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# People Living With, Not Dying From Disease: Patient Empowerment Through Anti-Retroviral Therapy and Possibilities for Social Change

Xin Wei Ngiam  
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**People Living With, Not Dying From Disease:**  
*Patient Empowerment through Anti-Retroviral Therapy and  
Possibilities for Social Change*

Xin Wei Ngiam  
SIT Cape Town, Fall 2005  
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## **Abstract**

In South Africa today, it is estimated that there are 6.5 million people living with HIV/AIDS, at least half a million of whom require urgent treatment. On the continent of Africa as a whole the numbers are even more startling. Unfortunately, although the South African government has now committed itself to rolling out anti-retroviral therapy through the public healthcare system, progress has been slower than expected. Yet in numerous sites around South Africa, rollout centres have been established successfully, even in the most rural parts of the country. These programmes rely on existing community initiatives, community health workers and volunteers, and positive people themselves to educate, counsel, and monitor ARV patients.

In this study I suggest that this model of care can be extremely empowering for the patient and reconceptualises healthcare as a path to social change. Drawing primarily from the examples of Madwaleni Hospital in the Eastern Cape, and the Edendale community in KwaZulu-Natal. I examine the dynamics of ARV programmes and the ways in which they create the "empowered patient"-- one who is knowledgeable, articulate, and motivated to effect change in his/her personal life and the social conditions under which he/she lives. Finally, I relate the idea of patient empowerment to a philosophy of primary healthcare and analyse the potential of primary healthcare to improve health in communities through permanent social transformation.

## **Methods**

I spent my ISP period in three different locations: Cape Town, the vicinity of Edendale Hospital in KwaZulu-Natal, and Madwaleni Hospital in the Eastern Cape. My work in Cape Town comprised mainly interviews and library research, while my work in KZN and the Eastern Cape involved observation, interviews, and everyday interactions.

### *Cape Town*

In Cape Town, I interviewed Gilles van Cutsem, a physician at the Khayelitsha Site C clinic. I interviewed Gilles to gain a sense of how the doctor's experience of HIV/AIDS care has changed pre and post-ARVs. I was also interested in how he saw the role of the medical doctor in the network of relationships that surround the sick in ARV treatment. I also interviewed Andrew Boule, a researcher at the UCT Medical School and a physician in Khayelitsha, around similar topics, focusing more on delivery systems.

### *Edendale, KZN*

In Edendale, I observed a three-day adherence training session run by a team from BroadReach Healthcare (BRHC). BRHC is a non-governmental organization that utilizes existing resources in communities in ARV rollout. They facilitate relationships between private doctors, support groups, treatment buddies, and patients to ensure that patients receive treatment, counseling, and psychological support. The three-day adherence training session targets new members of BRHC's ARV care programme. In those three days, patients and their "treatment buddies" are educated on the nature and transmission of HIV/AIDS, adherence to ARVs, possible side effects on ARVs, in preparation for the

commencement of treatment on the fourth day after the sessions.

I also held a short focus group session with three members of the BRHC team-- Bongani, Zendile, and Themba. All three of them work in different parts of the country, coordinating the rollout effort at different sites and facilitating the enrolment process as education sessions take place.

I lived in the home of Molly Kubheka, a support group leader. Thus I also gained a great deal of information through formal and informal conversations with her. I also spoke to a number of support group leaders, most significantly Nokuthula Biyela and Siphon Mncwabe, all of whom act as community facilitators to BRHC.

#### *Madwaleni Hospital, E.Cape*

In Madwaleni Hospital, I spent most of my time with the HIV/AIDS team. I observed a morning meeting with the HIV/AIDS team, comprising Dr Richard Cooke, ARV clinician; Lynne Wilkinson, site administrator; Christina Kopana and Busiswa Joya, peer educators; sisters at the hospital, and community health workers. I spent time shadowing one of the peer educators, Christina Kopana in a satellite clinic visit, an adherence counsellor, Anemari Buitendach during clinic day at Madwaleni, and also followed Christina on her ward rounds to hand out pamphlets and conduct impromptu education sessions in wards and waiting rooms. I also observed the proceedings of World Aids Day at Madwaleni Hospital.

Other than observing, I spoke informally to Christina and Busiswa on the topic of support groups and their role in treatment, stigma in communities, and adherence and education sessions about HIV/AIDS. I also spoke to Lynne during an information session about stigma in communities.

## Literature Review

In my discussion of the primary healthcare model and its applications to ARV care, I refer to the article, *Can health promotion and primary healthcare achieve Health for All without a return to their more radical agenda?*, by Frances Baum and David Sanders (1995). This article provides an in-depth discussion of strategies of “health promotion” and “behaviour change”—ostensibly part of a primary healthcare agenda—in fact fail to conceptualise healthcare in a way that allows it to address problems of poverty, deprivation, and disempowerment. *Primary healthcare in the era of HIV/AIDS: Some implications for health systems reform* by Petersen & Swartz provides a more theoretical framework to understand the subversion of “expert” power and patient empowerment in HIV/AIDS treatment.

There is a wealth of research on community-based healthcare and activism around HIV/AIDS in the developing world, including *From Directly Observed Therapy to Accompagnateurs: Enhancing AIDS treatment outcomes in Haiti and Boston* by H.L. Behforouz, P.E. Farmer, and J.S. Mukherjee (CID supplement 5, 2004:38); and *Community-based approaches to HIV treatment in resource-poor settings* by Farmer P, et al (Lancet 2001; 358: 404-9). Specific to South Africa, *Outcomes after two years of providing antiretroviral treatment in Khayelitsha* by Coetzee, D., et al provides an insight into the clinical aspects of the first ARV rollout site in South Africa; *The Impact of ARV Provision on HIV/AIDS Prevention* by Jo Stein (AIDS Bulletin, March 2005); *Building ‘AIDS-competent communities’* by Catherine Campbell, Yugi Nair, Sbongile Maimane and Zweni Sibiyi (AIDS Bulletin, September 2005). These articles examine the role of community support structures—including community health workers, support groups and



faith-based organizations—in ARV treatment. *The Impact of ARV Provision on HIV/AIDS Prevention* in particular focuses on the potential for the effects of treatment to spill over into prevention efforts, for example in lessening stigma around HIV/AIDS, encouraging testing, etc.

Two fascinating articles on the history of patient-led activism in South Africa can be found in the volume *Democratising Development: The Politics of Socio-Economic Rights in South Africa* (Jones P & Stokke K eds, 2005). The first, *Shaping, Making and Breaking the Law in the Campaign for a National HIV/AIDS Treatment Plan* by Mark Heywood (2005) tracks the strategies of the Treatment Action Campaign (TAC) to situate the language of HIV/AIDS struggle in human rights discourse. The second, *The TAC and the History of Rights-Based, Patient-Driven HIV/AIDS Activism in South Africa* by Mandisa Mbali (2005) describes the roots of “patient activism” and the effects of the TAC’s “campaign for openness” in the early 1990s.

Last but certainly not least, for critiques of market-driven healthcare and concepts of “sustainability” and “cost-effectiveness” as philosophically flawed arguments that prolong suffering in the developing world, refer to *Pathologies of Power: Health, Human Rights, and the New War on the Poor* by Paul Farmer (2005) as well as *Against Global Apartheid* by Patrick Bond (2001).

## **Limitations of Study**

This study was first of all limited by time. Spending 4-5 days in each site gave me time to speak to several people involved in HIV/AIDS care, but often did not give me the opportunity to observe their general routine and their work with others. A longer time in communities would also have given me the opportunity to gain a better sense of the communities in which I was researching.

In the study, most of the people I cite either work in the field of health, or are positive people who have been trained to play a support role in ARV treatment. I consider it a great honour to have met them and heard their insights. For a project that repeatedly emphasizes patient-centred healthcare, however, I did not manage access to patients who were not also in the position of activist, support group leader, counselor, peer educator... I was also constrained in this respect by the language barrier, since many patients did not speak English.

As a perhaps overly-optimistic study on the positive impact of ART, this report perhaps concentrates on better- developed ARV programmes that do not reflect the state of ART provision in South Africa. It could also consider in greater depth the modes of delivery and evaluate the impact of ART accordingly. In other words, the existence of education does not mean education is effective; and existence of counseling does not mean that patients are necessarily changing their behaviour.

Lastly, ARV treatment is relatively new to South Africa, and a study of its impact may be premature. More importantly, this study essentially examines the growth of personal agency through a model of healthcare provision. While this looks optimistic, the initial positive impact on small groups of people living with HIV/AIDS may be diffused as programmes are scaled up and become more impersonal.

## Introduction

Since the inception of the South African National AIDS Plan in 1994, it has been accepted, in theory at least, that HIV/ARV care should exist within a primary healthcare system. The National AIDS Plan prioritized not simply medical care, but also education, prevention, counselling, human rights, welfare and research. (Marais, 2000) Unfortunately, implementation of the National AIDS Plan failed to materialize, and AIDS care was further jeopardized in the late 1990s and early 2000s by suspicion of antiretroviral therapy (ART) and arguments that alleviating poverty should be prioritized over HIV/AIDS care (Mbeki, 2003). Others argued that one cannot expect poor, uneducated populations to stay on lifelong drug regimens requiring >95% adherence—certainly, the developed world has not done spectacularly on that count either.

More fatally, arguments against ARV treatment (including the prevention of mother-to-child transmission) subscribe to market-influenced conceptions of medical care, which employ cost-effectiveness and sustainability assessments in decision-making. Joia Mukherjee, a physician with Partners in Health, points out the contradictions of this framework, and its failure to serve those in resource-constrained settings:

“The first (argument)... is that ‘we have limited resources, can we figure out what gives us the biggest bang for the buck?’ That is the ‘small pie’ argument. The second big argument is ‘even if you had all the money in the world, the infrastructure is lacking so you cannot just throw money at a problem.’” (Interview in AIDS Bulletin, September 2005)

This represented a philosophical shift away from the primary healthcare model, in which, as Baum and Sanders put it, "considerations of equity, intersectorality and community involvement were dismissed in favour of technical feasibility and cost-effectiveness of programs." (1995)

It was further suggested that providing a complex drug adherence requiring strict adherence to poor and largely uneducated peri-urban and rural populations would be virtually impossible. (Interview with Hermann Reuter, AIDS Bulletin, March 2005) Thus, when Medecins Sans Frontiers (MSF) set up the first ARV clinic in South Africa in 1999, in the township of Khayelitsha just outside Cape Town, there was a great deal of skepticism as to its viability. Six years later, management of the Khayelitsha clinics has been largely transferred to the provincial government. A new MSF pilot project in Lusikisiki, in the rural Eastern Cape, recently enrolled its 1000<sup>th</sup> patient onto ART. Adherence rates in Khayelitsha stand at approximately 70%, far higher than rates in Europe and North America, which stand at approximately 40%.<sup>1</sup>

The notion that complex drug regimens can be understood and adhered to in areas like Khayelitsha and Lusikisiki has deeply jolted the assumption that the poor sick are unsuitable candidates for ART. More crucially, it has resurrected the focus on primary healthcare as a philosophy for HIV/ARV care by showing how healthcare *can* be delivered in a viable, “sustainable“ fashion in resource-poor communities.

In delivering HIV/ARV care in the peri-urban and rural communities of Khayelitsha and Lusikisiki, MSF marshalled forces within the community, involving counselling, support group participation, and community health workers in the treatment programmes. In particular, the Treatment Action Campaign (TAC) provided volunteers, treatment literacy educators and lay counselors in support of the MSF effort. The TAC also played an important role by encouraging disclosure and organizing patient-led campaigns and movements.

MSF’s success in forming partnerships within the community to deliver quality

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<sup>1</sup> Statistics provided by Gilles van Cutsem, MSF, Khayelitsha

ARV treatment demonstrates the notion that *how* treatment is delivered should receive equal attention as the fact that treatment is provided at all. This question becomes especially crucial in an epidemic so strongly associated with intimate questions of sex, shame, and death, as well as with social issues of ignorance, stigma, gender inequality, and poverty. By incorporating support groups, disclosure counselling, and education into ARV programmes, these programmes acknowledge the responsibility of public health towards both the sick and towards understanding the social context of sickness. Within this framework, treatment becomes an opportunity for personal empowerment and social transformation.

In this study I focus on the empowering nature of ARV care in resource-constrained settings, drawing from examples of treatment sites in Khayelitsha in the Western Cape, Madwaleni Hospital in the Eastern Cape, and in the Edendale community in KwaZulu-Natal. I examine how patient empowerment takes place through learner-oriented education, adherence and disclosure counselling, and through the privileging of the patient's subjective experiences of sickness in support group settings; and demonstrate the ways in which the primary healthcare approach of these ARV programmes has created the "empowered patient"—one who is knowledgeable, articulate, and motivated to effect change in his/her personal life and the social conditions under which he/she lives. Finally, I consider the ways in which the philosophical underpinnings of these HIV/ARV programmes creates opportunities for South Africa to reconceptualise primary healthcare to not only provide access to care for all, but also to act as a change agent within communities.

## **I. Patient-Centered Education : Treating the patient as a learner**

ARV treatment, as my host Molly Kubheka put it, turns AIDS from a “death sentence” into a “life sentence”. The rigidity and complexity of the drug regimen, combined with the need for high adherence rates (>95%) to prevent resistance, present a huge challenge to any patient—and not least, patients who struggle under conditions of poverty and deprivation. Because of this, the consensus on several fronts has been that adequate preparation is needed before a patient can go on ART. Patient education was taken extremely seriously in both the BroadReach site in Edendale, and at Madwaleni Hospital. In this section I describe my observations in adherence training and counseling sessions in both sites, and suggest that the reorientation of health education to engage and involve patients contributes greatly to the process of patient empowerment through treatment.

### ***Observations at BRHC adherence training***

The team from BRHC conducted an adherence training session that lasted three full days (8.30am-4pm) for the 50 new patients enrolled on the ARV program, and their treatment buddies. The sessions were conducted in isiZulu and translated for me in part by Nokothula Biyela, a Siyaphila support group leader. I was present for the first two days and half of the third day.

Despite the large audience, the training sessions were highly interactive. Zanele, BRHC’s Information, Education and Communications (IEC) coordinator, led the session. She opened the session by asking what expectations the patients and buddies had of BroadReach, of ART, and HIV. A wide range of statements and questions were supplied, including: What happens if you stop ARVs after 2 months and start again? What changes

will appear in my body after ARVs? How do I look after my nutrition and diet? How do I encourage my partner to go for a test? These questions were written down on large pieces of paper and put up on a wall inside the room. Zanele promised to address all questions in the next three days. She then gave a short introduction to BroadReach, framing the treatment program as a partnership in which BRHC, the support groups, and the patients had equal responsibility.

The first day of the training session focused on introducing patients to the program, and educating them on HIV/AIDS, how the virus works in the body, modes of transmission, and opportunistic infections. The group was shown a series of pictures and asked to form a story around them. In the first picture, a woman was shown walking alone down a road in a village. The group named the woman “Katiwe”. Some suggested that she was going to visit a friend, and others that she was beginning a journey. The next picture showed two women sitting outside a house, and the group suggested that Katiwe was disclosing her status to a friend. Zanele then asked the group: now that you have seen where and how Katiwe lives, how do you think she got the virus? There was a range of answers; some said that she had been caring for a sick HIV patient and was exposed to blood, while others said that her husband works in a mine in Johannesburg and infected her with the virus.

This became a discussion on how HIV is transmitted. Attendees were asked to suggest other ways in which you could get HIV, besides unprotected sex. (Ideas included sharing toothbrushes, being pricked by needles, blood on toilet seats, etc) Each idea was discussed by the group and finally rejected or accepted. The group went through a series of pictures in this fashion, and ended (for the day) with Katiwe in the doctor’s office.

For the second half of the day, the group was educated on how the HIV virus

works inside the body. The analogy of the CD4 “soldier” was used to explain what the CD4 count meant, and also the processes by which the virus multiplies inside the body.

The second day of training focused on adherence and ARVs. Zanele opened the session with a discussion of the English word “adhere” and “adherence”, asking the group about what they associated with the words. The idea of “*itape*” was mooted and discussed briefly, as well as the idea of “sticking to the rules”. Around the issue of adherence, Zanele facilitated discussions on disclosure and the importance of disclosure, support groups, and explained the need for “triple therapy”.

I attended the second half of the third day, after a focus group session with the BRHC team. The third day consisted of role-plays put up by the facilitators from the support groups, and large group discussions where the whole group sat in a large circle. Later the group broke into four smaller groups, where they reviewed the information they had received over the past two and a half days, and presented it to the group.

### ***Observations at Madwaleni Hospital adherence counselling***

In Madwaleni Hospital, I had the opportunity to sit with Anemari Buitendach and her assistant/ interpreter, Zameka Ntibane, for a day of adherence counseling and follow-ups. Anemari is a pharmacist by training and is in charge of issuing pills to both new and old patients every month.

Before each existing patient could get a new supply of ARVs, he/she had a 15-20 minute conversation with Anemari about his/her experience of the past few months. Besides asking about side effects, Anemari concentrated on two aspects regarding adherence. She typically asked every patient what he/she was doing to ensure adherence. Some patients said they set watch alarms, while others timed their medicines by events in



the day—one man said he would wake up, take his medicines, then let the cows out; and at the end of the day, herd the cows back in, and take his second dosage. Secondly, she was concerned about the hospital-provided “treatment diary” and the “treatment buddy”, and whether these were helping the patient. Almost all the treatment diaries I saw that day were neatly filled in, and patients acknowledged that these forms were useful. Most also agreed that the treatment buddy was helping, especially if the buddy was part of the family and lived in the same house.

The general sentiment in these sessions was that the ARVs were “very right *kakhulu*”. Patients enjoyed sharing their stories and reporting successes, such as weight gain or re-commencement of work. Patients also reported being constantly hungry.

I also observed an hour-long “training” session that patients have to attend, on a one-on-one basis with Anemari, before they are given their first month’s supply of ARVs. The patients—a married couple—seemed to already know a great deal about ARV care. They could report the names of their medicines (3TC, D4T, efavirenz for the husband, and nevirapine for the wife), and could demonstrate the order in which drugs should be taken (2 in the morning, and 3 in the evening. The wife also appeared to be familiar with the side effects of nevirapine on the liver. Anemari further explained the effects of ARVs on the virus, and the importance of adherence.

The second half of the session focused more on practical measures that would aid adherence. The couple was asked where they would put their ARVs and if they would be easily visible. They also were taught how to fill their own pillboxes, and how to use the pillboxes and the treatment diary. There was a small struggle with relating the English initials on the pillboxes to the days of the week in isiXhosa, and how the compartments of the pillboxes worked.

I spoke to Anemari later on the protocol the hospital uses for adherence training and her personal philosophy towards it. She emphasized the need to “not treat an adult like a child”, and to help patients become responsible for their own treatment. She also noted the importance of support groups as another source of information, where positive people on ARV treatment can talk about methods of adherence and act as a source of inspiration and encouragement for each other.

### ***Interactive education as a form of empowerment***

Adherence training is unique to the developing world, driven primarily by a need to prevent drug resistance in the two drug regimens supplied in South Africa. Marcus McGilvray, IEC coordinator of BRHC, pointed out that the very existence of “adherence training” is a new concept that is significant in itself. (21/11/05) The impetus for developing education programmes for patients came from the high dropout rates from TB treatment programmes, even where directly observed therapy was utilized. ARV care thus took lessons from the failure of TB care in designing a more patient-centred approach to treatment delivery.

Because there is no precedent to “adherence training” in the developed world, adherence training programmes in South Africa and the developing world were designed on an “ad-hoc” basis. BroadReach Healthcare’s training model draws upon “the culture of storytelling, which is typical to African culture.” (06/12/05) Thus several of the exercises, as described above, involve forming narratives around HIV/AIDS and drawing lessons from them—for example, the picture exercise, and the analogy of the CD4 cell as “soldier.” Marcus suggested that, although little research has been done on the topic, it seems the more patients understand about HIV, side effects, and resistance, the more

likely they are to adhere to drug regimens. “It’s essentially active learning,” he commented, noting that a great deal of research has been done on topics such as learner involvement in education. (06/12/05)

However, Marcus pointed out several areas of the BRHC model that need to be further developed. The lack of one-to-one counseling by qualified counselors, for example, makes it close to impossible to find out what stage an individual is at in terms of psychological well-being and behavioural change. The cycle of first accepting one’s status or condition and then changing one’s behaviour is necessarily disrupted or restarted by side effects of ARVs. Thus one-on-one consultations with trained counselors are an imperative in ensuring drug adherence. (06/12/05)

The need to involve patients in learning around their own condition and treatment has become essential in any model of ARV delivery. But implementation of educational development theories are often constrained by factors ranging from a lack of personnel to poor choice of venue. Fundamentally, the belief remains that patients must possess understanding ways that they previously did not, with TB-DOTS, for example. Yet, the effectiveness of education is intricately linked with a need to understand and monitor the psychological condition of the patient. In the following section, I discuss the role of counselling and support groups in treatment, and the process by which patients come to accept their condition and develop a sense of community around being HIV positive.

## **II. Linking the medical and the psychosocial: Promoting openness and dialogue about AIDS**

### *The condition of disclosure*

In both programs I visited, disclosure was a prerequisite to the commencement of ART. The patient is encouraged to first disclose his/her status to at least one more person, with the dual assumption that 1) this person can become a treatment “buddy” or at least provide frequent reminders to the patient and 2) that a patient who has not disclosed his/her status still struggles to accept his/her status, and therefore is not yet the best candidate for lifelong ART.

The link between disclosure and adherence places unprecedented import on the psychosocial experience of the patient in medical treatment. It recognizes a link between the psychological and the physical experience of illness—that stigma within the community can impact a patient’s ability to adhere to treatment. This cuts a contrast to conceptions of compliance that rely on physicians’ assessment of “social worthiness” (e.g. alcoholism, inclination to violence) or educational status. (Farmer, 2005; Stein, et al, 2005) Furthermore, the emphasis on disclosure as a precondition to treatment creates a necessary journey that patients must make—towards accepting their own condition and finding pride in their personal act of disclosure.

In Edendale, I asked several support group leaders about conditions promoting adherence. My question was met with virtually the same answer each time: that people default on ARV treatment because they had not come to terms with their positive status. Siphon Mncwabe, the chairperson of support group Sbhongukuphila in Edendale, said:

“Sometimes people hide their pills from their family, they don’t put it in

the kitchen so they forget to take it, or the family will ask, ‘why are you taking these pills?’ That’s why people must disclose... People are staying together in one house but no communication, because they are scared to address their status.” (24/11/05)

Molly Kubheka, founding member of Siyaphila, an umbrella support group for groups in the Pietermaritzburg area, noted that there is a small minority of people who are “just not committed”, but for the most part, people don’t adhere because

“they are still hiding their status, they don’t dare to take their pills in front of their family.” (24/11/05)

Similar sentiments were echoed at Madwaleni Hospital. During a morning meeting for the HIV/ARV team, a support group leader suggested that using disclosure as a prerequisite to treatment might constitute a form of discrimination, or violation of rights on the part of the patient. Several of those present at the meeting disagreed with the statement, insisting that adherence to ARVs was impossible if treatment was taken in secret. Busiswa argued that lifelong treatment cannot be a solo effort.

“Sometimes I even forget to take the ARVs, and my mother will remind me, or my family will remind me. So I think if you say you don’t have to tell anyone, and you can do it by yourself, it is not like that.” (28/11/05)

Lynne Wilkinson, site administrator for the ARV program, noted that

“No one has ever refused a treatment buddy on the grounds that they feel completely competent... Mostly it is because they are afraid to disclose their status.” (28/11/05)

In general there was a great concern for the patient’s psychological condition and the effect this would have on successful treatment. Healthcare workers and counselors saw the act of disclosure as an empowering act, signifying personal reconciliation with the illness. Christina Kopana, a peer educator at Madwaleni Hospital, described the support they provide to patients regarding disclosure.

“We ask them to draw a family tree... then we see, who is suitable for the patient to tell. If they draw a tree and the father is an alcoholic, or the mother left the patient years ago, we don’t advise them to disclose to them. We find the best person and teach them how to disclose.” (30/11/05)

Busiswa, another peer educator, herself HIV positive, said that people now “feel bold, and can go home and disclose.” Further, in this process, counselors find themselves becoming more involved with the social and personal aspects of patients’ lives. Busiswa recalled an incident after a support group meeting where a woman realized that her husband who works in Johannesburg must have infected her:

“She said she wanted to call her husband in Jo’burg and scream at him, ‘how can you sleep around and give me AIDS?’ So I had to say, no, that is not how you should do it, you must wait for him to come home and talk about it.” (28/11/05)

Furthermore, it has been argued that the act of disclosure signifies more than an acceptance of one’s medical condition and the determination to change it. It represents a defiant exercise of individual agency despite the risk of discrimination, rejection and exclusion. Mandisa Mbali writes,

“As the first few brave openly HIV positive AIDS activists stepped forward, it showed that the right to confidentiality did not have to mean enforced secrecy, nor did people living with HIV have to give all their power to the doctors treating them; they had the right to either hide or reveal their HIV status, showing their agency in forming strategies and tactics to resist AIDS-related discrimination.” (2005)

In this sense, disclosure becomes an act of self-definition and empowerment. The condition of disclosure then signifies a renewed emphasis on the patient’s psychosocial condition in successful treatment. Inside this framework, it becomes possible to subvert the power of “experts” to predict categorically whether a patient can or cannot be compliant— an exercise long considered largely fruitless (Farmer, P. et al, 2004). The

patient is seen as a human being who can be empowered to act under social constraints, which are themselves changeable through public health measures. Healthcare workers invariably become more involved in patients' social realities and their personal journeys towards acceptance and disclosure. The healthcare sector thus takes on a new role of empowerment, one that is deeply embedded in social transformation.

*“It’s not just me, now it’s us”*

The task of ARV programmes to provide psychosocial support so as to ensure adherence, as I discussed in the previous section, has resulted in an expansion of networks surrounding the sick. There is an increasing awareness of the need to tend to the sick and the experience of sickness outside the doctor’s office. (Brouard, 2005) Thus, support groups, which provide a space for patients to discuss their HIV status and also their experience with ARVs, have become a central part of many ARV programs. Molly put it this way:

“The doctor will only see you for a few minutes, but the support group is always there.” (24/11/05)

The support group establishes a dialogue among patients where patients can learn from each other and derive encouragement from shared experience. Referring to her community in the township of Imbali, Edendale, Molly stressed the importance of structures of support to the sick. She pointed out the frustration that positive people feel about their status and the “life sentence” of ART, as well as the need to provide a space to talk about negative and positive experiences alike.

“Some days I just look at the pills and push them into my mouth, I’m so cross about taking the pills... Sometimes you see people coming out of the clinic and their test results are negative, and you think, ‘why me? What did I do?’ But

with the support group, it's not just 'me', now it's 'us', that's why support groups are so important." (24/11/05)

The social capital that grows out of knowledgeable and empowered patients, able to provide support to others, plays a huge role in ARV programmes. Anemari, the pharmacist for the Madwaleni HIV/ARV programme, observed that ARV patients themselves are themselves a great source of encouragement and support to newer patients, and make a great contribution to the rollout process. (29/11/05) This is what Farmer (2004) refers to as the "virtuous social cycle" that arises out of treatment programs, where "neighbours are enlisted in the struggle against tuberculosis and HIV infection."

Where the function of the medical doctor shrinks into a larger system including support networks, counselling and education, healthcare can begin its descent from the arena of "expert" knowledge and engage patients on the layperson's level. Gilles van Cutsem, a doctor at the Khayelitsha Site C clinic, noted that the ARV programme run jointly by Medecins Sans Frontiers and the Western Cape province uses lay counselors, treatment literacy educators, and support groups help to demystify potentially confusing medical explanations. Gilles observes,

"The language the doctor uses is rarely appropriate... We rely a lot on the counselors to transmit information and explain things to patients." (16/11/05)

Furthermore, advice given by support group members has the benefit of personal experience, which can often be comforting and encouraging as well. Gilles commented, describing the crucial role of support groups in ARV programs,

"If the patient comes to you with a rash, you can say oh it's normal, it will go away... but in the support group, someone will say, I understand, that happened to me two months ago, its normal... sometimes that is more effective



than the doctor.” (16/11/05)

I observed two support group meetings during my time at Madwaleni Hospital. The first took place at the hospital itself, and comprised mostly patients who were being prepared for ARV treatment. I struggled to follow the session with my thin understanding of Xhosa, but was able to get a general sense of the proceedings. Sister Willie from the HIV/ARV team led the session. All the new faces in the room—myself included—introduced themselves, and were welcomed by Sister Willie. This was followed by short introductions from some of the older members of the support group, one or two of whom had already started ART. For the next hour or so, Sister Willie led a conversation with the group, addressing individuals and answering questions about ART. Lynne Wilkinson, the site administrator for the Madwaleni HIV/ARV programme, later commented that one probably did not need to understand Xhosa to get a sense of how the support group operated—it was apparent from the Sister’s tone of voice, her encouragement of the quieter members of the group, and the evident engagement of majority of people in the room—despite frequent interruptions by crying babies and ringing cellphones.

The second support group meeting I attended took place in Nkanye clinic, about 40 minutes away from Madwaleni. This was a smaller support group for both patients already on ART and those being prepared for ART. At the start of the session, members stood up and introduced themselves, and stated the date on which they began ART. One of the sisters of the clinic led the session. A lively and informal discussion ensued, apparently sparked off by one member’s description of the rash he got from the ARVs. As new members filed in, they were welcomed warmly with songs. Most striking in the Nkanye session was the use of music to convey messages about HIV and ARV. One song roughly translates to, “Me, I have tested for HIV/AIDS, have you?” Another one

appeared to be a call to treatment, and involved complex medical terms such as “cryptococcal meningitis”, “fluconazole”, and “nevirapine”.

The familiarity of all the support group members with terms that other non-medical people routinely trip over only emphasized the notion that the poor, uneducated sick can indeed attain extensive knowledge about their medical condition. This phenomenon is not unusual: it has been observed from Lusikisiki in the Eastern Cape, to Cange, a slum area in Haiti (Farmer, 2005):

“(in Lusikisiki) Before long, people... were donning HIV-POSITIVE T-shirts, singing about the virtue of condoms and quizzing each other on the difference between a nucleoside-analogue reverse transcriptase inhibitor and a *non-nucleoside-analogue* reverse transcriptase inhibitor.” (Newsweek, 19/04/2004)

The role of support groups in ARV treatment cannot be overemphasized. Because of the psychological support and education received in preparation for ARVs, patients on treatment are mentally and physically more empowered than other members of the community. They have more knowledge about healthcare and nutrition, are familiar with the biomedical processes of the virus and complex drug names; most of all, having trodden the difficult path of personal acceptance, disclosure and finally treatment, they are in the best position to give advice to other positive people.

It is perhaps difficult to grasp the magnitude of empowerment that takes place when positive people come to play an equally important role—some argue, a more *involved* role—in treatment than healthcare professionals themselves. It has been argued that the ability of the support group structure to build confidence in more withdrawn members contributes significantly to the empowering effect of ARV treatment. It certainly takes courage to speak about one’s own condition in front of a group of at least

twenty individuals. As a result, many of the HIV positive people in Madwaleni and Edendale were extremely articulate about their own condition, and came to play an increasingly visible role in awareness-building, prevention, and treatment activism.

### **III. “Amandla Ngawethu”: Patient-centered Activism**

On World Aids Day, all the support groups from the clinics on the Madwaleni HIV/ARV program came together in the church at Madwaleni Hospital. Support group members sat in the church waiting for the program to begin, as gospel music and songs about HIV/AIDS played on the sound system. Then a recording of a rally for treatment came on, declaring “Amandla!” The support group members sitting in the pews raised their fists and chanted, together with the recording, “Ngawethu!” “Amandla!” “Ngawethu!”<sup>2</sup>

This spectacle represented to me the power of positive people themselves to effect change in their communities—to demand treatment, to educate others against stigma and ignorance, and raise awareness about prevention. In both Edendale and Madwaleni, support groups comprising positive people, many receiving treatment, formed the backbone of movements within communities to educate their communities, and to reclaim the right to be respected as a healthy and normal member of their communities. In this section I draw a link between patient empowerment through treatment as discussed in the previous section—where patients are educated and counseled so that they can take responsibility for treatment—and patient “activism”, where positive people stand at the forefront of efforts to halt the spread of the epidemic.

#### ***The unwitting activist: Impact of ART on perceptions of HIV***

It has been suggested that the fact of treatment can be a mode of activism in itself, where the visible effect of ARVs to “literally resuscitate people” lessens collective

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<sup>2</sup> “Amandla Ngawethu” translates to “the power is ours”. This chant was often used during anti-apartheid protests. Its use today situates the struggle for the rights of people living with HIV/AIDS as analogous to the struggle of the 80s: militant, unrelenting, and proud. See Mbali, 2005

suspicion towards the disease and also towards positive people. (Gilles van Cutsem, 16/11/105) Echoing Paul Farmer's assertion that "if care is available, stigma goes away", Gilles van Cutsem from the Khayelitsha Site C clinic held that the availability of treatment has increased the willingness of people to test for HIV, and aided the movement towards openness and disclosure. (AIDS Bulletin, June 2005)

"When we first started, stigma in the community was very large. HIV was always seen as someone else's disease. So everyone said, 'nobody will come' (to the clinic)... In the first year, 1999, we had just over 100 people testing. Now we have thousands testing a year." (16/11/05)

During a focus group session with three members of the BroadReach team, I asked if they had observed any changes in the communities in which they work as the roll-out continues. The positive impact of ART was recognized emphatically by all members. Bongani Nkosi, regional coordinator of Mpumalanga, described his experiences in an unnamed community where stigma was very high. He recalled their modest expectations at the start of the BRHC intervention given the level of stigma in the community, and compared it to the expected turnout at the upcoming enrolment:

"This time we are expecting about 150 patients, which is very big, we've never seen those numbers before. And so I think treatment itself breaks down stigma. People usually think HIV patients are very sick, cannot move, are dying, but then they see that positive people can lead a normal life... And so I think over time people will start to see HIV/AIDS as just another kind of disease." (23/11/2005)

Zandile Wanda, the regional coordinator for KwaZulu-Natal, agreed that there was potential for change, but pointed out that societal stigma remained high. She cited the local support group Siyaphila as an example of persistent ignorance and discrimination against positive people. Members of Siyaphila hold support group sessions at a nearby

“drop-in” center for hospice care; in the kitchen, they are not allowed to share silverware with the rest of the center. She stressed that it will take a long time, and lots more education in communities, for them to fully accept positive people. Still, the team remained optimistic on most counts. They acknowledged that the mere sight of someone coming with someone positive was a great thing, given the level of stigma “by association”— as Bongani put it— that existed previously.

Indeed, it has been argued that because ARV provision decreases the perception of HIV/AIDS as a “death sentence”, it is likely to decrease the fear around infection and by extension stigmatisation of HIV-positive people. Stein (2005) argues that the fear of infection does not in fact lead to safer sexual behaviour, but rather a continued rejection and denial of the virus and of others infected by the virus.

“The logic of current psychological theories of AIDS denial and stigmatisation strongly suggests that (the availability of ART) will result in *decreased* denial and stigmatisation and in *increased* safer sexual behaviour, not only among those who are infected, but in society at large.” (Stein, 2005)

By reducing the fear of infection and death, ART creates a beneficial spillover effect in communities. In the heading to this section, I used the phrase “unwitting activist”— in a very real sense, patients on ART exist as visible new symbols of AIDS in individuals and communities. In no way is this meant to dismiss the personal and social struggle for acceptance that the vast majority of AIDS patients necessarily experience before commencing treatment. In the next section I turn to the idea of the patient activist, a direct extension of the empowered patient, purposefully seizing upon his/her own new physical and mental condition to play a larger role in the fight against HIV/AIDS.

*Effecting change in communities: A task for empowered positive people*

In both the communities of Madwaleni and Edendale, positive people were active in treatment lobbies and educational campaigns. During the Madwaleni Hospital World Aids Day event, the burden of responsibility on positive people to fight against discrimination and for treatment was emphasized repeatedly. In Lynne Wilkinson's speech, she credited support groups for the success of the Madwaleni ARV program, and reminded support group members of their responsibility to raise awareness in their communities and to encourage people to test for HIV. Christina Kopana, speaking on her experience as a person living with HIV/AIDS and as a support group leader, declared an urgent need to fight discrimination against positive people. (World Aids Day Ceremony, 1/12/2005)

Many of the support group leaders I spoke to likewise expressed a sense of responsibility towards educating their communities. Siphon of Sbhongukuphila spoke of the importance of eradicating ignorance towards HIV/AIDS as a crucial step towards prevention as well as decreasing stigma in communities. Indeed, the general consensus among respondents was that stigma was caused by ignorance more than any other reason. I suggested to respondents that stigma could come from other factors, such as the association of HIV/AIDS with immorality or promiscuity. In reply, they associated HIV/AIDS stigma with fear (caused by ignorance) or superstition, rather than with moral arguments:

“I have disclosed my status, everyone knows I am positive. And sometimes people don't dare to talk to me. They think if they touch my gate they will also become HIV positive.” (Molly Kubheka, 21/11/05)

“They hear that the numbers are so high, that everyday more people are getting infected, so they say you are wrong when you tell them that you can't get

HIV from just talking to me or holding my hand.” (Molly Kubheka, 24/11/05)

“The positive people and their buddies must go into the community and talk to their neighbours, and spread the message. Then we can end the rumours about the witch doctors.” (Sipho Mncwabe, 24/11/05)

“There was a woman who came in with her sister, who is positive, and she was so worried about getting infected. After I explained to her that it’s okay to share your cups and bowls, but just be careful about blood, she was so relieved and happy. So we are working to fight that sort of ignorance.” (Anemari Buitendach, 29/11/05)

“People have a lot of wrong information. When sometimes there are a mix of people in my house, I try to hold some education, and tell people about HIV/AIDS, how you can get infected.” (Zameka Ntibane, 29/11/05)

In the Madwaleni HIV/ARV programme, positive people—both those enrolled in the programme, and those already on ARVs— are involved in the hospital campaign to encourage testing. At support group meetings it is common to see positive people wearing the badge that reads: “*Ndilixilongile igazi le-HIV. Wena?*” (I have had my blood tested for HIV. Have you?) The hospital has formally hired two participants in the ARV program as permanent staff. They work on an equal footing with community health workers, the ARV clinician, the site coordinator, nurses and counselors. I spent a morning with Christina, on ARVs since March, and now a permanent member of the Madwaleni HIV/ARV team. Our task that morning was to go around to the wards and the waiting rooms in the hospital with pamphlets, and encourage people to take the rapid test for HIV.

As I suggested in the previous section, the existence of treatment has the potential to increase the effectiveness of educational and awareness campaigns within communities. However, the fact that positive people are taking it upon themselves to educate their communities is a phenomenon that warrants further exploration.



Why are so many positive people involved in HIV/AIDS activism? Positive people on ARV programmes are acutely aware that they possess a wealth of knowledge that remains inaccessible to many. They recognize that the AIDS epidemic is spiraling out of control, and that government and international responses to the crisis have been weak and incompetent. Their motivation for involvement thus emerges from a deep understanding of the epidemic and empathy for those infected and affected by it. This understanding is directly facilitated, even created, by the processes surrounding ARV treatment.<sup>3</sup>

The active involvement of positive people in HIV/AIDS activism speaks in direct defiance of reductionist, flawed conceptions of “primary healthcare”, which situate the patient as a static entity in relation to “health promotion” strategies, ignoring the agency of the patient to influence the events that shape behaviour and decision-making:

“It suggests that the language (of flawed conceptions of primary healthcare) may have the effect of making the people health promoters work with passive actors who have no control over events: health promotion is something that happens to them.” (Baum & Sanders, 1995)

Within this framework, patient-led activism is at bottom a declaration of patients’ abilities to make decisions about their own condition. This comes from the tradition of the TAC’s “Campaign for Openness” in the early 1990s. (Mbali, 2005) The movement instilled a sense of pride and self-respect in positive people, and gave them a public voice in demanding the right to treatment and respect. Mbali writes,

“From a mere handful of openly HIV positive white gay activists in the

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<sup>3</sup> In my conversations with Molly, Christina and Busiswa, they constantly reminded me of the magnitude of the epidemic, and the massive ignorance surrounding it. Christina in particular repeatedly declared, during one of our conversations, “one out of four people in the Eastern Cape are HIV positive, and only a quarter of them know it.”

early 1990s, in the first years of the 21<sup>st</sup> century... TAC's protests would come to consist of a humn sea of thousands of HIV positive and HIV negative activists wearing t-shirts proudly proclaiming "HIV POSITIVE." (2005)

In 2003, Zackie Achmat declared that HIV positive people do not demand pity; they demand rights. (Mbali, 2005) Thus our understanding of the movement by prominent PLWAs within support groups to promote awareness and education on HIV/AIDS must also be linked to their demand for rights—the right to remain a social participant in their community despite illness, their right to be treated with respect and understanding, and their right to lead fulfilling lives despite being infected with HIV. What treatment has done, then, is provide the physical, psychological and intellectual support and agency needed by positive people to organize and effectively demand these rights.

#### **IV. Beyond empowerment: reconceptualizing the role of public health in South Africa**

##### ***The paradigm of patient empowerment: Responsible for good health, not blamed for ill health***

I wish to suggest in this section that ARV treatment as it is currently conceptualized provides an opportunity to interrogate the assumptions underlying current healthcare systems, and rethink the role of public health in community development and nation-building. The restructuring of healthcare systems is beyond the scope of this paper, although there has been a great deal of scholarly research into the relationship between ARV programmes and the primary healthcare framework. Here, I hope to highlight the impact of treatment on the ways in which we conceptualize patient agency and the potential for agency to translate into change. I also suggest that taking lessons from ARV programmes requires a deeper understanding of the relationship between care and agency, and agency and change.

There are several important ways in which aspects of current ART models embody the philosophy of primary healthcare<sup>4</sup>. Firstly, it signifies a shift away from “prevention-only” that, by promoting “life-skills” and informed decision-making, ignore the social context of decision-making. Implicitly, pure “prevention” strategies establish the “*responsibilisation*”, or blame, of individuals for their own ill health. (Petersen & Swartz, 2002)

In contrast, by seeking to understand and change social conditions impeding successful treatment, the primary care model recognizes constraints on patients’ choices and power in social situations. Furthermore, conceptualizing treatment as inextricably

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<sup>4</sup> A model long recognized to be moribund or an “experiment that failed”, despite good efforts to the contrary. (Sanders & Werner, 1997)

linked to prevention efforts recognizes deeper, more complex psychosocial factors that influence perceptions of disease and reactions to education and information. Recognizing the psychological logic of stigma and the effect of treatment on this “logic” is one case in point; understanding patient adherence as a function of the patient’s own psychosocial condition is yet another.

More significantly, by involving the patient and other support networks more extensively in the treatment process, treatment implicitly subverts the power differential that exists in the conventional doctor-patient relationship. Writing about this “unequal power differential,” Petersen and Swartz note:

“This approach is reflective of the dominance of scientific rationality over emotional and moral dimensions of illness. It is, however, antipathetic to the notion of ‘empowerment’ which underpins health promotion and arguably the success of psychological interventions.” (2002)

In ARV programmes, the subversion of “expert” medical power begins with and takes place through the process of patient education, counselling, disclosure and finally treatment. The involvement of HIV-positive people in established treatment programmes, working side by side with healthcare workers and professionals, attests to the leveling of that power. In patient-led activism, the subversion of medical power demands that the voices of positive people are heard and respected within communities, in the public sphere, and in policy-making surrounding HIV/AIDS. This is particularly important in the HIV/AIDS epidemic, where the distribution of physical suffering correlates strongly to distributions of poverty, gender inequality, and other experiences of social and psychosocial suffering.

The move from a healthcare philosophy which places the *blame* of poor health on individual belligerence and ignorance, to one which accords the individual the knowledge

and support required for him/her to take *responsibility* for his/her own health, may seem like little more than a play on words. Yet in terms of health policy and structures of delivery, it makes a world of a difference. It may be that the latter model stands as the only viable way by which healthcare—especially ARV care and treatment—can be extended fairly successfully to the vast numbers of people who need it.<sup>5</sup>

*Taking lessons from ART: Exploring the meaning of “empowerment”*

To truly take lessons from the ARV rollout to strengthen existing health systems in South Africa, one must assess the fundamental assumptions underlying both existing health systems, and successful ARV treatment models. As a part of a national health system, HIV/ARV programmes constantly experience a tension between national health policy and localised ARV treatment initiatives. Some have pointed out that the government has yet to recognize the importance of support networks for the sick, thereby systematically neglecting the well-being of those who provide the support—nurses, home-based carers, community workers. (Stein et al, 2005) Others resist the “over-medicalization” of HIV/AIDS care and argue against the “attraction towards a ‘magic bullet’ or technological solution” that shafts a multisectoral response to HIV/AIDS. (Chopra, 2005)

At bottom, these critiques speak to fundamental differences between existing localized ARV programmes, and the current governmental framework: differences in how HIV/AIDS itself is conceptualized, and in how the person living with HIV/AIDS is conceptualized in relation to the disease, his/her community, and to healthcare workers.

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<sup>5</sup> In my interview with Andrew Boule, a doctor at the HIV/ARV clinic in Khayelitsha and a researcher at the UCT medical school, he referred to this as a “revolution” in healthcare, noting that “you can’t police people forever.” In this sense empowerment-based care appears to be the only way to provide a complex,

Therefore, the acceptance that patient empowerment must needs sit at the centre of a primary healthcare approach entails also a consideration of what empowerment means in different settings: That is, how healthcare can and should marshal forces of individual agency and community cohesion in improving health. The closely-knit, supportive community does not form of its own accord; it is a result of a process of accepting members of their community living with HIV/AIDS, understanding and learning more about the disease, and finally taking personal and collective responsibility towards the health of communities. Currently the TAC acts as the agent of organisation in several communities; but the TAC as a grassroots organization—and one regarded by the government as adversarial—lacks the wherewithal to reach the number of communities and effect the level of change it desires. (Interview with Gilles van Cutsem, 16/11/05; Interview with Andrew Boule, 07/12/05) Taking lessons from the empowerment model then necessitates the establishment of means of communication between the state and community experience and activism, where communities can truly be given a voice and a hand in improving healthcare and health education.

Building a stronger health system that integrates ARV care, then, requires more than simply “reclaiming” in theory the focus of healthcare on the patient, and the patient’s experience of disease; it requires a strong reevaluation of what empowerment means and how it manifests itself in individuals and communities, and the new responsibilities of the state to that empowerment.

## Recommendations for Further Study

In the course of this study, I spoke to numerous healthcare workers—be they doctors, nurses, clinicians, counsellors, or educators. Most, if not all of them, attested to the profound sense in which ARV treatment had radically transformed HIV/AIDS care, their interactions with their patients, and their personal experience of caring for the sick. At the same time, most of them—especially clinicians, nurses, and counsellors working with populations that had poor access to health services or patients dealing with discrimination from family members and neighbours—expressed a great sense of frustration at the lack of resources and support they had on hand to help the sick in their communities. A study that examined the impact of ART provision on healthcare workers would not only shed light upon post-ART medical relationships, but also provide insight into studies on scaling up ART and strengthening the primary care framework.

Another interesting area of study is the role of traditional healers in HIV/AIDS care. In my conversation with Marcus McGilvray from BRHC, he pointed out that in general, when people in rural communities get sick, the first person they visit is their neighbour or close family. The second person they visit is the *sangoma*, traditional healer. Yet little or no efforts have been made to educate traditional healers about ARV treatment and HIV/AIDS care in general, due to the power embedded in that cross-cultural interaction. More broadly, this phenomenon suggests that a study into information networks around the sick and the social and cultural processes by which behavioural decision-making takes place.

Other ways of furthering this particular study could include a focus on stigma in communities and a study of the logic and nature of that stigma. A study of the effectiveness of training and counseling methods for HIV-positive people in resource-

poor settings would inform many of the observations and inferences made in this paper. Lastly, a study of patient-led activism and the impact of that form of activism on conceptualizing and achieving the right to health would provide great insight into theories of rural resistance and of social movements. This study might also examine the role of treatment and patient-led activism in strengthening political sensibilities in rural/ peri-urban areas, as well as democratic institutions as a whole.



## Conclusion

In this study, I have explored patient participant in an ARV programme as a journey of empowerment—through education, the building of self-respect and confidence, psychological acceptance and physical strengthening, and finally a heightened awareness of one’s voice and one’s agency in using that voice to demand and persuade change. Clinicians, community health workers, and counsellors alike have spoken to me of the spectacular impact ARV treatment has had on their patients, both physically and psychologically; as well as on stigma and discrimination in communities. As I noted in my recommendations for further study, the task ahead remains daunting. Numerous questions remain—largely revolving around how to scale up antiretroviral therapy in South Africa, and how to integrate ART into the national healthcare framework. Much of this work will involve systems research and planning, as well as economic and human resource evaluation. However, underlying healthcare reform must be a rethinking of the concept of “health”, and by extension a rethinking of how the sick are structurally defined in healthcare systems.

The notion that patient empowerment contributes tremendously to the success of ARV programmes, and has positive spillover effects for the community at large, suggests that we should no longer consider the viability of healthcare systems to be contingent upon theoretical models of “cost-effectiveness” or “sustainability”, which treat the patient as a static, passive recipient of healthcare. (Petersen & Swartz, 2002) To the contrary, if the patient is considered as a partner in healthcare who *can* be empowered, public health can reclaim its original goal of improving the health of communities as a whole—by treating ill health, the conditions that perpetuate ill health and, correspondingly physical,

psychological and social suffering caused by ill health. (Petersen & Swartz, 2002) Still others suggest that there is no other viable way of providing healthcare, especially ARV treatment, to large numbers of people if they cannot take responsibility

Even after we accept that patient empowerment must be the underlying philosophy to building a strong primary healthcare model, the *how* of empowerment proves even more complex than the *why*. ARV treatment is still extremely young in South Africa, and the number of people on treatment is but a small fraction of those who require treatment presently, and will require treatment in the following years. Those who do manage to navigate the difficulties of their environment to enroll in an ARV programme appear to have done exceedingly well; less is known about those who have not. We know that patients can be empowered; the next challenge is how to best educate and counsel the far larger numbers of people who thus far have not navigated through to highly inaccessible services to obtain treatment. (Interview with Andrew Boule, 07/12/05)

The potential for a strong ideological association between healthcare delivery and social transformation has implications not only for the nature of healthcare reforms, but also developmental strategies in the new South Africa. The lack of political will has been frequently raised as the root of the sauntering progress of ARV roll-out in South Africa. Stronger state commitment to the social role of healthcare could create opportunities for education and access that grassroots social movements—even well-organized, deeply influential movements like the Treatment Action Campaign—cannot create for themselves. Even in Khayelitsha, where the TAC is arguably the most active, messages have not broken through completely; a sizeable amount of people still do not know what the TAC stands for. (Interview with Andrew Boule, 07/12/05) The use of state-owned

media to remind patients to take their medications is an example of what stronger state commitment can achieve; having political leaders speak up about their status is another case in point. (Interview with Herman Reuter, AIDS Bulletin, March 2005; Interview with Andrew Boule, 07/12/05)

Finally, recognising the responsibilities of public health necessitates the linking of public health to other spheres of social experience (or social suffering). It requires an awareness of other modern day struggles—for land, housing, access to education, and privatization of public service, to name a few. As Joia Mukherjee puts it, “as physicians we should also be activists against the policies that we know are hurting our patients.” (Interview with AIDS Bulletin, September 2005) But the physician activist— or for that matter, the health activist of any form—can only do so much in situations of extreme resource deprivation and lack of support.<sup>6</sup> In the final analysis, only the “synergy between state response and community activism” can effect changes in the healthcare system that generate positive effects in the communities that either labours to serve.<sup>7</sup>

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<sup>6</sup> There are of course strategies of mobilization and legal activism that have in the past been extremely effective. The TAC’s lawsuit and civil disobedience campaign against the state arguably led to the government’s recent commitment to an ARV rollout. It may be less feasible, however, to suggest that grassroots activism in local community settings – especially settings of resource constraint—can have the influence or impact that the TAC does in its urban, intellectual-led movement.

<sup>7</sup> In my interview with Andrew Boule, he used the phrase “synergy between state response and community activism” in reference to the missed opportunity—due to government intransigence and AIDS denialism—to fight the AIDS pandemic both from the top down and the ground up.

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## **Interviews**

Interview with Gilles van Cutsem, 16/11/05

Focus group discussion with Bongani Nkosi, Themba Duze, Zendile Wanda, 23/11/05

Informal interviews with Molly Kubheka, 21/11/05-24/11/05

Informal interviews with Christina Kopana, 30/11/05, 1/12/05

Informal interviews with Busiswa Joya, 28/11/05, 29/11/05

Informal interview with Lynne Wilkinson, 28/11/05

Informal interview with Marcus McGilvray, 06/12/05

Interview with Andrew Boule, 07/12/05

## **Appendix: Interview Questions**

### ***Informal Interviews with support group leaders/ community health workers, 20/11/05-1/12/05***

(Molly Kubheka, Nokuthula Biyela, Sipho Mncwabe, Christina Kopana, Busiswa Joya, Zameka Ntibane)

In my time in Edendale and Madwaleni I had the chance to interact on a day-to-day basis for four or five days with the healthcare workers. Often informal interviews took place in between patients in counselling rooms, or on trips to the clinic. In these interviews I did not ask a specific set of questions, but directed the conversation to a few areas of interest.

Topics raised:

- Adherence—How difficult is it to establish adherence, and why do people default on life-saving treatment?
- Disclosure—how do you help people to disclose their status? Why is this so important for treatment?
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- How do you see your role as a support group leader/ community health worker in the fight against HIV/AIDS?
- What do you think should be done to reduce stigma in your community?
- How has your experience as a support group leader/ community health worker changed after ARVs are available?
- Why are support groups so important in ARV treatment? How much time is spent in support groups?

### ***Informal Interview with Lynne Wilkinson, site administrator for Madwaleni HIV/ARV programme, 28/11/05***

- What are the different aspects of the HIV/ARV programme at Madwaleni?
- Did Madwaleni build the support networks in the community or were they pre-existing?
- Has ARV treatment had an impact on stigma, in your opinion?

### ***Focus Group with BroadReach Healthcare team in Edendale, 23/11/05***

(Themba Duze, Regional Coordinator Gauteng; Bongani Nkosi, Regional Coordinator Mpumalanga; Zandile Wanda, Regional Coordinator KZN)

- What is your personal background and how did you enter the field of HIV/AIDS?
- Can you speak a bit about the philosophy of BRHC, the idea of the public-private partnership?
- It has been said that the public-private partnership idea has been around for a long time, but never quite been implemented successfully. What do you think?
- What is your perception of stigma in the communities you work in? Do you think it has changed after BRHC entered the community with ARVs?
- What are adherence rates like? In your experience what helps adherence and what

makes people default?

*Interview with Gilles van Cutsem, 16/11/05*

- What is your professional background with regard to HIV/AIDS work?
- How are ARVs being delivered in Khayelitsha? What are the processes that patients have to go through?
- What is the difference to you, treating patients before and after ARVs became available?
- What was the level of knowledge about HIV/AIDS in the community before MSF arrived, and the level of stigma?
- What is the philosophy of the ARV treatment programme?
- How do you see medical treatment in the greater context of social conditions e.g. poverty, malnutrition, unemployment?
- What role do the lay counsellors, support group leaders, and treatment literacy counsellors have vis-à-vis yourself, the doctors?
- How closely do you work with the TAC and other activist organizations?
- What are the reasons for poor adherence, when it happens, in Khayelitsha? What are the reasons for such good adherence statistics?
- How do you see the expansion of ART care in South Africa?

Interview with Andrew Boule, 07/12/05

- How does the MSF model compare to the ARV rollout in other parts of South Africa, or for that matter the Madwaleni model and the BroadReach model?
- What would the health system ideally look like, if HIV/AIDS care and ART in are integrated into the system?
- How different has it been treating patients pre and post-ARVs?
- Has it changed the way you interact with patients?
- What is the role of the TAC in Khayelitsha, and do you think that there are many positive people involved in HIV/AIDS activism?
- To what would you attribute the high rates of adherence that MSF reports?
- What sort of leadership does the HIV/AIDS movement need? Can the TAC provide this leadership?