

CENTRE FOR
SOCIAL SCIENCE RESEARCH

Aids and Society Research Unit

GENDERING THE THERAPEUTIC
CITIZEN: ARVS AND REPRODUCTIVE
HEALTH

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CSSR Working Paper No. 175

November 2006

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The author acknowledges, with gratitude, the support of the Rockefeller/Wrenner Gren Conference on Reproduction, Globalization and the State and the Danish Development Research Council (RUF).

Gendering the Therapeutic Citizen: ARVs and Reproductive Health

Abstract

Reproductive Health as a global agenda can provide an opportunity for including “social issues” under its vast umbrella. However, so far reproductive health has failed to go beyond family planning in large-scale, high impact interventions. Now, the impact of the HIV/AIDS pandemic has meant that the primary reproductive health goal of many African women in highly affected communities is to remain healthy long enough to reproduce. The case of ARV treatment in a township clinic in South Africa will demonstrate the need for a genuinely integrated global concept of reproductive health and rights that includes the realities of AIDS and its treatment. This research is in some respects an anthropological examination of AIDS interventions from a political standpoint. In this paper I examine the other side of the issue of AIDS and family planning integration: how are family planning technologies and contraceptive decision making integrated into HIV/AIDS treatment clinics? Reproductive decision making in the context of the AIDS clinic reignites classic debates over the rights of the individual versus the rights of the community, the meanings of motherhood and maternal identity, and the appropriate control of sexuality by the state vis a vis governance of the self. Yet, in the situation of reproductive decision making by HIV positive women, the stakes are higher, the boundaries less discernible, and the meanings even more contingent by the urgency of the disease and the poignancy of the processes of giving life. To begin to understand this, I argue, we must find a way to gender the therapeutic citizen in order to reintegrate the biopolitical struggle of ARVs with the “social issues” percolating within the therapeutic state.

Introduction

Globalisation is an econo-technological institutional process with a pervasive impact. It has brought technological access to the forefront of political debates over global inequality. In high-income countries, antiretroviral treatment (ARVs) became widely available in 1996, and AIDS-related mortality dropped sharply. UNAIDS reported similar trends in Brazil and predicted that we would

see similarly declining mortality rates in countries in Latin America, the Caribbean and Africa (UNAIDS, 2002). In contrast to conventional wisdom that anti-retroviral therapies would remain beyond the reach of most HIV positive people in developing countries, improving access to anti-retroviral drugs has become officially a global priority. While this has yet to be realised in most African countries, South Africa has undertaken the largest public ARV treatment programme in the world.

Reproductive health and rights agendas have focused attention on important issues that had not been emphasised in population debates: who controls fertility, reproductive decision-making, the ethics of contraceptive methods and the impact of gender relations in the household, clinic and national policy environment. Reproductive health as a global agenda can provide an opportunity for including “social issues” under its vast umbrella. However, so far reproductive health has failed to go beyond family planning in large-scale, high impact interventions. National reproductive health programs in developing countries are implemented through the same structures of the old population interventions. Yet, when global discourses are translated in local contexts of HIV/AIDS, reproductive health in many African communities might be best understood as remaining healthy enough to reproduce. South Africa has one of the highest rates of contraceptive use and the lowest fertility rates in Africa, yet the gendered importance of childbearing persists perhaps both in spite of and because of the omnipresence of HIV/AIDS. An exploration of AIDS and contraceptives in South Africa cannot take place outside the macro-context of race, political struggle, state-building, and the economic realities of contemporary South Africa, best characterised by poverty, “empowerment” extremes¹, and gross and gaping inequality, known as the “distributional regime” (Seekings and Nattrass 2006).

In other work, I have explored how HIV/AIDS is integrated into family planning in African reproductive health clinics (Richey 2003; 2005; 2006). I argue that a population discourse dominated by concern for female fertility control precludes adequate incorporation of the challenges that AIDS brings to healthcare provision and development policies. I remain interested in continuing my explorations with how “scientific practices seep unevenly through the crossroads and chasms at which biotechnology and family life conjoin” (Rapp 1998, 68). Further, looking through a local clinic case study is conducive toward rethinking the way that health policy, international interventions and global priorities are performed. In this paper I examine the other side of the issue of AIDS and family planning integration: how are family planning technologies and contraceptive decision making integrated into HIV/AIDS treatment clinics?

¹ This refers to the contemporary debates surrounding “Black Economic Empowerment” or “BEE” which are beyond the scope of this paper.

While this has not yet become a central topic of public health interest, women on ARVs will make it one.

Bayer argues that “AIDS has represented a challenge to the central impulse of liberal individualism, forcing into the social realm matters that had come to be viewed as of no legitimate public concern; it has revealed the limits of the ideology that had provided the wellspring of cultural and political reform” (1990, 179). Reproductive decision making in the context of the AIDS clinic reignites classic debates over the rights of the individual versus the rights of the community, the meanings of motherhood and maternal identity, and the appropriate control of sexuality by the state *vis a vis* governance of the self (cf. Glenn, Chang and Forcey 1994). The self on ARVs as linked to the geopolitical realm of AIDS treatment both globally and locally has been termed the “therapeutic citizen” (Nguyen 2004). Yet, in the situation of reproductive decision making by HIV positive women the stakes are higher, the boundaries less discernable, and the meanings even more contingent by the urgency of the disease and the poignancy of the processes of giving life. To begin to understand this, I will argue, we must find a way to gender the therapeutic citizen in order to reintegrate the biopolitical struggle of ARVs with the “social issues” percolating within the therapeutic state.

Methodology

This research is in some respects an anthropological examination of AIDS interventions from the standpoint of politics and policy. The empirical material for this paper comes from fieldwork in the Western Cape Province of South Africa from June until December 2005. I conducted interviews, attended meetings and seminars and consulted local researchers within the Province on the “roll-out” of ARVs and issues of access and adherence. In the process of researching the local politics of access to ARVs, I became most interested in the participant observation work I was permitted to conduct at the Heshima Clinic² for HIV/AIDS treatment on which most of this paper will draw.³ Together with my Xhosa translator,⁴ I sat in on adherence counseling sessions, ARV information sessions, and home visits conducted by patient advocates as part of the patient “work-up” for initiating ARVs. I also interviewed the various types of service providers affiliated with the ARV programme, engaged in unstructured observation at the clinic, attended the weekly meetings of the ARV

² A pseudonym.

³ I am grateful to the Metropole Region of the Western Cape for research clearance for this project.

⁴ To whom I am much indebted for her insight and extensive experience with research, provision of care, and individual negotiations around AIDS treatment.

treatment team and observed patients' visits to the physicians, which took place in English.

The clinic is my site of inquiry because of its unique position as a site of translation and struggle between high modernist discourses of medicine, neoliberalism and "development" and national discourses of cultural, Africanist, traditional medicines (sangomas), economic apartheid, and global discourses of abjection (Ferguson 1999; Kristeva 1982).⁵ My work differs from medical anthropology in that the clinic provides a way of examining the interactions between the state and its citizens. It is the most "local" of my methodological inquiries; even though I visited homes and interviewed individuals, these interactions stemmed from the clinic.

The clinic where I have worked is hardly a neutral geographical site. Consisting of a smallish, well-kept cement building, four prefabricated "bungalow" annexes, an AIDS support group's fledgling vegetable garden, and parking space for about five cars within a high chain-link fence, it is a highly politicised space. Patients, service providers and researchers enter at their own, varied, risk. Everyone in the township knows that this used to be the mother and baby clinic and now it is the AID clinic, although the sign outside says something less descriptive. Within the chain-link fence, power is legitimately wielded by the state.⁶ The inhabitants are commissioned with the authorised use of medicine.

Furthermore, in the province that least frequently resembles an integrated picture of the New South Africa's "rainbow nation," the clinic is a space of legitimate socio-racial-culture contact, if not equal exchange. Doctors (and researchers) drive in from Cape Town's leafy suburbs; counselors and nurses come from other townships or "mixed" geographical spaces, and patient advocates come from the diverse localities around the clinic's township area. Patients come from the local township, from other townships, or from other poorer parts of the country. There is no residency requirement for ARV treatment, just a commitment to return to the clinic for the required regular follow-up visits. The clinic provides the rare opportunity to examine the interesting mixes of different agendas that cut across lines of race, class and South African history.

⁵ Of course I am merely following a distinguished tradition in medical anthropology in my fascination with the clinic, but for some reason this site of biopolitical struggle is not central to much of the political science or development studies research.

⁶ I assume, with some hesitancy, that a notion of the "state" can be made relevant in spite of the vastly different and conflicting policies and politics between the national, provincial and regional levels of government that link this clinic to the system.

Rights, Reproductive Health and “Social Issues” of ARVs

The global development perspective on HIV/AIDS control in Third World countries has shifted away from rights and individual liberties, moving toward a greater emphasis on control and public good. The pandemic is represented as becoming increasingly unmanageable, and AIDS activists’ successful demand for more access to treatment has, in some instances, resulted in backlash. For example, former US President Bill Clinton is quoted in the popular media as supporting universal HIV testing in developing countries with high levels of HIV infection, like that done in Lesotho.⁷ Academically, a special issue of the *Journal of International Development* dealing with HIV/AIDS policies concludes that “enforced testing, enforced use of condoms, segregation of those who are positive, and perhaps enforced compliance with antiretroviral regimes: these are strategies which would have an effect” (Allen 2004, 1127). The editor acknowledges that such strategies involve “what might be regarded as infringements of civil liberties” but justifies that the human rights of those who are HIV positive have been privileged over the rights of those who are negative, and this is “potentially counterproductive” for public health (*Ibid.*). The argument throughout the volume is that Third World country contexts require extraordinary interventions and human rights may have to be compromised. Nowhere does the work explicitly outline whose rights are to be privileged, and nowhere is it explicitly acknowledged that such triage decision-making would be quite likely to exacerbate existing societal inequalities based on gender, class, ethnicity, religion or sexual orientation. As I will demonstrate from my clinic-level work, poor women on public ARV programmes are unlikely to be in a position to navigate the obstacles that stand in the path of exercising meaningful reproductive choices between the individual and the state. Thus, the impact of AIDS policies must be considered within the “social issues” of poverty. An explicit recognition and analysis of “social issues” provides a means of appreciating the efforts taken by therapeutic citizens in negotiating within them.⁸

Family planning decision making for women with AIDS destabilizes the philosophical foundations of reproductive choice, while simultaneously providing a global call-to-arms in defense of the very rights that are rendered hollow in the “social issues”: daily techno-battles for well-being and

⁷ “Clinton calls for rethink in universal HIV testing” Thursday 30 March 2006, AIDSMAP news (found at www.aidsmap.com/en/news/D5CBB09D-9940-4BFD-8FE8-54085F9CBB11.asp?type=preview).

⁸ One reason that these debates may have been bracketed is that they were often used as justifications for denying treatment to poor people, as it was incorrectly argued that the poor could not manage such a complicated regime. These debates have been resolved in so far as it is no longer a question of whether to bring ARV treatment to the poor, but how to do so.

biopolitical citizenship. The insight of the reproductive health agenda – particularly the synergy between reproductive health, empowerment and the right to health care – is not easily incorporated into the existing behaviorist models of HIV/AIDS interventions (Richey 2003). A situation analysis meant to outline the “critical relationships” between family planning and reproductive health programmes and HIV/AIDS in South Africa never even mentions the need of HIV positive women for reproductive health services (Advance Africa 2002). It concludes with the “lesson learned” that “the relationship between family planning, which deals with birth, and HIV/AIDS which deals with death, is complex” (*Ibid.*, 19).

Questions of rights, reproductive decision-making and “social issues” are negotiated within the practice of AIDS treatment counseling. Globally, the trend toward “nondirective” counseling can be traced to the new forms of social work that developed in the 1970s to support genetic counseling. These new counseling forms were purposefully elaborated as distinct from, and in opposition to, the heritage of eugenics that had lost political and social approbation after WWII. “Nondirective counseling” was meant to be “a type of social work entirely for the benefit of the whole family without direct concern for its effect upon the state or politics” (Reed 1974, 336, cited in Bayer 1990, 184). In spite of its discordance with the traditions of clinical medicine at the time, nondirective counseling quickly became the hegemonic discourse. It profoundly shaped notions of counseling in the context of both US national policy and practice and in international health (Bayer 1990, 185).⁹ This notion of nondirective counseling for genetic disorders coalesced nicely with the foundational elements of liberal feminism that women must be permitted to control their own reproductive lives and such liberty required a strong ideological attachment to notions of individual choice. Thus, nondirective counseling which focused on providing individuals with the knowledge necessary to make informed choices about their health was the standard that was meant to apply to family planning counseling, and to some extent to counseling for HIV testing and later AIDS treatment.

However, the cozy consensus on liberal choice was shattered by the problem of vertical transmission of HIV. As a result, the terrain of individual choice within reproductive decision-making was littered with ideological shrapnel, and demining efforts continue in global, national and local fields. The issue of vertical transmission was first addressed at the US Centers for Disease Control (CDC) in December 1985 and a recommendation was made that “Infected women should be advised to consider delaying pregnancy until more is known about perinatal transmission of the virus” (Bayer 1990, 189). This statement represented a

⁹ I refer to the US national context here as it has been for decades the global public health hegemon, particularly in reproductive health and HIV/AIDS (see Sharpless 1997).

dramatic break from all previous “nondirective” endeavors to support individual choice in the reproductive, private realm and instead it applied standard public health norms. Bayer emphasises that the tentative language used conveyed a less drastic impression of what was happening, as women were advised to “consider” the “delaying” of pregnancy; yet the preventive orientation actually required a fundamental curtailment of their reproductive lives (1990, 190-91).

The official discourse shift here was no doubt shaped by US public opinion, with global repercussions. The March of Dimes, a US charity established in 1938 to combat polio, had an explicit policy against directive counseling of women at risk for bearing children with birth defects. Yet, when HIV was the possible defect the entire perspective changed. A television spot in the US showed a baby-like marionette whose strings are cut by a pair of scissors, while an off-camera voice announced: “A baby born with AIDS is born dying” (*Ibid.*, 195). What is important here is that HIV radically altered the notions of reproduction, its location in the public versus private domain and notions of the individual as rights bearer in ways that no other disease, defect or disorder had done.

In this paper, I analyse how various interwoven levels of political imperatives call forth performances of therapeutic citizenship, dancing between the policy level (does the state matter?) and the local moral economy of the clinic. This work has been inspired in part by Randall Packard’s (1989) book, *White Plague, Black Labour: Tuberculosis and the Political Economy of Health and Disease in South Africa*, which blends a political economy of disease and health care with an analysis of medicine as an ideological construct. Packard’s contention for the case of TB can frame a useful critical perspective for analysis of HIV/AIDS in contemporary South Africa. He argues that “the South African experience with TB had not been produced by a unique set of social and biological phenomenon (either the racist state or the racially susceptible Africa). It must be seen instead as a product of a particularly pathological intersection of political, economic and biological processes that have a much wider distribution” (Packard 1989, 19). I will expand his line of vision to include the HIV/AIDS pandemic in which South Africa is neither typical nor exemplary.

Additionally, I draw conceptually on Vinh-Kim Nguyen’s discussion of the complex, biopolitical assemblage of HIV/AIDS that has been able to stitch together apparently disparate phenomena such as condom demonstrations, CD4 counts, sexual empowerment, compliance with drug regimes, retroviral genotyping, an ethic of sexual responsibility into a remarkably stable, worldwide formation (Nguyen 2004). “Therapeutic citizenship” is a biopolitical construct based on a system of claims and ethical projects that arise out of the conjugation of techniques used to govern populations and manage individual bodies.

Therapeutic citizens operate within a therapeutic economy (the totality of therapeutic options in a given location and the rationale behind legitimate access to them) –this may be structured by monetary exchange but is also embedded within “regimes of value” (moral economies, networks, patronage, etc.) (*Ibid.*). Therapeutic citizenship is useful for placing personal negotiations of illness within an explicitly political and institutional framework. Linking moral obligations with economic imperatives in a way that emphasises relationships and interactions, therapeutic citizenship provides us with a way of thinking about the individual and the collective.

However, further work is needed to conceptualise the therapeutic citizen, specifically as it relates to a particularly gendered notion of citizenship. Vinh-Kim Nguyen himself described an “unexpected challenge” to his clinical work as a physician providing ARVs in the Ivory Coast: women who got healthier returned to sexual life and childbearing. This turned up in the clinic as an “adherence problem.” Women would disappear from the clinics and come back nine months later with a baby. Nguyen explained that one of the nurses had summed up why the women felt they had to hide to reproduce: “It’s not authorized to get pregnant when you are on treatment.”¹⁰ Can it be possible for women in a culture of nearly universal childbearing and high levels of reproductive desire to act as therapeutic citizens within the ARV context? To do so, we must gender the therapeutic citizen. This paper will explore how we can gender the therapeutic citizen through an understanding of reproductive decision making by women on ARVs within a South African AIDS clinic.

Pregnant Women, ARVs and Motherhood

ARV treatment presents interwoven, relationships of treating the self and the mother—representing a new twist on the historical feminist debates between the self, the fetus and the maternal relationship. Exposure to pregnancy necessarily risks exposure to HIV, as procreation involves unprotected sexual intercourse.¹¹ As we will see from discussions of the clinic interactions, there is in effect, an implicit separation between procreative sexual relations and all other types of sexual behavior. The former, are being governed by appropriate consultative processes between the therapeutic citizen and her physician, and the latter, are under strict control of the condom. Yet, this separation between the mother and the sexually active woman is not only illogical (you cannot tell women that they

¹⁰ From a talk by Vin-Kim Nguyen at Copenhagen University 18 May 2006.

¹¹ This anxiety has become the focus of a new technofix in Kenya where currently newspapers are full of the story of the “historic achievement of In Vitro fertilization” where it is now possible to “wash a man’s sperm to rid it of the HIV virus before fusing it with a fertile embryo and implanting it in a womb” (The East African Standard, 11 May 2006).

must use a condom every time they have sex to protect themselves from reinfection with a resistant virus and to protect their partner, and at the same time advise them to plan pregnancies with their physician), it represents a fundamental difficulty of gendering the therapeutic citizen.

Women who are pregnant are accorded special status in the global hierarchy of ARV allocation. They are assumed to be the ones most in need of treatment, not for their own virus, but for the potential transmission to their fetus, capture of their family into treatment regimes and care of their children. There are three points of intersection between ARV treatment and pregnant women: pregnant women are to be given ARVs for the prevention of “maternal-to-child transmission”¹² of HIV; pregnant women are meant to provide an entry point to family care; and pregnant women are entitled to ARVs as a means to extend their own lives for the sake of preventing AIDS orphans (see McIntyre 2005).

In fact, it was the pregnant woman lacking in ARV access that epitomised the recent documentation of the failings of the World Health Organisation’s global “3 by 5” initiative. The headlines read: “ARVs Missing Pregnant Women – WHO.”¹³ The report of the shortcomings of the 3 by 5 began: “Fewer than 10 percent of HIV-positive women in developing countries received antiretrovirals (ARVs) during pregnancy and childbirth between 2003 and 2005, according to a new report . . . 1,800 children per day were born with HIV. . . over 570,000 children under the age of 15 die of AIDS, most having acquired HIV from their mothers” (*Ibid.*). This global construction of the sacrifices of motherhood is insidious, concealed behind the banal language of development statistics. Centering the gaze on the “pregnant woman” who did not receive ARVs, it shields the virtuous fetal citizen, constructed by default through the focus on the pregnancy. The rhetorical concealing of both the fetus and the woman, through the “pregnant woman” status is politically efficacious. Holc (2004) draws on the discourses of abortion in Poland to argue that the construction of fetal persons acts as process of subject formation that results in particular effects on other subjects. “The mythology of the personhood of the fetus gradually effaces another personhood – that which should be attributed to women” (Graff 2001, cited in Holc 2004, 766). However, the woman on ARVs is conspicuously absent from the PMTCT imaginary. Reinserting her into these discourses would confront us with both the possibility and even likelihood that AIDS-infected

¹² The term “mother-to-child transmission” is obviously problematic and epitomises the discursive focus on motherhood, and the mother’s ultimate failure to protect her child from harm by transmitting her own disease to an innocent victim. Unless I am referring to other discourses, I use the term “vertical transmission” in this paper to redirect the concept toward the actual process of viral transmission, not the responsible or irresponsible agents.

¹³ UN Integrated Regional Information Networks, 29 March 2006. <http://www.aegis.com/news/irin/2006/IR060385.html>, last accessed 27 Oct.2006.

women will reproduce like other women, and that a responsibility for treating the mother is ethically inherent in PMTCT, whether or not this is cost-effective in the public policy realm.

Mapping the Local Terrain of a Township in Western Cape Province, South Africa

It would be naïve to surmise that equitable systems for providing life-saving drugs could exist outside their historical context of overlapping indices of inequality. Global political economy, race/ethnicity, gender, regionalism, religion, nationalism and politics will all impact the way that the ubiquitous “roll-out” of ARVs will take place in developing countries. Furthermore, gendered constructions of the therapeutic citizens of the ARV state will serve multiple, if perhaps predictable agenda. For example, a doctor at a different clinic in the Western Cape characterised the ways in which “men are more likely to take a macho denialist approach,” but women “as caregivers are more immediately and forcefully concerned with their own health” (Casey 2005, 50).

The South African state-sponsored family planning programme officially began in 1974, a time of rapid urbanisation and forced resettlement of the Black population into ‘homelands’, vast labour migration, rising levels of unemployment and increasing militancy by non-whites against the apartheid regime (Kaufman 2000, 105). While the programme was officially non-racial, most research emphasised the provision of family planning with the state’s desire to control the Black and Coloured population (Brown 1983 and 1987, Chimere-Dan 1993, Klugman 1993 cited in Kaufman 2000). Still, ever-increasing numbers of Black women have been adopting contraception for as long as data has been available. South Africa has extremely high levels of contraceptive use, with 75% percent of women having ever used contraceptives and 50% currently using a modern method according to 1998 Demographic and Health Survey data. Kaufman concludes: “Economic conditions, employment opportunities and concern for the health and welfare of their families within the context of a racialized society have motivated black South African women to use contraceptives in spite of immense pressure, real or assumed to do otherwise” (Kaufman 2000, 113).

My analysis draws on a South African Case study from a vertically-structured, multi-sited ethnography. It begins in the Heshima AIDS clinic, located within the Provincial Government of the Western Cape, and also within the National context of President Mbeki, Health Minister Manto and “denialism.”¹⁴ In brief,

¹⁴ Forthcoming work from this project will analyse the national dimension of denialism in relation to the case study presented, but it is beyond the scope of this paper.

South Africa probably has more than 5 million people living with HIV/AIDS - the highest number of any country in the world.¹⁵ The national government is notorious for its lack of leadership on AIDS issues and for its President's questioning of the link between HIV and AIDS, accusing scientists of racism and ARVs as poison and supporting regimes of African potatoes and garlic as good alternatives to ARVs for AIDS treatment (see Nattrass 2004).

Whenever South Africa is taken as a case of "African" AIDS, it must be restated that the country has a Gross Domestic Product (GDP) of 104 billion USD in 2002 figures. Of all Southern African countries it is followed in wealth levels by Angola with a GDP barely reaching into the double digits of only 11 billion USD. It is simply not a poor country, but also a middle-income country like Brazil. The multiple and varied characterisations of South Africa as "poor" or "middle-income", and as running parallel to Europe or to Africa, serve highly political purposes.

With due recognition to the political complexity of the case and its data, a genuine attempt to map the local official terrain of ARVs follows. On 19 November 2003, the South African Government published the *Comprehensive Plan on HIV/AIDS Care*, which aims to provide universal coverage of ARVs within five years. This remarkable document is read as either marking the victory of civil society demands for public availability of ARVs, or as yet another stalling tactic by the recalcitrant National government for its inflated targets and lack of a workable implementation plan. Monitoring South Africa's public ARV programme has involved confrontations between civil society and the national government, with provincial ministries playing on various sides. A recent assessment of the roll-out by a University of Cape Town Economist on the basis of data collected by the country's premier demographic model (ASSA2003) argues that "South Africa may have one of the largest HAART programmes (as claimed by President Mbeki in his 2006 State of the Nation address).¹⁶ However, given its resource endowments, this programme should be even bigger" (Nattrass 2006, 3).

Policy progress is measured according to "roll-out" rates. These rates represent the percent of people who progress to AIDS and get ARVs. By the end of 2005, national HAART coverage was approximately 25% (meaning that only one in four people who would need HAART are receiving it) (Nattrass 2006, 5). The actual number of people on treatment was approximately 124,000 in mid-2005.

¹⁵ The HIV prevalence statistics are notoriously ideologically biased; reputable statistics from different sources vary by more than a million people in their estimates of the number of South Africans living with HIV.

¹⁶ Mbeki, Thabo. (2006) State of the Nation Address. Available on <http://www.anc.org.za/ancdocs/history/mbeki/2006/tm0203.html>, last accessed 27 Oct.2006.

There are significant differences between the provinces. Some provinces have exceeded a 50 per cent roll-out, but there are huge variations with worst-performing provinces (Mpumalanga, Free State and Limpopo) covering barely 20 per cent of those who need care. For example, in mid-2005, it was reported that Limpopo Province had no accredited HAART sites, and showed “inexplicable contempt for civil society organizations,” and refused to release information on its ARV programme.¹⁷ One member of the AIDS Law Project responsible for monitoring the status of the roll-out in the province described the data collection situation after a field visit as “misty up there and dusty down here.”

We also see radically different provincial pictures in terms of HIV burden and health care provision. The Western Cape has a lower disease burden than other provinces in South Africa. Its HIV Prevalence rate among antenatal clinic attendees was 15.4 percent, about half of the national average of 29.5 per cent (Department of Health 2005). Western Cape is not surprisingly doing the best in the treatment roll-out with total HAART coverage¹⁸ of over 55% by the end of 2005 (Nattrass 2006, 5). Why is this region so successful? To start, it has the highest development index ratings in the country alongside the highest gini coefficient: it is both rich and unequal. Western Cape is the best-endowed province in the country for doctors, specialists and hospitals, with approximately 73 doctors per 100 000 people (Abdullah 2005, 246-247). Geographically manageable, two-thirds of the Province’s population reside in greater Cape Town. However, the poorest areas with the highest burdens of disease have the fewest facilities and the lowest number doctors per inhabitant in the city (Department of Health, 2004).¹⁹ Furthermore, nearly three-fourths of the population is dependent on public health services (*Ibid.*).

The Western Cape Province more closely resembles Uganda in its political approach to AIDS than it does to the other provinces in South Africa. The provincial tactic has emphasised openness, diversity (embracing NGOs), and leadership (see Naimak 2006 on South Africa and Parkhurst 2001 on Uganda). Public-private partnerships flourish linking pharmaceutical companies, bilateral

¹⁷ Notes from the fifth meeting of the Joint Civil Society Monitoring Forum meeting, 29 August 2005, Khayelitsha, Western Cape. Official minutes can be accessed from <http://dedi20a.your-server.co.za/alp/images/upload/report5thmeeting.pdf>, last accessed 27 Oct. 2006.

¹⁸ This represents the number of people on HAART in both public and private sector provision as a percentage of the number of people needing HAART estimated by the ASSA2003 demographic model.

¹⁹ See Chopra and Saunders 2004 for a discussion of the public health disparities between communities within the Western Cape.

and multilateral donors (like USAID and the Global Fund) and the Provincial Government of the Western Cape.²⁰

Flourishing outside the national political party line—not affiliated until very recently with the ANC—the Western Cape was left aside by a national government struggling with more important political constituencies. However, when the Provincial Minister crossed the floor, effectively switching sides to the ANC in 2005, it had immediate repercussions on the ARV programme, exemplifying how highly politicised this programme is. The Western Cape Province wanted to expand their coverage in PMTCT to provide triple therapy for women defined as “high transmitters.” Still it is the only province to provide dual therapy. The national regimen consists of providing the single drug nevirapine only. Without any warning, the Provincial Department of Health was ordered at the last minute that no changes in the regimen would be permitted: the National Ministry had told the Province to come back into line with the rest of the country signaling a victory of politics over policy.

ARV provision in the Western Cape comes in the form of a highly verticalised intervention. One of the leading ARV doctors in the region compared the HAART rollout to a “military operation” (Naimak 2006, 13). For example, ARK (Absolute Return for Kids)²¹ comes into a clinic where the province would like to begin offering ARVs with its “SWAT teams.” The militarised language, coupled with claims of running development like a business and unsurpassed evangelical zeal, are typical of the activist-implementer in the treatment of AIDS. The South African ARK Director stated in a public conference—“I feel like Noah building something to save South Africa!”²²

But notions of saving South Africa cannot be disentangled from the country’s historically-rooted, but ongoing, struggle with building a national identity. The level of inequality in South African society presents particular challenges for providing and receiving health care for AIDS. Relations of struggle and blame

²⁰ The Provincial Government entered into partnerships with at least six other NGO or research-based initiatives for AIDS treatment in public facilities in the Western Cape (Naimak 2006,7).

²¹ The mission of this organisation is to prevent children from becoming AIDS orphans by treating their mothers with ARVs. According to their website, “ARK funds clinical staff required for the ramp up of treatment (“SWAT teams”), community-based adherence support (primarily through “patient advocates”) and the NGO team and structure to manage the programme. We also fund drugs, lab tests, infrastructure and key diagnostic equipment where necessary to prevent bottlenecks and ensure rollout is as rapid as possible” (http://www.arkonline.org/projects/aids_treatment/).

²² From the PATA Conference, Cape Town, November 2005, researcher notes. Conference transcript can be downloaded from <http://www.teampata.org/proceedings.html?PHPSESSID=1adc79ba9d042eabd2a33f7f21921212>, last accessed 23 October 2006.

shape the way in which therapeutic citizenship must be understood. The founder of one of the province's largest ARV clinics and co-author of the country's national ARV treatment guidelines concluded: "All programmes are focused on the 'oppressed' and the 'innocent'. . . . All of our programmes are focused on women and children. . . men are guilty. . . men are the perpetrators" (Casey 2005, 50). Cleavages of race, class and gender continue to exacerbate disparities between individuals, communities and provinces in the country. Who can help whom and under which circumstances would someone be legitimately entitled to obtain help make a difference when accessing health care.

Heshima Clinic

Heshima clinic is located within the oldest township in the Western Cape, dating back to 1927. In many ways, Heshima clinic is a 'best case scenario' for ARV treatment in South Africa. Unlike most of the Western Cape's HAART facilities, Heshima is an integrated clinic, where ARVs are distributed together with primary health services, including family planning, nutritional counseling and limited psychological services. The clinic is well managed and mostly protected from huge NGOs and their accountability demands in order to enable staff to conduct their clinic work with minimal disruption. The site is also groomed to demonstrate success in an ongoing sub-regional political feud in the health sector. Heshima has an ideal staffing ratio,²³ shared leadership instead of a military model, and is not a research setting but an operational setting, according to the Regional Director responsible for the clinic.

Before turning to descriptions of the clinical interactions, I will give just a rough outline of the treatment terrain in the clinic from the patient's perspective. In doing so, I am charting the "usual" path of treatment flow as I saw it most often: this is neither the official protocol for how treatment should happen, nor is it the path taken all the time. For example, often patients are so sick that they are seen by the doctors first and "fast tracked" onto ARVs. However, most often, ARV treatment should begin with a visit to the "Patient Advocates" for the first counseling session. These are the lowest paid, semi-skilled youth counselors who do home visits and are on-call around the clock for ARV patients. Patient Advocates provide meaningful links between the "real people" and their caregivers and are the only service providers who are required to be "local" to the Heshima community. After the session with the Patient Advocates, a patient should have two visits with the ARV adherence counselors. These are highly skilled counselors, one male and one female, with experience in voluntary counseling and testing (VCT) for HIV. They are responsible for counseling for adherence and detecting any potential adherence problems before patients are

²³ There were four doctors working on site for most of the months I was working at the clinic.

permitted to begin ARV treatment. A visit to the nutritionist should also take place, but this seemed more erratic. A psychologist visit was prescribed for patients facing psychological problems that could possibly be clinically managed.²⁴

On Thursdays, meetings taking approximately three hours are held at Heshima clinic, and attendance by all members of the ARV “team” is mandatory.²⁵ Together, they decide on ARV initiation. The terms for assessment are both medical and social. Patients must have a treatment buddy, have been to requisite counseling sessions, have a contact person if not a proper address in the catchment area, and have no significant drinking or drug problems or severe mental illnesses. Also, if you want treatment you must perform responsibly as a therapeutic citizen: say that you will use a condom, that you will plan pregnancies with your doctor, try to receive appropriate government grants if not working, agree to eat well, refrain from traditional medicines, inform the clinic before traveling—especially before returning to the Eastern Cape²⁶, and be adherent to your meds. In the next section, I will draw on notes taken during these meetings to illustrate the difficulties of gendering the therapeutic citizens of Heshima Clinic.

Border Defense of the Therapeutic State

While the global treatment activist discourse would lead us to believe that Universal Human Rights to ARV provision or reproductive choice are upheld through global covenants, national policies and local treatment protocols, the reality is that the ethics of treatment are manifested in the quotidian workings of clinic life. The service providers, whether Patient Advocates, adherence counselors or ARV physicians are left to negotiate the complex biopolitical imperatives of the technologies with the “social issues” of life in Heshima township. Without neglecting the importance of the strictly biomedical realm of treatment for AIDS, my discussion will center on the “social issues” and how these constitute integral challenges in the treatment process.

²⁴ The psychological aspect of ARV treatment and service provision is a critical and underemphasised area of translation that merits further research.

²⁵ In practice, usually one or the other of the adherence counselors attended each meeting, but not both. The attendance and attention of all Patient Advocates was required. Meetings were led by the Regional Director or by the doctor-in-charge of the ARV program if the director was unable to attend.

²⁶ The population movements between Eastern and Western Cape are a persistent challenge for the health sector, as most patients, even long-term residents of the township, can be expected to return “home” for traditional ceremonies, important holidays and to attend to family affairs.

At the Heshima clinic, approximately 15 people on average are considered for placement on ARVs each week. There are more women than men.²⁷ Most of the women are mothers; some are pregnant. In the province, at least one third of all HIV tests are done on pregnant women in the MTCT programme and the other two thirds of those testing for HIV also include mostly women.²⁸ In spite of the fact that the “typical” ARV patient is a woman of childbearing age, very few studies have been done so far on family planning for women living with AIDS in the Third World. The existing ones emphasise the need to link contraceptive and AIDS interventions into a convenient service for women (de Bruyn 2005; de Bruyn 2004; Preble, Huber and Piwoz 2003; Best 2004). However, family planning practices are also used as meaningful performances of therapeutic citizenship as I will demonstrate from the ARV team meetings at Heshima Clinic.

As mentioned above, once per week the entire ARV team meets to discuss the patients who are being “worked up” for ARV treatment. Each file is taken up for discussion by the team who sit around a long table with copies of the abbreviated case summaries of all patients being considered to start on treatment during the coming week. The dialogue on each case begins with a medical report from the physician responsible for the patient. This is then followed by reading from a report in the file written by the social worker; however, this report is often missing. Then, a summary of the home visit and personal situation is given orally by the Patient Advocate. Afterward, a description of the adherence counseling sessions is given by the adherence counselors. If the patient has seen the psychologist or nutritionist and there are further comments, they are given as well.

Together with other relevant social criteria for ARV readiness, such as alcohol abuse or difficulty disclosing to a treatment “buddy,” contraceptive status is assessed during these meetings for almost all of the women who seek treatment. This assessment is not a simple matter of insuring that women on ARVs do not reproduce, although that may be the outcome. It involves a complex negotiation of reproductive management for the patient’s own good. How this “good” is determined involves investigation, speculation and, to some degree, participation of the women themselves. The biomedical facts of AIDS treatment

²⁷ Physicians interviewed in Cape Town estimated that at least 70-80% of their ARV patients were women because men do not come forward to receive treatment (Casey 2005, 48).

²⁸ Notes from Fareed Abdullah lecture, Univ. of Cape Town, 23 September 2005.

are considered by the ARV team in conjunction with the “social issues” that inevitably come forth in the case descriptions.²⁹

The biomedical report is the first determinant of whether a therapeutic citizen is potentially reproductive. Some women who are very sick are not considered “at risk” of pregnancy. One example is the case of Xoliswa. Her case was discussed as a potential patient who might start on ARVs, but because she was so ill, the team agree that she had to be sent to the hospice center for constant care while beginning the treatment regime.³⁰ Still, her doctor noted at her case discussion that the team will “re-discuss family planning when she’s better.”³¹ Recognising that the goal of ARVs is to bring Xoliswa back to life, and in doing so, she will be likely to return to the possibility of reproduction.

“Social issues,” or the situations and relationships that must be negotiated as part of living with AIDS into which ARV treatment plays only one part, have a significant effect on how a woman can be a therapeutic citizen. One example comes from Phumla, a 24 year-old unemployed mother of two children, ages five and seven. The family sleeps on the floor of a one room shack owned by Phumla’s friend and her friend’s boyfriend. When she was being considered for treatment, the team’s discussion turned to her support structure. The Patient Advocate reported that her sister had refused to be her treatment buddy, but now she has found another friend to help out in this role. She has no regular sexual partner, was diagnosed positive six months earlier. Phumla says that she wants another child sometime in the future, but she is currently taking the contraceptive injection. Having successfully performed as a therapeutic citizen thus far, it was agreed that Phumla should begin ARV treatment. However the “social issues” of sexual and reproductive desire, gender relations, familial stability, and poverty persist as limitations on Phumla’s therapeutic citizenship.

Another example comes from Faith, a potential ARV patient who sparked a debate among the team members as physicians tried to negotiate their role in her “social issues” and her family planning. Faith and her family are victims of recurrent seasonal fires attributable to cheap cookers inside flimsy shacks that regularly raze sections of the local informal housing settlement to the ground. She has two children who stay with their grandmother in a different township. When the team met to discuss her case, Faith had been living for months in a tent, pitched in another informal settlement far from her home, and was

²⁹ Note that all information in this section comes from fieldnotes taken at the ARV team meetings which were held in English. Names and any distinguishing information have been changed.

³⁰ The clinic has a cooperative relationship with one hospice organisation which will admit patients who are very ill and starting treatment in case they become sicker while suffering from immune reconstitution syndrome.

³¹ Fieldnotes 27-09-05.

complaining about a lack of food. However, Faith traveled to the Heshima clinic for care because she said that she wants to return to Heshima and is ready to start ARVs. Her compliance with the TB treatment was reported as “excellent” from her files. The programme head then asks the physician: “So are you going to put her on family planning or not?” The doctor responds, “It’s up to them. If we are forcing them they are not compliant.” A different doctor supports the first one, “They didn’t understand that condoms are not as effective as the injection. What happens if they fall pregnant? How bad is it going to be?” The programme head replies, ending the discussion, “We should be thinking about family planning in a broader context of family planning, not just contraception.”³² Here it was implied that the “social issues” of Faith’s life must be taken into account when her treatment regime, and its contraceptive component, is formulated by the physician. However, the discussion by the doctors about who is responsible for making contraceptive choices and how these choices relate to compliance is informative. As both of the previous examples demonstrate, ARV compliance must be negotiated within fundamental poverty constraints (where will you sleep, where can you get money, what do you eat) that are likely to be exacerbated by having more children. Yet, women are entitled to make their own reproductive choices, and these choices may contravene such planning for many various reasons. Providers are relying on Patient Advocates’ descriptions of spaces (geographical, racial, sexual and economic) that they do not inhabit. This translation dance is not always successful. For example, one young woman whose name was on the pharmacy list for not having picked up the medicines that were prescribed for her was unwilling to start ARVs because she did not want to use the contraceptive injection, according to her patient advocate.

The choice of drugs that make up the ARV regime must consider the probability of pregnancy in each woman’s case. The possible drug interactions on a pregnancy is just one factor that must be considered, alongside the possible side-effects, effectiveness and if a pregnancy is desired. Additionally, there are macro-constraints of cost and availability and the disparity between regional health systems, which also must be considered for patients at Heshima clinic. One such example comes from the difficulty of prescribing the correct drug of a particular class necessary for the first-line regimen. Efavirenz is not recommended for use during pregnancy because of its link to birth-defects. Yet, for maintaining a woman’s health, Nevirapine needs better monitoring and more consistent follow-up as part of the first-line regimen than Efavirenz.³³ A physician stated that because this rarely happens, even in the best situations in

³² Fieldnotes 20-10-05.

³³ Efavirenz and Nevirapine are types of medicine called non-nucleoside reverse transcriptase inhibitors (NNRTI). NNRTIs block reverse transcriptase, a protein that HIV needs to make more copies of itself.

South Africa, that they were usually anti-Nevirapine at Heshima clinic. Instead, they usually make all women get a contraceptive injection³⁴ and be on Efavirenz. However, the Nevirapine is cheaper, so for patients who might be likely to transfer to another clinic in a province where Nevirapine is more easily available, like the Eastern Cape where there is significantly less funding for ARVs, it might be doing them a disservice to start on a better Efavirenz regime and then later have to switch to Nevirapine if they return home.

One example of struggling with these issues comes from the team meeting around the patient Catherine, a forty-year-old mother of five children. Catherine is married to an HIV positive man and depends on his government disability grant for support. She lives in a room that shelters seven families. It was in her file from the case work-up with the adherence counselor and physician that she was not on family planning, but had been encouraged to start. Catherine had already been in counseling to start ARVs months earlier, but she disappeared when the time had come to actually begin them. It was reported at the team meeting that she had said that it was because of the six other families that she did not want to start the drugs. It was noted that her living situation has not changed, but now she is so sick that she is ready to start the ARVs. Catherine is taking the contraceptive injection, and the doctor asks if it is current. After looking at her chart, it is reported that it is not. She is started on the ARV regimen that includes Nevirapine, just in case she falls pregnant.

Discourses of liberal individualism, choice-making and reproductive rights are framing the policies and practices at Heshima Clinic. Yet, a patient was noted to have “just started on contraception two weeks before because we forced her.”³⁵ Others are described as “being on family planning specifically for the ARVs.” Together with the “social issues,” women on ARVs must add the dual possibility of an AIDS-infected baby and one with birth defects attributable to the mother’s treatment regime. ARV treatment complicates the negotiating logics, already difficult to disentangle from poverty and fertility desires, for realising reproductive choice.

Is the very nature of being a woman with AIDS who is the mother of an infected child in the Western Cape excluded from the possibility of therapeutic citizenship because it can be assumed that you have “failed” PMTCT? The Provincial Deputy Director responsible for the ARV programme stated in a public lecture that in Khayelitsha where MSF has had the longest running ARV programme in Africa, they have been so effective with their PMTCT programme that today if a child is born with AIDS the presiding doctor will call all the other

³⁴ The injection is favored for its effectiveness and because its provider-dependency makes for easier monitoring by the clinic staff.

³⁵ Fieldnotes 20-10-05.

doctors to come and see. What will happen as more PMTCT services become available throughout the country and the Third World? Will women be penalised for bearing a positive child? Will these debates follow the examples of prenatal testing and genetic disorders?

The example of Vusiwa provides us with a twist on the notion of treating the mother with ARVs to protect the child, as in her case, the child's treatment resulted in a commitment to treatment by her mother. Vusiwa, a 31 year-old mother of an eight-year old and a three-year old child, was afraid to start ARV treatment. She was sent to the psychologist because it was reported that she had not processed her anger from her previous relationship where she was infected with HIV. She is now in a relationship where she gets support from her boyfriend who is reported to be HIV negative. Her three-year-old daughter has been on ARVs since 2003, and now Vusiwa feels confident about getting her own treatment at the same time as her daughter. At the time of the team meeting report, Vusiwa's CD4 count was down to 100. It was reported that she does not know if she wants to have more children, but for now she is using family planning and condoms.³⁶

Clinic level data remind us that it is worth explicit research consideration that women with AIDS do get pregnant, whether they are on treatment or not. As PMTCT expands into HAART in developing countries, more attention is needed to how mothers and their children negotiate AIDS care, and as such act as gendered therapeutic citizens. These examples suggest that while we can chart some of the parameters of the female therapeutic citizen, we cannot adequately describe the socially structured and heterogeneous processes that result from the decisions taken on these performances. ARVs and family planning for women do not come as a consistent imposition of biopolitical discipline relying on medical authoritarianism, as one might expect given the political, racial and economic history of the case. Instead, we see complex negotiations between "ought" and "can", "possibility" and "probability", ethics and protocols. All of which are conducted on the basis of highly imperfect information, requiring multiple layers of translation within a context of complicated and sometimes competing agenda. Women and their providers are pragmatically negotiating a very messy terrain of "social issues" and complicated biosociality in which the fact that women are regularly over-victimised does not mean that they adequately control their sexual or reproductive lives. It is in these interactions where women do have input into the decisions made over their health, even in a formal, medical setting, where the possibility of performing as a gendered therapeutic citizen becomes important.

³⁶ Fieldnotes 27-09-05.

Biopolitical technologies versus “social issues”: Counselling the Therapeutic Citizen for Family Planning

The counseling context for ARVs in South Africa is an overdetermined biopolitical arena into which ethnographic descriptions only scratch superficially along the grid. The historical legacy of apartheid predisposes us to question the motivations of health professionals, as the entire system of public health under apartheid was structured and staffed to insure that nonwhites were well enough to work but without excess energy for political struggle. Critical work on apartheid public health emphasises the elements of what Stoler terms biologised racism that “establishes a positive relation between the right to kill and the assurance of life” (1995, 84). Yet this authoritarian endowment has also resulted in a contemporary culture that emphasises Rights in post-apartheid South Africa. Reproductive rights are enshrined in the South African constitution, as are the rights of people living with HIV/AIDS.³⁷ Not only are these codified forms of authority, but also Rights are popularised notions as the earned inheritance of all contemporary South African citizens who have come out of the struggle.

In the previous section, we saw the “team” of ARV experts trying to negotiate these ethical dilemmas in ways that will determine when, how, and if, a woman will receive access to ARV treatment at the clinic. However, when a woman is being “worked up” for ARV treatment, it is the sessions on adherence counseling that are most central in forming the identity of the therapeutic citizen. The hard-working adherence counselors take patients alone, or with their “treatment buddies,” into one of the counseling bungalows and try to counsel them on how to negotiate the biosocial terrain of treatment. This can involve the dissemination of information, the management of concerns and fears, and the transmission of values within the counseling context.³⁸

One example of the kinds of negotiations around family planning while on ARV treatment comes from a young couple from the Eastern Cape. Nancy and her husband came in for the second counseling session with the female adherence counselor. They have been living in an informal camp for “temporary” housing since 1999 and have a seven-year-old child who lives with his grandparents in

³⁷ Launched in 1992, the Charter of Rights on AIDS and HIV is a bill of rights for people living with HIV/AIDS in South Africa and forms the legal basis for ending discrimination and promoting public health (<http://alp.org.za/images/upload/3rdAids%20finalss%20append.pdf>).

³⁸ Material in this section on counseling comes from fieldnotes written by the author at the time of simultaneous translation of the interactions into English. All sessions were observed with explicit permission from all participants involved, and all names are pseudonyms.

their home region but entitles them to state-funded child support. The adherence counselor explained to Nancy and her husband:

The drugs are not forced on people . . . the reason why we don't push people on these drugs is because it is a lifetime commitment. You are both young, and maybe one day you will want children. If the girl wants the drugs then she will have to hear all about what she must know. She must take her drugs every day. The virus is so clever that if you skip one day the virus will build resistance. The drugs suppress the virus . . . you're rebuilding your body and it becomes strong and the patient will live longer. These drugs we're going to give her are three different regimens: two you take twice a day and one at night. But if you decide that you want to have children, we will take out the one at night and replace it with Nevirapine.

But you must stay together. Talk together and come and sit down with the doctor so that you can have the chances explained. If you [referring to the husband] are HIV negative again then your chances are higher to get a child. You can be referred to a fertility clinic, and they will explain your chances of getting a child. Nancy has told the doctor that she doesn't need a baby now, so it's OK to start her on these three regimens. She cannot fall pregnant taking Stavodine because it can affect the pregnancy. This is why she is supposed to use contraceptives. If can becomes pregnant, the child won't be normal.

Being a successful therapeutic citizen requires choice, commitment, spousal communication, and control of a woman's fertility. Implicitly, it is recognised that a health child could be the potential reward for a job well done. The meaning that ARV treatment provides to couples is that they can resume their lives, and in doing so, reproduction will mark success.

Pregnant, young Thandi came in for her second counseling session with the male adherence counselor, bringing her mother to act as her "treatment buddy" in hopes of getting quickly on ARVs to treat her own disease and protect her unborn baby. After explaining the virus and the drugs, the counselor advised Thandi's mother:

She can come for the PMTCT programme so that the virus can be suppressed. The virus is in the blood so a child can be infected during pregnancy, labor and breastfeeding so these drugs, they're made to prevent that. The results are positive so the Americans said, 'So if this is working, why don't they give everyone the drugs so that the mother can raise her child on her own. At the same time, the English people said that this is good, now you are preventing the mother and child, but what about their fathers?' So in England they introduced these drugs to everybody, so now everyone can have a prolonged life.

Linking the drugs with international support may have been an attempt to reduce their stigma and build their associated credibility, in which my own presence as a foreign observer in the room may have provided a silent complicity. It also

provides an example of the external-orientation of the ARV programme specifically and the Western Cape health department in general. When the national government cannot be counted on to support the ARV programme, distant alliances are constructed within the viable discourses of cost-effective child raising by poor African women.

The counselor continued to explain to Thandi and her mother the biosocial regimen of childbearing on ARVs:

Let's say you don't want only one baby, and maybe you'll get married. These days you must suppress the virus so if you want another baby and your CD4 count is high [you can have one]. The first few months when we start treatment, we will draw blood to see the progress of the virus in your body. If the CD4 is greater than 450 and the virus is suppressed, then you can have another baby. If the CD4 is over 450, the virus is undetectable, and the chances of the baby being affected are slim. It depends on your partner. If he is also positive and has a suppressed virus, then the doctor will agree that you can have another baby. Now your CD4 count is low, and after this baby is born you can go for contraception. Afterward you must use condoms all the time. You are on treatment and your boyfriend is not, so if you don't use a condom he will need treatment and your drugs won't do. It is dangerous to sleep with somebody not on treatment. We say to use condoms because the contraception is not 100% safe. Sometimes a condom can be torn, then you must also be using contraception -- maybe Petogen or Depo Provera.³⁹ We always say to use contraception and condoms both. When you need another baby and both you and your partner have the virus undetectable then the doctor will arrange for you for that. This doesn't mean that if you are HIV positive you can't get a child, but if your CD4 is high we must protect the child.

The previous explanation by the counselor illustrates many of the complexities of reproducing the therapeutic citizen. The use of conditional language, "if, then" implies a management strategy and a controllable outcome. If, both parties are able to manage their sexual encounters and their viruses, then they have the chance of achieving a healthy child. The clinic team is there to help protect the potential child through management of the virus. However, the corporeal sign, drawn through the blood, will tell if a patient can reproduce or not. Furthermore, the regime of recommended reproduction is quite complicated, using dual method protection of condoms and contraceptive injections, and it is made more so in the context of the patients' "social issues."

In the counseling session described, after the extensive explanation of the possibility that she might want another child in the future, Thandi astutely ruptured the protocol of possibilities with the concern for her immediate, already pregnant, situation. Thandi asked the counselor at this point: "Are those pills not going to cause any problems for my baby [currently in utero]?" While the

³⁹ Both are injectable family planning methods that provide contraceptive protection for twelve weeks.

professional counselor had been quite effectively explaining the protocol of how a woman on ARVs might continue with a “normal” reproductive life, the patient’s response signals a pragmatism that brings forth the contradictions in gendering the therapeutic citizen. These protocols are based on forethought, evidence-based planning, and meticulous control of reproductive decision-making. They are not necessarily relevant for the woman who finds herself pregnant with a low viral load and need for ARVs for her own virus as well as for her child. The understandings gained by in-depth research on reproductive decision-making (cf. Bledsoe 2002; Johnson-Hanks 2002, Greenlaugh 1995) show that choices over childbearing and methods for its prevention are contingent upon women’s perceptions of their physical and social situation, and that the circumstances of auspicious childbearing vary greatly across individuals and communities. This attention to both the particular, and the social, has not been incorporated at all into the new and more complex settings of AIDS treatment. Instead, as a recent study demonstrates, a development intervention matrix on “pregnancy status, HIV status and service delivery needs” with two separate columns for “wants future pregnancy” and “does not want future pregnancy” is still used (Preble, Huber and Piwoz 2003). If there is any reasonable hypothesis to be made on the reproductive decision making of women living with AIDS, it would be that the issues of contingency become even more pronounced in their lives than in the lives of women who are not currently struggling with the virus.

Gendering the Therapeutic Citizen? Future Directions

Therapeutic citizenship exists as “a form of stateless citizenship whereby claims are made on a global order on the basis of one’s biomedical condition, and responsibilities worked out in the context of local moral economies” (Nguyen 2006, 142). The structures of both the global order and the local moral economies around the reproductive behavior of women on ARV treatment seem to exist simultaneously beyond impassable terrain, yet call for articulation to form the basis for action and activism. Evidence from fieldwork in the Western Cape suggests that these matters of clinical concern that come at the interface of “social issues” and ARV technologies are so jagged that they do not produce a reflexive response. We cannot simply use existing knowledge on ARV treatment regimes wedded together with models of reproductive desires and contraceptive use. Therefore, the performance aspect of the therapeutic citizen becomes invaluable, as does the translation effort of the Patient Advocate, who is situated in a no-man’s land of the biopolitical state – neither fully citizen nor sovereign.

Paul Roux, a well known Cape Townian physician and founder of the pediatric HIV clinic at Groote Schuur Hospital, described his treatment experiences with mothers on ARVs. These women have high rates of pregnancy when they feel that they have become healthy again with ARVs. A practitioner and pragmatist, he explained: “You can’t expect to restore someone to personhood and not allow them to procreate.”⁴⁰ How then will it become possible for women to be full “therapeutic citizens” whose gendered claims are taken seriously within both the global order and the local moral economy?

Implicit in most of the literature, discussions and activism is the notion that HIV positive women who are pregnant have often discovered their status in the process of antenatal care, not that they have knowingly conceived a pregnancy while aware of their positive status. Even activist organisations in South Africa and Uganda have had a difficult time dealing with the possibility of reproductively active HIV positive women. Therapeutic citizens, we might be led to believe, do not reproduce.

But as the case study here demonstrates, women on ARVs do reproduce, thus it is important for research to focus more specifically on the gendered realities of AIDS treatment. Do women who are already therapeutic citizens and biomedical beings, and who have become accustomed to routine monitoring, biosocial audits and complex negotiations between people and pills attribute different meanings to the clinic experience? If one’s life is highly medicalised, does then the demand for physician interaction, specialized decision making and incessant intervention in the reproductive process become routinised to the point of greater tolerability and increased effectiveness? Is it reasonable to expect that women on ARVs take a far more active role in evaluating, planning and controlling their reproductive lives than women who are not on AIDS treatment? How can we meaningfully integrate “social issues” into our understandings as more than just justifications for “noncompliance”? These issues coalesce around questions of the meanings of care, looking after one’s self, and the extent to which “self” and pregnancy are juxtaposed.

What are the implications of the conceptual difficulties of gendering the therapeutic citizen? Perhaps this speaks to the limits of HIV/AIDS in people’s lives: the disease is not determining in ways that are clear, unilateral, functional or consistent. If women with AIDS reproduce in ways that bear a striking resemblance to women without AIDS, why should this be so surprising? Are women with AIDS simply reflecting yet another identity, positioned strategically or haphazardly alongside the many other indices of social evaluation in South Africa (race, class, religion, etc.)? Women on ARVs who want to become pregnant while remaining good therapeutic citizens must

⁴⁰ Paul Roux, presentation at the PATA Conference, Cape Town 29 November 2005.

exercise a vast and steadfast discipline of the self and the sexual “other,” and additionally must master the performance and pragmatism of dealing effectively with the concurrent potentiality of life and death.

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