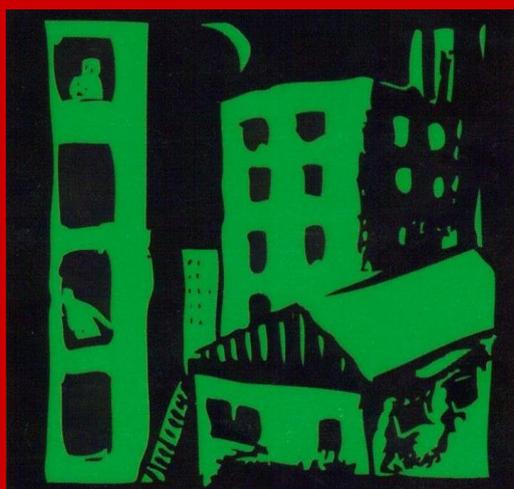


LAW
DEMOCRACY
& DEVELOPMENT



VOLUME 24 (2020)

DOI: <http://dx.doi.org/10.17159/2077-4907/2020/idd.v24.7>

ISSN: 2077-4907
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**Shifting
consciousness and
challenging power:
Women activists
and the provision of
HIV/AIDS services**

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ABSTRACT

In 2003, the South African government shifted AIDS policy making HIV treatment available in the public healthcare sector. The antiretroviral roll out, while hailed as a success, has required continued activism to ensure genuine implementation. Women particularly the poor, traditionally bear the brunt of the impact of HIV/AIDS

socially and economically. Very often they do this in most marginalised spaces. This paper draws on theories of participation and empowerment to understand female activism during the period of antiretroviral roll out in South Africa. The paper seeks to understand how processes of empowerment linked with the first stage – access to ARVs impacted on the second stage - ARV roll out .It also considers how female activists understand their empowerment in the context of their role. The focus is grassroots activism females in Lusikisiki and Khayelitsha. This paper draws from a qualitative study on bottom-up policy advocacy utilising participatory observation and in-depth interviews with activists and civil society organisations. The main findings are that during the roll out phase of the HIV/AIDS campaign women activists worked from transformed “ways of thinking and being” in terms of HIV/AIDS and in terms of their role in the struggle for health rights. Their contesting embedded notions of power contributed to the democratisation of HIV/AIDS services. The transformation also caused shifts in the ways women mobilised, framed their understanding of the struggle and accessed participation spaces.

Keywords: HIV, AIDS, ARVs, health activism, gender power.

1 AIDS POLICY AND THE ROLL OUT OF ARV TREATMENT IN SOUTH AFRICA

HIV/AIDS prevention and treatment policy has been the subject of much debate in South Africa. Anthony Butler has argued that two schools of thought prevailed in this debate in relation to the nature of the HIV/AIDS challenge and an appropriate government response thereto .¹ The first of these was what he terms the “mobilisation/biomedical” paradigm emphasising society-wide mobilisation, political will and antiretroviral (ARV) treatment. The second was the “nationalist/ameliorative” paradigm with an emphasis on poverty, individual responsibility, palliative care, traditional medicine and appropriate nutrition.

Activism associated with the first strand involved both anti-apartheid health sector organisations and organisations/movements centred on a legal and human rights focus.² Among these were the AIDS Consortium, the AIDS Law Project, the National Association of People Living with AIDS, and the Treatment Action Campaign (TAC). Their main call was for the provision of ARV treatment in the public healthcare sector which only came into effect in August 2003.³ Central to the initiation of an operational plan for an ARV treatment programme were the sustained activist campaigns of the

¹ Butler A “South Africa’s HIV/AIDS policy 1994-2004: how can it be explained? “ (2005) *African Affairs* 519 at 592.

² Schneider H “On the fault line: the politics of AIDS policy in contemporary South Africa” (2002) 61 *African Studies* 145 at 157.

³ Progressive health workers had taken up the issue of AIDS in the early 1990s to shape the first National AIDS Plan. See Mbali M *South African AIDS activism and global health politics* London : Palgrave Macmillan UK (2013) at 28.

TAC. These included a civil disobedience campaign as well as legal action brought against the State by the TAC resulting in a court judgement in 2002.⁴ The judgement ordered national and provincial governments to make the ARV nevirapine available to pregnant women in the public healthcare sector for the prevention of mother to child transmission of HIV.

The roll out of ARV treatment in the public healthcare sector only gained impetus in late 2004 or early 2005 and by 2006 less than one-third of the planned number of patients were being treated.⁵ Challenges to the roll out included a lack of political will in continuing with the AIDS denialism of the Mbeki Administration, where the Minister of Health for example promoted alternative remedies for HIV, such as “garlic lemon and olive oil”, referring to ARVs as “poison”.⁶ Other challenges identified at the inception of the roll out were in relation to infrastructural, resource and financial capacity.⁷ These challenges prompted continued activism by the TAC and activists which moved beyond advocating for the “right of access to treatment”⁸ to include supporting “universal access to prevention, treatment and care for all people living with HIV/AIDS and other illnesses”.⁹

2 SOUTH AFRICAN AIDS ACTIVISM AND THE ROLE OF FEMALE ACTIVISTS

Mandisa Mbali has noted that people living with AIDS in South Africa lacked hope and were ill-informed about HIV and that this was countered by their joining the TAC which empowered them as citizens.¹⁰ She notes that participating in the TAC rendered them “more informed, less scared and a step ahead of the virus”.¹¹ Steven Robins and Bettina von Lieres argue that the TAC utilised complementary modes and sites of activism ranging from transnational advocacy and networking to intensive lobbying with government, as well as litigation. In this sense “invented” as much as “invited” spaces of participation¹² were invoked.¹³ They also note that the majority of TAC volunteers were working class township youth and unemployed African women. Many of these women were HIV positive and in need of medication for themselves and their HIV positive children. They therefore represented those marginalised by an unjust health system

⁴ *Minister of Health & others v Treatment Action Campaign & others* (CCT8/02) [2002] ZACC 15.

⁵ Natrass N “AIDS and the scientific governance of medicine in post-apartheid South Africa” (2008) 107 *African Affairs* 157 at 167.

⁶ See Natrass (2008) 167.

⁷ See generally Willan S “Recent challenges in the South African Government’s HIV/AIDS policy and its implementation” (2004) 103 *African Affairs* 109.

⁸ Heywood M “South Africa’s Treatment Action Campaign: combining law and social mobilisation to realise the right to health” (2009) 1 *Journal of Human Rights Practice* 1 at 15.

⁹ See Heywood (2009) at 23, citing the TAC National Executive Discussion Document of 2007.

¹⁰ See Mbali (2013) at 173.

¹¹ See Mbali (2013) at 173.

¹² See generally Miraftab F “Feminist praxis, citizenship and informal politics: reflections on South Africa’s Anti-Eviction Campaign” (2006) 8 *International Feminist Journal of Politics* 194.

¹³ Robins S & Von Lieres B “Remaking citizenship, unmaking marginalisation: the Treatment Action Campaign in post-apartheid South Africa” (2004) 38 *Canadian Journal of African Studies* 575 at 579.

and often also by their own communities on the basis of their status. These women were therefore readily recruited into TAC campaigns, and “the most important reason for the successes of the TAC’s grassroots mobilisation has been its capacity to provide poor and unemployed HIV positive mothers with hope and support”.¹⁴ Mbali expands on this point pointing out that there were at the time limited sources of social support for women AIDS activists who had to contend with sexism in AIDS related science and the women’s movement’s low prioritisation of the epidemic.¹⁵ The aim of this article is to focus on female activists as women dominated the grassroots mobilisation in the case study areas. Their roles were critical in shifting consciousness and building the movement despite the social and cultural identities imposed on them.

The TAC creating spaces and platforms for democratic discourses on health provided previously powerless/voiceless people with political agency. In the case of women it provided an opportunity to assert control over lives and bodies.¹⁶ Robins and Von Lieres argue this is evident in the challenges to patriarchy that stood in the way of women accessing HIV testing/prevention and prevention of mother to child programmes.¹⁷ It was also evident in the challenging of the stigma around HIV. These new forms of bio-power discourse influence subjectivity and new forms of identities associated with illnesses. Robins further argues that experiences of illness, treatment and participation in the TAC¹⁸ have produced radical transformations in subjectivity and identity that go beyond conceptions of “rights and ‘citizenship’” to produce “responsibilised citizens”.¹⁹ Responsibilised citizens are required for effective AIDS treatment and adherence leading to the successful management of the roll out. Robins further shows how participation of HIV positive people, and particularly those who experienced a miraculous recovery through ARV treatment, promoted the commitment to a “new life” and to social activism (which sealed the TAC’s successful grassroots mobilisations). For Robins these experiences constituted the “raw materials” for the construction of a new *positive*²⁰ HIV identity together with the building of social solidarities.²¹

Studies focused on AIDS activism in Lusikisiki and Khayelitsha (two critical sites of AIDS activism) in the Eastern and Western Cape provinces, respectively, reveal the ways in which the new positive HIV identity became entrenched. Robins’s study shows how AIDS activists transformed the lives of people living with AIDS in Lusikisiki by positioning them to better manage their physical symptoms. They did this by translating

¹⁴ See Robins & Von Lieres (2004) at 580.

¹⁵ Mbali (2013) at 102.

¹⁶ Robins & Von Lieres (2004) at 580.

¹⁷ Robins & Von Lieres (2004) at 580.

¹⁸ Robins includes here the MSF sites as these were critical to the ARV roll out.

¹⁹ Robins S “From ‘rights’ to ‘ritual’: AIDS activism in South Africa.” (2006) 108 *American Anthropologist* 312 at 312.

²⁰ Our emphasis, noting the choice to take a positive rather than negative view of HIV/AIDS.

²¹ See Robins (2006) at 314.

biomedical ideas and practices into vernacular forms that could be understood and followed.²² In this sense rural dwellers were “converted” to AIDS science, and changed behaviours and practices as a result. This was vital in a context where dominant discourses questioned the efficacy of AIDS medication, and highlighted debates about potential toxicity. MacGregor’s study shows how AIDS activists in Khayelitsha (specifically a group of HIV positive women) came together in a “body mapping” exercise to “democratise AIDS science” and further AIDS literacy.²³ The idea behind the exercise was to “create expert patients” who understand their bodies. Through the “body mapping” exercise people living with AIDS had the opportunity to consider the relational aspects of being HIV positive. In this way the “activist emphasis” on body politics “became a way to counteract fears of the virulence” of HIV.

3 PARTICIPATION AND “EMPOWERMENT”

Faranak Miraftab notes that feminist theorists have challenged conventional notions of citizenship, revealing that political arenas of citizenship include the political activities and agency of women in grassroots spaces.²⁴ She adds that development projects acknowledge community based informal polices and grassroots activism even as prevailing neoliberal policies erode women’s livelihoods and opportunities for access while also “depoliticising grassroots participatory discourses”.²⁵ Miraftab argues that grassroots mobilisations occur within a wide range of spaces of citizenship. These may include formal or informal channels, “invited” and/or “invented” spaces. They may also incorporate survival/coping strategies. They may also extend to resistance in the form of challenging underlying structural and systemic causes of social malaise. For her, the challenge is to expand understandings of grassroots activism to consider how new spaces of citizenship practice are invented to achieve substantive citizenship.

Implicit in these forms of citizenship are the ways in which grassroots activism facilitate a process of Freirian “conscientisation”. Here “ways of thinking and being” are transformed to reach a new level of awareness as well as an awareness of oppression. This includes becoming aware of being an “object of others’ will” rather than a “self-determining subject”. This transformation, “empowerment” or liberation from “disempowerment” results in societal transformation.²⁶ John Harriss notes that in feminist theory, a society in which women are treated equally comes about as a result of “changed perceptions and ways of being through the transformation of the self”.²⁷ In

²² See generally Robins S “Foot soldiers of global health: teaching and preaching AIDS science and modern medicine on the frontline” (2009) 28 *Medical Anthropology* 81.

²³ MacGregor H “Mapping the body: tracing the personal and the political dimensions of HIV/AIDS in Khayelitsha, South Africa” (2009) 16 *Anthropology & Medicine* 85 at 87.

²⁴ See generally Miraftab F “Invited and invented spaces of participation: neoliberal citizenship and feminists’ expanded notion of politics” (2004) I *Wagadu* 1.

²⁵ See Miraftab (2004) at 2.

²⁶ Harriss J “Antinomies of empowerment: observations on civil society, politics and urban governance in India” (2007) 42 *Economic & Political Weekly* 2716.

²⁷ Harriss (2007) at 2717.

this sense social change is effected within individuals rather than from changes imposed from the outside. “Empowerment” therefore presents a challenge to existing power holders.

Srilatha Batliwala argues that the term “empowerment” in the context of women’s struggles has suffered various co-optations and in the process become significantly depoliticised.²⁸ Batliwala notes that “empowerment” was conceived as a “political and transformatory idea” challenging patriarchy as well as structures, such as, class, race and ethnicity. It was rooted in Gramscian notions of the subalterns - those denied a “voice” by virtue of existing outside of established institutions. For her “empowerment” is about “power” and more specifically “shifts in political, social and economic power between and across both individuals and social groups”.²⁹ She questions whether the term “empowerment” is worth reclaiming and argues that new concepts and strategies need to emerge through “listening to poor women, their movements ... their values, principles, articulations and actions”.³⁰

Andrea Cornwall draws on Batliwala’s work to examine the critical aspects of “empowerment”.³¹ She argues that the World Bank’s understanding of “empowerment” focuses on “assets” and “opportunity structures” women are able to access. This then is an example of how “the relational nature of empowerment has fallen out of the frame”.³² For Cornwall the transformative aspect of empowerment – addressing the root causes of poverty and the structural basis of inequality - requires more than access to assets or formulating enabling institutions and policies.³³ She argues that two vital “levers” are necessary to attain transformation. The first of these are processes that produce shifts in consciousness. The second is engagement with culturally embedded normative beliefs about gender, power and change.

In the case of the former, limited normative beliefs and expectations that keep women in subordination and dependency need to be overturned. This includes challenging cultural and social norms and contesting institutions. Cornwall illustrates this process with an example from a Brazilian training programme, *Chapeu de Palha Mulher*, where women received training which led them into employment but also transformed the ways they viewed themselves and vocations traditionally in the domain of “men’s jobs”.³⁴ This transformative process led to an expansion of horizons and access to an income.

²⁸ See generally Batliwala S “Taking the power out of empowerment: an experiential account” in Cornwall A & Eade D (eds) *Deconstructing development discourse: buzzwords and fuzzwords* Warwickshire : Practical Action Publishing & Oxfam (2010) at 111-122.

²⁹ Batliwala (2010) at 114.

³⁰ Batliwala (2010) at 120.

³¹ See generally Cornwall A “Women’s empowerment: what works?” (2016) 28 *Journal of International Development* 342.

³² Cornwall (2016) at 345.

³³ Cornwall (2016) at 345-346.

³⁴ Cornwall (2016) at 347.

In the case of the latter, different ways of framing the social world together with a “new language and lens through which to view realities” emerge. Cornwall adds that these processes include women coming together to share experiences and solidarity. Drawing from female empowerment initiatives in India, Batliwala argues that when women are facilitated to “recognise their own agency and power for change”, they begin to “locate and articulate the changes they want to make and evolve strategies to do so”. This was evidenced when grassroots Indian women were mobilised into “sanghs” through which they developed their own agendas for change.³⁵

Drawing upon a definition of empowerment as being about transforming power relations “in favour of those who previously exercised little power over their own lives”,³⁶ including control over resources and ideology, this article takes up Batliwala’s challenge to “listen” to women’s articulations and actions with the aim of expanding understandings of grassroots activism.³⁷ The focus of the article is to understand female activism during the period of the HIV medication (ARV) roll out in South Africa. Specifically, to understand how the processes of “empowerment” and “responsibilisation” linked with the first stage of the HIV/AIDS struggle (access to medication) impacted on the second stage (medication provision). Also, how do female activists understand “empowerment” in the context of their continuing role to ensure HIV/AIDS policy delivery in South Africa?

4 METHODS

This article is based on a qualitative study conducted in 2015/2016 focused on bottom-up policy advocacy and participation in AIDS policymaking in South Africa. The study utilised participatory observation and in-depth interviews with over 70 respondents, including activists, civil society and government health officials at various levels. This article, however, draws specifically upon ten in-depth interviews with female activists based in Lusikisiki and Khayelitsha. Lusikisiki and Khayelitsha represent a rural area and an urban township, respectively, in the provinces of the Eastern and Western Cape. Both sites have an entrenched culture of local HIV/AIDS activism and a significant role in policy influence. They are uniquely interesting as they represent sites of HIV activists who are crucial actors in shaping policy development and implementation. Further, they provide both a rural and an urban perspective on approaches to local activism and offer insights owing to the strong presence of the TAC and Medecins Sans Frontieres (MSF) which have a bearing on levels of participation and active citizenship through AIDS advocacy.

5 SHIFTS IN CONSCIOUSNESS

Activists interviewed for the study displayed a very clear sense of transformed “ways of thinking and being” on the issue of HIV. This was evident in the way they viewed

³⁵ Batliwala (2010) at 6.

³⁶ Cornwall (2016) quoting Sen G *Employment as an approach to poverty* (1997) Working Paper Series 97.07. UNDP Human Development Report, New York.

³⁷ See generally Miraftab (2004).

themselves in their context: “I am an activist all the time.”³⁸ There was also a sense of the positive rather than the negative in connection with having HIV : “When I got tested, I was fortunate enough to be called a survivor...in my space I never gave anyone a chance to call me negative names.”³⁹ This occurred in a context where “labelling” those who contracted HIV is common : “I have been called lots of things ... especially the nicknames we get from the townships like: you have battery.”⁴⁰ These accounts confirm shifts in perceptions around HIV and those who are HIV positive which had begun during the TAC’s original campaign. During the roll out phase activists operated from an entrenched “positive” HIV identity.⁴¹

This was apparent in activists arguing that they were not uncomfortable being identified as People/a Person Living with HIV (PLHIV) as it did not necessarily define them :

“... it’s not who I am, it’s something that I have because why don’t we call women with cancer PWC or those with diabetes PWD and what frustrates me or disturbs me is the term AIDS orphans. I hate it because if we are going to have AIDS orphans why don’t we have diabetic orphans or road accident orphans?”⁴²

In this sense, the stigma prevalent around HIV had been visibly broken down , and this was reflected in how activists identified themselves in relation to HIV as a treatable disease rather than an identity separating them from others. There were a number of accounts, however, detailing continued encounters with stigma :

“I was standing in a queue at the bank wearing my HIV+ t-shirt and suddenly realised that the queue was moving but the space around me was maintained with a significant distance between the person in front of me and the one behind me....The other occasion was when I purchased something at a shop and the shop owner literally avoided handing me the change in my outstretched hand but threw it on the counter.”⁴³

On a more personal level :

“I went to church with my boyfriend to support me because I was giving a talk and I was introduced as a person living with HIV and I could see the shame in my boyfriend’s eyes because he is negative (HIV-).”⁴⁴

³⁸ Interview with TAC0064.

³⁹ Interview with TAC0047.

⁴⁰ Interview with TAC0079.

⁴¹ See Robins (2006).

⁴² Interview with TAC0079.

⁴³ Interview with MSF0059.

⁴⁴ Interview with TAC0047.

Activists nonetheless see themselves as “survivors” and key components of a social struggle, indicating an emphasis on the victorious but also on the “change maker”. In this sense there was an emphasis on activism for the greater good, as an activist challenging the police during a march asked : “... Why beat us when we demand our treatment? What if it was your mother, brother, your sister, your blood? ... and some of you SAPS⁴⁵ members are also living with HIV and you don’t have access to treatment, you need us to make it available for you.”⁴⁶

Transforming views and frames related to HIV/AIDS and the role/place of female activists were in effect threefold. Activists noted that aside from stigma related to HIV/AIDS they also had to struggle against social and cultural identities imposed upon them while simultaneously struggling for access to healthcare. An activist born into an Indian community in a working class township where there was a very specific notion of a woman’s place or role in society argued :

“I had to struggle against the imposed notions of conservative, backward Indianism... (where) females have no value other than to ensure that the nuclear family remains intact.”⁴⁷

This was in the context where “[t]he very notion of self-respect and self-worth as a woman is denounced and equated with the work of the devil”.⁴⁸

6 CHALLENGING EMBEDDED NOTIONS OF POWER AND CHANGE

The majority of activists interviewed located their opportunities for participation in HIV/AIDS arenas as being linked to the TAC and MSF. Their involvements in these campaigns were usually based on necessity: “I had family members who were sick and I did not know what they were sick with...we suspected HIV but there was no confirmation”;⁴⁹ “I got tested in 2004 and the reason was because I had shingles ... I found out that there was an organisation called the TAC and I joined it ... because I wanted more information so that if I find myself in a situation then I would know what to do”;⁵⁰ “... for me it meant the organisation cares about the well-being of the people. I decided to stay with TAC so that I can be amongst people who care.”⁵¹

It was also noted that being unemployed provided the scope to join a campaign : “I filled in the membership form out of interest that maybe I will learn something and I’m

⁴⁵ South African Police Service.

⁴⁶ Interview with TAC0018.

⁴⁷ Interview with MSF059.

⁴⁸ Interview with MSF059.

⁴⁹ Interview with TAC0018

⁵⁰ Interview with TAC0073

⁵¹ Interview with TAC0073

unemployed and not studying so I had all the time in the world.”⁵² Participation was largely facilitated by the TAC’s treatment literacy campaign. In the pre – roll out phase this campaign was integral to dispelling myths about the dangers of ARV toxicity, shifting the way in which HIV positive patients came to view ARV treatment options.⁵³ In the post - roll out phase treatment literacy as popular education was utilised by activists to mobilise among the grassroots.⁵⁴ Furthermore, it aimed to continue the training of people living with AIDS to become experts in the science of AIDS , but it also played a critical role in encouraging people to participate in their health facilities, clinic committees and hospital boards.

The process of becoming “experts” and building a culture of participation in health services inherently required challenging existing power systems. This was significantly facilitated by the TAC which was well known for its consultation with “experts” , and this knowledge galvanised a sense of power and authority among the female activist group, most of whom originated from disadvantaged, marginalised environments.⁵⁵ The TAC had also built up a powerful network of alliances, such as, MSF and Section 27. This was once again seen as bolstering support systems and creating power through solidarity.⁵⁶

Activists noted how re-casting themselves in the role of health “experts” was challenging. It was stated that “... when you give an input as a PWA (Person with AIDS) you would feel undermined especially by the Department of Health crew, they would look at you and shake their heads, like what do you know, you’re not a doctor ...”.⁵⁷

The challenge was overcome, however, by being thoroughly informed on the subject of AIDS science and medicine, “... then you ask for a particular drug and it comes as a shock to them, they started to see that there is a lot of treatment literacy going on”.⁵⁸

This realisation by the traditional “experts” shifted power relations somewhat in favour of activists whose experiences came to be accepted as a necessary contribution to health debates. This also reflected the need to engage with people most affected by policies around the roll out of AIDS treatment and medicines:

“([A]t a policy meeting I attended) I had to bring my own experience to say well as much as you have prescribed this, this is what it does to people and these are the concerns we have and the stigma and discrimination that we often get.”⁵⁹

⁵² Interview with TAC0018

⁵³ Mottiar S & Lodge T “How social movements survive: the Treatment Action Campaign and the South African state, 2009-2016” (2017) 43(1) *Social Dynamics* 103.

⁵⁴ Interview with TAC0017

⁵⁵ Interview with TAC009.

⁵⁶ Interview with TAC009.

⁵⁷ Interview with TAC0079.

⁵⁸ Interview with TAC0079.

⁵⁹ Interview with TAC0079.

Activists regarded this as a critical role in that they are “giving voice” to the unheard, especially in forums of participation that were previously inaccessible by them:

“So having to give input on all of those it was scary at first because I remember thinking that I would be undermined by the professionals because I did not have a medical background. But I was able to give a voice of people living with HIV.”⁶⁰

The process of “becoming an expert” and representing the previously “unheard voice” instilled a further sense of confidence among activists :

“([W]hen I was delegated to attend an HIV summit in Canada) where I met the doctors and scientists who were part of the team that started doing the first trials on HIV...and in that high level meeting I was very confident because I thought to myself that if I came all the way to represent my organisation and my fellow comrades back home and in Africa then my voice made a difference.”⁶¹

Increased participation in health facilities, clinic committees and hospital boards resulted in shifts in consciousness in the way activists viewed HIV. It also deepened engagement with power and understandings/advocacy for change. Most activists noted that through participating they became aware of their rights and more importantly how to access their rights. This included demanding rights if necessary : “I have learnt and gained a lot. Like, confidence in my own voice, confidence of knowing how to use the Constitution rules and to claim my rights. And also to demand service delivery in our facilities.”⁶² Furthermore, activists gained the confidence to hold local authorities responsible in their direct contexts. An activist noted that her experiences at the local clinic were transformed in that she was able to challenge officials and clinic staff : “I was able to say that’s the old information, the latest information says this and the latest policy guidelines say x, y, z you should be able to provide me with what I need now.”⁶³ This resulted in a power shift from health authorities to the “expert” patient or “responsibilised citizen”. This is evidenced in the ways that the TAC, in general, impacted on the South African ARV roll out programme with reference to highlighting and curtailing drug stock-outs for example.⁶⁴

7 EMPOWERMENT

Claiming power in ARV treatment and medication sites allowed activists a greater and more impactful role in democratising healthcare. They understood this role as a continuation of the original campaign for the public provision of ARVs :

“In many ways although so many things have changed, so many things are still the same ... We have the NSP and all these platforms where we can participate and

⁶⁰ Interview with TAC0079.

⁶¹ Interview with TAC0079.

⁶² Interview with TAC0079

⁶³ Interview with TAC0079

⁶⁴ Mottiar & Lodge (2017).

engage but yet for some provinces there is no political role and there are no resources made available.”⁶⁵

Activists argued they had two specific roles to play to ensure a successful roll out. The first of these was ensuring that the policy of roll out was in fact implemented “... because policy versus implementation is always two different things”.

This constituted active support for the roll out on a day to day basis. This involved supporting communities whose clinics were not accredited for roll out and advocating for accreditation. There was also the issue of “lists” where patients would be obliged to wait for long periods before being started on treatment ; this would mean patients would begin treatment when their CD4 counts were too low⁶⁶ : “Branches mobilised communities, we collected data that said how many people were waiting for ARVs, how many have a CD4 count that qualifies for treatment and we worked with the feeder clinics that were sending people to hospital.”⁶⁷ In a number of cases mentioned by activists, roll out sites would fail to start patients on treatment owing to staff shortages. Delays around blood test results also slowed treatment commencement at roll out sites.⁶⁸ Activists saw their role as highlighting these challenges and advocating for efficient treatment. A vital element in the success of the roll out is the provision of information regarding nutrition and opportunistic infections (such as tuberculosis [TB], for example). Activists argued that the TAC, drawing on its history of treatment literacy, still had a vital role to play here, because “... despite the fact that there’s treatment you can’t give patients food and not prepare them to sustain that food ...”.⁶⁹ Further to this was eradicating continued stigma around HIV which has significant bearing on adherence and treatment success : “TAC had to continue with adherence support ... to address issues of stigma and discrimination, there were growing cases of stigma and discrimination.”⁷⁰

The second element for a successful roll out was ensuring accountability. This was especially with regards to services at clinics where activists noted they would “monitor” nurses dealing with patients and protest should patients be denied treatment:

“We found out that people were not going to start treatment as planned. When we asked the reason we were told that there was no time. Then later the nurse changed (the story) and said they will be started at 15:30 knowing that he clinic closes at 16:00. We refused and she ended up starting treatment immediately because we refused to leave until she gave people their treatment.”⁷¹

⁶⁵ Interview with TAC009.

⁶⁶ Interview with TAC0017.

⁶⁷ Interview with TAC0018.

⁶⁸ Interview with TAC0073.

⁶⁹ Interview with TAC0047.

⁷⁰ Interview with TAC0018.

⁷¹ Interview with TAC0073.

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The issue of drug stock-outs was also important in the context of transparency and visibility. Activists noted that they saw their role as highlighting the situation of drug shortages in identified clinics and then intervening through the TAC's 'Stop Stock Outs' campaign⁷² or resorting to pickets when formal participation methods failed - "... interventions through the provincial AIDS council and SANAC helped with the serious stock outs that were happening and the problems at the labs. So these interventions do help ... but if we can't sit around the table about it we will bring attention to it through pickets".⁷³

The ways in which activists undertook ensuring the roll out and accountability around the process reflect their claiming power at clinic sites. They did this through expert knowledge and being in possession of information. This was largely facilitated through a process of shifting consciousness that began in the first phase of the HIV/AIDS struggle. In the second phase, activists were embedded in "ways of thinking and being" that had broken beyond the barriers of the culture and norms and values of HIV and the "place" of women claiming their rights and, indeed, the rights of others. The claiming of power also challenged embedded ideas of who the holders of "expert" knowledge are. It also challenged notions of "patients" passively receiving health services versus engaged citizens asserting rights and impacting the way services are rendered.

Activists certainly understood themselves as being empowered in the sense that they held some level of power in the spaces in which they worked, and that this impacted on the way health services were rendered. They also drew power from previous victories of the HIV/AIDS struggle won through the TAC. They did however identify shifts in the HIV/AIDS struggle/campaign that pointed to disempowering trends in terms of female activism.

Activists noted that during the TAC's initial campaign, participatory spaces in the realm of the "invented" were much broader in terms of protest action and marches. The TAC's campaign following the roll out of ARVs, however, was more focused on "invited" spaces of participation, particularly engaging and negotiating :

"Before we used to march a lot and now when we have an issue we can sit with (Minister of Health) Motsoaledi and tell him what needs to be done. And also people who are in charge of clinics we can sit with them and tell them what needs to be done. Now we don't march a lot." ⁷⁴

The drawbacks of this according to activists were twofold. First, engaging in "invited" spaces limits the potential of participation from the grassroots, the marginalised and those living with AIDS :

⁷² The Stop Stock Outs campaign is a collaboration between the TAC and various other organisations including the Clinicians Society and MSF. It involves volunteer "treatment monitors" who are tasked with checking on treatment and medication stock levels.

⁷³ Interview with TAC009.

⁷⁴ Interview with TAC0022.

“I think we should go back to how we used to engage, have events as People with AIDS and continuous engagement so that people can be reminded of who they are and where they come from. Otherwise I think as PWAs we are losing the platform.”⁷⁵

In this sense spaces created from below through the agency of poor and marginalised groups are interpreted as more responsive to their needs and realities than spaces created from above.⁷⁶ These spaces are also more easily accessed by vulnerable women in a culture created by the TAC during the first phase of its campaign. The second drawback of participating mainly in “invited” spaces blunts movement dynamics :

“People now are not as many as before because we don’t go to marches a lot. People think TAC is no longer there because they don’t see those marches. We used to do workshops, door to door pickets and marches. Now we don’t do these things a lot that’s why people think TAC is no longer around”,⁷⁷ “... we tend to want to negotiate endlessly whereas in the past we were on the streets and this made us more visible”⁷⁸

The “streets” are also interpreted as being spaces occupied by the grassroots unlike elite and closed spaces where negotiations with officials and politicians are seen to take place.

Despite this, however, there was a sense that engagement and negotiation were important tools in terms of outcomes , and also following an era where AIDS activists were excluded from policymaking circles: “Back then before 2004 the participation spaces were not so open, we had to force spaces to open the in 2003/2004 the spaces started opening.”⁷⁹ The “opened” spaces were reflected in activists being able to participate in platforms created by the National Strategic Plan (NSP)⁸⁰ as well as at provincial level, in ward committees and in clinic committees.

Shifts during activism related to the roll out as opposed to activism during advocacy for ARV treatment included dealing with co-optations of activists. The provision of ARV treatment meant that staffing was required for the roll out:

“When the shifts happened a lot of civil society representatives were co-opted into government positions. Government started recruiting members of civil society groups through home based care organisations and a lot of comrades were able to find employment within government ... it was opportunities for employment.”⁸¹

⁷⁵ Interview with TAC0064.

⁷⁶ Miraftab (2006) at 200.

⁷⁷ Interview with TAC0022.

⁷⁸ Interview with TAC0018.

⁷⁹ Interview with TAC009.

⁸⁰ The National Strategic Plan (NSP) is the HIV/AIDS and STI national plan released by the Department of Health.

⁸¹ Interview with TAC0079.

It was noted though that this uptake of employment was devoid of the commitment associated with the activism of the past as employment was “for the sake of earning a salary, but they were not passionate about the vision and mission of that particular organisation they were working for”.⁸² This was in the context where volunteers had given up much of their time to be activists but still “had to put food on the table”.⁸³ For activists this loosened the fabric of grassroots membership and resulted in a loss “in the way of how we communicated with each other”.⁸⁴ It also reduced opportunities for sharing experiences, formulating common goals, and building solidarity.

There was further a shift in the nature of participants: “When we go to a PWA meeting especially an outside town meeting, you would see new faces, the very same faces you would not see at branch meetings.”⁸⁵ These shifts suggest that connections amongst members were being eroded or as it was described: the “DNA”⁸⁶ of female activism is changing: “A lot has changed. We used to have much more agency especially from women on the ground they used to be the ones that came forward feeling the pain of their dying children.”⁸⁷ Reasons for this shift were to an extent explained: “It’s almost like we have treatment and we have most of the things that we want and it’s okay for now. There’s no urgency for PWAs to lead these days. There is no urgency that we used to have before we had treatment.”⁸⁸ Even though it was noted that activists understood the necessity of continued action: “We should start going back into getting the combination of skilled PWAs that have their feet on the ground to start a revolution with PWAs.”⁸⁹

Discussions around female leadership within the TAC also emerged from the activist group interviewed. An activist argued that following the roll out, within the TAC women had more of a struggle for leadership positions/leaders’ roles: “([A]gency from women on the ground) led to TAC branches being dominated by women but funny enough not in leadership positions ... Setting up women’s spaces internally led to sabotages by male (and women) comrades undermining women who were in leadership positions. Today (post the roll out) our public face has changed we no longer have women leadership and if you watch the recent TAC pictures of public demonstrations you find mostly men who do not even have active branches leading marches ... I think down the line TAC will lose its DNA.”⁹⁰ This suggests that the roll out phase of activism displayed signs of default gender hierarchies being constructed which mirror a patriarchal society with all too much familiarity. An activist noted, however, that female leadership was more of a

⁸² Interview with TAC0079.

⁸³ Interview with TAC0079.

⁸⁴ Interview with TAC0079.

⁸⁵ Interview with TAC0079.

⁸⁶ Interview with TAC0018.

⁸⁷ Interview with TAC0018.

⁸⁸ Interview with TAC009.

⁸⁹ Interview with TAC009.

⁹⁰ Interview with TAC0018.

concern “higher up’ in the organisation. This was because at branch level, such as in her branch, leadership structures are “flat” and “... here, everyone is a leader”.⁹¹

8 CONCLUSION

During the roll out phase of the HIV/AIDS campaign women activists were clearly working from established transformed “ways of thinking and being” in terms of HIV/AIDS as well as in terms of their role in the struggle for access to health and health rights. In this way their challenge to embedded notions of power took the form of re-defining who the health knowledge holders are. This in turn contributed to the overall democratisation of healthcare through campaigns, such as the TAC’s ‘Stop Stock Outs’ campaign. It also impacted on HIV/AIDS services. This clearly suggests that power balances had, to an extent, shifted to allow women access to platforms and spaces. Importantly though, women have transformed their own perceptions of HIV/AIDS and their potential role in accessing healthcare and socio-economic rights. Transformation in the various spaces of participation, such as the TAC campaign, have however also caused shifts in the ways women mobilise, frame their understandings of the struggle and access “invited” spaces which now seem to feature more prominently in the HIV/AIDS struggle than “invented” spaces.

This shifting terrain will need to be negotiated in order for women activists to consolidate their power gains and to build on them in the next phase of the HIV/AIDS struggle which “... is far from over. We still don’t have a cure, when we have a cure we will still need PWAs to play a role in that”.⁹² The activist testimony from the study suggests that female activism has particular strengths, including a commitment to continuous action recognising that access to health is not simply a single-issue campaign. Furthermore, this action is viewed as an opportunity to share experiences, formulate solutions and embed ongoing solidarity beyond immediate campaign goals. The challenge for women activists in the case study sites is ownership of “their branches” in the more restricted “invited” spaces of formal campaign activity which do not recognise “flat” leadership hierarchies.

Individual Contributions:

The lead author wrote the manuscript, did the revision, approval and submission. Research planning and interpretation of findings were done jointly.

The co-author did the fieldwork, data collection and analysis.

⁹¹ Interview with TAC0022.

⁹² Interview with TAC009.

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