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THE ROLE OF HIV LITERACY  
- A COMMUNITY HEALTH WORKER  
PERSPECTIVE

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# The Role of HIV Literacy - A Community Health Worker Perspective

## Abstract

*HIV literacy has been emphasised as part of HIV/AIDS campaigns throughout the world. The South African Government's allocation of past and present funding indicates substantial support for HIV/AIDS education with the emphasis on prevention. Commitment to the new HIV and AIDS and STI National Strategic Plan 2007-2011 for addressing the epidemic emphasises the importance of speeding up the delivery of HAART in South. The link between education and the provision of antiretroviral therapy lies in the need for patients to understand the nature of the HI virus and the way the medication works physiologically in order to ensure adherence, control side effects and provide the best care possible for people living with HIV/AIDS. This paper assesses the role of HIV literacy from the perspective of community health workers working in clinics in the Western Cape Province in South Africa. It looks at their daily interaction with clinic patients, as well as their experience of the HAART roll-out. It aims to evaluate the impact of HIV literacy on the communities they work in and the limitations of education in supporting the provision of health care for people living with HIV/AIDS.*

## Background

The well known adage 'prevention is better than cure' changed to 'prevention is the only cure' within the context of the AIDS epidemic in Sub-Saharan Africa, especially prior to the year 2000 (Hardon, 2005). It also gained some notoriety within the South African context where it has been argued that concentrating on prevention at the expense of attending to the needs of those who are already HIV infected is not only callous, but also impedes efforts to curb infection rates (Mukherjee *et al*, 2003; Farmer *et al*, 2001). It has been found that with the provision of Highly Active Antiretroviral Treatment (HAART) people are more willing to come forward for voluntary counselling and testing (VCT), whereas without treatment there is little incentive for doing so (Mukherjee *et al*, 2003; Farmer *et al*, 2001). Farmer *et al* recorded a 300% increase in VCT in rural Haiti after the introduction of antiretroviral therapy (Farmer *et al*, 2001).

The Voluntary HIV-1 Counselling and Testing Efficacy Study Group has revealed that if people know their HIV status there is increased uptake of treatment before health deteriorates (Coates *et al*, 2000). Morah's study in Malawi reported that HIV-positive people who are aware of their status report better knowledge about HIV/AIDS and there is substantially higher safer-sex practice in this group (Morah, 2007). This suggests that VCT is a vital part of effectively preventing the spread of HIV, as well as treating and caring for HIV-positive people. It also supports the argument that prevention campaigns without the provision of HAART cannot be as successful as those that combine prevention, care and treatment (Morah, 2007; Heyer & Ogunbanjo, 2006). This is important in relation to the implementation of the new HIV and AIDS and STI National Strategic Plan (NSP) 2007-2011 in South Africa (<http://www.doh.gov.za/docs/hivaids-progressrep.html>).

HIV literacy encompasses a range of aspects and can be approached in different ways. The prevention message approach was the focus of many HIV education programs in South Africa, including government run *Khomanani* and the NGO *Lovelife*. The promotion of 'ABC – Abstain, Be Faithful and Condomise' has been criticised because it fails to take into account the socio-economic and cultural environments of people worst hit by the epidemic. The incompatibility of abstinence is particularly obvious in cultures where fertility is prized and traditionally minded young women are under pressure to prove their fertility (Jewkes *et al*, 2001). Abstinence also fails to take into account African gender roles and the dominance of male decision making with regards to the sexual and reproductive lives of women (Morah, 2007; Ntseane & Preece, 2005, Buvé *et al*, 2002, Wood *et al*, 1998). Furthermore, social circumstances and poverty that have promoted transactional sex and other unsafe sexual practices are not addressed (Ntseane & Preece, 2005; Eaton, Fisher & Aarø, 2003, Buvé *et al*, 2002).

The 'Be faithful' component has also proved problematic, especially since multiple studies have shown that condom usage within marriage or a 'love relationship' (as opposed to casual sexual partners) is neither acceptable nor practised (Morah, 2007; Bracher *et al*, 2004). In these cases condom usage is believed to imply lack of trust between partners and promote promiscuous behaviour, as well as deny the central purpose of marriage which is to have children. Other studies have revealed the deep mistrust of condoms by many African peoples due to the emergence of the AIDS epidemic at a similar time to the promotion of family planning programs (Kaler, 2004). This resulted in the common belief that condoms are responsible for the spread of the virus (Ntseane & Preece, 2004). The fact that condoms distributed are most often white or pale in colour and predominantly manufactured outside of Africa has further

emphasised the idea that they are a European invention and not in keeping with African beliefs or practices (Ntseane & Preece, 2004, 2005).

The 'ABC' prevention campaigns have not been alone in receiving criticism. Other HIV interventions built on the premise that better knowledge about HIV/AIDS will result in sexual behaviour change have also been criticised. The shortcomings of this emphasis on individual decision making have been well documented (Campbell, 2003; Ntseane & Preece, 2005). What has emerged from these studies is the understanding that in place of empowering individuals to make better health decisions, the emphasis should be on creating 'health enabling communities' (Campbell, 2003). Eliminating or reducing the challenges posed by socio-economic conditions and gender inequality amounts to massive social, economic and political change. It calls for poverty reduction, employment opportunities, skills development, education and social reform, along with health care services, voluntary counselling and testing (VCT) and the provision of HAART.

Apart from taking into account the socio-economic factors that give rise to high rates of HIV infection, there have been calls for an African context-specific approach to HIV education and prevention strategies (Chilisa, 2005; Ntseane & Preece, 2004, 2005; Airhihenbuwa & De Witt Webster, 2004.) While the importance of understanding HIV within a broader cultural and socio-economic context has been acknowledged, it is equally important to emphasise that education remains the foundation of any strategy to combat the epidemic. It is suggested that in place of 'information only' campaigns, the dual provision of HAART together with knowledge about HIV/AIDS is more effective (Heyer & Ogunbanjo, 2006). By emphasising the link between understanding the virus and how antiretroviral treatment works, HIV literacy has become an integral step in maintaining good health while living with HIV. For example, knowledge of personal HIV status has been shown to decrease the number of sexual partners and increase safer-sex practices (Morah, 2007). This has been explained by the fact that HIV-positive people who know their status report better knowledge and attitudes, often due to attendance of support groups (Morah, 2007; Mabunda, 2004). However, according to a 2005 national survey conducted by the South African Human Sciences Research Council only 20% of South Africans living with HIV/AIDS know they are HIV-positive (PlusNews, 2007). This suggests that VCT services should be heavily promoted for both prevention and treatment purposes.

A number of organisations and groups of people have been involved in the promotion of HIV literacy, together with the provision of HAART in South Africa. The NGO HIV Outreach Programme and Education (HOPE) based at Tygerberg Hospital trains and funds twenty-one community health workers who

work in sixteen clinics in the Western Cape. HOPE was one of the first organisations to provide HAART to children and carers in South Africa and is responsible for the Ithemba Ward for caring for children either infected or affected by HIV. HOPE not only provides training for its community health workers, but acknowledges that as comprehensive care givers, the community health workers also fulfil the roles of advisors, educators and counsellors. Apart from duties in the clinics, many of the community health workers also run support groups for people living with HIV/AIDS, arrange HIV literacy talks and camps in schools and youth groups and provide HIV education as part of their VCT sessions ([www.h-o-p-e.net](http://www.h-o-p-e.net)).

This paper assesses the role of HIV literacy from the perspective of these community health workers. It evaluates their needs as educators and health workers, as well as the needs of the people who seek their advice and care in the clinics and communities where they live. The primary research questions were: ‘What is the role of HIV literacy with regards to the care and treatment of HIV-positive people?’ and ‘Are visual and participatory approaches to HIV literacy both relevant and effective?’ The paper looks at HIV literacy as part of prevention, as well as care and treatment provision. It is built on the premise that with the provision of medical care and HAART, knowledge about HIV and the human body increases with education provided by medical staff, community health workers and others such as support group leaders.

## **Description of the Workshop**

The two-day workshop aimed to expose the HOPE community health workers to alternative approaches to HIV literacy, as well as expand their current knowledge of human anatomy and the biology of HIV. The content of the workshop included human biology, how HIV affects the immune system and how to prevent HIV infection. Exercises addressed issues such as opportunistic infections (OIs), information on how best to manage one’s health as an HIV-positive person, nutrition, household hygiene and ways of accessing social support. Topics surrounding disclosure of HIV status were also discussed because of their relevance in relation to adherence and access to HAART. Preparation for HAART, the different regimens available and side effects were also covered, along with socio-economic challenges.

Due to the nature of their work as community health workers, the author assumed that the participants would be familiar with some, if not most, of the workshop content. While the workshop intended to increase the knowledge of the participants, it also aimed to equip them with visual and participatory approaches that they could use in their work when educating people who attend

clinics and support groups and who live in their communities. The workshop made use of a chart that depicted each system in the body on separate layers of acetate that illustrate the anatomy of the human body. In the course of this paper the chart of the human body will be referred to as a Visual Body Map. This visual aid was used in collaboration with the creation of life size drawings based on the tracing of the outline of a human body. The workshop participants worked in groups of between four and six participants. At the start of the workshop one person in each group would lie down on a piece of card and allow the outline of his or her body to be traced onto the piece of paper. This tracing would provide a template for the rest of the exercises that sought to develop understanding about the human body through drawing and writing, as well as encouraging debate and problem solving. These detailed drawings generated by the groups will be referred to as body map drawings.

## **HIV Literacy, Health and HAART**

This section reviews the relevant literature to further develop an understanding of the relationships between education, health, HAART and HIV/AIDS. In this way it addresses various aspects of HIV literacy including prevention, care and treatment. It also looks at the advantages and limitations of using visual and participatory tools and techniques for HIV literacy.

### **HIV Literacy and HAART**

Popular and radical adult educators have long noted the potential of social movements to encourage informal learning to take place when people engage in a social cause (Foley, 1999). This is particularly true of the TAC and other grassroots organisations that campaigned for the provision of HAART in South Africa at a time when there was a great deal of resistance to understanding HIV and AIDS within the biomedical model. By acquiring and spreading the relevant knowledge about HIV/AIDS and treatment options including HAART, these organisations resisted the dominant dissident views of the time and illustrated how advocacy for HAART in South Africa has gone hand-in-hand with HIV literacy. In the process of fighting for treatment, these organisations generated awareness and spread knowledge about HIV in their communities and within the broader South African society (Ashford & Natrass, 2005). In this way it could be argued that it is only possible to campaign effectively for antiretroviral treatment if one understands how HIV affects the human body and how HAART works to slow down replication of the HI virus. The need to

grasp the biomedical nature of HIV/AIDS and HAART arises from the complexity of the virus itself, as well as the contention in South Africa over the link between HIV and AIDS and how best to treat it. The relationship between grassroots activism and the spread of knowledge about HIV has been well documented (Endreson & Von Kotze, 2005; Robins, 2004; Ashford & Nattrass, 2005).

One particularly powerful strategy used by these organisations is peer education by people living with HIV. In this way the information that is shared has added impact because it comes from people living with the virus who speak from personal experience. It also seeks to destigmatize the disease and change public perception of what it means to live with HIV/AIDS. Morah (2007) shows that HIV-positive people who are aware of their status have better knowledge about HIV/AIDS and safer-sex practices are substantially higher in this group. Mabunda (2004) recorded the positive impact of support groups on rural women's knowledge of HIV and AIDS. This suggests that peer educators are a powerful resource in that they are able to spread information on HIV/AIDS in their communities, as well as through the example they set.

Kalichman and colleagues (2000) assessed the relationship between health literacy and health-related knowledge among people living with HIV/AIDS and 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 hospitalised more frequently and reported poorer health (Kalichman & Rompa, 2000). This has serious implications for health care more generally, but specifically highlights the importance of HIV literacy as part of enabling people to live healthy lives and access and adhere to HAART.

In these previously mentioned studies, health literacy was measured using a specific test<sup>1</sup> based on the ability of the person to read and understand written medical instructions, a section of a Medical Aid form and a surgery consent form. This measure is built on the presumption that literacy is vital to understanding health and illness and does not consider other approaches such as visual and oral education. In contrast to the health literacy study built on reading comprehension (Kalichman & Rompa, 2000), this paper assesses a participatory workshop that focused on verbal and visual ways of learning and problem solving.

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<sup>1</sup> The Test of Functional Health Literacy in Adults (TOFHLA)

Regardless of how health literacy is measured the results from the previously mentioned studies remain important because they highlight that without knowledge about health and HIV/AIDS, patients are unable to take care of themselves and have difficulty in accessing and adhering to HAART. Biomedical knowledge about the body also means people are more likely to understand that HIV is a virus and that HAART can work to slow down viral production. Without basic biological understanding of the human body people need more time to prepare for HAART in order to ensure adherence and monitor and control possible side-effects.

The link between knowledge and personal health care is also important if one considers a separate study that investigated the health-related quality of life of people receiving HAART (Jelsma *et al*, 2005). Jelsma and colleagues (2005) concluded that even in a resource-poor setting, health-related quality of life is greatly improved with the uptake of HAART and that possible side-effects do not seem to have a large impact on people's perceived quality of life. Furthermore, the survival rate after two years of HAART was 86.4%, despite more than half the patients having a CD4 count<sup>2</sup> of less than 50 at the time of starting treatment. This suggests that even with seriously ill individuals, HAART does not only save lives, but also improves quality of life on a long-term basis allowing people to return to living an active and productive life. In order for these results to be achieved, an understanding of HIV and health has to be developed as a foundation before being able to explain how HAART works and ensuring adherence.

The attendance of a support group provides participants with psycho-social support, while also increasing their knowledge of HIV and AIDS and various treatment options. Furthermore, a treatment assistant ensures that the participant is able to disclose their HIV-positive status to someone. Many clinics providing HAART encourage patients to have a 'treatment buddy' who can assist them with taking their medication. It is also argued that if a patient has not disclosed to anyone in their home, it is more likely that they will default because of not being able to openly take their medication. Private disclosure can have both positive and negative outcomes, but it is generally agreed that disclosure of HIV-positive status to a carefully chosen family member or friend results in accessing valuable emotional and material support (Almeleh, 2004).

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<sup>2</sup> A CD4 count measures the number of T-helper or CD4 cells in 100 cubic millimeters of blood. The count is used as measure of how healthy a person's immune system is. A healthy HIV-negative person has a CD4 count of over 1000, whereas an HIV-positive person experiencing serious opportunistic infections has a CD4 count of below 300.

Booyesen and colleagues (2006) 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 the people living with HIV (Booyesen *et al*, 2006). 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. The study 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. The longer term benefits of being on treatment for more than three months were also noted as important indicators of a patient's physical and mental health. This study suggests that the resulting benefits of HAART extend beyond the physical aspects of healing and incorporate much wider issues pertaining to mental and emotional health, as well as social and political issues that impact on their lives. In this way access to HAART is an empowering experience that starts with learning about HIV/AIDS and treatment and results in greater satisfaction with life and increased agency in their personal and social lives.

## **Participatory Approaches to Adult Education**

Transformative and popular education is often associated with ideas of 'consciousness raising' and the creation of knowledge to enable people to challenge the dominant structures and create alternative ways of solving social problems (Endresen & Von Kotze, 2005; Ashford & Nattrass, 2005). The workshop loosely draws on Freire's idea of 'critical consciousness' and Mezirow's 'transformational learning' as a starting point for developing an interactive approach to HIV literacy. The reason for using Freire and Mezirow as a way of approaching adult education is the importance they place on participatory approaches to learning. Mezirow proposes 'critical conversation' as a way of engaging with issues and the use of debate and 'brain storming' sessions as a means of initiating social and personal transformation. Freire's techniques include presenting themes in the form of visuals in order to stimulate dialogue and problem solving. Since Freire was involved in class empowerment 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. This paper discusses a workshop based on the

creation of life-sized body map drawings together with group discussion, problem solving and role-play.

The participatory nature of the workshop provides a framework for engaging with a biomedical approach to understandings the human body, but also encourages discussion of alternative approaches to health and illness. In these ways possible problems arising from drawing on diverse healing strategies can be uncovered and potentially solved in the course of the workshop. These include the need for HIV-positive people to communicate their status and current medication to both traditional and allopathic practitioners to avoid negative interaction between the different treatment, or nullifying the efficacy of the one. For example, the use of purgatives would inhibit the absorption of antiretroviral treatment and the consumption of African potato has been shown to interfere with the metabolising of medication (Hooper-Box, 2005). The workshop creates a space where community health workers can discuss these potential problems and share their knowledge of traditional and home remedies to treat minor opportunistic infections in order to develop a greater understanding of alternative approaches to health that their patients often use. It also allows people to debate possible limitations found in the allopathic tradition, such as the need for dealing with the psychological aspects of illness.

When referring to education theories developed outside of South Africa, it is important to contextualise these approaches within the specific challenges and conditions relevant to the situation here. The limitations of Mezirow's 'transformational learning' include the over-emphasis of rationality, the failure to acknowledge societal inequalities and the lack of consideration for the interpersonal aspect of learning (Plumb & Berringer, 2003; Baumgartner, 2000). With regard to Freire's theory of the importance of developing 'critical consciousness' it has been argued that enabling a person to think more freely and creatively in terms of solving social problems affecting their lives is not always sufficient. Freire does not seem to adequately address the extent to which socio-economic and cultural conditions continue to inhibit individuals even once they have developed their 'critical consciousness' (Campbell, 2003).

## **Visual Learning Tools and Techniques**

Apart from the participatory nature of the workshop, another key element is the emphasis on visual learning. The use of the Visual Body Map as an educational tool and body map drawings as an educational technique demands some investigation into the benefits and limitations of visual tools and methods. Guillemin (2004) uses examples from two studies to illustrate how producing

drawings enables people to explore how they understand illness conditions. She argues that ‘the act of drawing necessitates knowledge production, with a visual product as an outcome.’ (2004:272).

Harrison (2002) suggests 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 the creation of body map drawings where workshop participants are given the opportunity to ask and answer questions visually with regards to human anatomy and how HIV/AIDS affects the human body. By drawing their bodies participants engage with the learning process in an immediate form and develop a personal understanding of how the body works, as opposed to studying a generic human body that often seems removed from the individual’s health-related decisions and lived experience. Collaborative and participatory approaches found in visual methods can also call into question traditional models of power and knowledge production (Harrison, 2004). This is an important component of HIV literacy in the Southern African context where there is a need to encourage discussion of both biomedical and traditional understandings of health.

Brice Heath (2000) uses neurobiology and physics as a starting point for developing an appreciation of the educational potential of the visual. She argues that the way the brain works, both when looking at and creating visual images, ensures interplay between the visual and the expression of meaning. This process assists in learning since seeing and focusing on features in images (such as the Visual Body Map) recalls information stored in the brain through prior experience and enables us to verbalise it. Conversation about problem solving strategies and collaborative decision making is an essential part of the learning process. This is in keeping with both ‘transformational learning’ and the development of ‘critical consciousness’. It is also 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).

An additional aspect to visual literacy and education is the use of pictures and illustrations in HIV/AIDS education. 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). The overwhelmingly positive responses to the Mkhize picture story that appears as part of *Learn with Echo* adult literacy education weekly newspaper supplement is further evidence of the potential power of pictures to address educational topics (Arbuckle, 2004).

However, the same research shows that 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 found in cartoons. A lack of illustrated educational material in most developing countries has meant that people such as community health workers rarely have visual educational tools. This is in contrast with wealthier countries where constant exposure to pictures results in students and adult learners developing complex visual literacy skills (Arbuckle, 2004). This has direct relevance to interventions that have used cartoons or illustrations to disseminate knowledge about HIV/AIDS.

Carstens and colleagues directly assessed the efficacy of various visuals used in HIV/AIDS related education in South Africa and compared low-literate and literate adults' ability to comprehend these materials (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.

Cornwall (1992) revealed that visuals can be misunderstood directly due to different cultural backgrounds. This suggests that the success of visual learning depends not only on the particular tool or technique used, but also the specific context in which it is being used and that assumptions cannot be made about transferring material. However, in her later work with women in Zimbabwe on developing understanding about reproductive health, Cornwall found that body mapping/drawing techniques similar to the one used in the workshop, were effective ways of gathering popular and indigenous knowledge (Cornwall, 2002). This is explained in the comment that '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, 2000: 221).

This review of the relevant literature looking at the successes and failures of participatory and visual learning approaches to HIV literacy reveals that these approaches to HIV can be very effective. It shows that it does make sense to use visual tools and techniques such as the Visual Body Map and body map drawings, but the needs of each group of learners has to be taken into account. Assumptions cannot be made with regards to transferring tools and techniques to different cultures and groups of people.

## Culturally Specific Interventions

The failure of Western models of HIV prevention and education calls for a reappraisal of these approaches (Chilisa, 2005; Preece & Ntseane, 2004). There is a need to go beyond merely acknowledging that culture and ethnic identity affect the way HIV knowledge is understood and acted on. It has been suggested that local understandings of illness and health based on specific indigenous world views should be used as the starting point for any HIV intervention 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 are the same and highlights the need to acknowledge the cultural diversity even within country borders where different groups of people practice specific customs and have different understandings of health and illness and HIV/AIDS (Chilisa, 2005). By demanding more culturally and community specific HIV interventions, this approach critiques the power dynamics inherent in using Western or First World approaches to the African experience of the AIDS epidemic. But it moves beyond an intellectual Africanist debate by grappling directly with the reasons why these interventions fail to effectively diminish the spread of HIV in Southern Africa and works towards finding new solutions.

The debate of whose knowledge and expertise is most effective in reaching African communities and bringing about real change in people's approaches to prevention and care automatically draws attention to allopathic approaches to HIV/AIDS. In the South African context the debate over the nature, causes, prevention and treatment of HIV and AIDS has been particularly heated. The valid call for 'African solutions to African problems' resulted in a destructive era of AIDS denialism. Apart from disputing the link between the HI virus and the AIDS defining illnesses, government authorities flirted with various anti-biomedical cures and treatments such as beetroot, garlic and lemons, as well as entrepreneurs such as Matthias Rath who promoted vitamins in place of HAART. Recent political changes and the formation of new HIV and AIDS and STI National Strategic Plan for 2007-2011 based on a partnership between government and civil society signals a new era of collaboration and action, as well as an endorsement of biomedical approaches to treatment, alongside prevention strategies (Tabane, 2007, Department of Health, 2007).

This paper suggests that rather than seeing biomedical and traditional approaches to HIV/AIDS as polarised it is more useful to engage with both. Research has shown that many South Africans consult both traditional practitioners and medical doctors (Wreford, 2005; Mills, 2005). Building on this

knowledge recent HIV interventions, such as the HOPE Sangoma Pilot Project, have sought to encourage collaboration between traditional practitioners and medical doctors ([www.h-o-p-e.net/06English/program\\_sangoma.html](http://www.h-o-p-e.net/06English/program_sangoma.html)). 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).

It is important to research culturally and community specific values and understandings of health and illness in order to address prevention, care, treatment and education. Apart from the socio-economic factors affecting people’s ability to protect themselves from HIV infection through unprotected sex, cultural understandings of health also underpin the choices that people make in terms of who they seek advice, protection and care from. This is particularly apparent in the case of HIV and AIDS where people often seek multiple approaches to address the physical, psychological, spiritual and social aspects of ill health. This is an area where traditional practitioners have been seen as playing a vital role since they have the confidence of their clients invested in them and can provide psychological support and counselling. Furthermore the different understanding of the various causes of illness, which are not addressed in the allopathic tradition, can also be provided by traditional practitioners (Wreford, 2005).

In the course of this section, four key components of HIV literacy have been discussed. Firstly the relationship between the provision of HAART and an increase in knowledge of HIV and health more generally was discussed. This was followed by looking at approaches to adult education that included ideas of ‘critical consciousness’ and ‘transformational learning’. This is closely linked to participatory approaches to education that encourage debate, conversation and problem solving. Thirdly, the important role of visuals in health education with specific relation to HIV/AIDS was addressed. And lastly, the need for culturally specific interventions was discussed.

## **Research Methodology**

The workshop assessed in the course of this paper was developed by the author over a period of eight month and tested in the field with the community health workers and two other groups which are not included in this paper. The research methods included observation of the workshop participants, administering questionnaires and conducting voluntary semi-structured group interviews on completion of the workshop. Participation in the workshop was not dependent

on taking part in either the questionnaire or the interviews. A predominantly qualitative approach was adopted, with the exception of some quantitative data collected in the questionnaire.

The author researched, developed, facilitated and evaluated the workshop. While some approaches to project evaluation recommend that an outside group or individual conduct the assessment (Rossi *et al*, 2004), in this case the evaluation process formed an integral part of the development of the workshop and led to changes in the workshop content. Workshop participants were encouraged to ask questions and also give feedback during the workshop. In this way the participants' experience as community health workers played an important role in evaluating and improving the workshop based on their real-life work experience. Participant observation enabled the facilitator to record responses to the workshop while it was in progress. The value of participant observation lay in the immediate and unmediated responses to the workshop content.

All seventeen workshop participants filled in the questionnaire. The questionnaire was designed to collect information about the workshop participants including their educational background, previous training and work experience and their current work environments and responsibilities. This data served to contextualise the participants as a group and as individuals so that their responses to the workshop could be more fully understood. This information was used to guide the content of the follow-up interviews. The questionnaire was written in English and translated into Xhosa to limit errors due to language-based misunderstandings and give participants a choice of language. However, only two people chose the Xhosa version and in retrospect an Afrikaans translation would have been more useful to the group. All the participants were proficient English communicators. The questionnaire consisted almost exclusively of tick items, where the participants could tick multiple choice options.

Following the questionnaire, thirteen participants agreed to voluntary group interviews. Small groups were chosen in place of individual interviews, in order to encourage informal discussion between participants and allow the interviewer to take on a listening role once each question was asked. Participants were interviewed on subsequent training days during informal 'house keeping' sessions before or after training talks. This avoided the problem of interview participants missing important activities. The participants were asked to come forward in groups of three or four. The interviews were recorded on a Dictaphone and transcribed verbatim afterwards. Only one participant said she would prefer to observe the process first, but then joined in the conversation less than five minutes into the interview. This indicates the informal nature of the

interviews and the way they were seen as conversations, rather than a test of knowledge or level of participation in the workshop. In the course of the workshop, the group camaraderie among the community health workers suggested that they would be confident to express their views. This was confirmed in the way they challenged and supported each other's comments during the interviews.

The interviews were semi-structured and each group answered the same questions, but not necessarily in the same order. The length and depth of the responses varied according to different participants and groups. In the course of the interviews the participants were asked to describe their past training and compare it with the workshop. In this way their attitudes towards visual and participatory approaches could be assessed, as well as broadening the discussion to include what they believed to be the most important things HIV education should address. Given the strong focus on human biology in the workshop and how the workings of the human body were linked to HIV/AIDS and HAART, the interviews aimed to assess the level of importance the participants attached to understanding human biology as part of successful HIV/AIDS education. The participants' opinions on the role of HIV education was based on both their needs and work experience and the challenges they face in communicating with their clients and developing greater understanding around HIV/AIDS. The participants were asked to draw on their experiences as community health workers and suggest changes to the workshop in its current form, as well as the addition of other information they thought should be added. This was a vital part of the development of the workshop.

The interviews were conducted in English and respondents replied in English and sometimes Afrikaans. The decision to conduct the interviews in English was based on information provided by the questionnaires and observation during the workshop where participants spoke English freely and confidently. The following section describes the workshop participants in greater detail and provides information about their educational background, previous training and past and present work experience.

## **Description of Workshop Participants**

All the workshop participants are employed full time by the non governmental organization HOPE to work in their communities. HOPE's policy is to employ people from target communities and to give them the necessary training to become the HIV/AIDS 'expert' in the community clinic. All HOPE community health workers complete the University of South Africa (UNISA) Diploma in

HIV Care and Counseling. The four month UNISA course includes the medical aspects of the virus, HIV/AIDS education, life skills training, traditional African world view in relation to AIDS and spiritual and emotional assistance for people living with HIV and those supporting them.

In addition to theoretical training, the community health workers also take part in practical training in the hospital working with the resident doctor and assisting with consultations, counting medication and calculating compliance. Since adherence to HAART is such an important part of ensuring health for people living with HIV, this practical training is important for when the community health workers go out into the field on their own. In-house training takes place every second week and provides the opportunity for debriefing and more in-depth coverage of specific challenges. This all goes towards the career development of the community health workers since HOPE has entered into a partnership with the University of Stellenbosch to get the training program accredited and to a level where it can be used to enter a nursing career ([www.h-o-p-e.net](http://www.h-o-p-e.net)).

The community health workers' training and experience clearly sets them apart from the people in their community in terms of their knowledge about HIV and AIDS, so their responses to the workshop should be understood from this perspective. The workshop was run for two days as part of ongoing bimonthly training and debriefing sessions at Tygerberg Hospital. The group consisted of twelve women and five men. The purpose of this section is to contextualise their responses as community health workers to both the workshop content and the visual and participatory approaches used to engage with the material. It is believed that the nature of their work will shape their opinions and expectations of what role HIV literacy needs to play within the broader context of health care provision in South Africa and more specifically in relation to the rollout of HAART.

As previously mentioned all the participants were proficient in the English language and could read and write English. Five participants claimed English as their first language, but concurrently included either or both Afrikaans and Xhosa. When asked to clarify their choice, the participants explained that they had grown up in households that used all languages and could not identify one single language as their first. Eight participants claimed to be Xhosa 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.

All participants had other forms of training, except for one who was still waiting to do the UNISA course on HIV Care. Aside from training on TB care, peer education, home-based care and other health care related courses, some participants had training in other areas such as computers, Call Centre work and clothing technology. Apart from the UNISA course most participants had attained additional training from AIDS Training, Information and Counselling Centre (ATICC), hands-on experience, being trained on the job and volunteering. Twelve of the entire group were familiar with participatory education techniques, as well as lectures, tests, long-distance learning and hands-on training. Except for two people, all the others in the group had worked as community health workers for more than one year, with nine having worked for longer than two years.

In terms of their current work experience, apart from serving as community health workers, the majority of participants also acknowledged fulfilling roles of 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 in their communities visiting homes and doing peer education. All participants claimed to use visual materials in their work, except for two. When asked if they were provided with visual educational material, all the participants, except one, said they would use it when talking to people about HIV/AIDS or when doing training.

The majority of participants indicated that they thought the Visual Body Map was 'very useful', with the remaining three finding it 'useful'. This is reinforced by the finding that nine in the group claimed they would use the Visual Body Map two to three times a week, four saying they would use it every day and three choosing once a week. There was unanimous agreement that based on their work and life experiences seeing pictures of the human body and learning human biology would help people better understand HIV/AIDS, encourage people to access treatment, decrease stigma and fear about HIV/AIDS and help people look after their health better.

In the final two sections of the questionnaire ten 'true or false' questions testing general knowledge about HIV/AIDS and ten questions on HAART were asked in order to assess the existing knowledge in the group. The questions asked were not related to the material covered in the workshop. The need to evaluate the level of knowledge in the group tested the assumption that as community health workers the participants would have a high level of knowledge in these two areas. This was affirmed with 86% of the participants providing correct answers in the section on knowledge about HIV and AIDS and 85% correct answers for

the section about HAART. This suggests that the training of lay people from communities can be very successful if a model similar to the one adopted by HOPE is used.

## Discussion

This section is based on the interviews conducted with the HOPE community health workers after completing the workshop. The interviews were semi-structured with between three to five individuals in each group. The intention of the interviews was to assess both the content and the visual and participatory education techniques used in the workshop from the perspective of the community health workers. The main focus areas included the most important facts to know about HIV/AIDS, approaches to HIV literacy, knowledge of human biology and HAART and their experience of the roll-out of antiretrovirals in the public health care sector. The interviews also encouraged criticism and feedback from the workshop participants in relation to any topics they felt the workshop did not adequately address, things they thought should be eliminated from the workshop and other recommendations.

## Essential HIV/AIDS Understanding

One of the key questions in the interviews encouraged the workshop participants to discuss what they believed to be the most important facts a person should know about HIV/AIDS. The participants were asked to think about situations in their work when this information would be useful, such as when they give educational talks to youth groups or VCT counselling. Based on their experience as community health workers the interview groups were encouraged to share ideas and suggest key pieces of information they believed to be important when educating people with limited understanding of HIV and AIDS. One recurring issue was the need to clarify the difference between the HI virus and AIDS as a syndrome with symptomatic illnesses. The transmission of HIV and the symptoms of opportunistic infections were also highlighted as important aspects of understanding the development of HIV into AIDS. This is clearly explained by Xolani<sup>3</sup> in the following statement.

‘I think that she or he must know what is HIV and AIDS. That’s the first step. That’s the most important thing ...that and the

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<sup>3</sup> All names used in this paper are pseudonyms, but refer directly to specific community health workers.

symptoms and the transmission and the progress of HIV to become AIDS.’ (Interview with Xolani, January 2007).

Another important role of HIV literacy highlighted by Grace was the need to explain that anyone can be at risk of HIV infection. Her concern addressed the incorrect perception that some groups or individuals are more likely to contract HIV than others. The need to separate society into groups who are different from you and who you perceive to be more at risk of HIV infection is a common response to the AIDS pandemic and is found throughout the world (Ranger & Slack, 2001). In some cases people might isolate certain sexualities, such as being gay, lesbian or bisexual, as the type of person who gets infected with HIV. This was perpetuated in the United States of America and other countries of the North by the initial identification of AIDS as a homosexual disease. In countries of the South, the grouping of prostitutes, sexually promiscuous people and women as carriers of the disease is extremely problematic and harmful. Apart from the inaccuracy of these ideas, the resulting stigma has damaged the lives of individuals and communities and hampers efforts to curb infection rates. In order to highlight the vulnerability of all people to HIV infection, Grace suggested:

‘You must reassure them that you get HIV, anyone, so take posters to show them how it [AIDS related illnesses] will look like because otherwise maybe they think HIV is something that won’t happen to them.’ (Interview with Grace, January 2007).

The ‘window period’ after HIV infection and before HIV antibodies can be detected in the blood stream was identified as another important piece of information for people to know. Most HIV tests used in public health care facilities look for HIV antibodies in the blood stream. The human body usually takes between three to six weeks to produce sufficient antibodies so it is advised to return three months later for a second HIV test. The period between HIV infection and HIV antibody detection in the blood is referred to as a ‘window period’. Pumla highlights the danger of patients not understanding the ‘window period’ and so distrusting biomedical equipment or techniques when she says:

‘And also to tell them 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 have tested positive...maybe you didn’t use the same equipment.’ (Interview with Pumla, January 2007).

Apart from understanding how HIV is transmitted, the group also discussed aspects of living with HIV and the importance of people being equipped with the relevant knowledge in order to ensure productive lives despite being HIV-positive. This is summed up by Cordelia when she says ‘They must understand that HIV in [their] body is not the end of [their] life. [They must understand] what precautions [they] must take now that HIV is in [their] body.’ (Interview with Cordelia, January 2007). Siphso elaborates on one aspect of living with HIV when he talks about the need to practice safer sex as an HIV-positive person in order to prevent being re-infected with other strains of HIV.

‘They [can] enjoy everything in life, especially sex because when they find out...if...it’s a female...she feels that it’s a man who infected her and vice versa. And you can still enjoy sex, but as long as you protect yourself.’ (Interview with Siphso, January 2007).

In this statement Siphso also hints at possible blame between men and women for HIV infection. The gender issues bound up with HIV/AIDS are complex and diverse. Some of them have been discussed in this paper with regards to the limitations of individualistic-based education programs that ignore powerful cultural and societal norms and expectations that prevent individuals from protecting themselves from HIV infection (Campbell, 2003; Chilisa, 2005; Ntseane & Preece, 2004).

Siphso goes on to talk further of other ways of taking care of your health as an HIV-positive person. He also insisted on the importance of focusing on developing understanding of how HIV infection can be prevented. He acknowledges the need for people living with HIV to live productive and healthy lives, but argues that as community health workers they do not spend enough time on discussing prevention. The link between the availability of antiretroviral treatment, VCT and prevention messages was discussed earlier in this paper.

I also emphasise nutrition and exercise, eat well and that kind of stuff. But more importantly how we can not get it [HIV/AIDS]...I think that’s very important because...we don’t spend enough time on that, on how you cannot get it [HIV/AIDS] and because...sex is the common way that ...HIV is transmitted. (Interview with Siphso, January 2007).

In one of the interview groups, the need for developing an understanding of the biology of human body was emphasised as a prerequisite for any behaviour change or better sexual decision making. In response to his interview group

listing safer sex, condoms and keeping to one partner as central to HIV prevention, Darren replied in the following way:

‘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 [harmful] things...So, if you know a lot about yourself and 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 Darren, January 2007).

This response is important because it suggests that the message found in ‘ABC’ campaigns cannot be effective without being coupled with knowledge about human biology. It also reaffirms the central belief underlying the workshop’s biomedical content and the argument that knowledge of the human body is a foundation for building understanding of HIV/AIDS. This suggests that from a community health worker’s perspective, knowledge of human biology is valued and considered an important part of HIV literacy. This is further discussed in relation to antiretroviral treatment in the following section.

## **Knowledge of and Attitudes towards HAART**

Many of the community health workers highlighted the importance of people having knowledge of HIV and HAART before their health deteriorates and they require antiretroviral treatment. They emphasised the link between an accurate understanding of how HIV affects the immune system and ensuring adherence to HAART. Pumla summarised this in the following statement:

‘I think first is to educate the people, so that they can understand before they go for the ARVs. They must know what is important [like] taking the medication [at] the right time in the right way and all that stuff. So I think the best way is educate so that they can get their knowledge before they start to have the treatment.’ (Interview with Pumla, January 2007).

Mary reaffirmed the need for understanding the human body and in particular the immune system and how it is weakened by the HI virus. Based on her experience as a community health worker she suggested that because most people do not know how their body works they do not understand health and illness in a biological way. She argued that without knowledge about how their bodies work, patients shift responsibility for their health onto the doctor. Patients expect the doctor to tell them what is wrong and to cure them. The

success of a patient-centred approach to treatment is built on the understanding that knowledge of their condition enables patients to adhere to HAART and ensures that they are empowered in the process. This is contrasted with the failures of the Directly Observed Treatment (DOT) approach used for TB where patients are reliant on clinic staff to take their treatment. Mary's experience is highlighted below:

‘...I found out in the counselling a lot of people don't know that their white blood cells are...fighting for them. So when you are telling them these things they are shocked because they never knew...and now they're feeling sick and now they need to come to the doctor 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 Mary, January 2007).

A potential danger with patients not understanding how HAART works, but knowing that it is the treatment they need, is the risk of non-adherence and possible resistance. With limited understanding of HIV and antiretroviral treatment patients can think that HAART is a miracle cure. Some of the community health workers suggested that in the rush to get antiretroviral therapy, many patients do not confront the realities of living with HIV and do not adequately prepare themselves for challenges such as disclosure of HIV-positive status and potential side-effects of antiretroviral therapy.

Renate's experience highlights some of these issues when she describes the reluctance to get tested for HIV and how people will wait until they are very seriously ill before coming to the clinic. This results in people needing to go onto HAART immediately because their CD4 count is already well below 200 by the time they are diagnosed<sup>4</sup>. The danger of the patient being this ill is that there is limited time to accept HIV status and receive proper education about the disease and antiretroviral treatment. Both these factors work against ensuring adherence to HAART. A further danger is that if a person's CD4 count is very low their health often deteriorates initially when they start HAART because their bodies are already so weak (Morah, 2007). Survival is substantially higher in patients who receive HAART before their CD4 counts drop too low (Coetzee *et al*, 2004).

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<sup>4</sup> WHO recommendations state that HAART should be administered to patients who have a CD4 count of less than 200 or who exhibit signs of Stage 4 illnesses.

‘In their hearts the people...don’t [want to] come for testing...like last week we had one...guy [who] was positive...we had to phone the mother to come to the clinic to explain to her because he said to us he can’t disclose to his mother and he wants one of us to and he just wanted to know about ARVs. When can he have it? Can he have it now? Because he just wants to get better...to him, ARVs will cure him now. If they in that state they are so sick they can’t do anything for themselves then they just will take the ARVs. And as soon they come to feel better they leave ARVs, they don’t want to take it anymore, because “Why must I take the tablets when there’s nothing wrong with me?”’ (Interview with Renate, January 2007).

Renate’s final statement points to another danger of people not adequately understanding HIV and antiretroviral therapy and stopping treatment once their health improves. Another reason for patients stopping antiretroviral treatment is side effects. Many of the community health workers listed side-effects as one of the most important things a person should know about HAART. This is explained by Bulelwa in the following story.

‘I think we must stress and educate our clients about the side effects. Because...one of my clients wanted the ARVs badly and her CD4 count was 12...And really the people think the ARVs will cure...Nearly a month later...[she] doesn’t want to take any of the pills because [of side effects]...And I said...“Did the counsellor tell you about the side effects?” [And she replied]...“I won’t lie. I wasn’t listening to anything because I was so excited because...the doctor said to me that I am going to get the ARVs...”’. (Interview with Bulelwa, January 2007).

Another difficulty encountered by the community health workers is the continuing misunderstanding of antiretroviral therapy as a cure as opposed to ongoing treatment that has to be taken for the rest of your life. Many of the community health workers said that often their clients wanted to go onto HAART as soon as they discovered that they were HIV-positive. Patients are unaware of the fact that HAART is only recommended when the CD4 count drops below 200 or the patient has Stage 4 defining illnesses (WHO, 2003). Other studies have even suggested that it can be disadvantageous to a patient’s health if HAART is given when the CD4 count is 350 or greater (Sterling, 2003). Many people believed that they were being unfairly denied treatment and saw no point in waiting for their health to deteriorate to the point when they were seriously ill.

The difficulties of adhering to medication that needs to be taken at the same time everyday for the rest of your life, as well as the social challenges of disclosure of HIV-positive status, were often not considered by clients. Like many of his colleagues Siphon highlighted these points.

‘I don’t actually encourage...clients to go on ARVs...because they’re expensive and [a] huge responsibility and the fact that 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...[If] you are staying here with your parents...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).

Amanda considers another aspect of disclosure of HIV-positive status with her discussion of the risks involved when starting a new relationship. The implications of not disclosing your HIV-positive status to a new sexual partner are both obvious and serious. You could infect your partner with HIV by not practising safer sex. Studies have found that condom usage is usually interpreted as a confession or implied accusation of infidelity (Kaler, 2004). The desire for trust in an intimate relationship often results in people not wanting to discuss condom usage in ‘love relationships’ in an attempt to distinguish them from casual sexual partners or transactional sex (Campbell, 2003). This obviously makes both partners vulnerable to HIV infection because it does not take into account their sexual histories. Amanda’s following statement looks at the challenges of disclosure within a new sexual relationship. By saying ‘people don’t want to sacrifice safer sex’ she implies that people do not want to use condoms because of the perceived denial of physical pleasure associated with condom usage. She then moves on to talk about a resistance to disclosing HIV-positive status in a new relationship because of the risks of rejection.

‘The main thing that people don’t want to sacrifice is safer sex...and the other thing is 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 implications of this statement are risk of transmission of HIV to a new sexual partner and possibly defaulting of antiretroviral treatment in order to keep it secret from them. The underlying reason for avoiding disclosure of HIV-positive status is stigma around HIV/AIDS. This will be discussed with reference to knowledge of the human body and HIV literacy in the next section.

## Knowledge of Human Biology and HIV/AIDS Stigma

Earlier in this paper the relationship between HIV literacy and stigma were discussed in relation to how an increase in knowledge about HIV is believed to reduce stigma around the disease, especially if this is coupled with the provision of antiretroviral treatment. In the course of the interviews the community health workers were encouraged to discuss if they had witnessed any changes in perceptions and/or fears surrounding HIV/AIDS. It is interesting to note the observations and at times contradictions apparent in some of the comments made. The contradictions indicate that the issue of stigma and its relationship with increased knowledge about HIV/AIDS are both complex and difficult to solve. While a person may intellectually understand HIV/AIDS as a disease there are many other more emotive responses that are derived from social and cultural understandings of health, illness, sexuality and death that drive people's decisions around disclosure. The following two comments made by Darren at different points in the same interview hint at the challenges of reducing stigma with increased HIV literacy.

'...a lot of people they are scared to come just for...an HIV test. Now...it's a fact ...that if they know more about it [HIV/AIDS], I assure you more people will come.'

'If a person is HIV-positive he won't speak. He won't talk about it. He will keep it all to himself, you see. That's mostly the cases when a person has TB.' (Interview with Darren, January 2007).

A more positive outlook on the relationship between increased knowledge about HIV/AIDS and a decrease in fear and stigma is expressed by Bulelwa. She highlights knowledge of the difference between HIV and AIDS as an important step in the process of understanding the nature of the disease and thus living positively with HIV.

'I have noticed that if you are infected [with HIV] 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, January 2007).

However, like Darren, Bulelwa also contradicts this by suggesting that despite the increase of knowledge of HIV/AIDS and the way this has made living with

HIV easier in some cases, personal disclosure of HIV-positive status within families and intimate relationships still remains difficult. This could mean that while on a larger social level HIV has become less stigmatised with an increase in knowledge about the disease, within the family it remains a complex personal issue. Many clinics recommend that a person who wants to go onto HAART should disclose their HIV-positive status to one member of their household so that this person can help them adhere to their treatment by supporting them and reminding them to take their treatment. The fear and extreme reluctance of disclosing HIV-positive status found in the following statement suggests that despite knowledge about HIV, people still face possible stigma in the home environment.

‘My biggest problem is this thing of the ‘treatment buddy’, because of the disclosure. Now when I am telling them that [they] need a ‘treatment buddy’ they say “Oh, now you want me to tell someone else...I don’t want [to], I am not ready to disclose.” (Interview with Bulelwa, January 2007).

The experience of HIV disclosure within the household and the difficulty that this poses is related to people’s understanding of what causes HIV infection and who is at risk of HIV infection. Amanda talks about the misperception that HIV does not affect married couples.

‘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” [reckless and promiscuous]. 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 who he doesn’t even know and maybe that person doesn’t even know that she is HIV-positive 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. That is the most important.’ (Interview with Amanda, January 2007).

It is interesting to notice the gendered way in which Amanda talks about HIV infection within a marriage. The fact that in Southern Africa between 60-80% of women have been infected by their husbands - their only sexual partner - supports Amanda’s assumption that the male partner would most likely be responsible for bringing HIV infection into a relationship (UNFPA, 2005). However, a study in rural Kwazulu-Natal revealed that in nearly one-third of discordant couples the wife was the infected partner (Lurie *et al*, 2003). These

disparate findings reinforce the need to raise awareness of the risks of HIV transmission without apportioning blame on either women or men. Amanda's closing remark that children should be educated about HIV is important because many South African families do not think it culturally appropriate for a parent to discuss sex with their children (Eaton, Flisher & Aarø, 2003).

A further aspect of addressing stigma associated with HIV/AIDS is highlighted by Bulelwa when in the course of the interview she explained that with many of her clients she likens HAART to other chronic disease medication, such as diabetes and high blood pressure. She argues that 'It will be just like that for the rest of your life...because to me ARVs are just like any medication. Like diabetic, like high blood pressure medication...' (Interview with Bulelwa, January 2007). This emphasises the need to medicalize HIV/AIDS and understand it as a disease that can be treated, as opposed to something that is brought about by other causes such as witchcraft. Furthermore, it also calls for treating HIV within existing clinics, rather than setting up special HIV/AIDS clinics that only reinforce stigma by separating HIV/AIDS from other diseases and treating it as something different.

## **Prevention and Living Positively**

In the course of the interviews while discussing the importance of working to reduce stigma and increasing knowledge of how to live healthy and productive lives with HIV, the community health workers re-emphasised the need for prevention messages. In some instances the group felt the drive to make HIV less stigmatised by promoting public disclosure had an adverse effect on VCT and prevention messages. It was felt that the use of public disclosure of HIV-positive status at events like World AIDS Day, assisted in creating the perception that coming for an HIV test would immediately result in discovering a positive HIV status. It was suggested that the importance of people coming forward for VCT and learning their status was a vital part of preventing further spread of the virus. This is clarified by Bulelwa below.

'I would like us as the counsellors when we are making...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 use of public disclosure was further debated by arguing that while personal testimonies of ‘positive living’ were a good way of increasing awareness of the vulnerability of HIV infection and working to reduce stigma, they should be coupled with strong prevention messages to combat the argument that if you can live so well with HIV there is no real need to prevent infection in the first place. This is further explained by the following statement made by Renate where she argues that public disclosure can undermine prevention campaigns by being seen as an advert for living with HIV and not adequately revealing the struggles that many HIV-positive people on treatment face such as side-effects and other adherence issues.

‘...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 Renate, January 2007).

Another important issue emphasised by the group was the need to start HIV literacy at a young age. While the debate has raged over what is appropriate for children to learn and at what age sex education and HIV can be discussed in school, the community health workers strongly felt that we need to stop shying away from adolescent sexuality and accept the reality that children in certain communities are sexually active from as early as primary school. Renate delivered an impassioned argument in the interview when she said ‘...if you get your women com[ing] with TOPs [Termination of Pregnancies] at the age of 12, then you need to start [education] at 10 years old...When they come for a TOP, it’s actually too late.’ (Interview with Renate, January 2007). This is reaffirmed by Charmaine in the following statement.

‘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 better decisions or 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 twelve, thirteen, fourteen coming pregnant [and] fifteen, sixteen 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 Charmaine, January 2007).

It is important that Charmaine underlines the need to avoid blame when approaching HIV literacy with children and adolescents and that the emphasis should be on making more informed decisions in place of punishment. While the

need to get young people to understand the consequences of their sexual decision making is indeed very important, the nature of the community that the children live in also needs to be considered. Studies in Southern Africa have looked at the impact of the environment on decision making and suggest that well informed individuals are not always able to act on their knowledge and that interventions need to work towards creating 'health-enabling communities' if they intend to have an impact (Campbell, 2003; Nseane & Preece, 2004).

The discussion thus far has looked at the content of the workshop and assessed it from the perspective of the community health workers. It has addressed issues such as the essential facts needed for any HIV literacy program, the relationship between knowledge of human biology and HAART and stigma and prevention and 'living positively' with HIV. The next section will look at the challenges that community health workers face, together with the way visual and participatory techniques can effectively address some of these issues.

## **Participatory and Visual Approaches to HIV Literacy**

One of the limitations of HIV literacy in general is that it often relies on literacy in order to reach its audience, as in demonstrated with billboards, pamphlets and posters. The community health workers were quick to point out that based on their experience in public health care clinics and hospitals, patients needed alternative ways of learning about HIV/AIDS. This need was not only to combat illiteracy, but also a lack of knowledge about human biology. In the workshop the Visual Body Map and the creation of body map drawings were both ways of developing an understanding of HIV/AIDS using visual and participatory methods. With regards to the importance of using visuals to communicate knowledge about HIV Mary suggested that often even verbal explanation is not sufficient.

'...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 [are] just telling them this is HIV...when you finish talking you will realize that person actually knows nothing because now you are asking him a question but he can't answer you back.' (Interview with Mary, January 2007).

Amanda emphasises the importance of understanding the whole body as part of HIV literacy. Unlike Mary who reported using drawing before the workshop, Amanda said that it was the first time she had been exposed to using drawing as an education technique. Apart from the advantages of visually grasping concepts of how the different systems in the body work, she also emphasised the importance of participating in the learning experience. She argued that in traditional forms of education, people listen and expect to have knowledge given to them, but this does not enable the educator (or community health worker) to gauge how much they actually understand. Using participatory techniques like drawing body maps ensures that learners demonstrate their understanding during the learning process.

‘For me it was something new. And it was simple because not all of them are literate and the examples we use when we do the drawing, anyone can do that. It makes it simple for the person to understand...own bodies better, how the body functions...because most of the time, they are listening to you, they are expecting something from you, but you don’t know how much do they know...But if they are part and parcel of doing it themselves...when we do the drawing...people will understand...’.  
(Interview with Amanda, January 2007).

The educational importance of the participatory nature of the workshop is further discussed by Siphon when he talks about how each participant was able to contribute to the learning process and once the drawing was complete you could identify with the biology of the human body and relate it to your experience. The ability to relate the content of the workshop to lived experience is a vital part of developing real understanding of the human body that translates into personal knowledge about each individual’s body and health and illness.

‘...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 ourselves, as well as our anatomies and what is happening within our body systems...I find it very relevant...with what we are doing there at the clinics in the communities...’ (Interview with Siphon, January 2007).

Darren identified the lack of formal education in his community as a stumbling block for understanding HIV/AIDS and how it affects the human body. He spoke about the value of a chart such as the Visual Body Map in that you are able to simply point out parts of the body while explaining certain concepts.

‘If you look at the area where most of us come from...[our] parents...left school since they were Grade 4...They will tell us that and...that’s where the charts [come] 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. It’s like telling her ‘Check here, this is this and this is that.’ (Interview with Darren, January 2007).

In this way the community health workers identified some of the ways that visual and participatory approaches to HIV literacy can effectively overcome the barriers of illiteracy and lack of formal education. When asked where they would potentially use the workshop the following responses were found.

‘I will use it...in support groups and in the youth groups at the clinic and the youth groups at church...I can integrate it in the clinic as well and...with youth groups...it will be effective in a way that they will know and they will understand a lot more...So it was a thumbs up for me, because I learnt a lot and I can carry it on to the next person.’ (Interview with Darren, January 2007).

‘For me I think I can take the whole idea because the support group that we run...is very active and is mostly having the younger mothers so some of them will communicate easily.’ (Interview with Xolani, January 2007).

In this way visual and participatory approaches to HIV literacy present solutions to the challenges in communicating knowledge to communities with limited formal education. The way in which charts such as the Visual Body Map are able to present complex anatomical information in a simple and clear format that can easily be compared to the patient’s body is one of the advantages of visual learning. In the process of creating body map drawings participants are able to share and exchange knowledge, as well as demonstrate their understanding.

## **Limitations of HIV Literacy and Provision of HAART**

Having demonstrated ways in which workshop participants were exposed to participatory and visual approaches to HIV literacy and the advantages of these techniques, the following section looks at some of the limitations of HIV literacy itself. While this paper promotes the need for knowledge about the human body as a vital step in the process of understanding HIV, it also

acknowledges that knowledge alone is not sufficient in curbing new infections and encouraging HIV-positive people to live productive lives.

One of the issues debated in the course of the interviews was the socio-economic reality of poor South African communities. Earlier in this paper the restraints to health and sexual decision making posed by underdeveloped areas with high unemployment, gender based violence and poverty were discussed. In the following example, Grace speaks frankly about the role transactional sex plays in the spread of HIV. She describes how people in the developed world are simply not exposed to the stresses of poverty and therefore cannot understand why people in countries like South Africa are unable to protect themselves from infection. The fact that HIV is one of many problems that poor South Africans face everyday undermines individual efforts to practice safer sex. For many women the possibility of HIV infection and illness in a few years time is often outweighed by more urgent needs such as providing food and education fees for their children.

‘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...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, January 2007).

Moving away from the link between poverty and HIV, other community health workers spoke more specifically about their experiences of the HAART roll-out in South Africa. Once again lack of money and resources was identified as adversely affecting their peoples’ ability to access and adhere to antiretroviral therapy. Mary clearly describes the difficulties of attending the HAART clinic on a weekly basis, as well as the dire need for food so that people can take their treatment. The fact that some antiretroviral therapy regimens increase the appetite poses serious adherence problems for people living in homes where there is already a food shortage. Other regimens also require that medication be taken on a full stomach.

‘And you get the person who wants to take the ARVs but some of them they haven’t got money and...every Monday you have 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>5</sup> and they can't afford to come here so that is what the problem is. Now they miss their appointments and now the sisters here are phoning us to go and trace those people. 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 Mary, January 2007).

Mary was not alone in arguing that lack of food was one of serious problems facing people on HAART. She proposed that in order to ensure better adherence and health for HAART patients, clinics and hospitals should provide nutritional support. She argued that this should also be extended to TB patients because of adherence issues and also the fact that TB treatment is unpleasant to take especially on an empty stomach. She suggests the provision of milk and porridge for children should be extended to include adults and that a needs assessment be implemented.

'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]...That person has to come to the clinic every morning to take his tablets and if he comes there he didn't eat. But it's ok, you can take the TB tablets on an empty stomach, but...it's not nice because the tablets haven't got a nice taste...[or] smell...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 Mary, January 2007).

Apart from the serious restraints of patients not having enough food to eat, another problem identified by Bulelwa was the requirement that HAART is only given once a person's CD4 count drops below 200 or who exhibits Stage 4 symptoms. While this is in keeping with the WHO recommendations Bulelwa believed that this was already too late for most patients and that they should be provided with HAART sooner. This is supported by the fact that most deaths of people receiving HAART occur within those who have very low CD4 counts (Coetzee *et al*, 2004; WHO, 2003). This is one of the reasons why VCT is so important in that it enables early detection of HIV. In the South African context many people only come to the clinic when they are very seriously ill and their

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<sup>5</sup> Disability Grants are awarded to people who are unable to work due to a physical or mental disability. The grant is in the region of R800 per month. Prior to HAART provision in South Africa AIDS sick people were also awarded Disability Grants if they were too ill to work.

CD4 counts exceptionally low. Bulelwa argues that in her experience people are already too ill by the time their CD4 count reaches 200 or below.

‘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).

Sipho identified the shortage of treatment sites in rural areas and dedicated health professionals as another factor inhibiting universal provision of HAART in South Africa. The training of community health workers has been posed as one of the ways in increase the number of patients on treatment (Marchal *et al*, 2005)

‘...to make more treatment sites available for rural areas and maybe to employ more people to work on those treatment sites. Not only to employ them but to make sure that they have training...[J]udging by the number of people...enrolled ...in the township on ARVs I think the number is still very low in terms reaching the targets...I don’t think we are reaching the target... 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 Sipho, January 2007).

While the practical restraints posed by poverty and shortages of treatment sites and medical staff do hinder access and adherence to HAART, it is interesting to note that HIV literacy was still believed to fulfil a central role in creating healthier communities. This sentiment is summed up by Grace.

‘...here in townships in the Western Cape I think at least more education is happening here...Most of the time you can get ill in the rural areas. There is no education, no *Lovelife*<sup>6</sup>, it’s better for those who are here in the active areas, because...in rural areas...really there is nothing, not even...clinics.’ (Interview with Grace, January 2007).

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<sup>6</sup> Lovelife is a non governmental organization involved in promoting knowledge about HIV/AIDS, especially targeting youth.

## Conclusion

Visual and participatory approaches to HIV literacy received support from the community health workers because they were shown to meet the challenges of communicating knowledge about HIV/AIDS to communities with limited formal education. The community health workers also emphasised the value of understanding human biology as a basis for HIV literacy and supported the use of the Visual Body Map together with the creation of the body map drawings.

However, based on the observations made by the community health workers it appears that current efforts to ensure universal access to HAART need to be supported by social services that assist people with food and transport. Furthermore, the socio-economic conditions of many South Africans are inextricably linked to the high rate of HIV infection. Job creation and social reform are vital. The large scale and long term commitment to these causes are the only real solutions to controlling the epidemic. But HIV literacy does play an important role of creating a culture of openness about the virus. With increased knowledge about HIV and AIDS, it is proposed that voluntary counselling and testing will increase and stigma and fear about the disease will be reduced. Recent changes in approaches to addressing the epidemic with the development of the new National Strategic Plan promise that many of the current limitations and challenges surrounding the provision of good health care for people living with HIV and preventing new infections are being addressed.

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