

# Mapping Change and Continuity :

## *Living with HIV as a Chronic Illness in South Africa*

When creating the body-maps the women were prompted to generate a space for the social, to think of the body as a 'museum of life'.

HIV brings frailty to bodies and treatment brings hope; these fears and hopes are visually inscribed through the body-maps and surface in new ways in our recently collected set of five narratives that trace change and continuity in the lives of the body-map artists from 2003-2008.

In South Africa, the period 2002-3 was a significant time for AIDS activists. Calling for the scientific governance of HIV/AIDS and challenging the state's dissident position on the aetiology of HIV, the Treatment Action Campaign mounted a legal challenge to force the state to provide life-saving treatment. Civil society mobilisation reached a peak in 2003 in the same year the body-maps were created. Activist discourses foregrounding science and challenging the state's equivocation on AIDS treatment are evident in the body-maps. The body-maps, published in the book *Long Life* (Morgan et al 2003), foreground the experiences of HIV-positive women who were swaying precariously between two narratives: one of terminal illness and the other of life. Fear of death and hope for life pivoted on antiretroviral therapy (ARVs).

The activist emphasis on body politics illustrates a way of counteracting fears of the virulence of the illness and offering hope through the resurrecting effect of medication. The body-maps capture a

point in time when this body politics was central to these women's lives. In contrast, the new accounts, collected in 2008 from the women whose maps are displayed, bear witness to five years of living with HIV as a chronic illness.

With a changing political environment AIDS activism has also shifted in focus, and the place occupied by the illness in these women's lives has changed. For some there is a positive side to this shift. They speak of the need to develop identities apart from being HIV positive, of wanting to forget about the illness after taking the medication, to foreground living over illness. This is only possible because of a sense that the virus has been contained by ARVs. The experience of having the illness has transformed into something more personal: a regime of drug adherence is fulfilled privately and stands between these women and a return to bodily frailty.

The vulnerability persists. Memories of illness, evoked in the scars of skin lesions, surface in the new narratives which bear witness to the 'Lazarus' effect of ARVs in bringing cohesion and hope. South Africa only offers two lines of AIDS treatment. Poor adherence to the first line of treatment can undermine its efficacy, at which time individuals are moved on to the second line of treatment. There is no further treatment if this

line fails. As such, the Damocles sword of second-line treatment, with its attendant side-effects, is held up as an incentive for strict adherence

In the body-mapping exercise, the women engaged with elements of medical knowledge, including anatomical diagrams of organs, visual representations of the virus and pathologies associated with active disease. Yet the maps are far more than depictions of bounded bodies invaded by disease. The women were prompted to generate space for the social, to think of the body as a 'museum of life'; their words and drawings are infused by their experience of life in Khayelitsha, obscuring the notion of a disciplined body of science. Drawings of organs speak to the social. The heart symbolises strength and the womb illustrates the women's hope to hold life.

Old hopes to have children have become a reality with a number of the women having children in the past five years. In the new narratives, the women refer to the challenge of providing security and education to their children in a context of intransigent poverty. In 2003, employment for these women was offered through activist organisations, particularly as civil society confronted the state to provide ARVs; five years later, however, financial insecurity is heightened by a shift in activist dynamics and high unemployment.

The body-maps speak clearly of sociality. The exercise started with a statement of the

relationality of bodies, in that each person was made to trace the outline of another as a shadow, a reminder of help received and the potential for future support. The new narratives reflect shifting dynamics of sociality; relationships feature as sources of struggle and of support. Sexual relationships hold potential for stigma, with many of the women noting their deep fear of rejection when disclosing their status to their sexual partners.

Patterns of sociality extend beyond intimate sexual relationships. The body-map artists formed a strong community when creating their body-maps, with the shadow outlines reinforcing this support. The new narratives indicate that the shift in AIDS activist communities has prompted new communities of support, particularly through faith-based organisations. The premise of faith invested in several places – biomedicine, churches, family, other healers - threads through the new and old narratives. Support takes different forms as the era of activism in South Africa evolves alongside the chronic management of HIV, responding to the body's myriad physical, social and spiritual dimensions.

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