

## **Rethinking rights and responsibilities in a time of AIDS**

**Professor Steven Robins  
Department of Sociology & Social Anthropology  
University of Stellenbosch**

In recent months a number of questions have been raised concerning ethical and pragmatic grounds for prescriptive measures to deal with HIV/AIDS. Professor Solly Benatar, Professor of Medicine and director of the Bioethics Centre at the University of Cape Town, recently suggested that the prevention of multi-drug resistant HIV 'may justify over-riding individual rights to treatment for those who may not be able to adhere to treatment' (Cape Times April 15 2005). Benatar has called for a balance between the rights of individuals and the public health needs of society. To maximise adherence to ARV treatment, he argues, requires that patients take some responsibility for their own health.

Dr. Udo Schuklenk, a bioethics professor at Wits University, takes Benatar's argument much further. He claims that the high infection rate of the AIDS pandemic warrants the introduction of compulsory HIV testing and counselling of pregnant women in the public health sector (Mail & Guardian April 1 2005). Schuklenk believes that compulsory testing would give pregnant women knowledge of their status and allow them to participate in prevention of mother-to-child transmission (PMTCT) programmes. Schuklenk's call for more prescriptive approaches to counselling is based on the argument that there needs to be a more equal balance between women's reproductive rights and their responsibility to give newborn children "a fair shot at life". Dr. Ruth Rabinowitz of the IFP also calls for compulsory HIV tests, notwithstanding women's rights and rights to privacy (Cape Times 18 August 2004). These views share the belief that the rights of the individual may, under certain circumstances, be compromised by the state's responsibility to 'protect' the public, including unborn children and HIV-negative citizens.

Benatar, Schuklenk and Rabinowitz, like many public health practitioners, argue that citizens have both rights and responsibilities when it comes to health matters. They also appear to believe that citizens are in a position to make responsible health-related decisions based on scientific information and "rational" decision-making procedures. The problem with this view is that it assumes that everyone is capable of acting from this position of rational choice and individual agency. However, if AIDS has taught us anything it has shown that millions of women in South Africa do not have bodily autonomy and "free choice" when it comes to health matters. Many of them cannot simply decide to go for an HIV test or participate in prevention of mother-to-child-transmission programmes without incurring the wrath of their male partners. Should they disclose their HIV-positive status this can result in possible beatings and eviction from the household.

These gendered realities were recently highlighted in the case of SM, an HIV-positive woman who tried to commit suicide by setting herself alight after her HIV-positive status was revealed in Independent Democrats leader Patricia de Lille's autobiography. SM claimed that she decided to commit suicide by pouring paraffin over her body in response to her husband's rage when he discovered that she had publicly revealed her HIV status (Cape Times 19th April 2005). These accounts reveal the limits of liberal individualist conceptions of rights and responsibilities. They also suggest that it is problematic to abstract the individual rights bearing citizen from his or her social and cultural milieu. The issue of rights and responsibilities is further complicated by the negative social constructions of HIV/AIDS and the profound fear, blame and shame that this can produce. So what are the implications of all of this for HIV testing, prevention and treatment?

In recent years there has been a call from progressive South African public health experts such as David Coetzee and Helen Schneider for a "new contract" between health providers and clients. The advocates of this contract suggest that the passive, authoritarian and paternalistic surveillance model of direct observation therapy (DOT) TB treatment is not a viable solution for life-long ARV treatment. Instead what is needed for successful ARV programmes, they argue, are highly motivated, "responsibilised" and knowledgeable clients. The argument is that citizens have rights to health care but they also have responsibilities, and that for ARV treatment to work, clients will have to be active, empowered citizens rather than passive patients of the "nanny state". The term "responsibilised citizens" is also used by some of the MSF doctors involved in ARV programmes in Cape Town.

It is perhaps not entirely coincidental that the concept of "responsibilised citizen" also appears in the recent work of political theorists writing about contemporary liberal rationalities of government in the UK and Europe. Nikolas Rose and his colleagues use the term to refer to the ways in which, under contemporary versions of liberalism, citizens are encouraged to "govern themselves." For instance, instead of burdening the public health system, they should take care of themselves through healthier diets, lifestyles and exercise. In other words, citizens are meant to become responsible for issues previously held to be the responsibility of the state and public health authorities. Can this model of self-governance be used to encourage people on ARV treatment to become "responsibilised clients"?

In a recent paper on treatment activism, I argued that social movements such as the Treatment Action Campaign (TAC) and Medecins sans Frontieres (MSF) provide examples of ways of promoting both health rights and responsibilities. For many TAC and MSF activists living with AIDS it was precisely the extremity of their "near death" experiences of full-blown AIDS, and the profound stigma and "social death" associated with the later stages of the disease, that produced the conditions for their commitment to treatment adherence, "responsible" lifestyles, and social activism. It is ARV treatment, together with TAC and MSF's provision of support and social belonging for people living with AIDS, that is capable of transforming these traumatic experiences of stigmatised illness into new forms social commitment and active citizenship. A

combination of treatment and AIDS activism created the possibility for transforming the negativity of AIDS stigma into a “badge of pride” and a new positive HIV-positive identity. These experiences can also produce the empowering sense of social belonging that is captured in activist statements such as “TAC is my mother, MSF is my father” and “Zackie and Mandla are like my brothers”.

While TAC and MSF are obviously not the only avenues for creating these commitments to treatment adherence and responsible health behaviour, they are nonetheless powerful examples of how a new “contract” is being forged between health providers and clients. It is becoming increasingly clear that what is required is not simply access to more AIDS awareness information and better medical surveillance systems such as DOT, but also transformations in the subjectivities and identities of people living with AIDS. It is here that TAC and MSF seem to be successful in creating new forms of health citizenship that challenge the paternalism and prescriptive approaches of DOT.

TAC and MSF have improved the lives of many of its members to the degree that one sometimes hears TAC activists say that “AIDS was a blessing in disguise”. This shocking statement makes more sense when one begins to understand the hardships experienced by many of TAC’s members. Many of the young female activists I interviewed spoke of traumatic experiences of rape, illness, AIDS stigma and expulsion from their homes and communities. Upon joining TAC they found a “new family” and close-knit community of activists. These activist organisations are clearly concerned with much more than life-saving ARVs. They are also concerned with creating “social capital” and facilitating radical transformations in selfhood, subjectivity and sociality. These transformations come from the ability of MSF’s treatment programmes to address both biological disease and the social, cultural and psychological dynamics associated with stigmatised illnesses and identities.

In his book *Witness to AIDS*, Judge Edwin Cameron provides a moving account of how the knowledge of one’s HIV-positive status can produce overwhelming feelings of fear, self-blame and self-loathing. Cameron, an internationally respected human rights lawyer and Judge who was actively involved in AIDS policy issues in the 1990s, was diagnosed in 1986. Yet it took him almost twelve years to publicly disclose his status. His courageous account of the agony of living in silence and shame provides a cautionary note to those who glibly claim that it is the responsibility of everyone to test for HIV and disclose their status. Cameron experienced these feelings of shame as a middle class, anti-apartheid lawyer who moved in progressive circles and who had a very supportive family and circle of friends. His story draws attention to how fear, stigma and denial can conspire to produce silence and denial about this devastating pandemic.

Judge Cameron’s account of the devastating power of AIDS stigma, shame and denial helps explain why so many people living with AIDS are staying away from testing and treatment centres. Given the power and pervasiveness of these responses to HIV/AIDS, it would seem that prescriptive methods of compulsory testing and HIV status notification are likely to push the disease even deeper underground. In addition, treatment adherence

is unlikely to succeed using traditional DOT methods. Adherence and openness will require radically changing individuals' sense of self-worth and dignity.

TAC and MSF have created particularly powerful social processes for transforming stigmatised AIDS sufferers into "responsibilised" and empowered activist-citizens. Other equally effective approaches are being developed in various parts of the country. These approaches, rather than relying on compulsion and prescription, may help us to achieve the balance between the rights of individuals and the public health needs of society that Professor Benatar and others are calling for.