on locally defined priorities and acknowledge indigenous knowledge and skills (Cornwall & Jewkes, 1995).

This dissertation evaluates a workshop based on a visual learning approach to HIV literacy. Two key visual tools were used collaboratively in the course of the workshop – body map drawings (See Figure 2.1) and the Visual Body Map chart (see Figure 2.2). The creation of life-size body map drawings was the key focus of the workshop and most exercises were



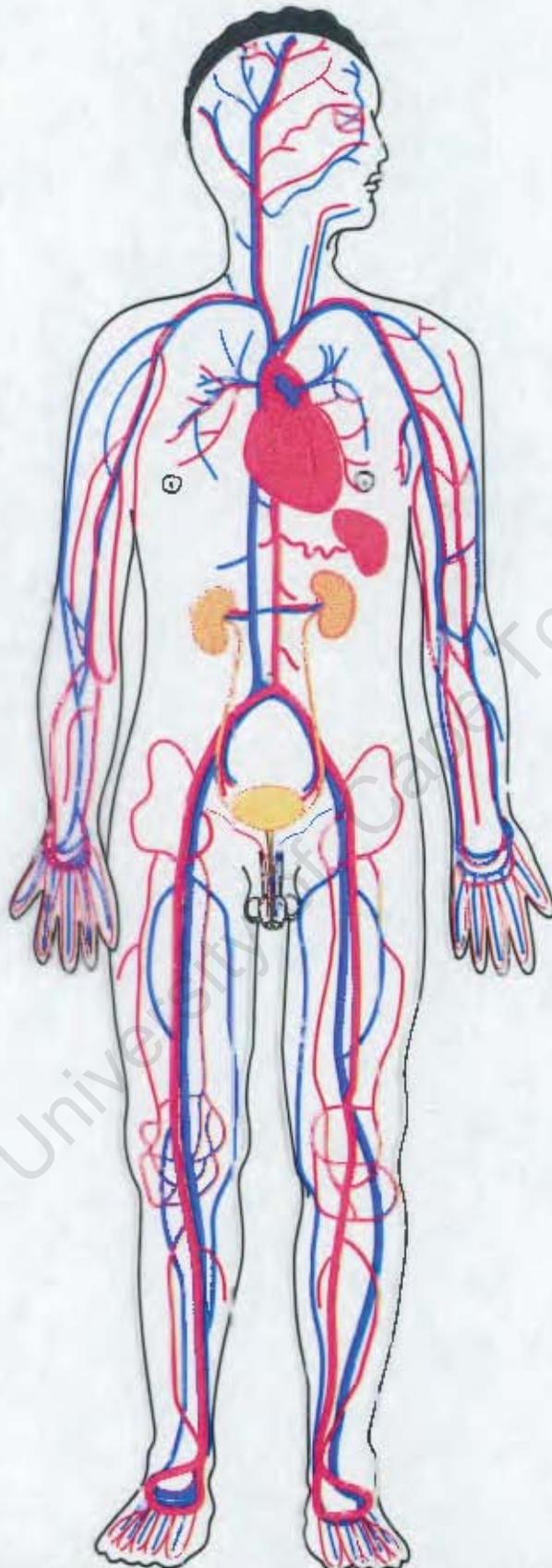


Figure 2.2: An example of the circulatory, digestive and respiratory systems as found in the Visual Body Map. The visual Body Map measures 1010x120 cm. It includes a male and female body that can be superimposed by 9 acetate layers representing the different systems.

recorded on these drawings. The Visual Body Map<sup>9</sup> is an educational tool depicting all the systems in the human body consisting of the different organs and grouped according to their function. Each system (i.e. circulation system) is represented on a separate transparent layer of acetate. The acetate sheets can be overlaid to illustrate the inter-related nature of the systems in the human body and how they work together.

The body map drawings were based on tracing around a workshop participant's body onto a large piece of card. The workshop participants worked in small groups of about five individuals that each created a body map drawing in the course of the workshop. These group drawings were used to capture existing knowledge of the participants, as well as record new information presented in the workshop, either by using the Visual Body Map, or in other interactive exercises. Both the Visual Body Map and the creation of body map drawings will now be discussed in relation to existing literature on the benefits and limitations of visual literacy.

The most obvious advantage of using visual techniques is the unambiguous, straightforward and direct presentation of concepts and information. Visual communication offers different advantages, and limitations, to verbal or written forms that rely on literacy or sharing a common language in order to be understood. The universality of visual literacy is demonstrated in road signs, instruction manuals and warning signs. But at the same time, many of these signals are also culturally encoded and are equally demanding in terms of understanding certain visual meanings. For example, whereas in many countries the yield sign is understood to signify that vehicles should yield to oncoming traffic, this is dependent on being previously exposed to such a symbol. For a culture not accustomed to vehicles or urban living, such a sign would be meaningless.

Cornwall (1996) suggests that the key principle of visualization techniques, such as drawing, is that they offer ways of collectively producing and representing information in a form that encourages debate and analysis. The participatory nature of the process also creates new

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<sup>9</sup> The Visual Body Map was developed by Colin Almeleh and Fiona Mendelson at the AIDS and Society Research Unit in the Centre for Social Science Research.

understanding by drawing on the diverse knowledge and experiences of those taking part. In this way, visual techniques engage in social action by actively encouraging people to explore and represent what they know, which 'can validate them as knowledgeable, active subjects capable of interpreting and changing their situations themselves.' (1996:95). Cornwall also draws attention to the way visual representations are never neutral and that they can capture both perceptions and facts. With the creation of body map drawings, the recording of perceptions of HIV and AIDS, as well as biomedical facts, is an advantage because it develops appreciation of different understandings of health and illness, as well as social issues separate from the physical experience of the disease.

In two separate studies that encouraged adult patients to draw their illness conditions, Guilleman (2004) assessed the potential role of drawing as a tool to develop understandings of how individuals experience health and illness. Guilleman interviewed her participants and then asked them to draw and discuss what they had drawn. In this way the participants were able to explore their emotional responses to their condition and develop a better understanding of their illness and in some cases a more positive outlook towards living with it. Guilleman argues that 'the act of drawing necessitates knowledge production, with a visual product as an outcome.' (2004:272). This principle is demonstrated in the creation of body map drawings described in this dissertation where participants actively demonstrate their knowledge by drawing, labelling and writing.

Harrison (2002) approaches the use of drawing as a visual methodology from within the field of sociology of health and illness. She not only notes the long history shared by art and medicine, but also comments on the increased emphasis on recording the ways in which patients themselves interpret and attribute meaning to their experiences of health and illness. She goes on to suggest that visual approaches are participatory by nature and that 'for participants the sense of being more active, of having some control over the research process, also gave them greater control over their illness.' (Harrison, 2002:862).

The same can be argued with regard to the creation of the body map drawings where workshop participants developed their understanding of HIV and AIDS through sharing

information and experiences, and then drawing and writing. By tracing around their bodies and using this outline as a template, the participants developed their personal understanding of how the human body works and how HIV affects it, as opposed to studying a generic human body that is removed from their health-related decisions and lived experience. The collaborative and participatory nature of visual methods also challenges traditional models of knowledge production (Harrison, 2002).

Brice Heath (2000) approaches the educational potential of visual methodologies from the perspective of neurobiology. She argues that both when looking at and when creating visual images, there is interplay between the visual and the expression of meaning within the brain. This process assists in learning because images serve to recall information stored in the brain through prior experience and enable the learner to verbalize the new information he or she has been exposed to. This suggests that the use of visuals assists the learning process and also stimulates conversation. This is summed up in the statement that ‘...the visual and the verbal reinforce one another in the sustained and adaptive learning necessary to increase learning from the theories of others and to build strength in one’s own theories.’ (Brice Heath, 2000:124).

The use of visuals to stimulate conversation and debate is in keeping with both the theories of critical consciousness and transformational learning discussed earlier. In his work with farm workers Freire presented social themes in the form of visuals in order to stimulate dialogue and problem solving (Freire, 1997). Since Freire was involved in a project to empower oppressed economic classes his use of visuals typically involved drawings that captured scenes depicting unequal relationships between landowners and farm workers or other social challenges faced by the labourers. In the workshop described in this dissertation, the Visual Body Map encouraged questions and debate about HIV, health and other illnesses. It also enabled participants visually to ‘solve’ gaps in their knowledge by looking at the chart and engaging in group discussion.

Throughout the world cartoons and illustrations have been used to promote understanding around HIV and AIDS, as well as other health related issues. In the South African context

where almost two-thirds of the population cannot read basic health education materials, visual media are often seen as a solution (Arbuckle, 2004). Arbuckle (2004) also refers to the positive response to the *Mkhize* picture story, which is part of the *Learn with Echo* adult literacy educational newspaper supplement, as further evidence of the efficacy of visual methodologies. However, the same research shows that visual literacy cannot be taken for granted, since non-literate people often experience difficulties in understanding certain visual conventions that use perspective to depict scale, size and movement, as well as concepts such as thought and speech bubbles. A lack of illustrated educational material in developing countries like South Africa means that child and adult learners alike have limited opportunity for developing complex visual literacy skills.

Carstens and colleagues assessed the efficacy of various visual materials used in HIV/AIDS-related education in South Africa and compared low-literate and literate adults' ability to comprehend these health messages (Carstens *et al.*, 2006). Apart from useful recommendations for the future development of HIV education material, the study revealed that representations of the human body are powerful in that all humans have comparable experiences of living in a human body and that this enhances the learning experience. This can be related to the use of the Visual Body Map and the creation of body map drawings in the workshop which gave participants the opportunity to relate their bodily experiences directly to the new biomedical information that my workshop exposed them to.

In her work with women in Zimbabwe on developing understanding about sexual and reproductive health, Cornwall made extensive use of drawing techniques to gather popular and indigenous knowledge (Cornwall, 2002). In her study each woman drew in the sand with a stick to illustrate her understanding of how the female reproductive system worked. Cornwall later copied the drawings in her note book. Her decision to engage with the women's existing knowledge as a starting point, before introducing the biomedical model in order to address problems experienced by both the village women and local clinic staff, is explained in the following comment.

I quickly realized that a simplified version of the biomedical model was not going to help me meet their concerns. What I needed was to understand what

they knew, and find a way of working from that to answer their questions. (Cornwall, 2002: 221).

In this way Cornwall's use of drawing is similar to the development of the body map drawings in the workshop assessed in the course of this dissertation. Prior to being exposed to the Visual Body Map, all participants created a group body map where everyone was given a colour pen and asked to add everything they knew onto the traced outline of a human body. The emphasis lay not in anatomical accuracy, but rather in generating as much information as possible about the human body, including lay understandings of the body. Participants could write in any language and given the diversity of people attending the workshop the body maps included a range of African languages, Afrikaans, English, biomedical language and more colloquial terms. Throughout the workshop, participants were typically first asked what they knew, before looking at the Visual Body Map. Other problem-solving puzzles<sup>10</sup> used during the workshop also first demanded their interpretation before I offered further explanation.

While artistic creation is often seen as an individualistic exercise, collaborative visual production has been used for both therapeutic and educative purposes. With their involvement in community art projects, Karkou and Glasman (2004) promoted the withdrawal of any aesthetic or artistic value judgments of what constitutes 'good' art in order to enable both learning and healing to take place. They argued that by making the level of skill irrelevant, greater social inclusion and participation was achieved. In my workshops, the process of creating the body map drawings was not framed as an artistic exercise, but rather as a way of reinforcing and recording the learning process. Participants were free to depict the body and parts of the body in any way they chose with having to consider anatomical correctness or aesthetic beauty. For example, some body map drawings represented the human heart as a 'valentine' heart.

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<sup>10</sup> These exercises included putting together a home-made puzzle to illustrate the cellular nature of the body, using a photocopy of a road map to explain the circulatory and nervous systems and a drama exercise using balloons to represent different cells in the immune system. They will be discussed more fully elsewhere, together with other workshop exercises.

This section has looked at the relative advantages and challenges of using visual methodologies within the context of participatory adult learning. It has also described how drawing in particular can be used as a way of encouraging people to learn more about health and illness. By engaging with literature that addresses the potential value of visual representations within adult learning contexts, this section has served to contextualize the use of both the Visual Body Map and the body map drawing. A more detailed description of how these two tools were employed in my workshop will be provided in the following chapter.

## Conclusion

This chapter has reviewed the relevant literature that has informed the development of the workshops discussed in this dissertation, as well as key approaches to adult learning that have been adopted and explored in the course of this project. It began with a discussion of different approaches to HIV literacy that have been used within and beyond Southern Africa and how these various HIV interventions shaped my decisions in the development of the body map drawing workshop. Literature on the relationship between the provision of HAART, VCT and HIV literacy was discussed, together with the need to situate interventions within existing socio-economic and cultural conditions. The use of participatory approaches to adult education and initiating social change were described in relation to the ideas of transformational learning and critical consciousness. In closing, the advantages and challenges of using visual tools and techniques were addressed.

## Chapter 3

### Workshop Development, Implementation and Evaluation

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It is estimated that less than half of South Africans requiring HAART are receiving it (Nattrass, 2007). While efforts are being made to increase the availability of HAART in South Africa, leadership failure and a shortage of health care workers is severely hampering the process (Bodibe, 2007; Cullinan *et al*, 2006; Nattrass, 2007). A number of non-governmental organizations involved with the provision of HAART in South Africa have stepped in to assist the public sector by actively recruiting and training lay people to prepare and support HAART patients. These community health workers help nurses and doctors in clinics within their communities and are also known as treatment literacy practitioners and community adherence workers. I was interested in their role as HIV educators, not only within the clinic context, but also in facilitating support groups and other forms of peer education. The workshop project described in this dissertation was developed to train such people and to enable them to use body mapping techniques in other HIV literacy contexts.

#### **Aim and intention of the body map drawing workshop**

Apart from increasing biomedical knowledge about the human body and HIV/AIDS, the body map drawing workshop intended to address social issues affecting people both infected and affected by HIV and AIDS in South Africa. The workshop did not aim to undermine indigenous understandings of health and illness, but rather provide information that many South Africans have been denied because of inferior apartheid era education and continued disparities in schooling, especially with regards to the sciences. The participatory style of the workshop fulfilled the dual purpose of exposing the participants to biosocial information, while also training them to replicate the workshop in other contexts, such as HIV-positive support groups, youth groups and VCT.

The workshop intended to build on the existing knowledge of the workshop participants<sup>11</sup> and enable them to find ways to explain human biology, the science of HIV and other social issues to their clients and people in their communities. Most of the participants were familiar to a greater or lesser extent with the biomedical content of the workshop, but the exercises that addressed social issues such as the challenges of disclosure of HIV-positive status were new to them. The use of visual tools and techniques, and the participatory approach to HIV literacy, employed in the workshop were also novel to most participants. In this way, the workshop intended to provide training in participatory and visual learning styles in order to assist the participants with their work as HIV literacy educators and trainers.

### **Workshop content and techniques**

The workshop was spread over two days and relied on visual and participatory approaches to present the HIV literacy material. The first day concentrated on the participants' understanding of human biology and how the body is affected by HIV/AIDS. The second day focused more specifically on living with HIV. It addressed social aspects of the disease and practical knowledge of care and treatment options. Home-based care, nutrition and hygiene were discussed together with when, how and where to access primary health care and medical treatment, including HAART. The combination of seemingly separate issues, such as nutrition, social support and HAART, was based on an inclusive approach to HIV literacy where the biomedical aspects of HIV are viewed together with the social and practical challenges of living with the virus.

Body map drawings (Figure 2.1) and the Visual Body Map chart (Figure 2.2) were the primary visual tools used in my workshop. The creation of life-size body map drawings was the central focus of the workshop learning experience. The Visual Body Map was initially absent from most workshop exercises and used as a reference source in order to further

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<sup>11</sup> Given the nature of their work and the organizations the participants were affiliated with, I presumed that most would be familiar with the content of the workshop. This was confirmed by data collected in the questionnaire (still to be discussed in full), that showed TAC and HOPE Cape Town participants had on average high levels of knowledge about HIV/AIDS and HAART.

clarify or explain certain aspects of human biology. Aside from visual activities, the workshop participants were also encouraged to take part in conversation-based, 'brainstorming' sessions, which were either written up in front of the entire group or directly onto the body map drawings. A drama exercise was also included in the workshop where four volunteers acted out the immune system response to an invading virus.<sup>12</sup>

At the start of the workshop I had the outline of my body traced on a piece of card as a way of demonstrating how to create a body map drawing and how to use it as a participatory way of collecting and recording information. Each participant was then given a pen and asked to add all the information they knew about the human body (Figure 3.1). This exercise immediately demanded the engagement of the workshop participants and made the collaborative and relaxed nature of the workshop clear from the start. It also provoked a humorous response from the group which helped them put aside their fear of making 'mistakes' when drawing and encouraged them to view the process as a fun way to learn. On another level it proved a useful means of assessing the level of knowledge in the group.

The workshop was run with three different groups, consisting of TAC treatment literacy educators and trainers, HOPE Cape Town community health workers and HIV-positive mothers. These groups will be described in greater detail later, but for sake of clarity when describing the workshop activities in this section people from all three groups will be referred to as workshop participants. Participants typically formed groups of four or five. One person in each group served as a model to trace around and create the template.

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<sup>12</sup> Each participant was given a balloon, which they labelled as a CD4 cell, CD8 cell, B-cell and influenza virus respectively. In the drama the influenza virus balloon was popped to illustrate how a healthy immune system can defend the body from invading viruses. This was followed by a different scenario where the influenza virus was replaced with HIV. In this case the drama ended differently as the participants explained how HIV takes control of the CD4 cell and inhibits the immune response.

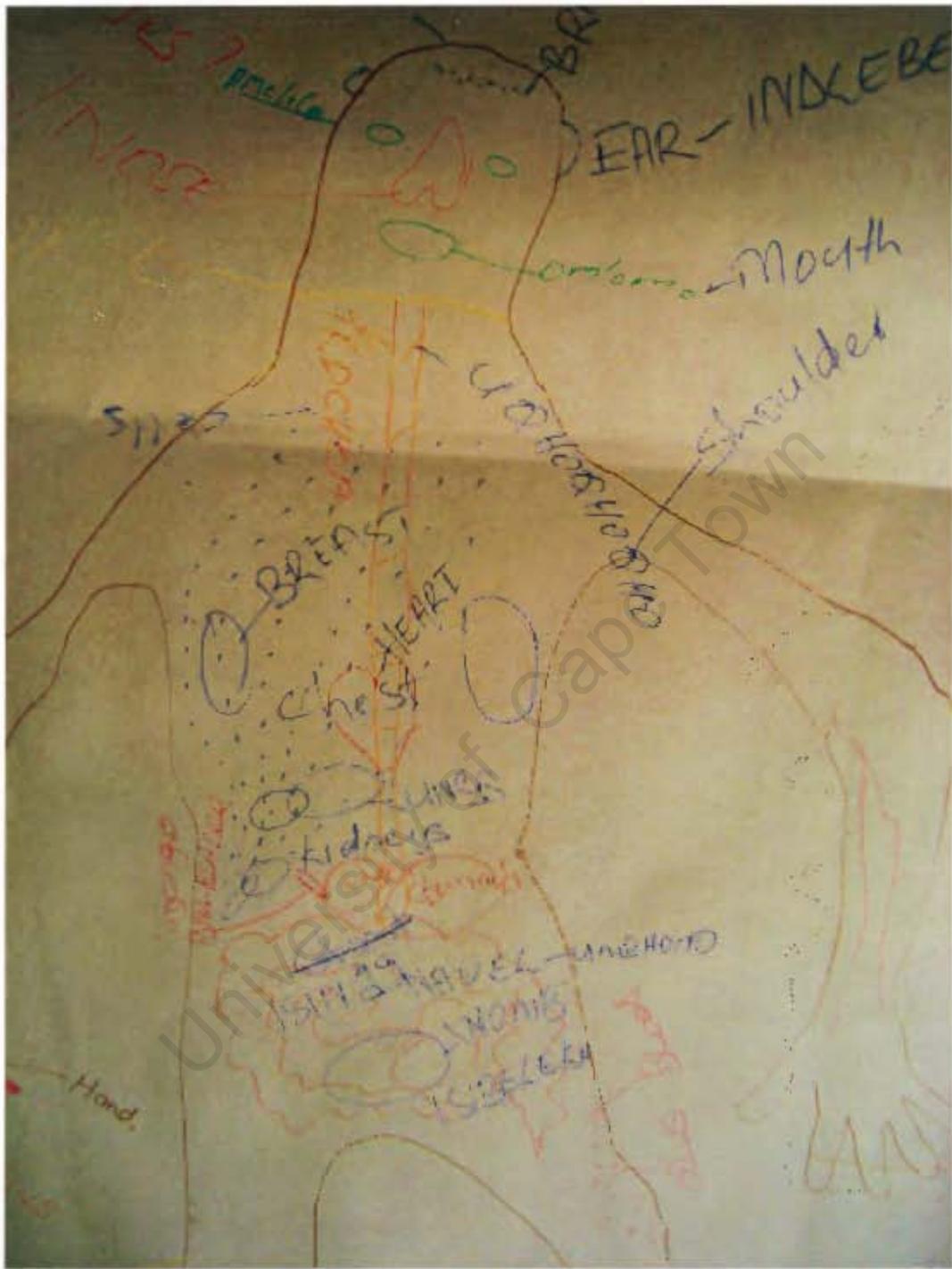


Figure 3.1 An example of how all participants were involved in adding everything to a single body map drawing at the start of the workshop. Note the use of different languages and the use of the 'Valentines' heart, along with dots to represent cells. This was drawn prior to participants seeing the Visual body Map.

Each group produced one body map drawing that was the result of collaborative drawing, writing and collage exercises. The drawings were complemented by other exercises which could be used separately, or as in the case of the workshops described here, could be glued directly onto the drawings. For example, each group was given a home-made puzzle (photograph cut into pieces) to put back together (Figure 3.2 and Figure 3.3). The participants were asked to think of anything in the human body which could be compared to a puzzle, with smaller pieces making up a whole. This 'puzzle exercise' developed the participants understanding of how different organs make up systems (i.e. the heart, veins and arteries in the circulation system) and also illustrated the cellular nature of the human body<sup>13</sup>.

In another exercise each participant was given a photocopy of a road map of the greater Cape Town area and asked to trace the route they took that morning from their home to the workshop venue (Figure 3.2). Following this, the participants were asked if the exercise made them think of anything inside the human body that could be compared to a road network. This started a discussion about the nervous system followed by the circulation system.

From the beginning participants were asked to contribute and share their knowledge and expertise in their groups. As previously said, the Visual Body Map was initially absent from most exercises when the groups discussed their understandings of how the human body works. It was then later displayed to clarify questions and further explain relationships between the different parts of the body and how HIV and AIDS affect the healthy functioning of the human body. In this way the Visual Body Map was used as a reference source, as opposed to the starting point of the body map drawings. The participants were not expected to replicate the Visual Body Map in the drawings, but choose what they thought was important to remember. Given the portable nature of the Visual Body Map it was easy to hang up or remove.

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<sup>13</sup> This exercise proved to be the simplest and most accessible way of explaining the cellular structure of the human body. In the pilot workshop, two other exercises were tested and failed. In the one I used a slice of onion and food dye. And in the other I tried the analogy of a house with bricks. The pilot workshop participants argued these exercises were too obscure and confusing and so they were discarded.



Figure 3.2 An example of the 'puzzle exercise' on the left-hand side of a body map drawing by a group from HOPE Cape Town. On the right-hand side is an example of the 'road map exercise'.



Figure 3.3 Another example of the puzzle exercise from a body map drawing produced by the group of HIV-positive mothers. Alongside the puzzle they wrote down some of the characteristics of cells that they have discussed in their group.

The immediate relationship between the Visual Body Map and the participants' own experiences of their bodies and health and illness further encouraged questions and learning. The Visual Body Map has no labels. The exclusion of written language not only simplified the presentation of human biology, but also encouraged participants to take ownership of the material and ask and answer questions verbally in their everyday language, as opposed to academic or medical language (which would have imposed itself if written labels had been placed on the Visual Body Map).

Exercises using both the Visual Body Map and the body map drawings encouraged the participants to add new material about human biology directly to the relevant area on their group drawings. The space surrounding the traced outline of the body was filled with other exercises that were pasted onto the card. Some of the exercises, like the two described above, illustrated biomedical facts, while others addressed social and practical issues. The end result was a densely-packed drawing of the human body with sketches of parts of human anatomy, information on the functions of different organs and systems, how HIV and AIDS affect different parts of the body, advice on healthy living, social support and treatment options.

The first day of the workshop focused on the systems of the human body. A series of exercises were completed enabling the participants to ask and answer questions about the functions of each system and how they work together. For example, when discussing the digestive system, the absorption of both nutrients and medication was explained in relation to diet and antiretroviral therapy. The Visual Body Map was used to demonstrate the way nutrients and medication leave the stomach and enter the blood and circulatory system. In this way the biology of the body was explained both generally and also with a specific focus on how HIV and AIDS affect it. Participants were encouraged to choose the level of detail they wanted to engage with the material.

The second day focused on HIV transmission and how the virus compromises the immune system. The group marked and labelled areas on their body maps where HIV can enter the human body and wrote short descriptions of how the virus could be transmitted in each

instance. The group also compiled a list of all the ways HIV cannot be transmitted, such as sharing a meal or embracing an HIV-positive person. Opportunistic infections were discussed and all areas in the body that can be affected by such infections were clearly labelled, along with available treatment options and home or traditional remedies (Figure 3.4). By looking at their body map drawings it was easy to locate which parts of the body are affected by which illnesses and what treatment options are available.

One of the ways nutrition was discussed was in an exercise that involved cutting out food items from advertisements from local supermarkets and pasting them onto the body map drawings (Figure 3.5). The pictures of the different foods could be grouped into possible meals and encouraged debate on how to ensure a healthy diet. The emphasis was on inexpensive and practical ways of ensuring a balanced diet. Apart from foods available in supermarkets, the participants also wrote up traditional meals in a group exercise. In order to emphasise that good nutrition need not be expensive, another exercise encouraged participants to share their typical meals over a course of a week. Household hygiene was discussed in order to ensure a relatively germ-free home environment to help prevent opportunistic infections. Participants also discussed cheap and effective ways of preventing HIV transmission in the context of providing home-based care, such as using diluted bleach as a disinfectant. Obstacles to health, such as living in an informal settlement and unemployment, were also discussed.

Many of the participants had also been trained as counsellors or provided counselling as part of VCT services at the clinics where they worked. Workshop exercises that focused on social support and the challenges of HIV-positive status disclosure were particularly useful tools to assist in addressing real life challenges, such as disclosing HIV-positive status to a family member in order to access antiretroviral treatment.<sup>14</sup> One particularly popular exercise involved tracing around both the left and right hand (Figure 3.6). In the one hand, participants would list all the people who provided them with support and in

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<sup>14</sup> Note that some HAART clinics, such as the MSF HAART programme, require HAART patients to have disclosed to at least one family member or a friend.

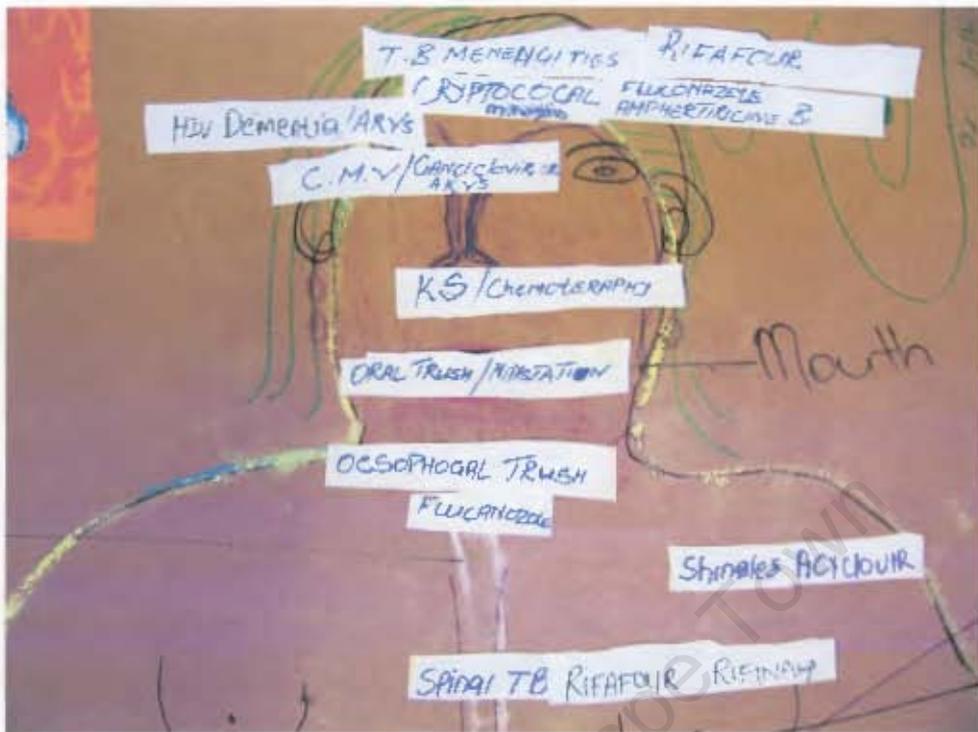


Figure 3.4 A detail from a TAC body map drawing that shows how the participants identified opportunistic infections and how they can be treated. The allopathic medication shown here was provided by the TAC participants and later added to the manual on their recommendation.



Figure 3.5 A detail from a body map drawing created by a group of HIV-positive mothers that shows their selection of foods from the shop advertisements.

the other, the names of all the people who they supported would be written down. This resulted in a discussion of different kinds of support, including financial, emotional, spiritual and material amongst others. Participants said this exercise would prove useful when providing VCT and also in support group contexts.



Figure 3.6 An example of the 'hand exercise' that was used as part of a conversation on the importance of social support. Many of the participants claimed they would use this exercise in counselling sessions and when discussing disclosure of HIV-positive status.

Preparation for HAART, the different options available and side-effects to medication were also covered. Factors that contribute to the spread of HIV/AIDS, such as socio-economic conditions and gender inequality were discussed in varying depth depending on the group. In this way the workshop aimed to increase biomedical knowledge about HIV/AIDS, while also addressing some of the social aspects of the disease.

## Workshop development

The initial development of the body map drawing workshop involved meeting with facilitators and professionals working in HIV literacy, as well as an extensive review of literature on adult education theory, workshop design and HIV literacy interventions in Southern Africa and elsewhere. I also visited local non governmental organisations (NGOs) in order to assess their HIV literacy needs and gather information on any other training programmes that were currently being used. After gathering information and ideas to be included in the workshop, I wrote a draft manual to assist me in further developing and facilitating the workshop.

Following the initial writing of the manual, the workshop was piloted with three HIV-positive adults who had attended support groups themselves and subsequently been trained to facilitate psycho-social support workshops to encourage HIV-positive people to accept their status and increase knowledge about HIV and health. Two of the three participants were HAART patients and exhibited excellent knowledge of treatment options, as well as valuable first-hand experience of the personal challenges of living with HIV and taking HAART. This knowledge was particularly useful and informed exercises in the workshop that addressed social support, disclosure of HIV-positive status and access and adherence to HAART. The piloting of the workshop also enabled me to test different exercises, some of which were discarded in the process<sup>15</sup>. After necessary changes had been made to the workshop manual, I approached four HIV literacy facilitators and adult educators for further comment and feedback.

The workshop was designed so that it could be run as either nine separate one-hour sessions or as a two-day training. I met with people and organizations involved with running HIV-positive support groups and learnt that support groups typically meet for one or two-hour sessions either once or twice a week. The two-hour sessions usually allocate one hour to

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<sup>15</sup> Apart from the previously mentioned exercises that attempted to illustrate the cellular nature of the human body, other exercises were also unsuccessful in the pilot workshop. The sequence of exercises was altered after the pilot workshop, as well as the inclusion of new exercises such as the disclosure of HIV-positive status and ways to support HAART patient with treatment adherence.

general conversation and counselling and the second hour is used for discussing educational topics. Those groups that met twice a week had a similar approach to dividing the time between 'sharing' and educational sessions. This encouraged the development of one-hour sessions that could be easily incorporated into existing support group structures.

In order to assess the potential effectiveness of the workshop I approached different organizations working in HIV literacy training and offered to provide workshop training free of charge on the understanding that participants would be invited to take part in voluntary interviews afterwards. I facilitated two-day workshops with three different groups. The first workshop involved a group of treatment literacy practitioners from the TAC. The second training was held with HIV Outreach Programme and Education (HOPE Cape Town) community health workers. The third workshop involved a group of HIV-positive mothers attending a clinic connected to HOPE Cape Town. While facilitating these workshops the manual was viewed as a working document and updated following the running of each respective workshop. Once all three workshops had been completed, final changes were made to the manual based on the recommendations of workshop participants, as well as my observations of what had failed and what had worked best.

All workshop participants were given a copy of the workshop manual on completion of the training (Appendix 1). The manual was also intended to serve as a reference book for HIV literacy educators and trainers and enable them to facilitate the workshop themselves. 'Fact File' sections within the manual provided detailed information about the human body and HIV/AIDS and were designed so that facilitators could refer back to facts covered during the workshop. Workshop participants were encouraged to use both the training and manual as a source of ideas and adapt it to their daily work needs. For example, individual exercises<sup>16</sup> could be taken from the workshop and used as stand-alone activities without the need to create a body map drawing. This was hoped to encourage the use of individual exercises in other contexts, such as VCT sessions, clinic waiting rooms and schools.

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<sup>16</sup> These exercises included the 'hand exercise', the 'balloon drama' and the nutrition exercise among others.

In this way the workshop went through five interconnected development phases: initial research and writing, piloting the workshop, external evaluation by adult educators, facilitating the workshop with the TAC, HOPE Cape Town and HIV-positive mothers and completing a final edit of the workshop manual.

## **Research methodology**

Having described the development of the workshop and manual, the methods adopted in order to evaluate the effectiveness of the workshop in the field will now be discussed in greater detail. The research methods included observation of the workshop participants, administering questionnaires, evaluation of the completed body map drawings and conducting semi-structured group interviews on completion of the workshop. As is demonstrated by the choice of observation and interview techniques, the methodological approach to this research project was predominantly qualitative with the exception of some descriptive, quantitative data collected in a questionnaire.

Qualitative processes, such as conducting interviews and participant observation, enabled me to get an in-depth understanding of how the participants responded to the workshop material and techniques. This increased the validity of the study, which was important given the relatively small sample, but means that further study needs to be done to determine the reliability of the results within the greater South African context.

In the course of the project, I researched, developed, facilitated and evaluated the workshop. Rossi and others recommend that external groups or individuals should conduct project monitoring and evaluation (Rossi *et al*, 2004). The benefits of this approach to project evaluation are based on the premise that an external assessor will be impartial and provide a more balanced and objective report. For these reasons I made use of external workshop facilitators, educators and academics in the earlier phases of the workshop development. However, I decided to facilitate the workshop with the groups affiliated to the TAC and HOPE Cape Town because it would enable me to observe participants myself. Participant

observation enabled me to record responses to the workshop content, tools and techniques while the workshop was in progress. These observations contributed to further improvements to the workshop structure and content.

At the end of the second day of the workshop, participants were asked to take part in a voluntary questionnaire (Appendix 2). Very few declined to fill in the questionnaire, but some people were unable to attend the second day of the workshop or had to leave before the end in order to catch transport home. The questionnaire was designed to collect information about the workshop participants' educational background, previous training and work experience and their current work environments and needs. This data served to gather background information that would shape the content of the follow-up interviews and help contextualize their responses to the workshop content and the visual and participatory techniques used to present the material. This data enabled me to calculate averages and percentages in order to compare the three different groups with regards to level of formal education and general knowledge of HIV/AIDS and HAART.

The questionnaire was written in English and translated into isiXhosa to limit errors due to language-based misunderstandings and also give the participants a choice of language. The majority of workshop participants were isiXhosa first language speakers, but also able to communicate confidently in English. In retrospect it would also have been beneficial to have had the questionnaire also translated into Afrikaans so that those Afrikaans speakers who attended the workshop could complete it their first language. At the time of developing the questionnaire I was unaware that a number of the HOPE Cape Town community health workers were Afrikaans speakers. The questionnaire consisted almost exclusively of tick items giving the participants a choice of options, as well as the opportunity to write alternative answers to some questions when the tick options did not correspond with their experience.

Voluntary follow-up interviews were arranged once the workshops were completed. The majority of participants agreed to meet for a group interview. Having established a relationship with the workshop participants, I believed it was important that I conduct the

interviews to gather their opinions of the workshop and further recommendations. While it can be argued that the participants may have responded more positively than they would have done if some one else was interviewing them (because they might not have wanted to offend me), if I had employed an alternative interviewer this could have introduced more room for misinterpretation of the questions and the workshop participants may not have been as willing to give as much of their time to someone they did not know.

I decided to interview participants either in pairs or groups of three or four, rather than individually, in order to encourage informal discussion. The rationale behind this decision was based on observing the camaraderie and humour evident during the running of the workshops. The participants appeared relaxed and confident to express their views in front of their peers and colleagues. It was important that the participants felt comfortable and that the interview process was more like a conversation, rather than a test of their knowledge or level of workshop participation. I took every effort to ensure a relaxed environment while guiding the interview conversation by asking questions and then allowing participants to talk among themselves.

The completed body map drawings were also present during the interview process. In this way, both the participants and I could refer to specific exercises recorded on the drawings. The participants were not interviewed in the same groups that created the body map drawings, so a number of drawings from different groups were typically viewed at the same time. I used the interviews to gain further clarity on how the participants had responded to the different exercises in the workshop. I was also able to check the validity of the questionnaire data by asking similar questions and cross-checking the answers I received.

Marvasti argues that the advantage of group interviews is that the ‘...participants are also stimulated and have the opportunity to add to each other’s answers and produce richer data.’ (2004:24). The disadvantages to this approach are that one individual might dominate the group and that introverted individuals could remain silent. I was aware of these challenges and because I knew the workshop participants by name I was able to guide the conversation

by calling on particular people to share their thoughts and also 'move' the conversation on if one person was speaking for too long.

Another potential disadvantage is that within the interview group there might be power dynamics that prevent some individuals from expressing their opinions. However, given the collaborative and conversational nature of the workshop, participants were able to communicate freely with their colleagues. One workshop participant addressed this point directly by saying "...when you are in a group there are all different personalities...Not everyone speaks easily, but in this group you could relate very easily...you can say if you want to and if you don't want to you don't need to...you were very much part of it." (Interview with Charmaine, January 2007).<sup>17</sup>

The interviews were semi-structured and each group answered the same questions, but the length and depth of the responses varied accordingly. The interviews were recorded on a Dictaphone and transcribed verbatim afterwards. The interviews looked at similar topics to those addressed in the questionnaire, such as past training, current work experience and their exposure to participatory approaches to HIV literacy. In addition to these topics the interviews also probed attitudes towards human biology and interrogated perceptions of any relationship between knowledge of human biology and improved health decision-making.

In particular, the participants were asked to reflect on their experience as HIV literacy educators, community health workers and HIV-positive mothers and provide examples of how knowledge of the workings of the human body could assist HIV literacy. These questions aimed to assess the level of importance the participants attached to understanding human biology and were believed to be critical in terms of testing the relevance of the workshop content. Furthermore, it was believed that without knowledge of how the biomedical material was received, it would be difficult to assess the efficacy of the visual and participatory tools and techniques employed to teach the content.

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<sup>17</sup> All participant names are pseudonyms but refer to specific individuals who took part in the project.

The interviews were conducted predominantly in English, except for two where an isiXhosa first language research assistant was present. In these cases participants responded in a mixture of isiXhosa and English. Three respondents answered almost entirely in isiXhosa. The isiXhosa sections of the interviews were subsequently translated by the bilingual research assistant who was present at the interviews and actively took part in asking questions and translating key words on the spot to help me follow the conversation. Some participants responded in a mixture of Afrikaans and English and in these instances a translator was not needed because I speak and understand Afrikaans.

The workshop itself was conducted predominantly in English, except for the TAC workshop where an isiXhosa speaking facilitator assisted me. She had been involved in the piloting of the workshop and so was familiar with the material and the intentions of the workshop. The participants were encouraged to speak and write in whatever language they chose while doing the exercises in their groups. While conducting the workshop predominantly in English was successful on the whole, I did notice some instances where one participant would further explain the exercise instructions to a person in their group who needed more clarity.

Once the workshop was complete I photographed the body map drawings and used these photographs to analyse them more carefully. The body map drawings provided an unmediated and direct documentation of the learning process. While most exercises were recorded on all body map drawings, the way in which this was done and the degree of detail included depended on each group. The level of engagement with the workshop process was immediately evident by looking at and comparing the body map drawings of the small groups within the same organisation and between the three larger groups. I used this visual analysis of the completed body map drawings, together with interview responses and participant observation, to develop an understanding of how the exercises were received. This assessment of a selection of exercises is illustrated in Table 3.1 below.

Table 3.1 An assessment of some of the workshop exercises based on the body map drawings, participant observation and interview transcripts.

Description of exercise*	TAC	HOPE Cape Town	HIV-positive mothers
Group body map	Well received	Very well received	Very well received
Cell puzzle exercise	Very well received	Very well received	Very well received
Magnification of a body organ♦	Failed completely	Failed completely	Did not attempt
Road map exercise	Very well received	Very well received	Well received
Balloon drama	Very well received	Very well received	Well received
HIV transmission ■	Bored because knew information but useful for beginners	Very well received	Well received
How to prevent HIV transmission◇	Bored because knew information but useful for beginners	Very well received	Well received
Hand exercise	Very well received	Very well received	Very well received
Opportunistic infections	Very well received	Well received	Limited involvement
Eating healthy	Well received	Very well received	Very well received
HIV disease progression●	Failed	Failed completely	Did not attempt

\* Some of these exercises have already been described. They can all be found in Appendix 1, but for ease some have brief descriptions provided here.

♦ In this exercise participants were asked to draw the magnification of an organ on their body map drawings in four frames with a single cell in the final frame. See Appendix 1, page 10.

■ Participants were asked to mark all the places on their body map drawings where HIV can enter.

◇ Participants were asked to write ways in which HIV transmission can be prevented next to each area where HIV was shown to enter the body.

● Participants were asked to draw a simple graph showing how the CD4 count drops and the viral load (number of HI viruses in the blood) rises as HIV disease progresses. After the initial failure of the exercise I intervened and drew the graph myself. It is interesting to note that TAC participants were then able to indicate on the graph the stage HAART should commence and how this reduces viral load and increases the CD4 count.

## Description of the workshop participants

As previously mentioned the workshop was run with three different groups - TAC Treatment Literacy Practitioners, HOPE Cape Town community health workers, and HIV-positive mothers attending a clinic affiliated to HOPE Cape Town. This section draws on the data collected in the questionnaires (Table 3.2) and provides descriptions of the three groups in order to contextualize their responses to the workshop's biosocial content and the use of

visual tools and techniques. In this way the differences and similarities between the groups will also be highlighted in relation to their needs and goals as activist educators, community health workers and mothers living with HIV.

## The Treatment Action Campaign

The relationship between grassroots activism and HIV literacy in South Africa has been well documented (Endreson & Von Kotze, 2005; Robins, 2004; Ashford & Nattrass, 2005). Throughout the world popular and radical adult educators have noted the powerful potential of social movements to encourage informal learning (Foley, 1999). The TAC's ongoing campaigning is a good example of how learning can go hand-in hand with activism. In the process of fighting for the provision of HAART in the public health care sector and addressing other issues related to HIV and health, the TAC members and educators have generated awareness and spread knowledge of HIV in their communities and in South African society (Ashford & Nattrass, 2005).

The TAC treatment literacy practitioners who took part in the body map workshop have been directly responsible for increasing knowledge of HIV and AIDS and treatment options in South Africa. The group was made up of predominantly young, female activists with twelve women and one man. Given the nature of their work, I presumed they would be familiar with some, if not most of the material covered in the workshop. This was confirmed by the results from the questionnaire administered at the end of the two-day workshop where on average 86% of the questions on general knowledge about HIV/AIDS and 97% of questions on HAART were answered correctly.

In the TAC group, of the thirteen who completed the questionnaire, ten stated isiXhosa as their first language, and the remaining three claimed Afrikaans. All the participants could read and write in English. Most members in the group were able to communicate in at least three South African languages with levels of competency ranging from conversant to fluent and confident. Ten out of the thirteen had been awarded a Matric or completed their final year of high school. The remaining three had completed between eight and eleven years of schooling. The level of formal education attained by the group places them among the 52%

of South Africans who have received full general education which includes Grade 9 and higher (Aitchison & Harley, 2006).

Table 3.2 A selection of the data collected in the questionnaires illustrates some of the similarities and differences between the three groups.

	TAC *	HOPE Cape Town $\diamond$	HIV-positive mothers $\blacksquare$
Women	12	12	4
Men	1	5	0
Matric / final year schooling	10	13	2
Between 8 and 11 years school	3	4	1
Between 5 and 7 years schooling	0	0	1
General knowledge HIV/AIDS	85% correct	86% correct	Not asked $\blacklozenge$
HAART knowledge	97% correct	85% correct	Not asked $\blacklozenge$
Visual Body Map 'very useful' (as opposed to 'not useful at all' or 'useful')	13	17	4
'Pictures of the human body and what is inside it help people to better understand HIV/AIDS'	13 yes	17 yes	4 yes
'Knowledge of human biology encourages HAART access'	13 yes	17 yes	4 yes
'Knowledge of human biology decreases fear of HIV/AIDS'	13 yes	17 yes	1 no 3 yes
'Knowledge of human biology helps HIV-positive people to look after their health better'	13 yes	17 yes	4 yes

\*TAC - 18 workshop participants, 13 questionnaires, 11 interviewed

$\diamond$ HOPE Cape Town - 18 workshop participants, 17 questionnaires, 13 interviewed

$\blacksquare$ HIV-positive mothers - 10 workshop participants, 4 questionnaires, 3 interviewed

$\blacklozenge$ The group of HIV-positive mothers were not given the true/false questions on HIV/AIDS and HAART. At the end of the second day I had a good idea of the level of their knowledge and thought that the questions would embarrass or make them anxious because they would be unable to answer many questions. When I designed the questionnaire it was with community health workers in mind.

The questionnaire also revealed that only one person in the group had not done biology at school, but only five had taken biology at Matric level. Apart from the HIV literacy instruction received from the TAC, some participants had received additional training from Cape Technikon, University of South Africa (UNISA), non-government organisations such as *Loveliflife*<sup>18</sup> and Community Health Evangelism. Acquired skills included computer literacy, First Aid, home-based care, women's leadership and radio work.

Most people in the group had worked or volunteered for the TAC for more than two years. During this time they had received TAC HIV literacy training, worked in their communities and in some cases been further trained as HIV literacy trainers. The TAC has an inclusive HIV literacy curriculum, which includes opportunistic infections, nutrition, antiretroviral therapy and human rights. According to the group, training methods and techniques included lectures and tests, hands-on training and workshops that made use of drama, singing and role-play. In this way they had been exposed to both didactic and participatory HIV literacy techniques and reported making use of both these approaches when working in their communities. The TAC is also responsible for distributing educational posters, pamphlets and their magazine *Equal Treatment*. All these media are used to increase knowledge about HIV/AIDS and related issues within the South African population.

When asked about the use of visual material in their work, nine out of the thirteen reported using 'drawings, photographs or any other visual material' and the entire group claimed they would use visual education material if they were provided with it. In addition to this the participants were unanimous in the assertion that the Visual Body Map was 'very useful', as opposed to 'not useful at all' or 'useful'. Their support of visual approaches to HIV literacy is further emphasized with nine of thirteen participants claiming they would use the Visual Body Map 'every day of the week' and the remaining four choosing 'two or three times a week'.

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<sup>18</sup> *Loveliflife* is a non-governmental organization focused on increasing knowledge of HIV/AIDS among South African youth. It has employed a range of media including billboards, a website, radio and a free magazine to increase understanding of how to prevent HIV transmission, especially through adopting safer sexual behaviour.

## HOPE Cape Town<sup>19</sup>

The UN Millennium Project recommendations stressed the important role of community health workers to bridge the gaps between the services provided by the formal health care system and the realities of resource-poor and remote communities (Abbatt, 2005). With direct reference to providing universal access to antiretroviral therapy, WHO and UNAIDS reiterated the need to scale up the training of community health workers in order to achieve the '3 by 5' initiative's goals of providing 3 million AIDS patients with HAART by 2005 (WHO, 2003). HOPE Cape Town has trained twenty-two lay people as community health workers in the Western Cape. Unlike other programmes that rely on volunteers, HOPE Cape Town employs these community health workers on a full-time basis.

In contrast to the TAC treatment literacy practitioners, the majority of the HOPE Cape Town community health workers were older and more established members of their communities and their work was more closely aligned to nursing than activism. The wearing of a uniform and nametags that closely resembled that of a medical worker further reinforced this identity. The group who took part in the workshop consisted of twelve women and five men, with one more man arriving on the second day. HOPE Cape Town's policy is to employ people from target communities and to train them to assist in their local community clinics. All HOPE Cape Town community health workers complete a four-month diploma in HIV Care and Counselling offered by the University of South Africa (UNISA).

In addition to this academic training, the community health workers also take part in practical training in Tygerberg hospital with the resident doctor and assist with consultations, counting medication and calculating adherence to HAART. This hands-on training is important preparation for community health workers when they go out into the field and prepare and assist patients with issues related to HAART. In-house training takes place every second week at Tygerberg hospital and provides the community health workers with the opportunity to prepare and present further topics related to their work, as well as debrief.

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<sup>19</sup> HIV Outreach Programme and Education asked that I write their name as 'HOPE Cape Town' in order to differentiate them from other organizations with a similar name.

All the community health workers were proficient and could read and write in English. Five participants claimed English as their first language, but concurrently included either or both Afrikaans and isiXhosa. When asked to clarify their choice, the participants explained that they had grown up in multilingual homes and could not identify one single language as their first. Eight participants claimed to be isiXhosa first language speakers, and the remaining four chose Afrikaans. Thirteen of the seventeen participants had completed their final year of high school and the remaining four had completed between eight and eleven years of schooling. In terms of assessing their previous exposure to human biology, only one participant had not taken biology at school, while thirteen had taken biology as a Matric subject.

Apart from the UNISA course most of the community health workers had attained additional training from the AIDS Training, Information and Counselling Centre (ATICC) or hands-on training while doing volunteer work. In terms of their exposure to participatory learning techniques, twelve members of the group reported being familiar with interactive approaches to education. Except for two community health workers, all the others had worked for HOPE Cape Town for more than one year and of these nine had worked for longer than two years. In a similar way to the TAC group, the HOPE Cape Town community health workers also exhibited good knowledge of HIV/AIDS and HAART. As a whole, the group provided 86% correct answers in the section testing general knowledge of HIV and AIDS and 85% correct for the section on HAART. While these averages are not as high as those recorded for the TAC educators they still indicate good overall knowledge. Apart from serving as community health workers, most participants also acknowledged serving as HIV counsellors, peer educators, HIV literacy trainers, treatment buddies and running support groups. This meant that their work environments included clinics, support group gatherings, trainings, clinic and hospital offices and homes in their communities when doing peer education.

Most HOPE Cape Town participants claimed to currently use visual materials in their work. When asked how many times a week they would potentially use the Visual Body Map (or similar chart) in their work, fourteen out of seventeen participants ticked 'two or three times a week'. While this is not as often as the TAC educators who claimed they would use it every

day of the week, it still demonstrates substantial support for the use of visual HIV literacy tools. As with the TAC group, there was unanimous agreement, based on their work and life experiences, that learning human biology would help people better understand HIV/AIDS, encourage uptake of HAART, decrease stigma and fear about HIV/AIDS and help people look after their health better.

### HIV-positive Mothers

On completing the workshop with the HOPE Cape Town community health workers, I was approached by the resident doctor affiliated to HOPE Cape Town and asked to facilitate a further workshop with a group of HIV-positive mothers at a clinic based in Paarl, Western Cape. I believed it was important to test the workshop with a group of people with no previous HIV literacy training. As with the TAC and HOPE Cape Town groups, I organized a two-day body map drawing workshop with the group of mothers, administered questionnaires and interviewed them afterwards. A nurse involved in the clinic also attended the workshop out of curiosity. Ten participants referred by the doctor attended the workshop on the first day. Unfortunately due to prior work commitments as domestic workers and other unknown reasons, only four women returned for the second day and of these three agreed to voluntary interviews. The nursing sister also wanted to be interviewed, but I have not included her comments in the dissertation because her position as a nursing sister excludes her from the project.

Despite the small sample size of this group in comparison to the TAC and HOPE Cape Town groups, the interviews yielded useful data in terms of assessing how the workshop would potentially be received within contexts such as support groups. In a limited way, the responses of the group of mothers also served to either verify or contradict predictions made by the TAC educators and HOPE Cape Town community health workers about how ordinary people would respond to the workshop. However, the small sample severely impacts on the extent to which these results could be applied more broadly as an assessment of the potential implementation of the workshop in support groups. The questionnaires and interviews followed the same format as those used for TAC and HOPE Cape Town community health

workers, but all content pertaining to past and current HIV literacy work experience and the sections testing knowledge of HIV/AIDS and HAART were removed.

Of the four women who filled in the questionnaire, two were isiXhosa first language speakers, one was Afrikaans speaking and one Tswana speaking. All the women were either semi-literate or literate in at least one language. Two had completed their Matric, one had completed between eight and eleven years of schooling and one between five and seven years. All the women claimed to have done biology at school, but none had taken it as a Matric subject. All women found the Visual Body Map 'very useful', as opposed to 'useful' or 'not useful at all'. When asked if learning about human biology would encourage HIV-positive people to access HAART and look after their health better, all the women ticked yes. One of the women did not support the idea that knowledge of the human body would decrease stigma. All the women believed seeing pictures of the human body and what is inside it helps people to better understand HIV/AIDS.

One of the women had been involved with providing informal counselling to people living with HIV in her community. The second woman was involved with a beading project run at the clinic that sought to generate income for HIV-positive mothers. And the last woman in the group was applying for a job in a VCT clinic at the time of the workshop. Two of the three women who attended the workshop expressed interest in starting an HIV-positive support group in Paarl and said they would be able to use my workshop within the support group context. This initiative was supported by the doctor affiliated to HOPE Cape Town because previous support groups in the area were no longer active and there is a need for such a group to be set up.

The woman involved in the beading project stated that she would prefer to return to her home community in the former Transkei and start a support group there for people living with HIV. This anecdotal evidence suggests that support groups are believed to play an important role not only in providing people with necessary emotional and psychological support, but also as a way of disseminating knowledge of HIV and AIDS and how to manage one's health as an HIV-positive person. This is supported by studies that have revealed that better knowledge

of HIV and AIDS and positive health related behaviour change has been attributed to support group attendance (Morah, 2007; Mabunda, 2004).

## **Conclusion**

This chapter provided a description of the processes involved in developing, implementing and assessing the workshop. It provided a description of the workshop content in order to clarify the material presented to the participants. Information about the participants, such as their level of education and experience, was arranged according to the groups they were affiliated to. This was done in order to contextualise their responses to the workshop content and the use of participatory and visual tools and techniques and prepare the reader for the following chapter.

## **Chapter 4**

# **Evaluation of the body map drawing workshop as an HIV literacy tool**

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The workshop described in this dissertation aimed to develop biomedical understanding of HIV and AIDS, and address some of the social aspects of the epidemic in the South African context. It was informed by a biosocial approach to HIV interventions built on the premise that the AIDS epidemic is a social phenomenon, as well as a disease that demands that those who are infected are provided with care and treatment (Farmer, Connors & Simmons, 1996; Farmer, 2003; Green, 2003). The workshop intended that ordinary people understand both the science of HIV and the social aspects of the virus. It is also suggested that community health workers and treatment literacy practitioners are particularly good at reaching people who need information about HIV/AIDS because they live in the communities they work in. The value of having local 'experts' living in communities with high HIV prevalence and low levels of knowledge is that they can serve as peer educators.

In order to assess the potential effect of my workshop two key questions were asked. Firstly, 'Is it necessary for people to understand human biology and social issues related to HIV/AIDS in order to make more informed health decisions?' and secondly 'How effective are visual and participatory approaches to HIV literacy?'

Before assessing the potential value of the visual and collaborative techniques used in the workshop, it was important to know if the participants supported the biomedical content of the workshop. In the course of the interviews the participants discussed past HIV literacy training sessions, workshops and lectures that they had received and compared it to the body map drawing workshop. This process revealed the relative successes and shortcomings of the intervention. By discussing my workshop in relation to previous HIV training and their work experience, the participants provided a frank assessment of both the workshop material and

the way it was presented. For example, some participants said they could use particular visual exercises in VCT sessions to help patients understand why they needed to take a blood sample. Others said that they would be able to use body map drawings in support groups, but not in their clinic work. In this way, the chapter will draw on the participants' interview responses as a way of assessing the workshop.

The chapter uses data collected in semi-structured, in-depth interviews with workshop participants to evaluate both the workshop content and the tools and techniques used. The interview data was analysed and grouped according to dominant themes that emerged. Some themes were found across all three groups, while others were particular to one or two groups. This chapter compares and contrasts opinions and experiences described in the data in order to measure the potential efficacy of the workshop as an HIV literacy tool, as well as develop an understanding of the challenges and needs of the workshop participants.

The chapter discusses the workshop participants' opinions on the value of understanding human biology and the science of HIV. It also assesses the educational potential of VCT and the preparation for people accessing HAART. Following this, the chapter will discuss the potential for collaboration between allopathic and traditional healing practice with regards to HIV/AIDS. The effects of HIV stigma and fear of the disease will also be addressed, followed by an assessment of the need to address the social aspects of living with HIV. The chapter concludes with an evaluation of the potential effectiveness of visual and participatory approaches to HIV literacy.

### **The science of HIV- who needs it?**

Not all HIV literacy interventions aim to increase knowledge of human biology as a foundation for discussing HIV and AIDS. For example, the ABC approach discussed earlier in the dissertation, typically appeals to individuals to change their sexual behaviour without necessarily providing biomedical reasons why this is preferable. This section aims to assess if the workshop participants valued learning about human biology and the science of HIV.

All three groups were asked a range of questions to measure their attitudes towards a biomedical understanding of HIV and whether or not they believed HIV literacy should adopt this approach. When asked what they believed to be the three most important things a person should know about HIV and AIDS, it was interesting to note how many times the participants listed knowledge of human biology. This was not unexpected in the case of the TAC participants who belong to an organisation that emphasises the importance of understanding the science of HIV. Nor was it surprising to find this response among the HOPE Cape Town community health workers who have some biomedical training. But it was particularly interesting to find that the group of mothers living with HIV also highly valued accurate knowledge of how the body works and how HIV affects the body. This is exemplified in Noluthando's comment:

The most important thing I think is that of cells. The people must know what cells are doing in our body...I think it is important even to know how the blood in the body...how it is working and the food processing and how it is done in your body. (Interview with Noluthando, April 2007)

Noluthando's emphasis on understanding the inner workings of the body and especially her mention of cells is striking, because of her limited formal education. Most public HIV education campaigns focus on messages such as safer sex, use of condoms and abstinence. It is interesting that Noluthando chose to focus on knowledge of cells in place of these more common messages. Noluthando also drew cells on the group body map drawing (Figure 4.1). Despite being the only mother to do this, her comment remains unusual in its emphasis. This is especially true when compared with the responses of TAC and HOPE Cape Town participants who did not always refer to knowledge of human biology in answer to the most important things a person should know about HIV/AIDS.



Figure 4.1 A detail from the group body map drawing from the workshop with the HIV-positive mothers. Each participant was given a pen and asked to add anything they knew about the human body. The dots labelled as cells and blood were drawn by Noluthando.

Not all of the comments among the group of HIV-positive mothers were as scientific as Noluthando's. Most of the mothers listed practical aspects of how to live with HIV. These included eating healthily, exercise, condom usage to prevent re-infection with HIV and regular medical check-ups. Later in the interview Noluthando emphasised the role of the clinic in monitoring the health of HIV-positive patients. She also identified the need to treat opportunistic infections as soon as they develop, as opposed to waiting until they are severe and cause damage to the immune system.

It can help by all means that everybody must understand HIV. Like...if you're told that you are HIV-positive, [you must] come to [the] clinic and don't come once, come every time when you have something, come to [the] clinic.' (Interview with Noluthando, April 2007).

While fears have been voiced about making people dependent on medical drugs and experts and the 'medicalisation of poverty' (Robins, 2004), the efficacy of medication and in

particular HAART in treating HIV/AIDS is undeniable (Coetzee *et al*, 2004a; Jelsma *et al*, 2005; Badri *et al*, 2004). It is also important that HIV-positive people manage their health by stopping infections before their immune systems are severely compromised. The need to access medical care before becoming AIDS-sick has been documented in a number of studies (Coetzee *et al*, 2004a; WHO, 2004). It is also possible to prolong the period before requiring HAART by learning one's HIV-positive status early and controlling infections. One of the HIV-positive mothers, Selena, identified the sense of agency that knowledge of how to manage their health gives HIV-positive people.

You know what you have to do and what not to do, so if you have a pain you go to the doctor or to the clinic and they will help you. Instead of just sitting here, doing nothing...(Interview with Selena, April 2007).

This statement identifies how HIV literacy enables people to better understand the relationship between illness and the human body by knowing that something can be done to alleviate pain and treat infections. Selena's comment shows the potential of HIV literacy to have a positive impact on HIV-positive women without much formal education, no full-time employment and living in the difficult socio-economic circumstances of a South African township. In this way HIV literacy can potentially challenge disempowering socio-economic situations that often result in people 'doing nothing'. It is also important to note that these women were on HAART and were also caring for at least one HIV-positive child. The potential for HAART provision to increase a patient's knowledge of HIV will be discussed in greater detail later in this chapter.

One of the HOPE Cape Town community health workers also commented on the potential for knowledge of HIV to increase a patient's ability to take control of their lives and their health. Beatrice argued 'They must understand that HIV in the body is not the end of the life. [They must understand] what precautions [they] must take now that HIV is in [their] body.' (Interview with Beatrice, January 2007). In this way, knowledge is regarded as an important part of health management for people living with HIV.

Knowledge is also vital in terms of preventing new infections. In the interviews the HOPE Cape Town community health workers often described how, despite public awareness campaigns, patients still lacked basic knowledge of HIV. This lack of knowledge in the general South African population is verified by a nationwide study (Shisana *et al*, 2005). It also continues to expose people to HIV infection and limit the uptake of HAART. While most patients knew they should, for example, use condoms, the community health workers argued that without knowledge of human biology this message did not reduce risky sexual behaviour because it did not reveal vulnerability to HIV infection. This suggests that knowledge of human biology assists in behaviour change because people understand why they should adopt certain precautions, as opposed to hoping that they will blindly follow health public service announcements.

Jason, a TAC educator, identified knowledge of HIV as a way of reducing new infections by highlighting the need for people to understand how the virus is transmitted, the development of HIV into AIDS and how it affects the immune system. He draws particular attention to the simplicity of the visual body map as a tool for conveying this knowledge, which is discussed in greater detail later in this chapter.

I think maybe that will be even the breakthrough to stop the new infection rate...because people don't have that visual [body map] in front of them where they can see 'Wow, so this is how HIV gets into your body, this is how it grows, and this is...how your HIV goes to AIDS and your CD4 count drops'...Sometimes when we tell people that [they] are HIV-positive...they don't know what is actually happening inside...and when the virus is multiplying what is happening. (Interview with Jason, November 2006)

Jason's positive evaluation of the impact of knowledge in reducing the spread of HIV contrasts with South African studies that have shown that despite knowledge of HIV/AIDS, people do not take steps to protect themselves from being infected with HIV (Shisana *et al*, 2005; James *et al*, 2004). Despite this seemingly gloomy prognosis for South Africa, new evidence from Zimbabwe, urban Kenya and urban Haiti suggests that behaviour change, such as delayed start of sexual activity, a reduction of partners and increased use of condoms, has contributed to a decline in HIV prevalence in those areas (Hallet *et al*, 2006; Gregson *et al*, 2006; Mahomva *et al*, 2006). It is suggested that a range of factors contributed to this

change, including fear of AIDS-related death, STI control, availability of VCT, good health service infrastructure, condom availability and HIV literacy (Gregson *et al*, 2006). In this way the role of accurate information about the science of HIV is reaffirmed.

Another possible advantage of adopting a biomedical approach to HIV literacy to address behaviour change was revealed in an interview with three HOPE Cape Town community health workers. In answer to the question of the most important things a person should know about HIV and AIDS, two participants starting listing safer sex, using condoms and keeping to one partner. In response to this, a third participant argued:

Ok, that's the facts that we need to give them, but I would rather say the body itself. Because if you don't know what is going on with your body, you will do a lot of things...So if you know a lot about...your body itself, then...all this that we mentioned now about safe sex and all that, it will come to mind as well. (Interview with Darryl, February 2007)

What is implied in this statement is a relationship between understanding the biology of the human body and positive changes in behaviour to protect themselves from HIV infection. In this example Darryl argued that without knowledge of the body 'you will do a lot of things', which he later explained as drug or alcohol abuse and unsafe casual sex. In contrast to this, with knowledge of the human body and its vulnerability to HIV, Darryl suggested that people will understand the importance of 'safe sex and all that'. In this way he suggested that prevention messages without knowledge of the human body could possibly be seen as restrictions, rather than life-saving advice on preventing HIV infection.

Within the TAC group, the relationship between knowledge and making better health decisions was also identified as an important part of HIV literacy. Abulelwa suggested that with knowledge of the human body, patients are able to understand the link between illness and negative habits, such as alcohol abuse. She suggested that because people are often not told what is causing their illness, they continue to do things that are damaging to their health out of ignorance. Abulelwa argued for developing knowledge of human biology as a way of including the patient in the process of healing and increasing their responsibility for their health.

I think it helps people...I mean I can understand now why I have got 'flu...Because other people they don't understand why they are ill...They go to the doctor and the doctor gave them the pills and then they are cured...but the doctor won't tell you the reason why you are like this...And then because you don't know anything...you won't know what causes that illness and you will go back and drink again...You don't [know] the reason why you are ill is the same thing you are repeating. So the biology it helps, it helps too much. (Interview with Abulelwa, November 2006)

Jason, a TAC educator, argued that it is important for the patient to be informed about the state of their health. He argued that the first step to better health is knowing one's HIV status and then taking responsibility for it, as opposed to deferring responsibility onto a health practitioner. As noted earlier, the discourse of 'responsibility' in the context of HIV can be problematic because socio-economic circumstances can limit the ability of individuals to protect themselves from HIV infection (Campbell, 2003; Farmer, 1996). Having acknowledged this, it is nevertheless important to find ways in which individuals can be empowered, despite adverse social circumstances. Jason suggested that knowing one's status is the first step to increasing personal agency and being 'more health wise'.

The most important thing is, if you talk about health issues then I will say that that person firstly needs to accept his status and then that person can be... more health wise, more involved, because he cannot put his health on someone else. No, he has to take responsibility [for] his own health. (Interview with Jason, November 2006)

Perhaps it is also worth noting that this statement comes from an AIDS activist – someone who has publicly disclosed his HIV-positive status on national television and continues to raise awareness through other campaigns and public events. In this instance, the call for increasing people's ability to take responsibility for their health came from someone who has himself experienced limited opportunity to protect himself from HIV infection, because of harsh socio-economic conditions, gangsterism and imprisonment. Despite, or perhaps because of, his experience of adverse social, political and economic challenges that continue to limit so many South Africans with regards to HIV and health, Jason still valued understanding the science of HIV.

When discussing the biomedical aspect of the workshop, participants were asked to reflect on and draw from their experience working in communities where people have limited formal schooling. They were asked to consider where they could potentially run the workshop and who they believed would benefit from the visual and participatory approach to teaching the material. All the groups were asked if any of the material or exercises should be excluded from the workshop or altered in any way. In answer to whether or not they considered learning human biology potentially 'too academic' for their work with people in clinics, support groups and other contexts, TAC trainer Noluvuyo replied:

...people will understand...that these cells they need energy to help us fight the infections and to carry oxygen...Energy comes from food, so without food the cells won't be able to function, therefore the organs won't be able to function. So as long as that can be linked so people don't forget all the time that there is a link between everything that happens in your body because it is a co-ordinated system. (Interview with Noluvuyo, November 2006).

In this example, Noluvuyo argued that the onus is on the educator to link the biological information and explain it in such a way that people will be able to understand the theory in relation to their lived experience of health and illness. In this way she affirmed the need for learning about the human body, but also emphasised that the challenge lies in how the material is presented, rather than the biological content itself.

One of the HOPE Cape Town community health workers identified another important reason why patients need to understand how HIV affects the human body. Pumla described instances when patients doubted the processes and tests used in the clinic because they were not adequately informed about the 'window period'<sup>20</sup> between HIV infection and the detection of HIV antibodies in the blood. She suggested that patients need to

...know more about the window period, because sometimes people are tested negative and then maybe after one month she will come back and test positive...She will just ask you '...I was tested negative and now you tell me I

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<sup>20</sup> Once HIV enters the human body it is not immediately detectable in the blood. It can take between two weeks and 6 months after infection for the virus to reproduce to a level where it can be detected by an HIV test. The gap between infection and testing HIV-positive is known as the 'window period'.

have tested positive...maybe you didn't use the same equipment.' (Interview with Pumla, February 2007).

In this way, the workshop participants suggested that ordinary people need to be informed about the science of HIV and the biology of their bodies so that they are in a better position to make more informed decisions and take responsibility for their health. With knowledge of their status and how to manage their health, people living with HIV will be able to live productive lives and prevent the spread of HIV to future sexual partners. HIV-negative people can learn how to prevent HIV infection by being alerted to their physical vulnerability. While acknowledging how adverse socio-economic conditions negatively impact on individual and community health, the workshop participants repeatedly affirmed the need to learn about the science of HIV and human biology. They suggested that this knowledge would empower individuals in the communities where they live and work.

### **The educational potential of VCT and HAART**

This section continues to assess the participants' opinions on the potential role of increased understanding of human biology as part of HIV literacy. In particular it examines the educational potential of VCT services and the ways the provision of HAART increases patient levels of knowledge. It argues that both VCT and HAART provision play an important role in potentially increasing ordinary people's knowledge of HIV and AIDS. This section discusses the degree to which the workshop participants believed this to be true, based on their work experience and knowledge of their communities.

As was argued in chapter two, there is increased willingness to come for HIV testing if HAART is available (Mukherjee *et al*, 2003; Farmer *et al*, 2001). VCT serves as an important entry point into the health care system. It also enables people to make decisions regarding treatment and the reduction of harmful behaviour (Coates *et al*. 2000). Increased use of VCT services has a positive effect on both individuals and their community. Apart from preparing patients for the possibility of a positive result, the counselling included in VCT services also aims to educate individuals about HIV and AIDS so that they can protect

themselves in the future. VCT is important in that it serves to increase knowledge about HIV amongst sexually active people who are at risk of both acquiring and spreading the virus. This information aims to alert individuals to potentially risky behaviour and enable them to make more informed decisions.

Once individuals know their HIV status, they can either take steps towards remaining negative or, if they are positive, they can access the necessary health care. People who test HIV-positive are often referred to support groups where they receive information about HIV and AIDS and how to take care of themselves and their loved ones. There is evidence that this knowledge can translate into behaviour change. Mabunda (2004) recorded a marked increase in knowledge among rural women in the Eastern Cape after they joined a support group. Morah (2007) found a significant reduction in risk behaviour amongst HIV-positive people who knew their status, as opposed to HIV-positive people who did not.

Community health worker, Maryanne, affirmed the need for VCT sessions to provide clients with information about human biology as part of HIV literacy. She explained how in her experience, when people come for VCT, they have exceptionally limited understanding of HIV and in particular the immune system. Maryanne suggested that if people had better biological knowledge, they would understand the way the immune system fights infection. She linked a lack of knowledge with a passive approach to health, where 'the doctor needs to tell them what is wrong'.

...I found out in the counselling...a lot of people don't know that their white blood cells are their soldiers...that they are fighting for them...They are just accepting that their bodies are like this...and now they're feeling sick and...the doctor needs to tell them what is wrong. But they never think what is happening in their body, like the blood cells are fighting and maybe they can't fight now and that is why they are getting sick and that is why we have to test now for HIV. (Interview with Maryanne, February 2007)

After discussing the potential role VCT can play in providing HIV literacy to patients, the workshop participants were also asked if HAART provision could increase peoples' knowledge of HIV/AIDS. In a similar way to the information provided during VCT, preparation for going onto HAART also requires that the patient receive further counselling

and education. HAART patients are provided with information about how the medication works and possible side effects, as well as the need for regular clinic check-ups.

When asked if there was any relationship between HIV literacy and the provision of HAART, the workshop participants responded with a range of opinions. Four interlinked themes emerged. The first theme addressed the link between understanding how antiretroviral therapy works and how this could encourage people to access treatment. Nolwazi, a TAC treatment literacy trainer, suggested that without knowledge of human biology, a person would be unable to understand how HAART can improve their health by slowing down the viral replication.

If a person doesn't know what exactly...is happening inside, doesn't know biology...it is not important for going on treatment...If you know everything...then you say '...I must go for treatment...because this is what is going to happen when I am not taking my treatment'. So it [knowledge of biology] is very good. (Interview with Nolwazi, November 2006).

In contrast to this positive outlook on how knowledge about the human body would increase the uptake of HAART, the second theme that arose in the interviews was the issue of disclosure of HIV-positive status and how this often prevents people from accessing HAART. As part of ensuring that patients adhere to antiretroviral therapy, many clinics advocate that they disclose their status to a family member so that they will have support at home in the form of a 'treatment buddy'. However, one of the HOPE Cape Town community health workers, Siphon, revealed that even if people choose not to disclose their HIV-status to a family member, it is extremely difficult to keep the medication secret. For this reason he suggests that patients need to be prepared for disclosure once they consider starting HAART.

...sometimes they have not disclosed to even their families and in a way they will be forced to disclose...You cannot hide now forever the secret of the pills... sometimes you have to eat the tablets in front of your parents...So there [are] actually a lot of things to consider. (Interview with Siphon, January 2007).

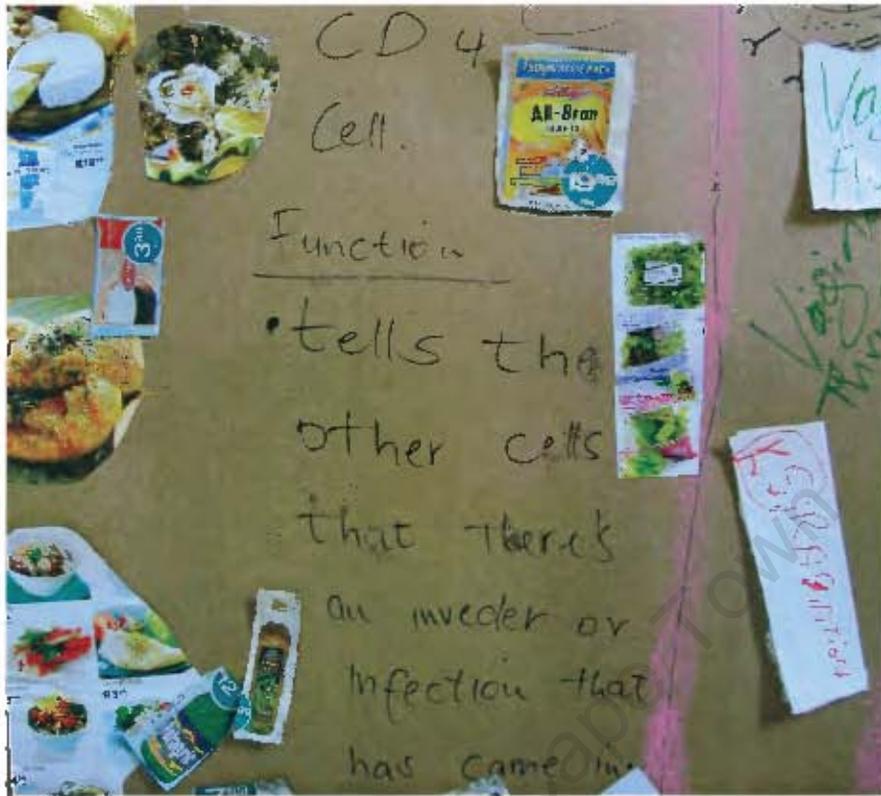


Figure 4.2 A detail from one of the body map drawings produced by TAC with a description of the role the CD4 cell plays in the immune system. This is the kind of information that the community health workers suggested HAART patients should get before starting treatment.



Figure 4.3 An illustration of HIV (bottom left) and a CD4 cell (middle) from a body map drawing.

Amanda (HOPE Cape Town) also spoke about the challenges of disclosure by drawing attention to how HAART can potentially impact on intimate personal relationships. In the instance of a new sexual partner, there is the dual challenge of keeping HAART medication secret and convincing the partner to practice safer sex and use a condom. It is extremely difficult to sustain a sexual relationship without disclosing one's HIV-positive status, especially if one is taking medication. In the interview Amanda argued that this poses adherence problems, because patients would often abandon their treatment or skip doses in order to keep their HIV-positive status secret.

They are scared of disclosure. Meet a new boyfriend, start a new relationship. 'I can't tell this person that I am HIV-positive. I am not going to tell this person I am on ARVs.' (Interview with Amanda, January 2007)

The third theme to emerge in the interviews involved the need for accurate information on HAART to allay people's fears of side effects. The need for people to be adequately prepared for the commitment of HAART in order to ensure adherence was also addressed. In the course of the interviews, the community health workers often recounted stories of how patients were so desperate to start HAART, that they were not sufficiently prepared or sometimes would choose to ignore the possibility of experiencing side effects. This is clarified by Chantal, a TAC educator.

I think especially...when they are first going to start with ARVs...sometimes people get to default [because] they do not know how it works. They get to the side effect part [then] they leave the ARVs and I think it is very important for us to explain how...it is going to work in the body. (Interview with Chantal, November 2006).

The importance of understanding the science of HIV and HAART is further demonstrated by one of the HIV-positive mothers. Joy clearly identified the key relationship between HAART and the slowing of the replication of the HI virus. It is remarkable that a woman with basic formal education and no medical training is able to grasp and also explain this process in a language that is not her mother tongue. This powerfully demonstrates the fact that people with limited education can, and indeed want to, understand the science of HIV. In a similar way, Siphon Mthathi, TAC General Secretary, argues "People who are treatment literate take

medicines because they understand the evidence that shows they work, not just because they have been told it works.” (Mithathi, 2007).

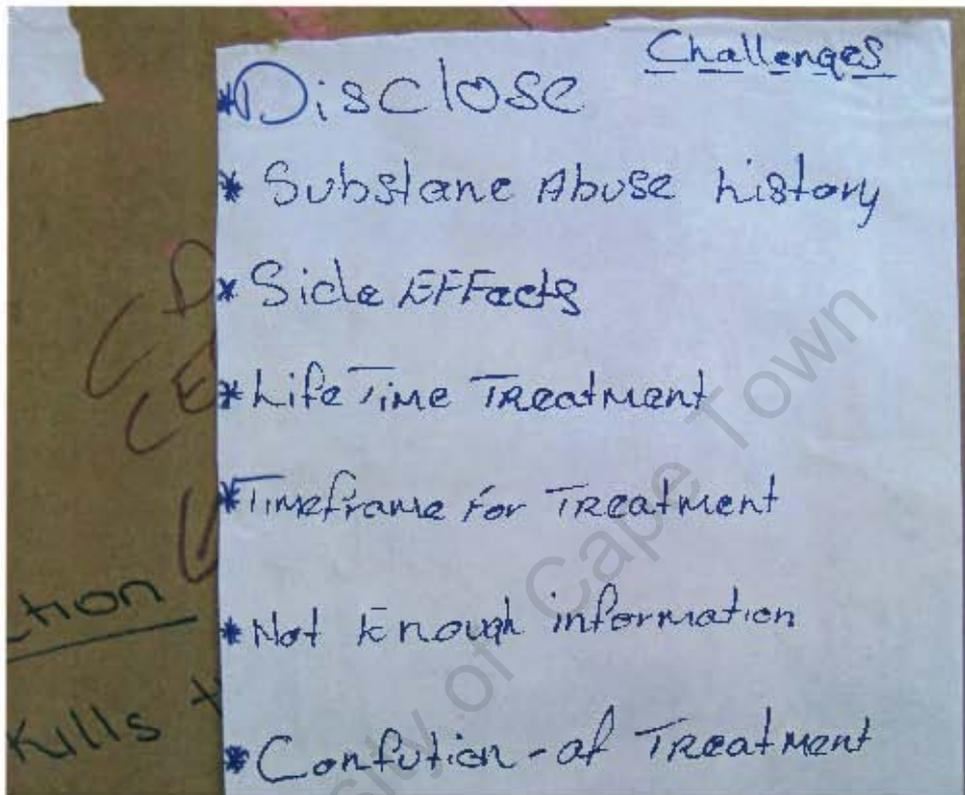


Figure 4.4 A detail from one of the body map drawings that records a group discussion on the challenges that HAART patients should be made aware of before they start treatment.

In the following statement Joy emphasised the need to understand how HAART works to slow down replication of the HI virus, while also commenting on the challenges of being on HAART and the commitment of check-up clinic visits.

Because you understand how to take the ARVs, you understand that if you take the ARVs, that is hard and [you] have to meet the doctor...And if you take the ARVs they go inside your body and the ARVS will fight the HIV, but if there are not three [triple therapy] they cannot fight, then HIV is going to overpower them. (Interview with Joy, April 2007).

When asked if people in her community knew about HAART, another HIV-positive mother, Noluthando replied 'No, they don't know... They should know, because those who don't have ARVs can take ARVs.' (Interview with Noluthando, April 2007). In contrast to this lack of knowledge within their community, the group of HIV-positive mothers demonstrated a working understanding of HIV and HAART, albeit with some gaps and misunderstandings. This knowledge was a consequence of the fact that they had been AIDS sick before commencing HAART. Most of the women claimed that what they knew about HIV and HAART came from what the sister and doctor at the clinic had told them. This demonstrated a potentially positive relationship between uptake of HAART and increased knowledge of the human body.

The fourth theme related to VCT and HAART, was the need for accurate information about how HAART affects the body due to public confusion surrounding antiretroviral therapy. Given the Department of Health's support of alternative approaches to treating HIV and AIDS, it is not surprising that people who lack information on the topic are sceptical of the efficacy of HAART (Robins, 2004; Nattrass, 2007). Information campaigns have variously argued that HAART is toxic and that food and vitamin supplements are a preferable approach to treating HIV. This conflicts with evidence that records marked improvement in HAART patients' health and negligible side effects (Jelsma *et al*, 2005, Coetzee *et al*, 2004a). Evidence from a clinic in Khayelitsha township, which is arguably one of the most poorly resourced environments in South Africa, recorded that 86.3% of HAART patients in the study were alive after two years and had a low chance of viral rebound (Coetzee *et al*, 2004a).

In the interviews, the participants argued that knowledge of the human body increased people's ability to make better informed decisions with regards to treatment options. TAC treatment literacy educator and trainer Nolvuyyo highlighted some of the ways the discourse of HAART being toxic had negatively affected public opinion of HAART.

I think it's confusing messages people get out there... Then a person will rather to go for traditional medicine, because... people believe that [they] have no side effects and the ARVs in ten years time your liver will be damage[d]... So

it's more important for the person who is going to take ARVs to be more empowered than anything...I think preparation has to start early so the person can make the choice if you're wanting to take ARVs. You can try all these other *goetis* [things]...so that by the time you want to take ARVs you are committed and ready for ARVs. (Interview with Noluvuyo, November 2007).

This comment introduced into the discussion the interesting dynamic of traditional healing as an alternative to HAART, because of the fear of side effects. Noluvuyo suggested that people need to learn of their status before they are seriously ill so that they can be well informed and ready for the commitment of HAART if they choose to go that route. She suggested that this also gave people time to try alternative therapies. While some health practitioners might find this troubling, because of the potential for some traditional medical treatments, such as purgatives, to harm the patient's health, it also has to be acknowledged that this approach allows an HIV-positive patient to arrive at their decision to take HAART on their own terms.

### **Traditional healing and allopathic approaches to HIV/AIDS - is collaboration possible?**

This section looks at how the workshop participants viewed the relationship between traditional healing and treatment of HIV/AIDS. Given their alignment with organisations that promote a biomedical approach to HIV/AIDS, it was important to assess their opinions to see if they supported collaboration between traditional and allopathic approaches. I acknowledge the initial bias that these organisations may have had against indigenous healing practice. With this in mind, it is particularly interesting that both HOPE Cape Town and TAC have organised collaborative meetings between traditional healers, medical doctors, community health workers and HIV literacy educators.

In the South African context it is generally agreed that depending on the type of illness, people will move between indigenous and allopathic medical practitioners (Nattrass, 2005; Wreford, 2005; Mills, 2005). This suggests that in order to provide care and treatment for

patients, clinics and doctors cannot ignore the possibility that their patients may well be consulting an indigenous healer and taking traditional medicine. It is equally important to acknowledge the limitations of the allopathic tradition and that for many South Africans a biomedical understanding of the body does not resonate with their world view or spirituality. One reason for this is the emphasis on the physical or scientific aspect to health that often disregards that the patient may also need emotional and spiritual guidance to assist their healing process. This is perhaps particularly relevant with regards to chronic illnesses, such as AIDS, that require treatment to be taken for the rest of your life. For this reason HIV interventions and organisations have increasingly made attempts to engage with traditional medical practitioners. Both HOPE and TAC have hosted collaborative workshops with traditional healers.

In the course of the workshop, participants were encouraged to discuss either their own or their clients' experiences with traditional healing practice and ways they have addressed it in their work as treatment literacy educators, trainers and community health workers. One of the ways this was done was to encourage the participants to add any home remedies or alternative therapies to their body map drawings. This was often met with some initial hesitation, which could possibly be explained by the fact that I do not share an indigenous cultural heritage. After further discussion participants added a range of home remedies, such as plain yoghurt to help treat mild thrush, how to mix salt and sugar for oral rehydration solution and what foods to give patients with diarrhoea (Figure 4.5).

On the whole, most participants did not appear knowledgeable about specific traditional remedies, but discussed broader concepts linked to traditional healing practice, such as the use of purgatives. Given the nature of the groups and the biomedical content of the workshop, a bias could have influenced this outcome. This is despite one of the community health workers being a traditional healer and some of the participants openly referring to past visits to traditional healers.



Figure 4.5 Examples of how to mix sugar and salt solution and prepare apple when caring for people with diarrhoea can be read in the bottom right quarter of the drawing. The areas marked X identify places in the body where HIV can be transmitted.

The limited knowledge of traditional medicine among the groups was consistent with the finding that only 1.1% of South Africans reported using traditional medicine (Shisana *et al*, 2005). However, a study in Khayelitsha township recorded 6% of respondents who had visited a traditional healer the last time they were seriously ill (Nattrass, 2005). This suggests that the exact number of South Africans seeking traditional healers remains uncertain. Given the secret nature of traditional healing, and in particular the safe-guarding of the 'recipe' or combination of herbs used in remedies, it is perhaps not surprising that workshop participants appeared to know so little. Regardless of whether or not individuals actually visit traditional healers, perhaps what is more important to consider is the extent to which indigenous understandings of health and illness, such as ideas around pollution, influence their health decisions.

The participants were asked if they had any experience of training or working with traditional healers. Within the TAC group, some of the trainers had been involved in a workshop with traditional healers. Noluvuyo described how this workshop had enabled the TAC members to learn more about traditional healers, while in exchange they provided information on allopathic medicine. In this way, Noluvuyo acknowledged the need for a two-way process.

For me it was challenging because we don't know much about traditional healers. We think we know. We have so much myths and stereotypes about them...[I]t was more than training for traditional healers it was a training for us as well...What unites all of us [is that]...HIV-positive people consult all of [us]...for spiritual healing or others for physical healing and others for other things. And we cannot deny that...80%<sup>21</sup> use traditional medicine and that is why we need traditional healers in the training. (Interview with Noluvuyo, November 2006).

Her response not only highlighted the diverse needs of people who are suffering from ill health, but also emphasised the understanding that many South Africans consult traditional healers at some stage of their lives. Noluvuyo also spoke openly about the way that traditional healers are often dismissed by medical workers without adequate understanding of traditional medicine practice. She went on to explain that in the course of the workshop the TAC members also learnt the distinctions between the different types of healers and the different services that they offer to their clients.

One of the challenges of collaborating with traditional healers was the issue of language and the fact that many biomedical terms are not easily translated into isiXhosa. Linked to the difficulty of language is the expression of certain concepts of health, illness and healing which are embedded in biomedical language. Noluvuyo described her experience of these barriers to mutual understanding and the way that the TAC members and traditional healers overcame them.

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<sup>21</sup> While people refer to the figure of 80% of South Africans consulting traditional healers, I have been unable to find its source. In contrast, the figure of 1.1% recorded by the HSRC study (Shisana *et al*, 2005) does seem exceptionally low. Natrass (2005) reports 6% of Khayelitsha residents visited a traditional healer the last time they were seriously ill.

...most traditional healers are uneducated. The whole thing needed to be in isiXhosa from the start to the end and when we talked about ARVs it was complicated...We had to have new names [like] *amakhubalo kathikoloshe*...[to] relate to traditional healers. You cannot just use a name that is something strange for them. So we have to use the same terminology that they use and adapt it to them...You will have to explain what it does and...and then they give you the name and we end up using their own language. (Interview with Noluvuyo, November 2006).

This statement provides important insights into the challenges of collaboration, but also shows that it can be done. The TAC has exhibited innovative ways of negotiating the use of traditional healing. For example, one of TAC's posters features a traditional healer disclosing her HIV-positive status and the fact that she takes HAART. The traditional healer recommends that people communicate their HIV status to both traditional and allopathic practitioners. The call for open communication is one way of allowing people to use both approaches to healing without one form of medication interacting adversely with the other.

It is interesting to note that in the group of HIV-positive mothers, who were the least educated group in biomedical terms, an overwhelmingly negative impression of traditional healing practice was found. While this group was substantially smaller than the other groups from HOPE Cape Town and the TAC, it is interesting to note the divergence of opinion, which suggests that while many South African may consult traditional healers, there are those who do not. According to Joy, an HIV-positive mother, one reason why people should not consult traditional healers is the potential danger of one medication inhibiting the efficacy of the other. Due to her previous statement that she had received most of her HIV knowledge from the clinic, it is reasonable to suggest that this opinion was also informed by the clinic. In particular, Joy referred to the use of purgatives and incisions in the skin which can be part of traditional healing practice.

But sometimes it is very dangerous if you use both because...if I have TB now and I come here to the doctor and I get the medications for TB and then I go to the witch doctor, the witch doctor is going to give another medication. ...and then I will have to vomit and...the sores are going to be very big and then the tablets won't help me from the doctor...because of those cultural...medications. (Interview with Joy, April 2007).

It is interesting to note that she uses the term 'witch doctor'. While it is difficult to gauge if this was a deliberate choice over the more neutral term 'traditional healer', Joy later clarified her position on the use of traditional medicine by saying that it should not be encouraged<sup>22</sup>. This was followed by an exchange between two of the mothers that affirmed the role of religion and prayer in their lives. In response to other ways to aid the healing process they argued that '...you can just say you believe that God will help you...' (Interview with Selena and Joy, April 2007). The two women appeared surprised that I had even suggested that traditional healers could be approached. The view that traditional healers should not be consulted appeared to be formed by both their Christian faith and advice they had received from the clinic. In this way they rejected traditional healing on both a fundamental belief level, as well as the knowledge of the potential contra-indications.

In a separate interview with another one of the HIV-positive mothers, a different theme emerged. Noluthando acknowledged that people may seek both traditional and allopathic treatment because they are desperate to find a cure and it is known that ARVs cannot cure a person of HIV. Noluthando went on to express her own view on the matter by arguing that a traditional healer does not understand how HIV affects the body in a biomedical way. She dismissed the efficacy of traditional healing on the grounds that traditional healers lack the medical skills to treat HIV and AIDS.

They go to both because they don't know where are they going to get healthy. Because if you know ARVs, they are not going to cure me of this HIV. Maybe they think the traditional healer can make them better...But a traditional healer doesn't know how...HIV is working inside your body. He will just give you that medicine and not know how this medicine is going to work. A traditional healer doesn't know your CD4 count, your body. They just give you the medicine. (Interview with Noluthando, April 2007).

Later in the interview, Noluthando expressed another reason why she was suspicious of traditional healers with regards to the treatment of HIV and AIDS. She argued that 'They want money. It's useless to use the herbalist because they use money and the ARVs you don't buy them.' (Interview with Noluthando, April 2007). In this way she drew attention to

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<sup>22</sup> Anecdotal evidence from speaking to other researchers suggests that many HAART patients do not want to be seen to be supportive of traditional healers, because clinics often forbid patients from seeking their advice.

the expense of consulting traditional healers, which in her opinion undermines the integrity of their treatment. Noluthando implied that many traditional healers are driven by profits that can be made by treating people living with HIV. The provision of antiretroviral therapy free of charge in the South African public health care sector has been celebrated as a triumph for human rights. However, perhaps it is also worth considering that the fact that it costs nothing is not necessarily the best reason for choosing HAART. People should rather take HAART based on an informed decision, including knowledge of potential side effects and how to manage their health.

### **Can knowledge of the human body reduce fear and stigma related to HIV/AIDS?**

There is extensive literature on the negative impact of stigma on HIV-positive people throughout the world (Maughan-Brown, 2006; Herek, 2002; Herek *et al*, 2003; Chesney & Smith, 1999). In the course of the workshop and in the interviews, the participants discussed the issue of stigma and fear. Some literature suggests that increased knowledge about HIV, especially how it is not transmitted through casual contact, can reduce stigma (Herek, 2002). This section describes the workshop participants' opinions on ways that knowledge of the human body can potentially reduce stigma and fear of HIV and AIDS. In the context of this dissertation, HIV stigma is defined as discriminatory behaviour towards HIV-positive people or those associated with the virus and AIDS-related illnesses.

It is suggested that understanding AIDS as a disease caused by a virus allows it to be treated as a chronic illness, as opposed to being attributed to moral and superstitious reasoning that almost always stigmatise HIV-positive people. One of the TAC trainers, Nobahle, emphasised that one way to reduce stigma is focusing on the similarities and not the differences between HIV-negative people and those living with HIV. She suggested that understanding human biology was one way that this could be achieved.

For me...doing the human body...will reduce stigma because each and every person will know I have these body parts, there is no difference [with] a person who is having HIV. Each and every person has the same body parts as I am having...(Interview with Nobahle, November 2006).

This argument was similarly expressed by one of the HIV-positive mothers, Noluthando, when she suggested 'They will see that HIV is like every disease. You get it as other diseases because you get TB, you can have cancer and that is also a disease.' (Interview with Noluthando, April 2007). In this way, these two participants affirmed the idea that 'medicalising' HIV and presenting it as a chronic illness could work towards reducing stigma in their communities. Noluthando went on to suggest that another way to reduce stigma around HIV would be to incorporate health facilities that address HIV and AIDS-related illness within existing clinics as opposed to separating the treatment of HIV from other illnesses. Noluthando based this suggestion on her experience of attending an HIV clinic and her understanding of how her community views the clinic. She explained how people would rather not take HAART than be seen at the HIV clinic.

It's because they don't want to be seen by others here, because when we are here we are many. So maybe I don't want you to see me that I'm here, that I'm also HIV-positive. And many go to special [private] doctors. It's better if you can mix it [HIV] with all the other diseases. (Interview with Noluthando, April 2007).

Noluthando also spoke of how the support group that used to run in her community had been discontinued due to poor attendance. Once again the reason that people stopped attending was because of the fear that people would see neighbours and people from their community at the support group and then spread word of their HIV-positive status in the general community. Both the instances of the clinic and the support group emphasise fear of public disclosure of HIV-positive status and indicate that many communities are still governed by a climate of secrecy, humiliation and stigma.

Two main reasons why people felt the need to keep their HIV-positive status secret from their communities emerged in the course of the interviews. One reason was the perception that if a person is HIV-positive they are promiscuous. This was obliquely referred to by one of the

HIV-positive mothers, Noluthando, when she suggested 'I don't know. Maybe it's that...they heard that if you are HIV-positive that you are walking all around [promiscuous]. I don't know.' (Interview with Noluthando, April 2007). Her repetition of the phrase 'I don't know' reveals hesitancy to discuss the issue of promiscuity and sexuality. In contrast to this, one of the community health workers, Amanda, directly addressed perceptions of sexual risk-taking with regards to HIV transmission. She argued

The other thing they are supposed to know [is] HIV doesn't discriminate. Because there was that time when people [thought people] who are HIV-positive are...living like 'I don't care'. And most of the married couples think they are untouchable when it comes to HIV and all, not knowing that...the husband is going out meeting somebody...and they have unprotected sex. So those are the things we have to talk about and even to talk to our children about those things. (Interview with Amanda, January 2007).

Apart from her emphasis that 'HIV doesn't discriminate', Amanda drew attention to some of the complexities of addressing not only stigma, but also the vulnerability of women with regards to being infected with HIV by their primary partner. She commented on how married couples often believe that the morally sanctioned institution of marriage immediately offers them protection from HIV infection and choose to ignore that many marriages are far from monogamous. Amanda's reference to 'there was that time' suggests that the discourse around blame and innocence, particularly related to promiscuity, has been challenged more recently.

Later in the interview Amanda addressed the role that class and level of education can play in people's perception of who is at risk of being exposed to HIV. She recounted an experience she had in her clinic where a young lawyer was referred for TB treatment. When starting TB treatment, it is recommended that an HIV test be conducted so that the clinic can know the patient's HIV status. If a person is on HAART their regimen may need to be altered if they are going to start TB treatment because of the additional strain placed on the liver. The lawyer refused to have an HIV-test and her condition worsened. Amanda advised her again to have an HIV test and again she refused, but after a while she asked for antiretroviral therapy. Amanda explained that she could not prescribe HAART without an HIV test and a CD4 count. The patient left the clinic and never returned. Amanda expressed her worry and

deep concern that the patient would not survive and believed that stigma associated with HIV and AIDS is what had driven the young lawyer into a state of denial.

Apart from stigma and peoples' perceptions of who is at risk of being exposing to HIV, another reason given for people's fear of the disease is that despite the advent of HAART many people still believe HIV to be a death sentence. One of the TAC treatment literacy educators, Chantal, supported the idea that if people were exposed to the biology of HIV and learnt how HAART works to slow the replication of HI viruses, they would have less fear of HIV.

I think...they will be less afraid because many people see someone...with full blown AIDS...and then they [think]... 'Am I going to be that way if I've got HIV?'. But as soon as you can show them that body and put ARVs in that body they can see 'No, this can work and it will work'... because I know how to look after my body now. (Interview with Chantal, November 2006).

In this way Chantal asserts the potential for knowledge about HIV and the human body to help people understand that HIV does not necessarily have to deteriorate into AIDS and that HAART, along with lifestyle changes, can enable an HIV-positive person to remain healthy. The expectation that someone living with HIV will look ill and be unable to live a productive life is still very much present in daily interactions with people. Another TAC trainer remarked on this when he told the story of an encounter he had on the train when he was wearing the TAC 'HIV-positive' t-shirt.

...there was this lady even in the train and she asked me 'Why are you wearing a HIV-positive t-shirt?' She would never wear a HIV-positive t-shirt in a train and I ask[ed] her 'Why? Do I look sick?'. And she said 'No, but it doesn't seem you are HIV-positive' and then I told her 'Don't judge a book by it's cover.'...When I told her 'I am HIV-positive', then she wanted to know...more...Then she said but she didn't know, but from now on she will have much better understanding and she will respect people living with HIV. (Interview with Jason, November 2007).

Jason also argued that the perception of extreme illness as a consequence of being HIV-positive contributed to people not wanting to use VCT services. In a similar way to his colleague, Chantal, he also believed that this perception was due to the experience of seeing a

relative or someone in the community die of AIDS. This highlights the need for more widespread HIV literacy in communities hardest hit by the AIDS epidemic and the promotion of VCT services together with the provision of HAART. Jason also identified the necessity for people to test early so that their health can be monitored and they are able to make decisions benefiting their health that would prevent the rapid deterioration from HIV to AIDS and also prolong the period of not needing HAART.

I think it's maybe because some of them were affected by someone which was HIV-positive and that [by] the time they find out that person was HIV-positive it was too late... So he has that thing in his mind 'No, being HIV-positive, you can do nothing for yourself, you look like a skeleton'... And that is also why we are trying to encourage people, that they need to go and get tested that they know their status... If they know their status they will know they will have a positive life. (Interview with Jason, November 2007).

When discussing the effects of stigma on general perceptions of HIV and AIDS, the impact of looking different or having a disease that cannot be cured or, is not adequately understood, was identified as one of the major factors contributing to stigmatising attitudes. This is suggested by one of the HIV-positive mothers, Noluthando.

I think that it's because they are afraid to tell other people that they are HIV-positive, because if you tell something that you are HIV-positive he will [think]... he is not going to look like other people. It's maybe if you are HIV-positive we have something that they don't know. (Interview with Noluthanda, April 2007).

This is also affirmed by another mother, Selena, when she says 'What makes them scared is to see when you are thinner than you were before...' (Interview with Selena, April 2007). Both these instances emphasise the way that looking ill contributes to HIV stigma and suggests that the provision of HAART and the way it improves patient's health can help ameliorate stigma in communities with high HIV-prevalence. Apart from the provision of HAART, education was identified by one of the HOPE Cape Town participants, as another way of reducing stigma.

I have noticed that if you are infected it won't...harm...you, because I understand that before there was a lot of...stigma, but education has come. I

can see a lot of people have got that little [bit] of education because when I am doing the counselling, the first question 'What do you know about HIV and AIDS? What is the difference?' And I can see a few of them know the difference... (Interview with Bulelwa, February 2007).

Bulelwa's comment suggests that basic knowledge of HIV and AIDS is increasing in her community with ordinary people being able to explain the difference between the two. However, on the whole the communities where the HOPE Cape Town and the TAC participants work are characterized by high HIV prevalence, poverty, lack of formal education and knowledge of HIV/AIDS. While positive stories like Bulelwa's are true, a lot remains to be done to further increase knowledge of HIV/AIDS, reduce stigma, increase VCT and the uptake of HAART by those who need it. Another possible benefit of increased HIV literacy is noted by one of the TAC educators, Sesethu, when she emphasised the hope and agency that knowledge about health and HIV gives HIV-positive people.

I think it reduces [fear of HIV] because they teach...how you can stop HIV from reproducing. At least somewhere, somehow you have that hope...at least you can do something from avoiding the [virus] reproducing in your body. I think...it reduces stigma. (Interview with Sesethu, November 2007).

This section has addressed the potential for increased knowledge about the human body and HIV/AIDS for reducing fear and stigma and also increasing HIV-positive people's sense of agency and control over their health. By drawing on the opinions of the workshop participants, this discussion has attempted to describe the complexity of the issue. Stigma and fear are still prominent in many communities and a discourse of immorality and irresponsibility is still used to discriminate against HIV-positive people. On the positive side, many participants did point to the empowering nature of increased understanding of the human body and HIV/AIDS. Given the small sample size it is difficult to draw conclusions for the greater population, but the study does suggest that increased HIV literacy, together with the provision of HAART and VCT services, plays an important role in creating a more health-enabling environment.

## **Addressing social issues related to HIV/AIDS**

As has been previously argued, it is important that HIV interventions address the medical aspects of the disease and also take into account the social challenges that people living with HIV often face. The socio-economic limitations to providing South Africans with good health care and treating HIV-positive people will be addressed in detail in the next chapter. This section will discuss the participants' responses to particular exercises in the workshop that aimed to address some of the social challenges surrounding HIV and AIDS.

The group of HOPE Cape Town community health workers and HIV-positive mothers particularly valued the exercises that addressed social support and the challenges of disclosing HIV-positive status. In the 'hand exercise', which has been previously discussed, participants worked with a partner and traced around both their hands. In the one hand they wrote all the names of the people who gave them support and in the other they wrote the names of those they supported. This followed a discussion of the different kinds of support, including financial, emotional, spiritual and material. One of the HIV-positive mothers articulated these different forms of support discussed in the exercise.

Praying, emotionally, financially. Emotionally you can talk to your family and friends about what is bothering you...so that they can help you...Financially they can help you by giving you money or by leaving something that you want to. (Interview with Selena, April 2007).

The groups reported that they had never looked at the role of social support before and found it very useful. They enjoyed discussing the many forms that support can take and also gaining an insight into how different people in their lives provided them with different kinds of support. It made them appreciate that they often received more support than they originally thought. The converse was also found when some participants said that they felt that they gave more than they received. This stimulated a discussion on the need for support for people, such as community health workers, who suffer burn out and most often do not receive any form of debriefing or psychological support. In this way the participants identified that this exercise was useful, not only for their clients, but also for themselves.

One of the HIV-positive mothers, Noluthando, identified the value of thinking how particular people in her life provided her with different kinds of support.

I learnt that if you are a human being you are depending on these persons around here, sisters and brothers, and kids and husband and parents and pastor, neighbours and colleagues. So this shows us that we depend on these people. (Interview with Noluthando, April 2007).

Bulelwa (HOPE Cape Town) echoed these sentiments and explained how the visual nature of the exercise based on tracing around both hands had emphasised the importance of touching and holding people living with HIV. This addresses the physical isolation that many HIV-positive people experience because of stigma.

...first when you talked about the hand, I didn't understand but then lastly I said 'Ok I need all those people, that hand, I make it as if that is the hand that can touch me. Even if I need someone to touch, you see when you are hurt, you just need someone to rub you...and I said 'Ok I need even the second hand because I got a lot of names, I need this one, I need this one.' (Interview with Bulelwa, January 2007).

Throughout the interviews with the TAC, HOPE Cape Town and the mothers, the participants listed this exercise as one of their favourites. The community health workers in particular said that they often lacked tools or even the skills to counsel people, especially when they just learnt of a positive HIV test result. The benefits of the practical nature of the exercise are demonstrated by a comment made by Joy, a mother living with HIV.

That was perfect because there I remember who...where I can go for support and who I always call if I got support. It made me feel great. It helps a lot. (Interview with Joy, April 2007).

Following this exercise, the challenges of disclosing HIV-positive status was discussed using another drawing-based exercise<sup>23</sup>. In this exercise, participants identified key people who they thought they would disclose their status to, followed by other people further removed from their immediate support network. The emphasis of this exercise was to understand disclosure as a way of accessing social support, but it also served to prepare people for any

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<sup>23</sup> This exercise is indebted to Colin Almeleh and his work on disclosure of HIV-positive status.

negative reactions they might experience. The participants remarked that this exercise would be particularly useful in support groups for HIV-positive people.

In this way the advantages and limitations of disclosing HIV-positive status to family and friends were debated. This brain-storming session also encouraged participants to discuss other related topics, such as gender inequality, the impact of living in an informal settlement and experiences of stigma and discrimination. These exercises dedicated to social support and disclosure revealed the ability of visual cues, like the drawn hand, to stimulate discussion and problem-solving strategies. The conversations that emerged from these exercises were important in developing an understanding of the social, psychological and emotional challenges of living positively with HIV.

### **Efficacy of visual learning**

Up until this point, the chapter has presented the workshop participants' opinions on the content of the workshop and in particular their views on developing understanding of human biology in relation to HIV. The creation of body map drawings is both visual and participatory by nature. This section will focus on visual learning in the body map drawing workshop. The following section will address the advantages of using participatory learning techniques in the context of HIV literacy.

In order to assess if visual approaches to HIV literacy are effective, participants from TAC and HOPE Cape Town were asked to relate the workshop experience to their work as HIV literacy educators and trainers and community health workers. They were asked to describe how they could potentially use the visual exercises demonstrated in the workshop. In particular, they commented on the Visual Body Map and the creation of the body map drawings. The group of HIV-positive mothers was asked if the use of visual material and drawing had increased their knowledge of health and illness in relation to HIV and AIDS.

Visual leaning is essentially built on the premise that words and images convey information in different ways. The advantage of using images is the direct, unambiguous and clear way that visuals are able to present ideas and information. This is demonstrated with street maps, instruction manuals and cartoons, but visual literacy cannot be taken for granted. Some visual conventions such as speech bubbles are based on previous knowledge or exposure to such conventions and are not always clear to non-literate people (Arbuckle, 2004). However, the efficacy of visual representations of the human body has been noted because the experience of living in a physical body is shared among all people (Carstens *et al*, 2006). This is particularly encouraging in that it supports both the use of the Visual Body Map and the creation of body map drawings.

One the dominant themes to emerge in the course of the interviews was the way visual learning was particularly powerful within the context of illiteracy or low literacy environments. The community health workers in particular noted the lasting legacy of *apartheid* educational policy that has left many South African adults with very poor formal education. Both Darryl and Maryanne made references to the educational gaps found with many of their patients and also closer to home within their own families. In Maryanne's words 'Yes, adults are not aware of their body parts, because some of them don't even know where their lungs is...because [in] those days there wasn't much school...' (Interview with Maryanne, February 2007). When discussing the lack of formal education within his own family, Darryl noted the potential for the use of visuals to assist with the learning process.

If you look at the area where most of us come from...[our] parents...left school since they were Grade 4 [or] something. They will tell us that and...that's where the charts get in...because you can show it to them...My parents, my mommy actually, if you show it to her she will pick it up quicker. (Interview with Darryl, February 2007).

It is also worth noting that prior to the workshop some of the community health workers and HIV literacy trainers and educators already used drawing as an educational tool<sup>24</sup>. This suggests that the drawing exercises used in the workshop have a good chance of being

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<sup>24</sup> Colleagues have suggested that drawing as a medium, as opposed to singing or drama, is not common in Southern African culture and could be seen as essentially 'Western'. I would suggest that regardless of cultural background, people are open to visual approaches to learning if they are included in the process.

employed since the participants already believe visual learning to be helpful. The way that drawing can develop a person's understanding of HIV and the human body is described by Maryanne (HOPE). She suggested that verbal explanations have a limited impact on people, especially if they have a low level of education.

And now sometimes I draw to show them...the body and then show them this is where it [HIV] can enter...because you get people that...can't write and read...so it's better that you use the drawings so now they understand what you are talking about. Because if you just telling them this is HIV...when you finish talking you will realize that that person actually knows nothing because now you are asking him a question, but he can't answer...so that's why I am using the drawing. (Interview with Maryanne, February 2007).



Figure 4.6 Participants marked and labelled those parts on the human body where HIV can be transmitted. In this example, sexual transmission and mother-to-child transmission during pregnancy or while breast feeding, can be seen most clearly.

Another advantage of using visuals is the absence of medical terminology. This eliminates the power dynamics inherent in using jargon or academic language. The following comment comes from a HOPE Cape Town participant who had never used drawing as an educational tool before, but had previously employed other participatory techniques such as role-play activities. Amanda explained why she thought drawing would be useful for HIV literacy education in the following way.

...it was simple because not all of them are literate and the examples we use when we do the drawing...makes it simple for the person to understand...their own bodies better, how the body functions...Because most of the time they are listening to you...but you don't know how much do they know...But if they are part and parcel of doing it themselves...if there is one who doesn't want to talk, it makes her also to be part of it...when we do the drawing ...people will understand. (Interview with Amanda, January 2007).

Amanda also commented on the way that drawing encourages participation and enables learners to demonstrate their new knowledge in the process. This is an important aspect of the learning process since it reinforces new understandings and also enables the facilitator to see whether or not participants have understood what has been discussed. Amanda also notes the potential for drawing to include reserved participants who lack confidence in expressing their opinions verbally, but are able to do so visually. She went on to identify the way that medical language can exclude people from understanding how their bodies work and make it difficult for them to engage with medical practitioners.

Charmaine (HOPE Cape Town) also identified the way that medical language immediately creates a power dynamic between those who can understand and speak it and those who cannot.

It's a nice way of getting to know about HIV in a...way that suits them... Because in training sometimes the words is up there [difficult] and we can't really talk together...And if you are illiterate you don't want to hear those words...because it scares you...The struggle is going to be there because some [people] feel maybe inferior... (Interview with Charmaine, February 2007).

In these examples the community health workers supported the use of drawing as an HIV education tool based on their previous experience and knowledge of how the people who attend their clinics and support groups typically react to medical language and information. Their projections proved to be true when compared with the responses of the group of HIV-positive mothers. While the mothers were able to read and write at a basic level, on the whole they did not have good formal educations. The group of mothers were drawn from an HIV clinic where two HOPE Cape Town community health workers were currently employed. In this way they provided an insight into the educational needs of the clients that the community health workers would see on a daily basis.

The mothers emphasised the ease with which they could learn visually. When asked if they thought that the creation of body map drawings had confused their understanding of how the human body works, Noluthanda replied in the following way.

No, I think by drawing it is clear more than [if] you are taught... When you see it in drawing it is clear. You understand it more... because maybe if you learn about something that you don't see it's not easy to understand, but then you see it and it's easy to understand. (Interview with Noluthanda, April 2007).

The simplicity of learning about the human body with the creation of body map drawings and the use of the Visual Body Map was affirmed by two other mothers, Selena and Joy. In Selena's words 'We enjoy it because you can see such and such a part.' (Interview with Selena, April 2007). They both drew attention to the ease of discussing illness and opportunistic infections by being able to simply point out the different parts of the body that are affected. They suggested that by seeing where a particular organ is found in the human body they could more readily understand the relationship between different organs and the way that the systems in the body are interconnected. The need to show people the part of their body that is causing their illness or show which organ is being affected by HIV was also echoed by Chantal from TAC.

...sometimes [you] educate people about their body or their immune system and sometimes people don't actually understand what...you are saying about their bodies inside...and...that map will be very useful if you can use it in the

clinics or in any training... You can exactly show the person that is the thing that is wrong...(Interview with Chantal, November 2007).

Similarly, Siphso (HOPE Cape Town) also emphasised the need for patients to understand the interconnected nature of the human body, because it clarified the relationship between the immune system and the way that HIV affects the entire body. Like Chantal, he also referred to the Visual Body Map and the simplicity of the visual representation of the human anatomy.

I think all the exercises were very good, but the map...was good in the sense that...you also saw the interconnectedness between the veins, your immune system and...the cells with the body map. (Interview with Siphso, January 2007).

TAC trainer, Nolwazi, also noted the potential for the Visual Body Map to clarify the relationship between the immune system and the other systems in the body. The importance of understanding the link between the immune system and the rest of the body was considered vital by many of the workshop participants because in many ways it is the key to explaining how HIV and AIDS effects a person's health. Nolwazi believed that it was important for people to understand how the body works when it is healthy, before they learn about illness and infection. She believed that the use of visual education techniques such as the Visual Body Map and the body map drawings simplified this explanation enormously.

But first explain what is happening...without opportunistic infections, without HIV...It's important to show again how HIV attacks our bodies, especially...the different systems when we are doing the visual mapping...Then the person will see 'Ok if my immune system is not working that means other systems will be affected.' (Interview with Nolwazi, November 2006).

Apart from the simplicity of using visual representations of the human body to educate their patients and people from their communities, a further advantage of using the Visual Body Map and body map drawings is that they enable participants to relate the information that they are exposed to in the course of the workshop with their own experience of their bodies. By tracing around a human body as a starting point for the creation of the body map drawings, the connection between the drawing and the participants' own bodies is emphasised. This highlights the relevance of what the participants are learning while also

reinforcing the personal nature of the participatory exercises. Siphho (HOPE Cape Town) goes on to comment on this relationship.

...you can relate it to yourself because it was...[about] our own bodies, because we did our own drawings. So it was a reflection of our selves, as well as our anatomies and what is happening within our body systems l...I find it very relevant...with what we are doing there at the clinics in the communities...(Interview with Siphho, January 2007).

Another community health worker, Celeste, also affirmed the ease with which people with no biological or anatomical knowledge of the body would be able to relate to the material presented in the workshop. In reference to the potential use of the Visual Body Map, Celeste noted 'But then they will say "That is my body, so if there are veins then I must also have veins." So then it will let them wonder what is happening to [their] body.'(Interview with Celeste, February, 2007). In a similar way, her colleague, Amanda noted the empowering potential of being able to show and explain to the client what is happening inside their body. Amanda commented on the importance of patients being able to 'see it themselves', as opposed to being told they have a particular illness and leaving the clinic without having a basic understanding of the implications of their diagnosis. She explains this in the following way:

It makes it easy to understand, because now they know what is going on in their body and how the HIV travels, how do I get pain and swollen? Why do I get a pain here? What are they talking about with a liver? Where is this liver? Sometimes people don't even know the first thing...And I think it is much easier so that you can even explain and show and they see it themselves, what it is all about. (Interview with Amanda, January 2007).

Apart from the advantages of people being able to relate the workshop material directly to their health and that of their clients, the usefulness of the body map drawings to illustrate complex concepts was further explained by TAC trainer and educator, Nolwazi. She used the specific example of explaining the difference between HIV and AIDS using the body map drawings.

...so if you draw a human body that means you are able to show the people everything... where are the opportunistic infections that build up to AIDS. So

it is very simple for a person to understand. Because the thing is out there they do not know the difference between HIV and AIDS. And then when we have a human drawing we will say 'Ok this person is HIV-positive...' And then you place the opportunistic infections and then you say 'This is AIDS.' And so it is very simple and nice. (Interview with Nolwazi, November 2006).

This comment affirms the direct nature of visual learning and the use of body map drawings. Nolwazi went on to discuss ways the body map drawings could be used to demonstrate side effects that HAART patients can experience. She suggested that if people could be shown the areas on their bodies that could potentially be affected by side effects, there would be less fear. By being able to isolate the exact area, such as the example of the feet being affected by *peripheral neuropathy*, Nolwazi believed that patients would be able to grasp the idea that side effects are localised and can be controlled. She said that often patients think side effects can kill them and that this perception could potentially be changed by explaining the exact nature of the side-effect and where in the body they are found.

Maryanne (HOPE Cape Town) commented on the potential for the Visual Body Map to be used to help explain medical procedures to patients and reduce their anxiety. For example, she suggested the use of the Visual Body Map in VCT sessions would make it easier for her to explain the need for a blood sample and to test for HIV antibodies.

You can even use it in the [VCT] counselling...because a lot of people are scared because of the test and they don't know what's going to happen now. So...you can show them the [visual] body map and you can show them 'Ok, this is what's going to happen. There's your veins. Sister just wants a little blood.' And it makes it easier. (Interview with Maryanne, February 2007).

The creation of the body map drawings included a range of other visual exercises that did not use drawing to illustrate a particular concept. One exercise, which has also been previously discussed, involved cutting and pasting particular foods from the advertisements of local supermarkets. In groups, the participants would plan meals and cut out their choice of food and paste them on the body map drawing in order to illustrate a balanced diet. The emphasis was on choosing foods that were inexpensive and also available from local street vendors and markets, which are common in South African townships. The response to this exercise was good, because many of the participants noted the practical value of it. One of the community

was on choosing foods that were inexpensive and also available from local street vendors and markets, which are common in South African townships. The response to this exercise was good, because many of the participants noted the practical value of it. One of the community health workers, Pumla, suggested it would encourage debate not only on what foods to include, but also how the food was prepared.

I also like your information...about the food. You give us papers so each and every person must go and take the picture and put the balanced diet. So it was easy for us because now we see there is chicken and you just cut it and put it down and then finish all the different types of food. So it...also makes us interested. (Interview with Pumla, January 2007).

Her closing remark of the way cutting and pasting held their interest is worth noting because it highlights the advantages of using material from real life, such as advertisements. The use of visual methods for educational purposes does not necessarily have to involve collaboration, but in many ways visual learning does encourage both individual and group participation. This was clearly demonstrated in the course of the workshop with the creation of the group body map drawings.

### **Efficacy of participatory approaches to HIV literacy**

As was suggested in the previous section, the creation of body map drawings was both visual and collaborative. Apart from drawing, other workshop exercises included group discussion, role-play, collage and other forms of visual puzzle solving. One of the dominant ideas behind participatory learning practice is the need to affirm the existing knowledge that adults bring to the learning experience. While this is well documented in adult education literature (Cornwall, 2002; Freire, 1997; Mezirow, 2000), it was interesting to note the frequency with which the workshop participants referred to this aspect of participatory learning.

One of the TAC treatment literacy educators, Abulelwa, described how in her work in the clinics she asks the people in the waiting room to discuss issues among themselves and then come to a consensus on a particular health issue.

‘What do you want to say about HIV and AIDS?’ so that we can communicate better...I will ask one of my audience... ‘Is there anyone who can answer that question because I want to listen to you also?’ So they will talk and talk and talk and finally that is what I was going to tell them so...I am saying “Wow, I am not clever alone...[you] people are also clever”. (Interview with Abulelwa, November 2007).

In this way Abulelwa engaged with the people in the clinic and in so doing observed one of the most important aspects of participatory learning by building on their experiential knowledge. In a similar way, she also identified the way that the workshop encouraged the exchange of ideas and placed value on the contribution of the participants by acknowledging their experience as community health workers and HIV literacy educators.

It’s the way you done it and you are also looking for our views and you also didn’t say everything on your own. We actually are the ones...working with you and we have helped you a lot. And I mean you’ve asked us many questions so we are able to listen to you... (Interview with Abulelwa, November 2006).

Her opinion on the active role the participants played in shaping the workshop manual through their criticism and comments reveals how she viewed collaboration as a two-way flow of information between the participants and myself. In her opinion, my insistence that they share their expertise made the workshop participants more willing to listen to what I had to share. This sentiment was also found among in the HOPE Cape Town community health workers.

I’ve been to quite a lot of workshops and this was different. You were more part of it...and you could express how you feel or what you think a specific thing is that you are asked about. (Interview with Rosemary, January 2007).

Rosemary identified the way that participatory approaches demanded active engagement with the material through expressing thoughts and emotions. In a similar way, one of her colleagues, Bulelwa, also noted the way different exercises and the creation of the body map drawings engaged the participants.

I can say that I have attended a lot of training also, but what I liked about this one ...you want us to make it like a play and make it more visible even to us, not only by writing and listening ...but you make us feel a part [of] those drawings and [asking] how do you feel about this...(Interview with Bulelwa, January 2007).

Apart from sharing their opinions and experiences, the participants also referred to the way that the group work enabled them to express and discuss emotional responses to their work. In many ways the group learning experience also served as an informal debriefing session where colleagues could share their experiences of counselling and providing HIV literacy to their clients. This was particularly evident with the group from HOPE Cape Town, but also emerged in the interviews with the HIV-positive mothers. For example, Noluthando commented on the therapeutic potential of group work.

Because in a group you are talking and you hear something that is for the first time you heard of and while you are alone you have stress...but while you are learning you are always talking. (Interview with Noluthando, April 2007).

In the experience of the HIV-positive mothers, their exposure to HIV literacy usually took place within a support group context. Therefore learning about HIV and health was often associated with the psychological benefits of being part of a group and not only sharing knowledge, but also providing each other with support. This is clarified by Noluthando when she compared staying at home to the experience of attending a support group.

Because when you are in your house you are alone. You don't know anything about HIV. But when you are here, maybe you told someone that I have this problem. She will tell you 'No that problem is made by HIV and you must not worry about it.' (Interview with Noluthando, April 2007).

This emphasises the important role that support groups play in the lives of people living with HIV. It also suggests that the use of the workshop described here could potentially prove very useful within support group contexts. Further aspects of the implementation of the workshop are discussed in the concluding chapter.

Another important aspect of the workshop was the way that participants were included in the learning experience without being placed under pressure to contribute or demonstrate their knowledge. The nature of group work allowed the workshop participants to share their knowledge within their small groups without having to stand up in front of the whole workshop group. In some groups, one or two people would take on the task of drawing or writing down what the rest of the group suggested on the body map drawing. In other groups each person would take a turn. In this way the learning process was not intimidating and took place in a relaxed and encouraging environment. This was emphasised by a comment made by Beatrice (HOPE Cape Town).

I really appreciated this workshop because...it accommodated everybody. Every time when there's a lecture or educational topic they are teaching I think I am the last person to talk. I am a very shy person, but with the kind of workshop that you did, the practical one...I think the other people were so amazed so see me so active like this. So I liked it very much... (Interview with Beatrice, January 2007).

Sipho (HOPE Cape Town) also noted the way that participatory learning includes reserved people, as well as the way that the creation of body map drawing encouraged the participants to identify with the material they covered. In this way the biosocial content was directly related to their own health and also their experience as community health workers. He suggests that this identification with the process and the material being presented made it an engaging learning process.

...even if you are not that active and you are shy, you can participate in the other activities...the fun of it was...when you actually are finished with the drawing and you [see] the parts and the cells, then you can actually identify yourself and the human body. So...there is no way you can shy away from it all...you feel you have to participate whatever you are doing, you have to do something. (Interview with Sipho, January 2007).

When discussing the participatory nature of the workshop a number of themes emerged. They included the importance of acknowledging and building on the experience that participants bring to the learning process, as well as encouraging the sharing of opinions and experiences. The therapeutic potential of group work was also noted, which points to the

potential for the workshop to be used in support group contexts. The participants also commented on the way that participatory exercises encouraged reserved people to contribute to the learning process. The final theme to emerge was the close identification between the workshop content and the practical utility of the material and techniques in their work environments.

## Conclusion

This chapter explored the content of the interviews conducted with the workshop participants. It assessed both the responses to the workshop biosocial content, as well as the use of visual and participatory tools and techniques. Based on the interview data, it is suggested that it is important that ordinary people understand the science of HIV. It is suggested that the provision of HAART and VCT services increase levels of knowledge of HIV/AIDS. According to the workshop participants, generally speaking knowledge of human biology reduces fear of HIV and AIDS and assists individuals to make better informed health decisions. In the South African context, visual and participatory approaches to HIV literacy were also shown to be effective ways of increasing knowledge and encouraging debate.

## **Chapter 5**

### **Recommendations and Limitations**

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This chapter discusses the limitations of my project and in particular makes recommendations on how to improve the body map drawing workshop. As part of this process, it also assesses the potential for the body map workshop to be implemented by the participants who took part in this study. It looks at the work experiences of the community health workers and treatment literacy practitioners in order to understand better the limitations of the workshop and HIV literacy interventions more generally. While solutions to the socio-economic problems described in the chapter are not the concern of this project, and are well beyond its scope, it is important to discuss them. This is because people living in poorly-resourced communities are the worst affected by the AIDS epidemic. It is in these communities that the workshop described in this dissertation, and other HIV literacy programmes, are most needed.

#### **Future implementation of body map drawing workshop**

In the course of the interviews, the TAC and HOPE Cape Town participants were asked to identify particular groups of people they thought would benefit from the workshop. The participants identified a number of different contexts, including support groups, schools, home-based care training and also in-house training within the two organizations. The diversity of the contexts where the workshop could potentially be used was affirmed in the following response by TAC treatment literacy educator, Noluvuyo.

I think it can be useful in support groups and in the training of home carers, but also if you are training professionals like health care workers and nurses and our Treatment Literacy people in our branches. (Interview with Noluvuyo, November 2006).

It was interesting to note the number of times TAC trainers referred to the need to further train health care workers and nurses with regards to HIV and AIDS-related illnesses and in particular antiretroviral therapy. This anecdotal evidence suggests that there is perhaps a need for continual professional development of health workers with ongoing HIV literacy. This was supported by another educator, Sizwekazi, when she described the different channels that the TAC uses to bring information to people in diverse contexts ranging from clinics, prisons and churches to municipal meetings. She suggested that the workshop could be added to the TAC's current approach to presenting HIV literacy material in the settings she described.

We take the information to the clinics, schools, churches and our community health centres to the doctors and nurses and with TAC members in support groups... We also give out information to the people in prisons and sometimes it depends who called us at that time, maybe a NGO has asked us to go and give information... And in the community meetings like the municipality we ask for a platform, 'Please before we start, can we have ten minutes of education?' (Interview with Sizwekazi, November 2007).

Another observation made by a couple of TAC trainers was that they believed the workshop would be a good beginner's level course. At the same time they also commented that it was useful for them to do the workshop in order to see alternative ways of presenting the material using visual and participatory techniques. This suggests that the train-the-trainer purpose of the workshop was successful in exposing participants to a new approach to presenting HIV literacy material. Nolwazi, a TAC trainer, emphasized that while many of the participants in the workshop were themselves familiar with the material, it remained a challenge to explain it to others.

...we were struggling a lot because we [did] human anatomy...in a very advanced way [and] doing the systems without starting with the cells the way you were doing the drawings and everything...As TAC we say we are going to use that tool [with] the beginners ...because it is very simple and it's very understandable. And I think the peer educators and trainers are going to use this information, because as I told we were scared of doing the human body and anatomy in the trainings...because it is difficult. (Interview with Nolwazi, November 2006).

At an earlier stage of the interview Nolwazi also drew attention to the fact that human biology and anatomy was a particularly difficult aspect of HIV literacy to teach because of the medical jargon and large volume of detailed information. The simplicity of the Visual Body Map used in the workshop to explain the workings of the human body was commented on by most participants. During the interviews, many of the participants, like Jason, discussed the potential use of the Visual Body Map in their daily work and lives.

I would use it in my own house, number one, to educate my kids. I will use it in the clinic, use it in trainings, [every]where I go...because I am doing one-to-one counselling as well and home visits to people living with HIV and [who are] on treatment. [I]t will be very useful to me. (Interview with Jason, November 2006).

Participants also discussed the flexibility of the body map drawing workshop and suggested that it could be used with different age groups, including children and adolescents. Many studies that discuss drawing as an educational technique focus on its use with children or within therapeutic contexts. In the course of this study, the way in which the participants engaged with the creation of body map drawings, as well as their suggestion of using it with adult learners debunks the notion that art is only for children. However, based on observation of the workshops it was noticed that the older adults preferred the younger ones to have their body traced, but would readily contribute information to be added to the body map drawing. Darryl, a community health worker, argued that the onus rested on the workshop facilitator to pitch the workshop at a level appropriate for each age group.

...you can implement it in a lot of age groups, but it's the way you are going to bring it across to them. Now you can sit with your idea the way we did it now and I can take from that and implement into whatever age group I am going to work with. Now I can look for other ideas, maybe similar to that we used...so I will use it definitely. (Interview with Darryl, February 2007).

Darryl later discussed how he planned to use the workshop in a youth group affiliated to his church. He identified the way that the workshop could be integrated into the existing structure of the youth group schedule. This comment is useful in that it reveals the potential for the workshop to be adapted to existing programmes or group gatherings. Other participants from both TAC and HOPE Cape Town identified a range of contexts, such as

support groups for HIV-positive people and those on HAART, as well as those specifically for children and young people such as pre-school and youth groups. Charmaine (HOPE Cape Town) also commented on the way that the workshop could be spread over a couple of months and treated as an ongoing exercise that took up a certain amount of time at each meeting.

And with a support group I think this would be an excellent idea, an ongoing project in a support group. You don't need to cover everything in one, you start off with the one and if it takes a year, then it takes a year and then at the end you would have covered everything. (Interview with Charmaine, January 2007).

Despite many of the TAC workshop participants working in clinics providing HIV literacy to people waiting in queues, most did not think that the workshop or the Visual Body Map could be used in the clinic waiting room because it was too crowded and chaotic. The TAC educators generally agreed that if the Visual Body Map was made smaller to A3 size it could be used more easily in clinics. The HOPE Cape Town community health workers did not think the current size (120 cm x 1010 cm) was a problem and claimed that they would be able to use it in clinics and VCT sessions. Apart from the Visual Body Map, I suggested that perhaps a body map drawing could be attached to the wall of the clinic and that people could then be asked to add information to it. The potential use of both the Visual Body Map and the body map drawings in the clinic context was rejected by TAC trainer, Nolwazi.

So you cannot use it in the waiting area in the clinic set-up because there are many people walking up and down and then there is no space for putting our body maps. (Interview with Nolwazi, November 2006).

One of the obvious challenges to using visual and participatory techniques is a lack of resources and the expense of the workshop materials in contexts where funds are limited. The materials included pattern card, colour pens, wax crayons, blackboard chalk and a few pairs of scissors and a bottle of wood glue. All these materials were inexpensive and in the case of the pens, chalk, crayons, just one of the mediums could be chosen. Most of the participants did not think the materials were expensive for their organizations to acquire, but acknowledged that if the workshop was going to be done by individuals the expense would

pose a problem. One of the TAC educators, Jason, went on to identify possible alternatives to the materials used in the workshop.

If we have a budget for it [the brown card] and know where to get it or the organisation we are working with, if they are prepared to provide it, then I don't think it would be a problem. But if it had to come out of our own pocket, yes, then it will [be a problem]...[We could use] the newspapers (newsprint paper) we are [already] using...I think it would cost less and ...maybe in the future...we can think of that whiteboard thing where you have different markers...(Interview with Jason, November 2006).

Given the fact that many of the participants worked full-time in their roles in clinics and support groups, another limitation identified by the participants was not having the time to do the workshop or prepare for it. This feeds into another factor that has to be taken into account when assessing the impact and efficacy of the body map drawing workshop. It is acknowledged that like many interventions, the initial energy and enthusiasm for the project cannot be sustained on a long term basis, unless time and support is given to the project participants. This is probably the biggest limitation of this study and while there were follow-up visits to the organizations involved in the study, in order for the training to be its most effective there would need to be continual follow-up trainings which are beyond the time limits of this study.

However, one potential way that the workshop could be sustained is through the adoption of its techniques by one of the organizations. I was invited to present a condensed version of the body map drawing workshop at the annual TAC training week for Eastern Cape and Western Cape treatment literacy practitioners. The session focused specifically on human biology and how HIV affects the body and was followed by other sessions led by TAC trainers. The detail found in the body map drawings created by this group of treatment literacy practitioners recorded not only their knowledge, but also their enthusiasm for this drawing-based approach to HIV literacy (Figure 5.1 and Figure 5.2).



Figure 5.1 An example of the Eastern and Western Cape TAC treatment literacy practitioners working on a body map drawing.



Figure 5.2 This workshop produced incredibly detailed body map drawings despite time constraints – only a morning was spent on the drawings.

By being afforded the opportunity to demonstrate the body map drawing technique to the sixty-nine Eastern and Western Cape TAC educators and trainers, it is hoped that this visual and participatory approach to HIV literacy will be implemented more broadly within this particular organisation. It was encouraging to see the level of detail recorded in the body map drawings despite the time constraints. When compared with the body map drawings from the preceding three workshops, which were produced over two days, it was interesting to see how quickly this group developed complex drawings documenting human biology.

In order to make the workshop more accessible one of the HOPE Cape Town participants suggested the manual should be translated into other languages apart from English. The expense of translation costs was the only reason this was not done for this study. Every effort was made to ensure that the manual was written in straightforward, everyday English. But this is not enough to make it accessible to the majority of South African HIV literacy educators and community health workers for whom English is not their first language. If the body map drawing workshop were implemented on a larger scale, translation of the manual would be essential.

When asked to comment on the use of drawing as an educational technique, most participants reported to have enjoyed the medium of drawing. Some did comment that they had initially been unsure of how they could learn something through drawing, but that their scepticism had left them once the workshop got underway. Only one participant, Chantal (HOPE Cape Town), suggested that drawing was not a medium she thought people in her community could relate to.

I think people can express them more if they do drama or something. Because many people they can't express them[selves] very easy[ily] on a piece of paper. (Interview with Chantal, November 2006).

Another criticism of the creation of the body map drawings related to the way participants were encouraged to lie on the ground so that their outline could be traced. One of the male HOPE Cape Town participants, Sipho, commented that it was inappropriate and undignified for adults to lie on the ground.

I felt personally it was not appropriate to me to lie down and be drawn...And that's why I feel it will be so difficult like if you do a similar workshop [with] adults...Because...if it is difficult for us to lie down how much more difficult for other people who are not so...educated like us...So it would it be very difficult, especially for women, it is very difficult for a woman to lie on her back. (Interview with Siphso, January 2007).

In response to his comment, future workshops included the option of standing against a wall in order for the tracing to be done. Where the option was given in these subsequent workshops, most groups opted to use the floor. This could be explained by the familiarity between the participants. However, Siphso's comment does demonstrate the need for the facilitator to adapt each workshop to the needs of the people in the group, depending on their age, familiarity with each other and also possibly their cultural attitudes to what is appropriate for people of different ages and gender.

In contrast to Siphso's views on the inappropriateness of lying on the floor and the intimacy that tracing around a person's body involves, the group from the TAC did not find this a problem and were physically comfortable with each other. However, it should also be noted that the character of the two groups was quite different. While the TAC group consisted of predominantly young women in their twenties and thirties, the HOPE Cape Town community health workers included both men and women and many of them were closer to their forties. But the biggest distinction was the way the groups saw themselves, with HOPE Cape Town positioned as pillars of their communities and the TAC participants seeing themselves as outspoken and controversial.

Another limitation of the workshop, from the perspective of the group of mothers, was the suggestion that they could have remembered more of the workshop content if they had written it down. Given the participatory nature of the workshop, all writing that did take place was recorded on the body map drawings. Participants from all three groups were given workshop manuals on completion of the workshop. Given their level of education, the group of mothers would in all likelihood not have found the manual as useful as the HOPE Cape Town and TAC participants. In answer to whether the workshop had left her with any questions, one of the mothers, Noluthanda, replied in the following way.

No, all the things are answered. But because we are not writing other things maybe now I have forgotten them. So if we are writing and you told us what is the use of the liver, we must write down so we can remember what is the liver...doing and what is the use of the heart. (Interview with Noluthanda, April 2007).

This section has looked at the opinions of the workshop participants and has described all the factors that could prevent or limit their ability to run the workshop on their own in their work contexts. The following section addresses broader challenges not only to the implementation of the workshop described in this dissertation, but also to other HIV literacy interventions in South Africa.

### **Limitations to health enabling communities and individual health**

In the course of the interviews all participants were asked to describe what they would like to see in terms of providing good health care to all South Africans, regardless of their HIV status. Current socio-economic realities were repeatedly discussed as limitations to both individual and community health. Given the nature of their work, I assumed the participants would list the need for more clinics and staff and improved access to HAART. While these things were discussed, it was both remarkable and disturbing to note the number of times participants listed food and income to be the most serious barrier to health. It is important to relate this to the argument for the provision of a Basic Income Grant (BIG) which would assist in alleviating dire poverty and increase food security among the poorest South Africans. Apart from the comments made by HOPE Cape Town and TAC participants, the TAC actively supports the implementation of a Basic Income Grant on an organisational level. The fact that poor people in this country are unable to meet even the most basic of needs is highlighted by Maryanne (HOPE Cape Town).

Every household to have decent food. Just to see that everybody is eating healthy and that the people that they have money to afford these things, because you can tell somebody eat healthy...because you think he can pay 50c for an apple, but sometimes that person doesn't even have the 50c to buy that apple. (Interview with Maryanne, January 2007).

Noluvuyo, a TAC trainer, also addressed the lack of food security for many South Africans. She argues that poverty and the attendant social problems posed by informal housing, inadequate nutrition and poor living conditions predisposed poor people to HIV and AIDS and ill health more generally.

...the fact that we don't have incomes or financial support to sustain our food security therefore we are more prone to be sick than people who have food or who have better houses and that is why HIV then takes [the] opportunity with poor people...(Interview with Noluvuyo, December 2006).

The need for adequate food and income was identified across all three groups including the HIV-positive mothers. Selena, one of the mothers, also alluded to the issue of unemployment and the high expense of transport in order to reach clinics. It is interesting to note the order in which she listed the needs with medication coming after food and easy access to clinics.

I would like to give people food parcels for those who don't work and to help them [with] transport...clinics have to [be] nearer to the places...to be easily reached. And give people medication. (Interview with Selena, April 2007).

Maryanne, a community health worker, also noted that lack of income and transport costs inhibited patients' ability to adhere to their antiretroviral medication. She was not alone in the way that she described the dire conditions in which many HAART patients live.

And you get the person who wants to take the ARVs but some of them they haven't got money...to come and fetch the medicine here and every Monday you need to have a R20 or R30 to get here. And it's not all of them who is getting a [disability] grant<sup>25</sup> and...now they miss their appointments...But when you come to the peoples' houses you can see there is a need. Maybe that person is hungry, but this morning he had to take the ARVs, but there's nothing for him to eat. (Interview with Maryanne, January 2007).

In response to the need for adequate nutrition, Maryanne suggested that hospitals should extend the provision of milk and porridge for children to include adult patients. She

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<sup>25</sup> Disability grants are given to people who are unable to work due to illness or physical disability. They are given to AIDS-sick individuals once their CD4 count drops below 200. However, if their CD4 count rises they stand to lose the grant. This has posed serious problems for HAART patients who default on their treatment in order to keep their grant, which in many cases is the only stable income for their family.

described how in the case of TB treatment the medication is foul tasting and smelling and although it can be taken on an empty stomach it is unpleasant. In the case of HAART, food has to be taken before some of the medication which means that a lack of food inhibits the patients' ability to take their pills and further compromises their health. It also can result in patients defaulting on their treatment.

I saw at the hospital the children that are underweight, they get milk and porridge free. So I think they can provide [food] for the HIV people also...Not...just for the HIV, but for the TB [as well]...Now you got a TB patient and you can see there is a need. You know...there is nobody working in this house [and] there's no food...And then we are sending him to the dietician and...they're sending him back because his weight is ok. But...they are just checking the weight and not checking the need, because tonight he is going to sleep and there will be no food again. (Interview with Maryanne, January 2007).

Another dominant theme that emerged was the disparity between the levels of care offered in cities, as opposed to that available in the rural areas. This was commented on by a number of workshop participants from all three groups. Perhaps it is also worth noting that many of the people who took part in the workshop were originally from rural areas, such as the former Transkei. Most of them still had family living there and also returned to visit so would be aware of current conditions. Alongside care, many participants also commented on the need for education in the rural areas in order to raise awareness about the risks of HIV transmission and also the availability of VCT services and HAART. This is summed up by Beatrice (HOPE Cape Town) who draws strong links between the spread of HIV and the circular migration between rural and urban areas fuelled by the search for employment.

...I would put more clinics, more educational programmes, because in the rural areas really there is a problem...I am from the Eastern Cape and...people...don't have any idea, especially in HIV things...like the men they used to come to maybe Cape Town, Johannesburg, Durban to work there. Then they leave their families behind so that gap makes them...maybe to be exposed to many things... they get another girlfriend and so on. So...in the rural areas I would make of more educational talks and more clinics so that they can understand the risk. (Interview with Beatrice, January 2007).

The disparity between rural and urban health care is further emphasized by one of the mothers, Noluthando, when she compares Cape Town to her birth place in the former Transkei. She also draws attention to the lack of services, such as the limited provision of antiretroviral therapy. But what is perhaps most noticeable is the apparent lack of knowledge of HIV among health care workers in the rural areas where, in Noluthando's words, people are simply told to 'wait for the day that you die' when they test HIV-positive.

At this moment it's better here in Cape Town, because the doctor is here and ARVs...Because in Transkei if you are HIV-positive, they say to you go to your house and wait for the day that you die. They just told you like that...They don't know. Even the nurses in their clinics they don't treat people like here. If you are HIV-positive they...are not going to tell how HIV is doing in your body. (Interview with Noluthando, April 2007).

The need for further HIV literacy training for health care workers is directly addressed by Nobahle, one of the TAC trainers. She called for something to be done to 'Start putting [together] a curriculum of HIV [for] health care workers...because some of them don't know about HIV and then they [are] ignorant when they talk about ARVs.' (Interview with Nobahle, November 2006). In a similar way, one of the HOPE Cape Town participants, Siphso, also addressed the issue of increased training and support for health care workers. He identified the need to increase the availability of antiretroviral therapy, as well as the number of clinics and clinic staff. The necessity to motivate nursing staff speaks of a need for more support to be given to medical staff, especially those working in areas that experience high HIV prevalence and related illness.

...to make more treatment sites available for rural areas and maybe to employ more people to work on those treatment sites...You hear that the clinics are understaffed...[We need] to employ more staff for the clinics and...also to make sure...to motivate the staff because it's one thing to employ more staff, but then you put them in a facility and you can see that they are not motivated, they are not committed to their work...' (Interview with Siphso, January 2007).

Noluvuyo from TAC commented on the need to further train nurses to administer HAART in order to speed up the delivery of antiretroviral therapy, especially in rural areas where there is a chronic shortage of doctors. Noluvuyo also spoke about the role played by volunteers who

work as community health workers in many clinics in South Africa. She suggested that the Ministry of Health should utilize these volunteers by developing a career path for them in order to enable them to qualify as nurses or doctors and ensure that they can be paid for their services. The need to adequately remunerate nursing staff was also commented on by another TAC educator, Sesethu, when she said 'I will firstly build a lot of hospitals and increase [the] salary for health workers so that they do not [go] across overseas and...[to the] private sector.' (Interview with Sesethu, November 2007)

One final suggestion with regards to antiretroviral therapy was to change the current stipulation that patients can only receive HAART when their CD4 counts are 200 or below or when they exhibit Stage 4 defining illness. Bulelwa, a community health worker, argued that by the time patients receive HAART their health is too compromised. This is further supported by the finding that HAART patient mortality was highest among those who commenced treatment when their CD4 count was low (Coetzee *et al*, 2004a).

I would change this thing of only getting ARVs when you are under 200...Because at that time the person is very, very sick...I think it would be much better if the people can start ARVs before. (Interview with Bulelwa January 2007).

As has been previously discussed, another limitation to community and individual health identified by the workshop participants is unequal gender relations. A number of workshop participants discussed poverty and how it adversely affects women as they try to meet basic needs. Grace (HOPE Cape Town) addressed the issue of transactional sex as a consequence of living in poverty and women being financially dependent on men.

...I think it's starting from poverty, because I am not rich and the poverty I think is the main cause of those things. Because...it's not love really, it's just that you get something and how must you get it, you must give to get...because you wanted money to go to tertiary, money for food...Those countries who have got money they don't think at all of those things as we would, all those problems, because they are rich. And I must take another man because they give the money, then what am I going to give? (Interview with Grace, February 2007).

Another issue related to gender that was discussed by women across the three groups was the hesitancy of men to go for VCT and discover their HIV status. Some of the participants observed that women access medical services more often than men because of pregnancy and childbirth and in these instances their HIV-positive status would in most cases be discovered before their husbands'. One of the TAC educators, Nozipho, commented on the refusal of men to visit clinics, even once their wives disclose their HIV-positive status. She draws attention to the fact that this further puts men's health at risk because they will not access treatment and care.

No man...wants to go [to] the clinic even if the wife comes and says 'I am HIV positive.' The man...will say if [she is] positive, then he is also positive. But there are times that you need to get vitamins and...to check you CD4 count. He doesn't even start to do any of those things. That will be the end of him, saying 'There is no need for me to go to the clinic...' (Interview with Nozipho, November 2006).

The observation that men are unwilling to attend clinics is supported by another TAC educator, Chantal. She reasons that male 'self esteem' and 'self respect' are what prevent men from attending clinics or returning for test results. I would suggest that she is referring to ideas of masculinity that are defined by being tough and invincible, which extend to include immunity from HIV/AIDS.

...because they have their self esteem, they go to their self respect....They will come to the clinic today and have a test and won't come back the next day or for the next appointment...they won't...even if they got STIs they will go that day and won't come back again...(Interview with Chantal, November, 2006)

One of the HIV-positive mothers, Noluthando, also commented on the way that a woman would in her opinion always share her knowledge of her HIV-positive status with her husband, while a man would keep his HIV status secret. She said that based on her observation of her community there were men who attended the clinic, but did not tell their wives. In her words 'But the problem of men, if the doctor tells him that he's HIV-positive he won't tell his wife. He just keep quiet and come to clinic.' (Interview with Noluthando, April 2007). When asked why she thought this was the case, Noluthando was unable to

provide an answer, but implied that the situation could not be changed and seemed resigned to the problem.

In the TAC interviews, a range of opinions were expressed for the reasons why men did not use clinics and VCT services or battled to accept their HIV-positive status. These included explanations such as 'Ego and peoples beliefs...that I am a man ... I will be touch[ed] by those women, and undressing for those women [nurses].' (Interview with Sizwekazi, November 2007). Sizwekazi went on to comment on how pregnancy and reproductive health meant that women were more familiar with clinics. She also draws attention to the way that women care for men when they are ill, which can delay visiting the clinic.

...women are more exposed to clinics because we are the ones who get pregnant and test. Also it's us that can see illnesses and look after them [men]. Most [men] can't go to the clinic when they see something for the first time. They get scared and unable to go to the clinic, but us as women when you see something wrong you attend to it immediately. (Interview with Sizwekazi, November 2006).

Some of the respondents seemed resigned to the fact that male patients did not generally behave in a way that was beneficial to their, or their partner's, health. Others discussed efforts that had been made to engage with men and recruit men as treatment literacy educators. As has been previously noted, the majority of the TAC educators and trainers and the HOPE Cape Town community health workers are women. The gender norms that associate caring for sick family members with a woman's position in the household only go so far to explain the dramatic imbalance between the genders when it comes to HIV-related work.

Nolwazi, a TAC trainer, commented on the challenges that this posed for female treatment literacy educators and the way that the TAC has actively tried to recruit more men.

Reaching out to men...they don't want to even hear about the word HIV...I think we are trying...to recruit men because it is very difficult to be a woman speaking to a man about HIV...it's very difficult so...it's better to train...a few men and let them go to other men...It's the 'how'...that...is the problem.

Otherwise we all have that vision of recruiting men, but how? (Interview with Nolwazi, November 2006).

The need to recruit male HIV literacy educators and encourage men to access public health care services remains one of the chief challenges facing organizations working in HIV literacy. One of the ways this is done is through the creation of 'male friendly' clinics that employ male nurses and doctors and also stay open after the end of the working day (Dlamini, 2006). This is just one way that service delivery can encourage men to access public health care and HIV-related services such as VCT sites. Much more needs to be done to encourage men to be more proactive in terms of taking care of their health and protecting their sexual partners from HIV infection.

This section has looked at the limitations to community and individual health from the perspectives of the community health workers and HIV literacy educators. It has attempted to define some of the relationships between social, economic and living conditions and how these factors can work to limit individual ability to make the best health decisions. It also described the challenges of gender inequality and how this negatively impacts on preventing the spread of HIV. The solutions to many of the socio-economic problems lie in improved government service provision and increased employment opportunity, which are not the concern of this project. It is important to develop an appreciation of the enormously challenging conditions that many South Africans live in, because it is precisely these communities that are worst affected by the AIDS epidemic and who most need HIV interventions like the one described in this dissertation.

## **Recommendations**

In the course of the workshop and during the interviews, participants were asked for their critical opinion of the workshop process and the visual and participatory exercises used to present the biosocial content. Their assessment of the tools and techniques, as well as the content of the workshop has already been dealt with in chapter four. The participants' views on the role of HIV literacy more broadly will now be discussed. This is done in order to

situate the workshop evaluated in this dissertation within the bigger picture of the challenges faced by HIV literacy educators and community health workers and what they believe HIV literacy should include.

One of the dominant themes to arise within the HOPE Cape Town group was the continued need for HIV literacy to focus on 'prevention messages' that addressed ways to stop the sexual transmission of HIV. Many commented that since the availability of HAART, the overwhelming message was that HIV is treatable and that HIV-positive people can continue to live a productive life. While they whole-heartedly supported this and also the provision of HAART, there was some concern that prevention messages have been lost along the way. This is summed up by community health worker, Penelope:

...like when you with AIDS Day get somebody that's telling 'I am positive', so now the people are saying 'So why must I use a condom? Look at that person, he's healthy, there's nothing wrong with him, so why must I condomise?' That's also one thing...it's like an advert. (Interview with Penelope, January 2007).

The community health workers suggested that in communities with high HIV prevalence it was important to emphasise the need to stop the spread of HIV, while also offering HAART. It was also felt that since the advent of HAART, people with limited knowledge of HIV believed antiretroviral therapy to be a 'magic bullet' that would immediately restore their health. It was argued that this was a dangerous perception because it did not adequately prepare patients for possible side effects and the seriousness of a life time commitment to therapy. This highlights the gaps in knowledge about HIV and antiretroviral therapy where ordinary people may know some facts, such as that HAART enables patients to live for longer, but will not comprehend the broader implications of treatment for chronic disease.

In order to balance the perception that HIV and AIDS-related illnesses are no longer life-threatening and harmful, one of the community health workers, Bulelwa, suggested that during HIV literacy campaigns, it would be good to promote testimonies of people who have remained HIV-negative. Apart from the importance of emphasizing a prevention message, Bulelwa also suggested that this approach may increase use of VCT services. She argued that

there was a need to make people aware that coming for an HIV test, does not always result in testing positive.

And the other thing is, I would like us as the counsellors, when we are making like this World AIDS Day, we always like to put there the person who says 'Look I am HIV-positive.'... How about if someone is tested and come out 'I have tested for the third time and I am HIV-negative'. So that the people can come for a test, because a lot of people don't want to go for testing because they are afraid if they go for testing it will be positive. (Interview with Bulelwa, January 2007).

The concerns of the community health workers are summed up by Rosemary when she argued that the most important thing was to keep people HIV-negative. Based on her experience working in the Tygerberg ward run by HOPE Cape Town, she had noticed that there are still patients who need education in HIV and that the ignorance of issues such as mother-to-child transmission was still a serious challenge to overcome.

It's also important to help people to stay negative. I think that is the most important, like I am working in the ward now and this mummy couldn't understand that the child is negative and she is positive and I had to teach her...'You need to keep this child negative.' And that's also difficult because some of them can't understand...(Interview with Rosemary, January 2007).

Another concern with regards to the role of HIV literacy was that children needed to receive sexual and reproductive health education at a much younger age to what is currently practiced. Based on their experience of working in clinics in their communities, a number of community health workers argued that primary school children should receive education from as early as seven years of age.

I feel that we as community health workers must start with Primary Schools, because if you can change that child's mindset in Primary School they will make...more informed decisions when they get to High School, because if I look at my community, it's just getting out of hand. We are getting children 12, 13, 14 coming pregnant, 15, 16 coming with their second child and I think it's not about blaming the children, but [getting them to] make more informed decisions. (Interview with Rosemary, January 2007).

Another recommendation made by the participants, was the need to establish more support groups. As has been previously mentioned, support groups also play an important role in providing HIV literacy and other information on where and how to access better care and support. While in some areas there are established support groups, many communities do not have this facility. This was the case with the group of mothers who attended the workshop and, with the clinic doctor's support, expressed interest in starting a support group for their community. One of the community health workers, Siphso, also called for specific groups to be formed to meet the different needs of people on HAART, those who have recently discovered their HIV-positive status and then also for teenagers and children.

Not enough is done for children, especially in terms of the support groups. The support groups tend to focus on the mothers, but not on their children that are on ARVs. So maybe if we can do something for children with ARVs, as well as children who have got their siblings who are HIV-positive and that their mothers are HIV-positive. (Interview with Siphso, January 2007).

Another recommendation that could be linked to the provision of support groups was the need to educate HIV-positive people about their legal rights. One of the TAC participants, Jason, commented that despite laws that prevent employers from dismissing employees based on their HIV-positive status, this and other forms of discrimination still take place. He provided anecdotal evidence based on his work with farm labourers who refused to get tested for HIV because of their fear of being dismissed from their work. Jason also mentioned the importance of HIV literacy including information on access to grants and other forms of support that enable people to take steps towards improving their situation and accessing good care and, if necessary, antiretroviral treatment.

...people still don't know where to go when they are discriminated against and which ways to follow on getting grants and things like that...because sometimes people think... 'Oh, this is a dead life'. They don't know there [are] other routes that they can still go to. (Interview with Jason, November 2006).

This section has highlighted the need for continued prevention messages to be provided, together with information on HAART. It has also shown the necessity for HIV literacy to target primary school children in order to help them make more informed sexual decisions in

their adolescence. Increasing the number of support groups and developing ones that target particular priorities, such as HIV-positive children, was identified. Finally, the importance of people having access to legal information and social security was emphasised.

## **Conclusion**

This chapter has discussed the possible implementation of the workshop by the TAC treatment literacy practitioners and the HOPE Cape Town community health workers. It has taken into account the participants' views on the limitations of the visual and participatory approaches to HIV literacy utilized in the workshop. The participants situated their recommendations on how to improve the efficacy of HIV literacy interventions in relation to the challenges they experience in their work. Having identified some of the shortcomings of both the workshop discussed in this dissertation, and HIV literacy more broadly, it is vital to go beyond identifying limitations and develop strategies to make HIV literacy as relevant and effective as possible.

One of the ways my workshop attempted to make HIV literacy as accessible as possible was the adoption of visual and participatory tools and techniques. On the whole, these approaches were positively evaluated by the workshop participants. Another important practical aspect of this project was facilitating the workshop with existing organizations such as the TAC and HOPE Cape Town, as well as the group of HIV-positive mothers who had no HIV literacy training. By testing the workshop on people working as HIV treatment literacy practitioners and community health workers, the project aimed to answer some of the real needs of people working in this field. The input and recommendations made by the participants strengthened the 'street credibility' of the workshop. While the sample size of the group of HIV-positive mothers was small, they did provide some useful insights into how the workshop could potentially be received in contexts such as support groups.

The workshop also addressed the building of positive social networks and increasing personal agency to assist people living with HIV and AIDS. Particular exercises enabled the

participants to discuss social support and issues surrounding disclosure of HIV-positive status. These exercises encouraged debate related to HIV stigma, the importance of support group attendance, referral to social services, and emotional and psychological support from friends and family. However, the degree to which these exercises will have a positive impact is difficult to gauge, but the positive feedback on the 'hand exercise' in particular, suggests that it could potentially prove very useful. These exercises were designed in such a way that they could be used independently of the creation of body map drawing in contexts such as VCT services and other counselling sessions.

The workshop described in this dissertation aimed to increase biomedical knowledge of HIV/AIDS, and address some of the social issues related to the disease, by adopting visual and participatory approaches to HIV literacy. The project set out to assess whether or not the treatment literacy practitioners, community health workers and HIV-positive mothers who participated in the workshop valued human biology as part of HIV education. It also aimed to assess the efficacy of visual and participatory tool and techniques within the context of South African HIV literacy.

Based on interview responses, participant observation, the study of the completed body map drawings and questionnaire data, it is argued that knowledge of human biology plays an important role in developing understanding of HIV and AIDS. This is particularly significant in South African where the legacy of *apartheid* education has left many adults without basic education. It also suggests that young people should be exposed to this information in order to develop their understanding of health and illness. It is proposed that HIV prevention messages are best followed when people understand why they need to adopt certain behaviours, in place of simply being told to do so. The same can be said in relation to enabling ordinary people to understand how HAART works.

The workshop participants provided some positive evidence, drawn from their experience of working in clinics, that HIV literacy does result in improved individual and community health. For example, Sizwekazi from the TAC reported a decrease in sexually transmitted infections and TB in the clinics where the TAC treatment literacy educators work.

...I told you that we are working with stats. Every quarter we ask for the VCT clinic statistics and STIs and TB, everything we educate about...[P]eople go do VCT and people do identify their STIs, people know what they have...and know their treatment so they know their bodies and the statistics [cases of STIs and TB] and are going down.” (Interview with Sizwekazi, November 2006).

In a similar way, Jason also linked the work the TAC do in clinics with an increased use of VCT services.

...from 7 to 8 o'clock in our clinic where people [are] coming to give in their cards for their folders...then we are giving general information on HIV, VCT and try[ing] to encourage them for go for a test if they never went for a test...but then...later...you will see that person stand in the queue to go for rapid [HIV testing]. (Interview with Jason, November 2006).

And yet, is it interesting to note that later in the interview Jason argued that regardless of the efforts of HIV education, the fight against HIV and AIDS will not be won until there is a climate of openness and acceptance of the disease by the general population.

I will say people in the work place, in the communities, need to take a stand and say ‘Yes, I am HIV-positive, I am living positive.’ People need to come out and speak more about it...[W]e can educate as long as we want, but as long as we don't get people to talk it's [HIV/AIDS] still not going to go [away]... (Interview with Jason November 2006).

One of the aims of HIV literacy is to reduce discrimination against people living with HIV and develop an open climate by increasing people's knowledge about the disease. This knowledge is geared not only towards people living with HIV, but also towards improving general public understanding of HIV/AIDS. On the whole, the participants in this study supported the idea that knowledge of the biomedical nature of HIV would help reduce fear and HIV stigma.

The use of visual and collaborative approaches to learning was shown to be very effective in presenting HIV literacy material in a straight forward way that people could readily apply to their lives and working environments. The significance of this finding is that visual and

participatory techniques and tools were shown to develop understanding of the biomedical aspects of HIV in such a way that it was relevant to participant needs. Given the density and complexity of the biomedicine of HIV, it was exciting to see how the creation of body map drawings developed real understanding of human biology in relation to HIV prevention and treatment. However, given the small sample size, further research is clearly needed into the value of visual and participatory methods in HIV literacy contexts in order to explore the extent to which these findings apply elsewhere.

One of the unexpected outcomes of the research was the extent to which knowledge genuinely flowed in both directions. Participants learned about human biology and visual and participatory facilitation techniques – but they also taught me a lot about their lived experiences and their understandings about what is needed to combat the AIDS epidemic. Participatory learning methods have the potential to educate both the participants and the educators.

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University of Cape Town

# BODY MAP DRAWING WORKSHOP

## Facilitator's Guide



AIDS and Society Research Unit (ASRU)  
University of Cape Town



## **Acknowledgements and Contributions**

This workshop has built on the work of people and projects affiliated with the AIDS and Society Research Unit (ASRU). In its current form it has been written and developed by Annabelle Wienand, but could not have reached this phase without the contributions and valuable work of those acknowledged below.

The Visual Body Map and Educator's Guide were developed by Colin Almeleh and Fiona Mendelson and form an integral part of the workshop. This workshop aims to work hand-in-hand with the Visual Body Map and promote its use in support groups, clinics and other environments.

The workshop has also been informed by previous training booklets developed for the AIDS and Society's Research Unit's outreach work, such as the *Mapping Workshop Manual: Finding your way through life, society and HIV* rewritten primarily by Colin Almeleh. Colin Almeleh's continuing research on HIV status disclosure has also informed how it is discussed in this workshop.

The *Community Adherence Worker Training Manual* written and compiled by Fiona Mendelson, Colin Almeleh and Ashraf Grimwood for Absolute Return for Kids (ARK) has provided substantial biomedical information for this manual, particularly in the Fact File sections. All illustrations used in this manual were created by Colin Almeleh and Ohad Shachar and were originally used in the ARK training manual.

The workshop has also been informed by *The Longlife Project* and the work of the Bambanani Woman's Group, Jonathan Morgan, Jane Solomon and others involved in the project. In particular it is indebted to Jane Solomon for the idea of tracing around the body and using it as a template for learning and recording information.

Finally, advice and suggestions from Nicoli Nattrass, Nondumiso Hlwele, Colin Almeleh, Salma Ismails, Victoria Ndyaluvana, Thobani Ncapai Babalwa Cekiso and workshop participants from TAC and HOPE have been essential in shaping the workshop.

All materials in this manual have been written and produced by people working in the AIDS and Society Research Unit (ASRU) and may be reproduced and distributed by anyone wishing to make use of it.

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# Introduction

## **Who is the workshop for?**

This workshop is for people who work in HIV/AIDS literacy and training, including Community Health Workers, support group counsellors and others providing support and education for HIV-positive people. It can be done as a refresher course for people already with experience, or as training for those new to the field.

## **Workshop Aims**

The workshop aims to increase biomedical knowledge about HIV/AIDS by using a Visual Body Map (chart of the anatomy of the human body) together with exercises using drawing, group discussion and role play. It also covers issues such as social support for people living with HIV, access and adherence to antiretroviral therapy (HAART) and other practical advice. The workshop is based on the belief that better biomedical knowledge about HIV/AIDS will assist people in making more informed decisions about their health.

The workshop acknowledges that information alone does not always enable people to act on their knowledge. The context in which people live, work and ultimately make decisions about their health does not always support them. The workshop intends to make accurate biomedical knowledge about HIV/AIDS more widespread.

## **How long does it take?**

The workshop takes roughly 9 hours depending on the group involved and can be shortened by skipping some exercises. Session one is not necessary if the group know each other - start with 'Getting Started' in this case (pg 8). The workshop is broken into sessions that can be used in support groups or other places like youth groups and schools. If it is used as a full day workshop it is recommended that 2 days be set aside. Breaks for tea and lunch can be decided upon by the facilitator and the group.

## **What materials are needed?**

The materials needed to run a body map workshop can be simple and inexpensive to buy. The basic materials include sheets of paper or card large enough for someone to lie down on and have their body traced. A roll of bulk paper, sheets of brown pattern card or flattened card board boxes are

the cheapest options. Drawing materials can include pens, pencils, wax crayons, chalk, charcoal and poster paint or food colouring.

A Visual Body Map is an important tool and used throughout the workshop. Alternatively most public libraries have books on the anatomy of the human body. Visual Body Maps can be obtained through the AIDS and Society Research Unit at the Centre for Social Science Research:

University of Cape Town

Private Bag

Rondebosch 7701

Tel: (021) 650 4656.

Email: kforbes@cssr.uct.ac.za

### **List of Workshop Materials:**

Name tags and pen

Black / white board or large pieces of paper and pen

One piece of card or paper per group

(big enough to lie down on and trace a person's body)

Pile of pictures from magazines and newspapers

Advertisements for food and household products

Pencils, pens and colour markers

(or wax crayons and food colouring with paint brushes)

Newspapers

Scrap/recycled paper (printed on one side)

Photocopies of a road map of the area

Candle and matches

Scissors (one pair per group of four)

Glue (one pair per group of four)

Zip and lock and key

Balloons (five per group of four)

### **How to use the Manual**

The manual divides the workshop into 9 separate sessions and allocates rough time estimates to all activities and discussions. The time allowed for participants to complete each session is approximately an hour, but this is flexible and largely depends on the facilitator and the group participating in the workshop.

The workshop is a flexible education tool and people are encouraged to adapt it and use it in whatever way suits them and the work they do. Many of

the workshop activities can be done as independent or 'stand alone' exercises with individuals or groups.

The 'Fact File' blocks provide additional biomedical information. The facilitator is not expected to cover all this material in the exercises – they can use what they believe to be most important depending on the group's level of knowledge. The aim of the workshop is to expose participants to accurate biological facts and allow them to understand the relationship between the body and HIV/AIDS. The facilitator should approach the workshop with this aim in mind and not be too concerned with biological details as long as the concepts are understood.

**Enjoy using this manual as a workshop guide, a source of ideas for HIV/AIDS education and also as a reference book to use in your work.**

## **Session 1**

### **Getting to know everyone** (10 min)

As each person arrives, they write a name tag and take a seat in a large circle. Everyone introduces themselves in an active way. Some ideas are:

- a) Singing or rhythmic clapping in a circle
- b) Each person chooses a picture from a pile cut from magazines or newspapers and uses it to introduce him or herself by talking about the picture and why they like it.
- c) Participants are given a few minutes to find a partner to 'interview' so that they can introduce their partner to the group afterwards.

### **Ground Rules** (5 min)

Quickly write up a list asking the group for guidelines or 'rules' they want during the workshop. Ideas might include:

- ✓ Respect for other people's opinions
- ✓ Confidentiality
- ✓ Tolerance of different views
- ✓ Allow everyone a chance to speak
- ✓ Cell phones off
- ✓ Ask questions

### **What you want to learn** (5 min)

Make a list on a large piece of paper of what the participants aim to learn from the workshop. To make sure everyone contributes suggestions use random selection (i.e. anyone wearing blue, who's name starts with 'S' etc). Participants may want to tell the group what their training or job is. This list is kept for the rest of the workshop, and will be checked and added to.

### **Group Body Map** (15 min)

A volunteer can trace the facilitator's outline onto a piece of paper/card. One person lies down on a large piece of card and another person takes a pen and draws around their body. This can also be done by standing against a wall. Participants are then invited to add pieces of information by drawing all they know about the

human body on the body map. To get things going ask questions such as:

- How do we see?
- What keeps our bodies upright?
- Where does food go when we eat it?
- What are some of the ways HIV affects the body?
- How do we feel?

Drawing the group body map is a useful way of seeing how much the group knows about the human body. It also shows everyone how to make a body map. Encourage participants to draw by making it as fun as possible - don't worry about being 100% accurate!

## **Getting Started**

- Ask the participants to divide themselves into groups of 3 - 5 people. Each group is given a large piece of card/paper. One participant can volunteer to have the outline of their body traced. This can be done by either lying down on a sheet of paper or standing against a wall while the body is traced. (5 min)
- The group draws the face of their volunteer on their body map, adding any other features or accessories that are particular or special, such as earrings, bangles, birthmarks etc. (10 min)

## **Session 2**

### **Cells as Building Blocks in the Body**

- Give each group an envelope containing a picture from a magazine or newspaper that has been cut into pieces like a puzzle. Ask the group to put the image together again. (5 min)
- Ask the group if there is anything in the body similar to the parts of a puzzle. Introduce the idea that the human body is made up of billions of cells that the human eye cannot see. Cells are the building blocks of the body and are like pieces in a complex puzzle that fit together to make up the body. Ask volunteers to come and add any information they know about cells to the board. The following questions might be useful:

- Can we see the cells in our bodies?
- What cells have you heard of?
- How does human life begin?
- How do we grow? (10 min)

#### **FACT FILE**

Cells are like building blocks making up the human body. A human life begins when a mother's egg is fertilized by a father's sperm. This single cell divides itself in two, which then divides into four and so on until the body is formed. When we are children new cells create tissue and bones in order for us to grow. This process continues even once we are adults as the body continually renews itself. Our bodies are constantly making new cells to replace old ones. This is more obvious with things we can see growing like our hair and nails, but happens throughout the body.

- Make a mark with the tip of a sharp pencil on a sheet of paper and hold it up for the group to see. The human female egg is roughly the size of the mark and is the largest cell in the body. It is 85 000 times larger than a sperm. There are many things the human eye cannot see without the aid of a microscope or magnifying glass. Ask what other things the human eye is unable to see such as bacteria and viruses. (5 min)

### **What do cells do?**

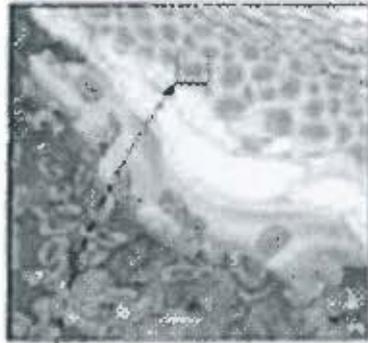
- Ask the participants what they think cells do in the body. Were they born with the same number of cells? What do cells need to live? What does DNA control? Create a list while answering these questions by asking volunteers to come up and write on the board. (10 min)

#### **FACT FILE**

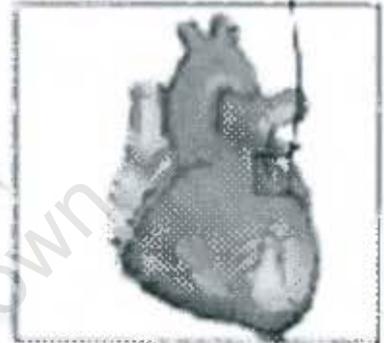
Cells need food and oxygen to do their work in the body. A healthy diet helps build cells which make for a healthy body. We already know cells die and reproduce everyday in our bodies. Cells also produce chemicals that control body functions and maintain the body. Cells know what to do and how to divide because inside each one there is genetic code. This code is like an instruction manual for our bodies and is called DNA (deoxyribonucleic acid).



**A vein in the heart**



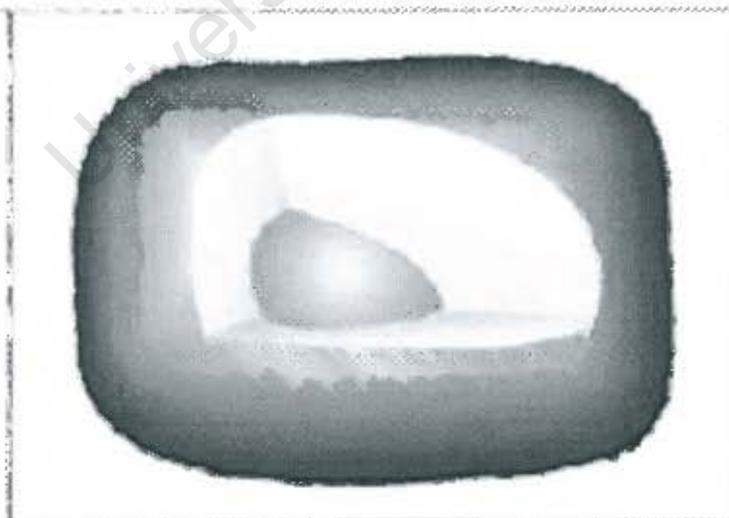
**Different tissues of the vein**



**The heart**



**The circulatory system**



**A cell from the vein tissue**

## **Skeletal System and the Skin**

- Refer back to the initial body map created by the whole group and ask the group to explain how their bodies stay upright. Introduce the skeletal system using the Visual Body Map. Ask each group to choose a part of the skeleton to draw on their body map. They can add facts about the skeleton directly to their body maps:
  - gives body shape and support
  - consists of 206 bones
  - protects internal organs and tissue (i.e. brain inside skull)
  - produces blood cells in the marrow (5 min)

### **FACT FILE**

Skin is strong, waterproof and elastic. It has sweat glands that produce sweat to get rid of waste and keep the skin cool. It has nerve endings that allow us to feel things we touch. Feeling pain is one way the body protects itself. Some special skin cells produce pigment (colouring) that provide some protection against the sun. Some cells around the eyes produce tears to keep the eyes moist and to keep them free of germs /micro-organisms.

- Why do we need skin? What would happen if we had no skin? Discuss the skin and what function it performs. Each participant can choose a colour and trace over the contour of their body on their body map to represent skin. They can also add information and illustrate details like tears, sweat etc. (5 min)

## **The Nervous System**

- Light a candle and ask a volunteer from the group to hold their finger in the flame. Why do they refuse? Ask the group what happens if we put our hand near a candle flame. Discuss nerve endings in the skin as a way of introducing the nervous system using the Visual Body Map. (5 min)
- Give each participant a photocopied map of the area and ask them to find their homes, work, clinic etc. Ask participants how they got to the workshop? Did they use a taxi or a bus or a train? Ask them to draw their route getting to the workshop on the map with a colour pen. They can stick the maps onto their body maps.(10 min)

- Ask the group questions on the similarities between a map and the nervous system. For example, when we put our finger near a flame, the message of pain travels all the way to our brain, which tells us to remove our hand. Draw this 'path' from the finger tip to the brain directly on the Visual Body Map's nervous system. (5 min)

#### **FACT FILE**

Sensory nerves carry information received from the senses (i.e. sight, hearing, touch, taste and smell) to and from the brain. Motor nerves carry messages from the brain to muscles to control movement. Other nerves control unconscious actions such as breathing, digestion and keeping the heart beating.

### **Session 3**

#### **The Circulatory System**

- Get the group to do a 'body alphabet' exercise to get them active again. Ask volunteers to call out the letters that spell their name. The group then responds by matching the shape of their body to the letter. Usually the group finds this a fun and humorous exercise. (5 min)
- Ask the group to check their partner's pulse. What is a pulse? Introduce the circulation system by showing them the Visual Body Map. The circulation system and the nervous system are similar in that they both reach all parts of the body. Refer back to the photocopied map comparing highways, roads and streets to arteries, veins and blood vessels. (5 min)

#### **FACT FILE**

Blood vessels are tubes which carry blood throughout the body. They become smaller and smaller as they form a network reaching every part of the body. Arteries carry blood from the heart to the rest of the body. Veins carry blood back to the heart. Red blood cells are like a fleet of delivery vans carrying oxygen as blood is pumped to all parts of the body. White blood cells are like a clean-up service cleaning up dead blood cells and fighting infections.

- Ask a volunteer to illustrate on the Visual Body Map how oxygen travels in the blood from the lungs to reach all parts of the body. Ask another volunteer to show how food and medication are swallowed, pass into the digestive system and then pass through the lining of the stomach and small intestine into the circulatory system. Participants can add information about the circulatory system onto their body maps. (10 min)

## The Immune System

- Introduce the lymphatic system using the Visual Body Map by overlaying it on the nervous and circulatory systems. Ask what happens if we cut or graze ourselves by accident. Apart from blood what else do we see? What does it do? Apart from cuts how else can our bodies get infected or sick? How does the body fight things like 'flu'? Do a brain storming exercise on the immune system and how it heals the body including the role played by the B lymphocytes, CD4 T lymphocytes (Helper Cells) and CD8 lymphocytes (Killer Cells). (10 min)

### FACT FILE

The colourless liquid that can be seen when skin is grazed or cut is called lymph fluid and is part of the immune system. Lymph fluid helps fight infection by sealing the broken skin and killing germs. Lymph fluid circulates the body in the lymph vessels and clears the body of germs and dead cells. The immune system works closely with the circulatory system. There are red blood cells (that carry oxygen) and white blood cells (that work for the immune system). White blood cells are found in the lymphatic system, body tissues and blood. We cannot see them as easily because they are not as many as the red blood cells. There are different kinds of white blood cells, including those known as lymphocytes. (cytes = cell, lymphatic system = lympho). B Lymphocytes (B cells), CD4 T Lymphocytes (helper cells or CD4 cells) and CD8 Lymphocytes (Killer cells or CD8 cells) are a vital part of the immune system.

- Hand out 4 balloons (different colours if possible) to volunteers and label them CD4 T-Lymphocyte (CD4 cell or Helper T-cell), CD8 T-Lymphocyte (Killer T-cell) and B-lymphocytes (B-cells). Make sure to draw the receptors on the CD4 cell. Label the last balloon as a 'flu' virus. (5 min)

- Ask the volunteers to act out the different functions of the immune system when a 'flu' virus invades. Each person has to introduce the cell they represent and what its functions are. Secretly give the person representing the B-cell a pin to pop the 'flu' virus balloon at the end to show how the immune system is able to beat the 'flu' virus. The rest of the group can call out and tell the actors what to do. Keep the labelled immune system balloons. (15 min)

#### **FACT FILE**

When the 'flu' virus enters the body it travels in the blood stream. The CD4 cell is the first to notice it and sends messages to the rest of the immune system to come and help get rid of it. The CD8 Lymphocytes directly touch and destroy the viruses. When B-cells find a virus they react by producing antibodies that attach to the virus so that the white cells can destroy them. This process takes a bit of time (usually 2 weeks for 'flu') and a person only gets well once all the viruses have been destroyed.

## **Session 4**

### **How to Prevent HIV Infection**

- Ask the group if any of them had 'flu' during the past winter. The purpose of this exercise is to look at how viruses are transmitted. It introduces the idea that there are different ways for a virus to enter the body and we are able of protecting ourselves from infection. Ask the following questions to generate some discussion.

- How do they think they got the 'flu'?
- Can someone give you 'flu'? How? Why?
- Is there anything you can do to prevent yourself from getting 'flu'?

(5 min)

- Ask the group how HIV enters the human body. Get participants to mark those places on their body maps where HIV can enter the body. They can mark it with an 'x' or they can draw it. Depending on the group, their age and cultural background there might be embarrassment when drawing sexual organs. In these cases an 'x' avoids this problem. Participants write next to each area to explain how the virus enters the body in these places. (10 min)

**FACT FILE**

Unprotected sex is the main cause of the HIV infection in South Africa. HIV can also be transmitted through open cuts and wounds, car accidents, blood transfusions, shared needles and mother-to-child transmission. HIV is present in infectious quantities in blood (including menstrual blood), semen and pre-ejaculate, vaginal and cervical secretions, wound secretions, amniotic (pregnancy) fluid and breast milk. Very low secretions are found in saliva, sweat and tears. HIV is not normally present in urine, faeces and vomit, unless there is also blood present.

- Test the group's comprehension of ways of transmission by asking questions like 'Can you get HIV from sitting next to someone?' etc. Ask the group to call out all the ways a person cannot get HIV such as hugging someone, sharing cooking utensils etc. while one or two participants write up a list on the board in front of the group. (10 min)
- Discuss ways the group can protect themselves from getting infected or potentially infecting others. Add the preventative measures they can take next to each area they have marked with an 'x' on their body map. If the workshop is being used in a support group with people who are HIV-positive, this knowledge is also important for them. They can avoid passing on the virus to future children born to them, they can prevent being re-infected with different strains of HIV or infecting future sexual partners and they can be a source of knowledge for people in their community. In this way they could prevent their children, family and friends from getting HIV if they share this knowledge. (10 min)

**FACT FILE**

Both male and female condoms help prevent HIV transmission. Even if both partners are HIV-positive, they still need to use condoms so they do not re-infect each other with different strains of HIV. As HI viruses reproduce in the body there are slight mutations (changes) in the virus. This means that HIV is constantly changing in the body, developing different strains (kinds) of HIV. This does not mean HIV-positive women and couples cannot have children. If someone wants to have a child, they should discuss the options available with their clinic or doctor. HIV-positive people can have children, but they need to take extra care with their health and can prevent infecting their baby by taking antiretroviral drugs to prevent mother-to-child transmission.

## **Social Challenges and Solutions**

The following exercises aim to encourage debate and acknowledge that HIV/AIDS is also connected to social and economic conditions that can make it difficult for individuals to make the best decisions about their health. It also aims to give workshop participants some practical solutions.

- As a group discuss how living conditions can contribute to the spread of HIV/AIDS. A volunteer can write a list on the board of possible topics which might include:
  - poverty
  - high unemployment levels
  - migrant labour
  - transactional sex in exchange for food, school fees etc.
  - living conditions in informal settlements
  - alcoholism and drug abuse
  - rape
  - violence (5 min)
- Once the list is complete, participants can discuss possible solutions to some of these social and economic challenges. This could also include practical steps such as using Social Services to access grants or contacting other organisations such as the AIDS Law Project, support groups in your area etc. This exercise can also serve as a way of the participants sharing their knowledge. (10 min)

## **Session 5**

### **Social Support**

The different kinds of support people get from family, friends, partners and the greater community play a very important part in their lives. The decisions people make about their health often depends on whether or not they feel supported. This is why it is important to encourage people living with HIV to access as much support as they can so they are free to make the best decisions about their health.

- Get participants to discuss in pairs or in their groups all the people in their lives who give them support. This includes emotional or

financial support, looking after children, providing meals, help with cleaning, advice etc. On a piece of paper participants list all the people who support them. The list can include family, people from church or another social group, a treatment buddy, a teacher, a friend from a sports team, a work colleague etc. (10 min)

- Each participant draws an outline around both their hands on their group body map or on a piece of paper. In the one hand they can write the names of all the people and places that support them and in the other hand they can list all those people they provide support for. (10 min)

## Talking about Disclosure

The aim of this exercise is to introduce the issue of disclosure for people living with HIV. The facilitator should be sensitive to the possibility that within the group there may be people who are HIV-positive. This exercise should encourage conversation and create awareness around the issues of support and how disclosure of HIV-positive status can affect relationships and families both positively and negatively. The emphasis is on disclosure as a way of accessing different kinds of support from family, friends and sexual partners.

- In their groups the participants discuss what advice they would give to someone who is HIV-positive and wants to disclose to someone close to them. The following suggestions have been made by HIV-positive people who know what it is like to disclose their status.
  - Accept your HIV-positive status first before telling anyone.
  - Think it through carefully, imagining the kind of questions the person might ask.
  - Prepare yourself mentally and emotionally for any unsupportive words or actions.
  - Attend support groups where you can get support from other HIV-positive people.
  - Choose someone in your support group to be a friend - someone you can call when you need to talk to someone.
  - Don't stay alone - keep busy and active.
  - Choose your friends carefully – you don't have to tell everyone.

- It might be easiest to disclose to your family first, because they will stand by you.
  - Telling your partner is important if you care for them and want to prevent infecting them. But sometimes the risks are highest when disclosing to your partner, because they might accuse you of cheating on them and bringing the disease into the relationship. Or you might be financially dependant on them. One solution is to go and get HIV tested together and learn your results together.
  - If someone knows in advance that you are HIV-positive they can help you should you fall ill. They can also start to learn about the virus and give you support. (10 min)
- In pairs ask the participants to role-play or discuss potential situations HIV-positive people might encounter in real life when disclosing their status. Examples include telling a parent, a sister, a sexual partner or a friend. Ask the participants to include both positive and negative responses and to discuss how someone might best prepare themselves for potentially unsupportive responses. (15 min)

## Session 6

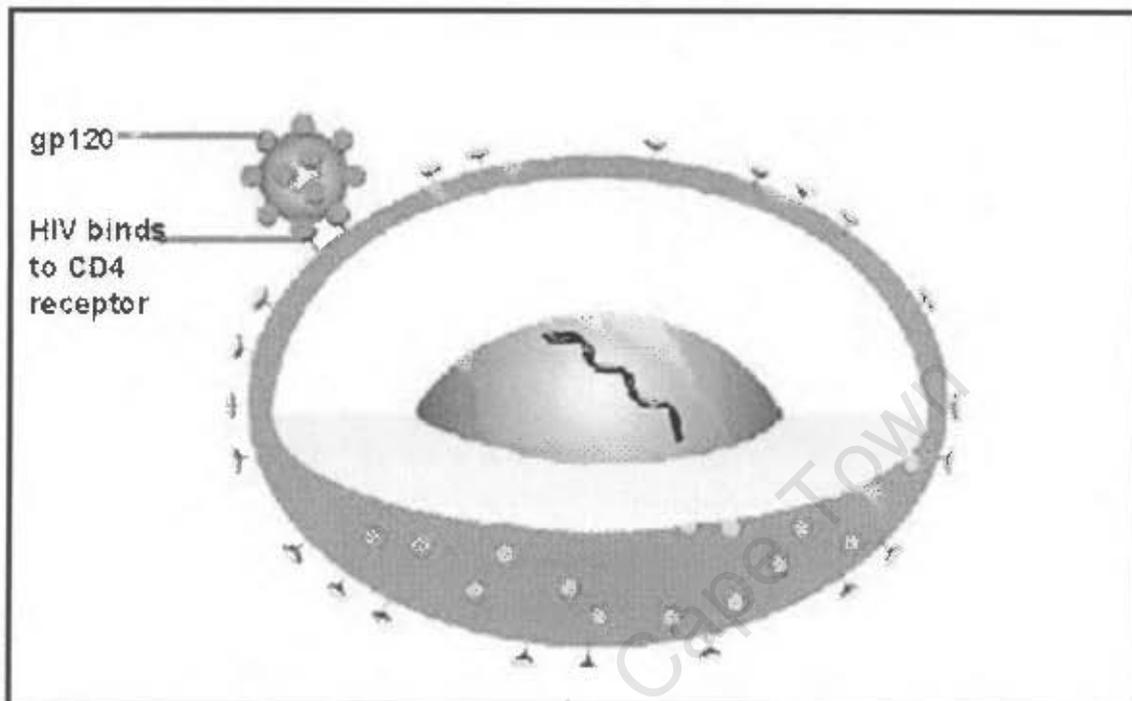
### What happens when HIV enters the body?

#### **FACT FILE**

Like all viruses, HIV has only one purpose and that is to multiply. It cannot multiply outside the human body because it needs human cells to replicate (reproduce or multiply). The HI virus needs DNA in order to multiply, but it does not have its own DNA so it enters the CD4 cell and uses the CD4 cell's DNA to reproduce. Once inside the CD4 cell it is also safe from antibodies (created by the B-cells), as well as killer T-cells. The HI virus releases its instructions (RNA) into the CD4 cell together with other enzymes called reverse transcriptase and protease. Reverse transcriptase enables the RNA to become pro-viral DNA which can then fit into CD4 cell's DNA. This makes the CD4 cell start producing HI viruses instead of more CD4 cells.

- Ask a volunteer to draw a CD4 cell on the board. Make sure the CD4 cell has receptors clearly drawn. Ask another volunteer to draw

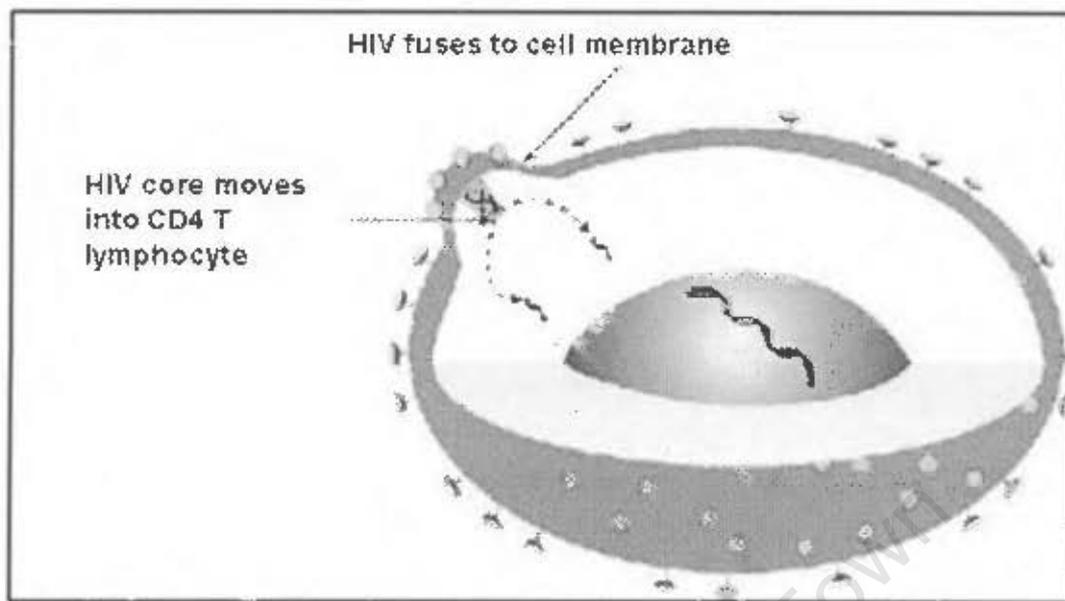
an HI virus illustrating its unique shape and how it attaches itself to the CD4 cell. (10 min)



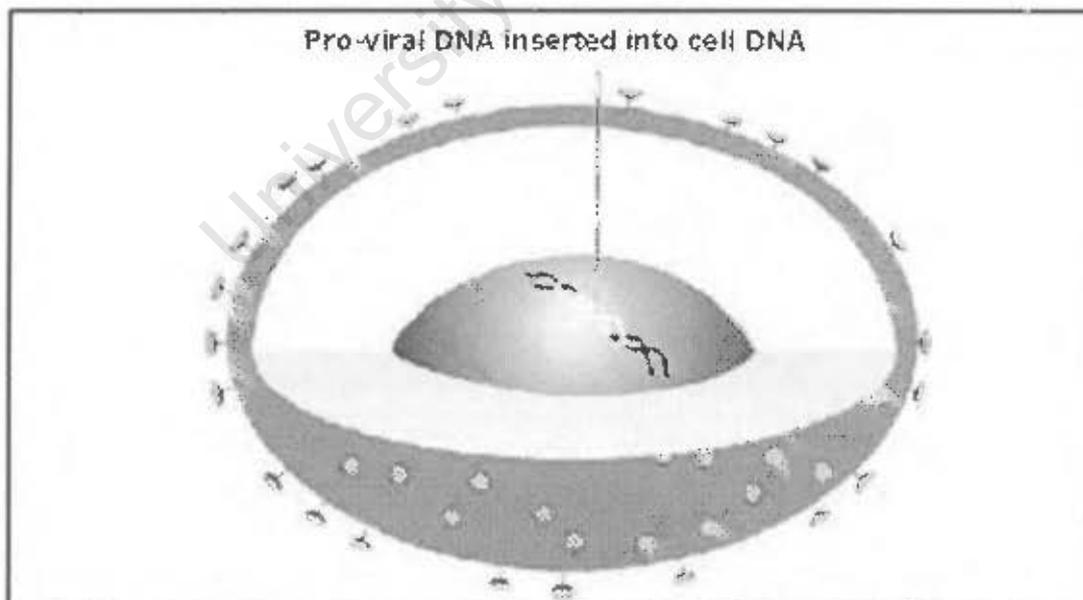
- Show the participants a lock and keep the key in your pocket. Ask if anyone has keys with them. Call on volunteers to come forward and try to unlock the lock with their keys. Ask the group why they are unsuccessful. On their prompting use the key in your pocket to open the lock. Use this example to illustrate the way the bumps (gp 120) on the HI virus lock with CD4 receptors. (10 min)

### What happens when HIV enters the CD4 cell?

- Ask volunteers to add to the drawing and show the steps involved as an HI virus enters a CD4 cell. Ask and answer questions to clarify the process:
  - Why does the HI virus enter the CD4 cell?
  - What does it want to do once it is inside the cell?
  - What does it need to reproduce?
  - What does the HI virus release into the cell?(10 min)

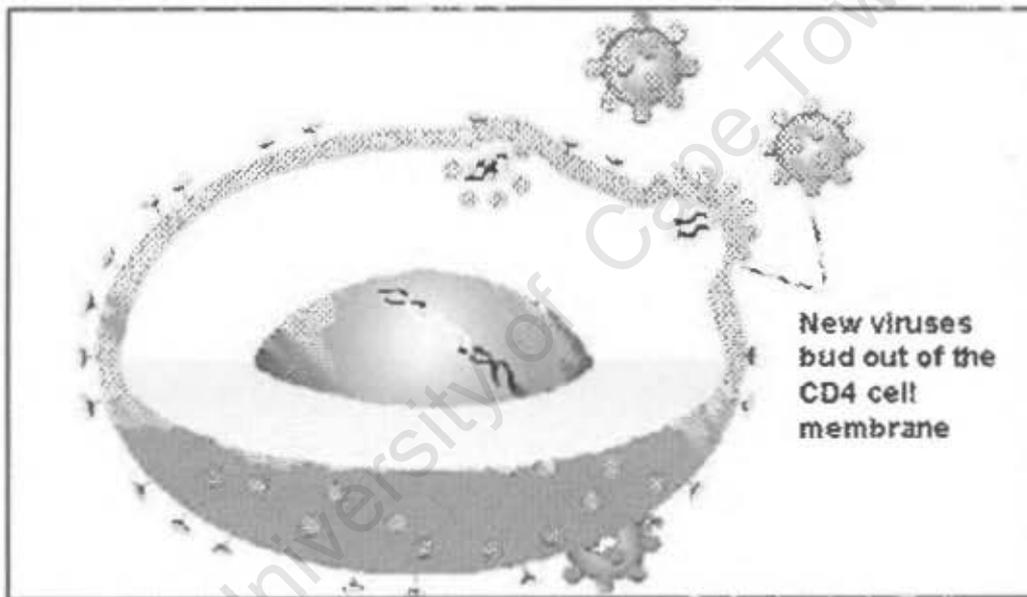


- Use a zip to illustrate how the reverse transcriptase transforms the RNA to match the CD4 cell's DNA. One side of the zip can be likened to the CD4 cell's DNA. The other side of the zip can represent the HI virus's RNA, which is made to fit or lock with the DNA with the aid of the reverse transcriptase. Ask volunteers from the class to come and explain the process using the zip. (10 min)



### FACT FILE

Once the HI virus has control of the CD4 cell's DNA, it becomes part of the CD4 cell and uses the CD4 to make new HI viruses. Protease is responsible for organizing the building of the new HI viruses. These new HI viruses are released from the CD4 cell back into the blood stream where they attack more CD4 cells. Once an HI virus has taken over a CD4 cell and used it to make more HIV, the CD4 cell dies. As more HI viruses are reproduced and released into the blood stream, fewer and fewer CD4 survive. Eventually there are so few CD4 cells that the immune system cannot work properly and will be unable to fight infections.



- Discuss the differences between a 'flu' virus and an HI virus with the group by asking questions such as:
  - What does the HI virus do that a 'flu' virus cannot do?
  - What is special about the shape of the HI virus?
  - Why does HIV enter the CD4 cell?
  - Can the immune system beat the 'flu'?
  - Can the immune system beat HIV? Why not? (10 min)
- Call on volunteers to represent the CD4, CD8 and B-cells in the immune system using balloons. One volunteer can represent an HI virus. Ask the group for comparisons between the immune system's

responses to HIV and a 'flu' virus. It is very important that participants are able to explain why the immune system cannot successfully beat HIV infection. Once the group has clarified the differences between a 'flu' virus and HIV, the volunteers can act out how the immune system is incapable of successfully beating HIV using the balloons, but no pins this time round. (10 min)

## Session 7

### Opportunistic Infections

- Ask the groups to return to their body maps and think of all the opportunistic infections or other health related issues related to HIV they know of. As a group they can then label the parts of their body maps affected by specific opportunistic infections. (10 min)

#### **FACT FILE**

An HIV-positive person is more likely to get ill because their immune system is not able to fight infections. These illnesses are known as opportunistic infections. Common opportunistic infections include TB (Tuberculosis), thrush, shingles and PCP (Pneumocystis Pneumonia) among others. Many of these infections affect people who are HIV-negative as well, but they are less likely to get them because their immune system can protect them better. When someone falls ill with any of these infections they should visit a clinic immediately and get treated. If someone's CD4 count is very low, they may be given antibiotics as a prophylactic to prevent an opportunistic infection before it occurs.

- Once they finish identifying various infections and illnesses related to HIV and AIDS, call on each group to call out the names and describe the symptoms. The Fact File on pg 23 lists the most common opportunistic infections and treatments. Participants can write the relevant medication and treatment options available for each infection. Encourage the discussion of 'home remedies' and traditional medicine, as well as medication available at clinics and hospitals. Some symptoms such as rashes, diarrhoea and thrush can be treated effectively with home remedies if they are not too serious. (10 min)

## FACT FILE

If a person is HIV-positive they are at greater risk of getting opportunistic infections because their immune system is weakened. It is different for each person. Here are some of the most common opportunistic infections.

**Tuberculosis (TB)** – TB is a bacterial infection treated with a combination of different drugs. If someone is treated for the first time they will need to take medication for 6 months. It is very important that they finish the full course to prevent developing multidrug resistant TB (MDR-TB).

- **Thrush (oral candidiasis)** is caused by a fungus and infects the mouth and throat. If the infection is in the mouth, *nystatin* lozenges or liquid can be used. *Amphotericin B* lozenges or *miconazole* gel can also be used. *Fluconazole* is used when the infection is in the throat.
- **Diarrhoea** is caused by a number of parasitic and bacterial infections and can cause severe dehydration and weight loss. Depending on what is causing the diarrhoea, different antibiotics are used. Bacterial infection can be treated with *cotrimoxazole* or *doxycycline*. Some parasitic infections are treated with *metronidazole*. Drugs such as *loperamide* and *codeine* can help control the diarrhoea and water mixed with sugar and salt can be drunk to rehydrate.
- **Pneumocystis Carinii Pneumonia (PCP)** – PCP is a life-threatening and preventable lung disease. PCP can be treated and prevented by taking *trimethoprim* and *sulfamethoxazole* also known as *co-trimoxazole*.
- **Skin problems** are caused by a number of germs and can result in rashes, bumps, scales and itching. Most of the time a cream or liquid treatment is used.
- **Kaposi's Sarcoma (KS)** is a kind of cancer that causes dark red or purple patches on the skin and can spread to other organs in the body. Radiation therapy and chemotherapy is used to kill the cancer cells.
- **Toxoplasmosis** is a disease that affects the central nervous system (the brain) and sometimes the eyes and lungs. Treatment includes taking 3 drugs (*Pyrimethamine, Folinic Acid, Sulfadiazine*) for 6 weeks, and then usually continued for life. Like PCP, *co-trimoxazole* is the most effective prophylaxis.
- **Cryptococcal Meningitis** is an infection of the spinal cord and brain caused by a fungus. It is treated with a drug called *fluconazole* and will need to be continued for life to stop the infection returning.
- **Genital Herpes** is an STI caused by the *herpes simplex virus* or HSV. There is no cure for genital herpes but it can be treated with one of the drugs *Acyclovir, Famciclovir* and *Valacyclovir*.

- **Vaginal Candidiasis (Thrush)** is caused by a fungus and is treated with the drugs *Clotrimazole* or *Fluconazole*.
- **Syphilis** is an STI caused by a bacterial infection. It is usually treated with penicillin.

## Keeping Healthy

- Call on volunteers to come forward and write up a list of all the ways people, regardless of their HIV status can keep their bodies healthy and strong. Suggestions might include a healthy diet, how to prepare foods to retain their nutritional value, keeping warm, keeping the house clean etc. (5 min)
- Hand out shop advertisements of foods. Ask participants to cut out those foods they think are important to eat and stick them onto their body maps. A healthy diet helps cells to repair themselves, as well as boosting the immune system. Poor nutrition makes us more vulnerable to HIV and other opportunistic infections. (10 min)
- Eating healthily doesn't mean that food has to be expensive. Ask the groups to discuss nutritious meals that are inexpensive to prepare. Also discuss ways of cooking food to ensure that the vitamins remain in the food. For example, not boiling vegetables, but rather making stews or using the water that has been used to boil the vegetables to make soup. The groups can then write up menus for each day in the week on a piece of paper and stick it to their body maps. (10 min)

### FACT FILE

Some examples of inexpensive and nutritious foods are:

Fresh fruit and vegetables, maize meal, samp, soya mince, beans and lentils, rice, potatoes, tinned sardines or pilchards, oats, brown bread, chicken livers, peanut butter and oats.

It is important to eat a variety of foods including protein (meat, chicken, fish, eggs, beans, peas, lentils), fruit and vegetables, grains (bread, pasta, rice, sorghum, maize, oats) and dairy products (milk, *amasi*, cheese, yoghurt).

**What foods to avoid:**

- ✓ Too much greasy or fatty foods, coffee, salt, sugar and sweets.
- ✓ Processed and refined foods are high in sugar, salt, fat and artificial additives and have less fibre and nutritional value.
- ✓ Alcohol and tobacco
- ✓ Drinking tea and coffee with meals reduces the body's absorption of iron

• Hygiene is important for everyone's health, but it is especially important for preventing opportunistic infections if someone is HIV-positive. Call on volunteers to come up and compile a list. Some hygiene tips could include:

- Wash hands before food preparation and after going to the toilet.
- Clean the home regularly and keep it well aired.
- Fresh foods should be washed before cooking.
- Water should be boiled if it is unsafe (contains harmful bacteria).
- Meat should be refrigerated or bought fresh before cooking.
- Jeye's fluid, Jik (bleach) or Detol are all useful disinfectants that can be used in the house. (10 min)

• Cut-outs of advertisements or drawings of cleaning products can also be added to the body maps along with written explanations. (10 min)

**FACT FILE**

**Guidelines for home-based care:**

- ✓ Avoid skin contact with body fluids and open wounds, sores and breaks in the skin. If you have a cut, make sure it is dressed and covered with a watertight material (i.e. latex gloves).
- ✓ When cleaning blood spills and soiled clothing and bedding, use latex gloves or plastic bags to prevent infected blood touching the skin.
- ✓ Place clothing or bedding in a strong solution of bleach for 30 minutes and then wash in usual way.
- ✓ Mop hard surfaces with hot water and soap and wipe over with strong solution of bleach.
- ✓ A break in the skin accidentally exposed to HIV should be rinsed with running water. Visit the clinic for post-exposure prophylaxis (PEP).

## Session 8

### How to find out if you are HIV-positive

- Encourage the groups to discuss the things that prevent people from getting tested. Ask them to come up to the board and make a list. This could include previous bad experiences at the clinic, fear of discovering they are HIV-positive and not knowing what to do next, fear of medicine and hospitals etc. (5 min)

#### **FACT FILE**

One way of finding out your HIV status is to go to a clinic for Voluntary Counselling and Testing (VCT). Most tests require that a little bit of blood is taken. The most common tests (i.e. ELISA or rapid tests) check to see if there are HIV antibodies present in the blood. When a virus enters a human body, the immune system (B cells) creates antibodies to fight the virus. If there are HIV antibodies in the blood, it means that HIV must be inside the body. The immune system takes a bit of time to fight a virus. The time gap before there are enough antibodies to be detected by a test is called a 'window period'. This is why it is important to return for re-testing after three months.

- Two volunteers can do a role play exercise in front of the group where one person can pretend to go to the clinic and ask a nurse or community health worker how they can find out if they are HIV-positive. The group can call out advice including how and where to get tested, the advantages of knowing your HIV-positive status before you get seriously ill etc. Alternatively this can be discussed in groups. (10 min)

### Monitoring your health if you are HIV-positive

- Once someone knows they are HIV-positive it is important they monitor their health. In particular they need to watch the immune system closely to see how it is coping. Ask the group how an HIV-positive person can do this? Answers might include:
  - Regular visits to the clinic
  - Prophylactic use of antibiotics to prevent opportunistic infections
  - CD4 count and Viral Load tests (5min)

## **FACT FILE**

A viral load test counts the number of HI viruses in the blood. This is mainly used with HIV-positive patients to see if they need antiretroviral treatment or to monitor how well treatment is working. When someone is on antiretroviral treatment, an increasing number of HI viruses (viral load) shows treatment is not working. This can mean the person is not taking their treatment properly or that they have developed drug resistance and their body no longer responds to the antiretroviral treatment. In this case they will need a different drug. This can happen if a patient does not take their medication correctly. With successful treatment the HI virus can become undetectable in the blood. This does not mean the person no longer has HIV. They still have the HI virus in their body, but their immune system is strong enough to control it from multiplying. Viral load is calculated by counting the number of HI viruses in a cubed millimetre of blood ( $\text{mm}^3$ ).

A CD4 cell count test counts the number of CD4 cells in the blood to see how healthy a person's immune system is. This test can be used to monitor how well a patient's body is responding to antiretroviral treatment or decide when to use medication that prevents or helps fight opportunistic infections. If a person's CD4 count is very low (below 200) they are often given antibiotics to prevent disease before it occurs. A CD4 count can also help decide when to start antiretroviral treatment. CD4 count is calculated by counting the number of CD4 cells in a cubed millimetre of blood ( $\text{mm}^3$ ).

- CD4 count and viral load tests are particularly useful ways of measuring how the immune system is coping. Divide the group in two and let one group ask questions to test the other groups' understanding about viral load and CD4 count tests.

How are these tests measured?

Why is it important to do these tests?

Why are CD4 cells counted and not other kinds of cells?

How do they do the tests?

Why is it important to return to the clinic for check-ups even if you are not on treatment? (10 min)

## **Stages of HIV/AIDS**

- Ask if the group has heard of the different stages of HIV as it progresses towards AIDS. Draw a timeline showing the four stages.

Mark the level of the CD4 count resting at 200 as illustrated (pg 29). Choose one colour to represent the CD4 count and another colour to represent the viral load. Ask two volunteers to draw what they think happens to the CD4 count and the viral load as the disease progresses without antiretroviral treatment. Make any necessary adjustments and add any other information the group might know about the different stages. (10 min)

### **Stages of HIV Infection**

In the first stage, the HI virus has just entered a person's body and starts to replicate (multiply). The HIV antibodies cannot be detected in the blood yet and so this is often called the window period and can last from three to twelve weeks. During this time the person is still infectious. Four to sixteen weeks after infection the person's HIV status will change from negative to positive (seroconversion). Some patients may have 'flu-like' symptoms, but otherwise appears well and can remain so for many years.

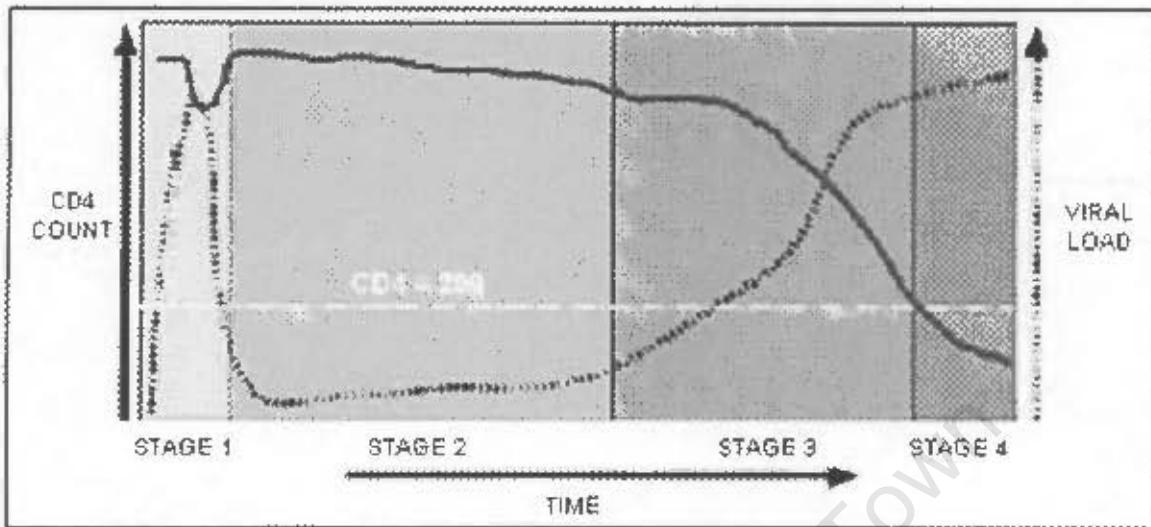
In Stage 2 the immune system starts to be overwhelmed by the HI virus and will start to get infections and symptoms. The CD4 count decreases while the viral load increases.

Stage 3 means that the immune system continues to deteriorate and the person gets weaker and experiences more infections and illness. The CD4 count continues to drop while the viral load increases.

Stage 4 is when the person is said to have AIDS. The immune system can no longer work, since the CD4 count is very low and the viral load is very high. The person is seriously ill and is often in bed.

The way HIV affects our bodies differs from person to person. If we are healthy it might take our body a long time to show signs of struggling to fight infection. That is why many people can live for years and not realize they are HIV-positive. The way HIV affects the human body has been broken up into different stages to help doctors monitor the virus and how it affects our bodies.

## HIV DISEASE PROGRESSION



### What does Antiretroviral Treatment do?

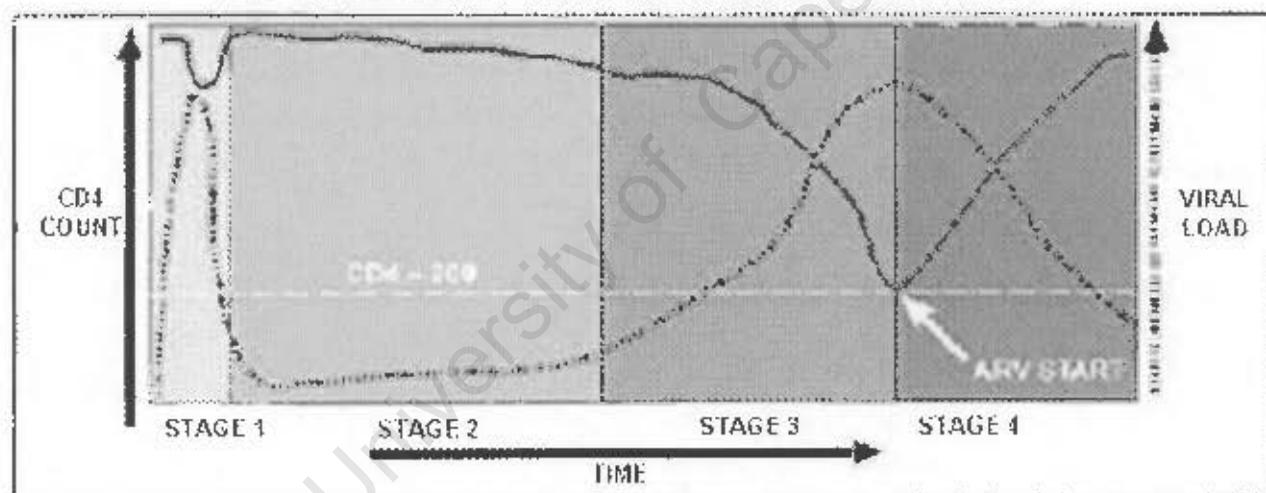
- Refer back to the drawing completed earlier of HIV entering the CD4 cell. Ask a volunteer to draw over it to show the stages in the production of HIV that antiretroviral treatment halts. Even if the names of reverse transcriptase and protease are not used, the emphasis is on understanding that treatment prevents more HI viruses from being produced. (5 min)

#### FACT FILE

Antiretroviral (anti = against, retroviral = retroviruses like HIV) drugs prevent or slow down the production of the HIV virus by blocking the action of the reverse transcriptase and protease. By stopping the production of more HIV viruses, antiretroviral treatment helps the immune system by reducing the viral load (number of HIV viruses in the blood), as well as preventing further loss of CD4 cells. When doctors first started giving HIV-positive people treatment only one drug was used, but it did not stop all replication of HIV viruses. When the virus mutates it becomes resistant to the treatment and is able to continue reproducing. Now doctors usually use a combination of three different antiretroviral drugs to slow down the rate the HIV virus reproduces. It is called HAART (Highly Active Anti-Retroviral Therapy). To stop HIV from replicating there needs to be the right amount of antiretroviral drug in the patient's blood stream all the time. To make sure that there is the right amount 24 hours a day the drugs must be taken in the right amount, at the right time every day.

- Participants return to their body maps and draw the path the drugs take from the mouth, down the throat into the stomach and then the blood stream. Any other information such as the names of specific regimens can be added to the body maps as well. (5 min)
- Bring out the drawing of the different stages of HIV that was used to describe how CD count and viral load tests are used to monitor the health of someone who is HIV-positive. Ask the group at what stage someone usually goes onto antiretroviral treatment. Mark the point on the chart where the CD4 count reaches 200. Ask for a volunteer to come and alter the drawing to show what antiretroviral treatment does to the CD4 count and viral load as seen on pg 30. Ask them to explain as they draw. (10 min)

### HIV DISEASE PROGRESSION WITH ART



## Session 9

### How to Prepare for Antiretroviral Treatment

- Ask volunteers to compile a list of all the things a person needs to know before they go onto antiretroviral treatment. Make sure the following are covered:
  - When you find out you are HIV-positive you don't need to go onto antiretroviral treatment immediately, unless your CD4 cell count is less than 200, or you are diagnosed with a Stage 4 defining illness.

- You have to be willing to go onto antiretroviral treatment before it is prescribed.
- ARVs are for life. You cannot stop taking them when you feel better.
- You must be prepared to disclose your status to at least one person who you are living with or a 'treatment buddy'.
- It is very important to attend clinic appointments regularly.
- If you have other illnesses like TB, pneumonia or diarrhoea you might have to wait until you are strong enough before starting treatment.
- If you have a problem like depression, alcohol or drug abuse, treatment might have to wait until you are well again.
- A home visit might be necessary to see what support you will get at home or if help is needed (such as food parcels etc).
- ARVs do not reduce the risk of passing the HI virus to other people, so use condoms or abstain even if you are married.
- Do not share your ARVs with other people.
- Go to the clinic as soon as possible if you are ill or have any side effects from the ARVs.

(10 min)

## Antiretroviral Treatment Options

There are a number of different antiretroviral treatment options. Like many other medications, antiretroviral therapy has specific instructions of when and how to take the pills and there can also be side effects.

- Ask volunteers to come forward and list all the different treatment options they know, along with information such as storage and how and when to take the medication. The facilitator may need to check with the Fact File section on page 31 and 32. (10 min)

#### **FACT FILE**

##### **➤ D4T, 3TC, Efavirenz**

Store in a cool, dry place.

Take one tablet of D4T and ATC in the morning and in the evening take one tablet of D4T and ATC and 3 Efavirenz.

Don't drink alcohol when on this treatment.

Possible side effects are fever, diarrhoea or stomach problems, dizziness, loss of appetite, tiredness or weakness, trouble sleeping, mild depression, some hair loss and shift in body fat location.

##### **➤ AZT, 3TC, Nevirapine**

Store in a cool, dry place (Do not freeze).

Take one of each tablet morning and night.

Don't drink alcohol when on this treatment.

Possible side effects are fever, mild stomach problems, nausea, dizziness, loss of appetite, headaches, cough, tiredness or weakness, trouble sleeping and shift in body fat location.

##### **➤ AZT, DDI, Kaletra**

Store AZT and DDI in cool, dry place.

Store Kaletra in the fridge and use within 2 months.

Don't drink alcohol.

Take 4 DDI tablets on an empty stomach 30 minutes before breakfast with a full glass of water.

Take 3 Kaletra tablets with food in the morning and evening.

Take 1 AZT tablet morning and evening.

Possible side effects are fever, mild stomach problems, nausea, dizziness, loss of appetite, headaches, tiredness or weakness, trouble sleeping, changes in how food tastes, discolouration of nails and shift in body fat location.

##### **➤ D4T, 3TC, Nevirapine**

Store in a cool, dry place.

Don't drink alcohol when taking this treatment.

Take one tablet of each both morning and evening.

Possible side effects are fever, mild stomach problems, cough, dizziness, loss of appetite, headaches, tiredness or weakness, trouble sleeping and shift in body fat location.

A person taking antiretroviral therapy should visit their clinic as soon as possible if they experience any side effects or unexplained changes in their health and body. These can include skin rash, sores in the mouth, irritated eyes, swelling, difficulty breathing, nausea, vomiting, stomach pain, diarrhoea, tiredness, yellow skin or eyes, dark urine, strange coloured stools, burning or numbness or tingling in the hands, arms, feet and legs, and joint and muscle aches.

- In their groups participants can mark, label and describe all the possible side effects from each of the antiretroviral treatment combinations on their group body maps. Once again the Facilitator may need to refer to the Fact File information. (10 min)

## **Adhering to Antiretroviral Treatment**

- Divide the group into two to discuss what often stops HIV-positive people from going on antiretroviral treatment. Each group should create a list of all the things they think prevent or make it difficult for people to access treatment. The following list was created by HIV-positive people who are on antiretroviral treatment.
  - fear that the medication is harmful to their body (toxic)
  - fear of side effects
  - difficulty of taking the medication twice a day at the same time each day
  - knowing that they will have to take the treatment for the rest of their lives
  - having to prepare food before they can take some of the treatment
  - needing to disclose to people you live with
  - afraid of being seen taking treatment and then having people ask questions or gossip about you
  - denial of being HIV-positive
  - living in a remote area where the nearest treatment centre is far away
  - fear of violence if they disclose their HIV-positive status
  - money for transport to get to the clinic (10 min)

- Ask the groups to swop lists. Now each group can discuss and write down solutions or ways of assisting someone who has the difficulties described in the list they have been given. This can also be done as one large group. The following suggestions made by HIV-positive people.

- attending a support group where they can get support and also learn more about HIV
- receive education about HIV so that they can understand how treatment works - in clinics or support groups or peer education
- read pamphlets
- watch 'Beat it' and 'Soul City' and other programs about HIV/AIDS
- choose a treatment supporter or 'buddie'
- making a close friend in their support group, someone they know they can phone at any time
- use pill boxes to help take the treatment at the right time
- set a reminder on their cell phone when to take their treatment
- speak to a social worker or someone at the clinic if they need food parcels or apply for a social grant if you are eligible
- join a group such as TAC or other community or activist groups
- spend time with other HIV-positive friends who share your experiences
- don't stay alone, keep busy (10 min)

- Ask the group to think of a slogan for their body map. Each participant can create a personal slogan that expresses what they believe or think or feel. It may have to do with their stand against HIV/AIDS or an unrelated philosophy or attitude to life. They then write their slogan on their body map. (5 min)

- In closing take out the list of things the group wanted to learn in the workshop and check that everything has been covered. Use this time to answer questions, clarify anything that may have been misunderstood etc. Finally thank the group for their time and commitment. (5 min)

## **Appendix 2**

English version of the questionnaire answered by the workshop participants.

University of Cape Town

## BODY MAP WORKSHOP QUESTIONNAIRE 2006

<b>Module A : Personal Details of Person being Interviewed</b>			
A.1	Full Name		
A.2	Gender <i>(tick correct box)</i>	Female	Male
A.3	Current Address		
A.4	Community or Suburb		
A.5	Contact telephone		
A.6	What year were you born in?		

<b>Module B: Educational Background</b>			
B.1	What is your mother language? <i>(tick correct box)</i>	Xhosa	
		Afrikaans	
		English	
		Other (specify below)	
B.2	What languages can you read? <i>(can tick more than one box)</i>	Xhosa	
		Afrikaans	
		English	
		Other (specify below)	
		None	
B.3	What languages can you write? <i>(can tick more than one box)</i>	Xhosa	
		Afrikaans	
		English	
		Other (specify below)	
		None	
B.4	How many years schooling do you have? <i>(Tick correct box)</i>	None	
		Less than four	
		Between five and seven	
		Between eight and eleven	
		Twelve years (Matric/Gr.12)	

B.5	Did you do biology at school? <i>(Tick correct box)</i>	Yes	No
B.6	Did you do biology for matric (Grade 12)? <i>(Tick correct box)</i>	Yes	No

		GO TO B.8	
B.7	Do you have higher education or other training / certificates (i.e. HIV educator, Personal Assistant, computer course etc)?	Yes	No
B.8	Write down what type of education/training or certificates you have gained.		

<b>Module C: Training and Past Work Experience</b>			
C.1	What HIV/AIDS training or working experience do you have? <i>(Can tick more than one box)</i>	None	
		UNISA correspondence course	
		ATICC	
		Hands-on experience from working	
		Volunteering for an organisation or clinic	
		Trained by NGO or other organisation while working	
		Other (specify below)	

C.2	How long was the training? <i>(tick correct box)</i>	1-2 days	
		A week	
		A month	
		A few months	
		A year	
		Other (specify below)	
C.3	What did the training involve? <i>(can tick more than one box)</i>	Lectures and tests	
		Lectures and no tests	
		Long-distance learning	
		Hands-on training	
		Workshops that used drama, singing, art, role-plays, etc.	
		Other (specify below)	

C.4	How long have you been working and/or volunteering in an HIV/AIDS related job/organisation? <i>(tick correct box)</i>	Less than two months	
		Between two and six months	
		Between six and twelve months	
		More than one year	
		More than two years	

**Module D: Current Work Experience**

D.1	How would you describe your current work or job title? <i>(Can tick more than one box)</i>	Community Health Worker	
		HIV-positive Support Group Counsellor	
		HIV Counsellor (in clinics, for Voluntary Counselling and Testing etc.)	
		Treatment Buddie	
		Peer Educator	
		HIV/AIDS Trainer	
		Other (specify below)	

D.2	In you current job are you...? <i>(Tick correct box)</i>	A volunteer	
		Employed	

D.3	How long have you been working and/or volunteering in your current job? <i>(tick correct box)</i>	Less than two months	
		Between two and six months	
		Between six and twelve months	
		More than one year	
		More than two years	

D.4	Where do you work now? <i>(Can tick more than one box)</i>	In clinics	
		In support groups	
		Training other Health Workers, HIV counsellors, peer educators etc.	
		In an office organising and developing training.	
		In the community visiting homes and doing peer education.	
		Other (specify below)	

D.5	Do you currently use drawings, photographs or any visual material when you educate or train people about HIV/AIDS? <i>(tick correct box)</i>	Yes	No
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D.6	If you had visual educational material would you use it when you talk to people about HIV/AIDS or when you do training? <i>(tick correct box)</i>	Yes	No
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D.7	How useful is the Visual Body Map like the one used in the workshop when doing HIV/AIDS training? <i>(tick correct box)</i>	Not useful at all	
		Useful	
		Very useful	

D.8	If you had a Visual Body Map like the one used in the workshop, how often do you think you would use it? <i>(tick correct box)</i>	Never	
		Once a week	
		Two or three times a week	
		Every day in the week	
		Once a month	

D.9	Do you use any of the following when you educate or train people about HIV/AIDS? <i>(can tick more than one box)</i>	Singing	
		Drama (creating plays)	
		Role-play exercises	
		Music	
		Drawing	
		Art making (painting, cutting and sticking etc)	
		None	
		Other (specify below)	

D.10	Based on your work and life experiences do you believe seeing pictures of the human body and what is inside it helps people to better understand HIV/AIDS?	Yes	No
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D.11	Based on your work and life experiences do you believe learning about the biology of the human body		
D.11.1	encourages HIV-positive people to access antiretroviral treatment?	Yes	No
D.11.2	decreases stigma and fear about HIV/AIDS?	Yes	No
D.11.3	helps HIV-positive people look after their health better?	Yes	No

<b>MODULE E : Knowledge about HIV and AIDS</b>			
		True	False
E.1	When the viral load test cannot find HIV in a person's blood they are no longer HIV-positive.		
E.2	You can tell a person is HIV-positive by looking at them.		
E.3	If someone has TB, they are HIV-positive.		
E.4	Re-used surgical needles are the main reason people get infected with HIV/AIDS in South Africa.		
E.5	Sexually transmitted infections increase the chances of getting infected with HIV.		
E.6	HIV-positive couples do not have to use condoms.		
E.7	If an HIV-positive person uses traditional medicine they should tell the clinic.		
E.8	A CD4 count measures the number of HI viruses in the body.		
E.9	HIV-positive couples cannot have children.		
E.10	Women are more easily infected with HIV than men.		

<b>MODULE F: Antiretroviral Treatment</b>			
		True	False
F.1	Every person starts antiretroviral treatment as soon as they find out they are HIV-positive.		
F.2	Antiretroviral treatment slows down the production of CD4 cells.		
F.3	Children can also take antiretroviral treatment.		
F.4	Antiretroviral drugs need to be taken at the same time everyday.		
F.5	In South Africa antiretroviral treatment is recommended when a person's CD4 count is 700.		
F.6	If a patient forgets to take their antiretroviral treatment once they must throw away the rest of the packet.		
F.7	If someone wants to go on antiretroviral drugs they must disclose their status to at least one person they are living with.		
F.8	It is fine for someone to give their antiretroviral treatment to other people.		
F.9	When a person's CD4 count drops it will stay low even if they start taking antiretroviral treatment.		
F.10	When a person is feeling better they can stop taking their antiretroviral treatment.		

Thank you for taking the time to participate in this questionnaire. You will remain anonymous and all information you have provided will be treated as confidential. Your contact details will only be used to contact you to arrange further interviews related to this training.