

South Africa is in the throes of an AIDS epidemic compounded by tuberculosis. Nevertheless, responses to the recent launch of a colorful book promoting adolescent knowledge of HIV immunopathogenesis provide grounds for cautious optimism that education can induce a form of “social vaccination” in South Africa and elsewhere.

Positive about HIV—an immunological education project in South Africa

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“Siyathemba” (“we hope” in Zulu) is inscribed on the wall of the newly built Africa Centre in Mtubatuba, a project of the Wellcome Trust, South African Medical Research Council (MRC) and the University of Natal, South Africa (SA). These words contrast with the almost universal gloom currently attached to the subject.

Widespread awareness of the explosive AIDS-tuberculosis epidemic and its impact on all aspects of South African society has generated a growing response by South African health scientists, educators and governmental as well as non-governmental (NGO) agencies. Evidence for this more balanced perception was obtained by a small group of immunologists and their partners on a visit to several centers in SA to launch the children’s book *Staying Alive – Fighting HIV/AIDS*¹.

I became involved in this project in 1999, in Cape Town, SA, when I was struck by the still insufficient awareness of the scale of this threat to the continent, which carries the major burden of AIDS worldwide. My colleagues in this effort were Fran Balkwill, a tumor immunobiologist from London and Mic Rolph, a designer-illustrator—who, together, had produced half-a-million science books for children—and John Inglis, a Scottish-born immunologist who was the founding editor of *Immunology Today* and is now the executive editor of Cold Spring Harbor Laboratory Press, New York. The team was completed by Linzi Rabinowitz, a South African social worker, Lyndall Gordon, an expatriate biographer, and Tony Inglis, a British-born, American-educated liberal arts student. This commentary is based on our communal experience as well as my own reactions.

The text of the book, aimed at teenagers, provides up-to-date science accompanied by accessible illustrations from which self-protective actions can follow. Twenty-thousand copies of the 32-page book were distributed free in a pilot study to evaluate its impact and suitability. Future plans include greatly expanded distribution in Africa and elsewhere. The reception by children and adults alike was overwhelmingly positive, and the visit provided an opportunity to assess the present social response to the still-expanding pandemic.

A need to promote prevention

With hindsight, it is clear that the SA epidemic followed other countries outside Africa as well as further north in Africa. A major opportunity to limit the spread of HIV in SA was lost during the last years of the apartheid regime (even if it had not been distracted by its own survival, the motives of a white government campaign to limit sexual transmission among Africans would have been regarded with suspicion). After Nelson Mandela became the first democratically elected President in 1994, his power-sharing government was concerned with avoidance of a civil war between Inkatha-affiliated Zulus, the Xhosa-based ANC and the remaining diehard Afrikaners. Nation-building took priority over AIDS prevention, apart from misdirected efforts to find unique local solutions, such as a home-grown specious remedy known as Virodene. Thabo Mbeki, already running the daily affairs of the country while Mandela focused on reconciliation and diplomacy, and successive health ministers continued to obstruct a science-based response to the intensifying AIDS emergency. The South African



Students at Siyulame School, KwazuluNatal, making a presentation about AIDS to their classmates.

MRC², the judiciary, regional governments and NGO pressure groups such as the Treatment Action Campaign (TAC) have, however, done a great deal to document its impact and to promote public awareness and so, at the moment, the tide is turning.

Inevitably, attitudes have become polarized, as if prevention strategies, anti-retroviral drug costs, primary health care and counseling are separate issues. Although it is impossible to extrapolate from nonuniform local statistics and the public health system does not require notification and widespread testing, there is no doubt that HIV infection poses a massive threat to health management (many patients undergoing hospital admission are coincidentally HIV⁺) and is responsible for the spread of tuberculosis. More generally, it exerts a crippling effect on the economy, educational system, prison population and army.

Writing the book

The intention was to provide an up-to-date scientific explanation of the relationship between HIV and AIDS and the immunologic basis

for its pathogenesis. We opted for an English text, using simple language and phonetic spellings of scientific terms. Possible therapy and vaccination were placed in perspective, given the reality in SA at the time the book was written. The disease was treated in the context of human infectious diseases and is explicit about transmission. The book was designed to be attractive, even humorous, while not shirking the seriousness of the issues discussed. It does not moralize but advises sexual abstinence and permanent, loving relationships. The hopeful fact is made clear that HIV-infected people can live healthy, productive lives and that they deserve care and physical affection without stigma.

The content emerged from a series of consultations, starting with a visit in 2001 by Fran and Mic to SA (Mtubatuba and Gauteng), where—accompanied by Fran's teenage son, Barnaby—they met children and teachers in schools, squatter camps and townships. Children were invited to express their concerns, which were surprisingly uniform whether they came from urban or rural schools, and these were answered by the text. Other collaborative offerings took the form of drawings included in the book, in particular, drawings of a patient before and after he developed AIDS by Nelson Makhonya from the Zevenfontein squatter camp.

Reaching the children

Our small party of seven set out with some uncertainty. How would the book be viewed? Would it be understood, was it too explicit and was it appropriate for 11–16-year-old readers? Would we be received as well intentioned but ignorant outsiders? Was the message too late and had the book already been superseded by other educational materials? As it turned out, the book was well received and timely. Mic and Fran wished to return to the same schools they had originally visited in preparing the book and present children with books in which their own contributions and illustrations had been published. Their return was greeted with surprised pleasure. Mic's state-of-the-art video camera and blown-up photographs of many of the children evoked exclamations of delight. A return visit was made to Zevenfontein (an “informal” settlement cheek-by-jowl with luxurious homes nearby), C. R. Swart High School in Gauteng (a mixed-race dual-language school in Pretoria), its neighbor in Mamelodi Township and an AIDS orphanage.

At a launch held in an art gallery in Johannesburg on 23 July 2002, Justice Edwin Cameron, a leading activist, emphasized the need for access to anti-retrovirals as well as for prevention and the need for a language of care, rather than of “war”, against AIDS. Another HIV⁺ member of the community, Mercy Makhalemele, gave a sobering personal account. Contacts were established with a range of organizations involved in formal and informal education, including Lovelife, an NGO that provides information about sex for adolescents in youth centers all over the country. We next moved on to launches at Mtubatuba and Cape Town. As an ex-Capetonian I was no longer an onlooker, but deeply involved, as we visited community projects in

Gugulethu and Kayelitsha Townships. Five HIV-infected women explained a “memory box” project, in which people record their life-stories for their families, emphasizing living with HIV rather than leaving a post-mortem legacy.

At a public gathering in Cape Town, Kader Asmal, the Minister of Education, coined the term “social vaccination” through education and the eloquence of an HIV⁺ community activist, Lungi Mazibuko, electrified the audience. One of the most impressive features of our visit was the leadership displayed by HIV⁺ women and men, energized by knowledge of the risk to themselves, their families and the community at large.

Linzi distributed questionnaires to obtain more information about the suitability of the book and its impact—many requests for copies followed, from teachers, doctors and parents. Suggestions included a version for younger children before sexual attitudes form; a “granny” version for older caregivers to AIDS orphans; additional teachers' aides and translations of the book into Zulu, Xhosa, Sesotho and Afrikaans. Perhaps most surprising was the frank discussion and openness of teachers and church members.

Other members of the team returned to Europe and the USA, but my wife and I stayed on to meet educators, artists and the



Self-portrait of HIV⁺ woman, art project at University of Cape Town.

media. We were particularly pleased to compare notes with Takelani (“Rejoice”) Sesame, a South African version of Sesame Street that features an HIV⁺ muppet in their television broadcasts (it is not only the South African government that has difficulty with spreading the message—US congressmen recently objected to such a use of public funding).

Grounds for optimism

What, then, is the basis for my earlier optimism, even in the face of this still growing crisis? The situation in SA has changed dramatically over the past few years, as if a slumbering giant has begun to stir. People from all sectors in society appreciate the nature of the crisis, are eager to learn more about the specifics and want to do something about it, despite and perhaps stimulated by the widely publicized lack of consistent central government support. This represents grass roots democracy in action, not afraid to challenge drug companies and the government itself in court. Dramatic posters from Lovelife and the TAC catch the eye at every turn. Zackie Achmat, a dedicated HIV⁺ leader of the successful legal challenge to the South African government, has refused anti-retroviral treatment until programs (or pilots) are rolled out by the government.

Humor has provided an effective way to raise public consciousness and to puncture official denial. SA is blessed by the indefatigable efforts of Pieter-Dirk Uys, a cross-dressing cabaret artist who has taken the message single-handedly to Parliament and to hundreds of schools.

The South African government is also showing signs of a shift in its attitude. Apart from Kader Asmal's clear message, even the Minister of Justice and Constitutional Development, Pennell

Maduna, is on record as praising the TAC for using the Constitutional Court against his own colleagues. Regional governments are already deeply involved in Nevirapine treatment to reduce perinatal transmission and some are beginning other anti-retroviral treatment schemes, but the uneven availability across the country of Nevirapine treatment for rape victims is particularly demoralizing to doctors and victims alike. In fairness, the costs of universal treatment are considerable, even at a reduced price, and integrated health care, monitoring and support systems are required as well as clean water and nutritious food. The national government is legally entitled to declare an emergency and to produce generic anti-retrovirals in SA, which has the capacity to produce its own drugs, as in Brazil. It is hard to imagine that any government can resist the cumulative pressures now coming from all sides. Another hopeful sign is that resistance is growing, even within the ANC ruling party (often not in public view), and the opposition Member of Parliament Patricia de Lille is applauded everywhere, for her honest, articulate speeches against government inaction in the face of national disaster.

The ambivalent attitude of the government is hard to explain. The Minister of Health, Manto Tshabalala-Msimang, gave an embarrassing account of her policy at the recent International AIDS Conference in Barcelona. Within SA, speculation is widespread as to official motives and the government's refusal to admit that previous policies have been wrong. However, awareness is growing that visionary plans for development in Africa are jeopardized by AIDS.

In spite of the lost opportunity referred to above, Nelson Mandela is now throwing his considerable authority into the campaign against AIDS, especially to raise funds for children. Graca Machel, his wife, spoke out strongly at the recent Barcelona Conference.

The advent of HIV has been a powerful catalyst, not only for AIDS research worldwide, but also in many broader aspects of virology, immunology, vaccine development and therapy. Similarly, the dramatic effects of AIDS on South African society have the potential to generate unforeseen benefits in social cohesion, providing a positive stimulus to national transformation and development. Increased public awareness of health issues will benefit uptake of other vaccines and compliance with complex therapies, including those for tuberculosis.

A considerable research effort has begun to take shape in SA. The South African MRC has taken a clear stand on the nature and implications of the epidemic and supports an ambitious vaccine program. Outside agencies such as the Wellcome Trust, NIH and universities in the USA and UK have initiated research partnerships with South African institutions; local scientific entrepreneurs have not been slow to take advantage of funding opportunities. SA can be a resource for, as well as benefit from, the experiences of other countries in Africa.

There has been a marked shift in South African employers' attitudes to HIV treatment and prevention. Confronted with a massive effect on their workers, industrial giants such as Anglo-American and De Beers are making anti-retroviral drugs available to HIV⁺ employees and are hoping to develop partnerships with government. A trend has started in which other, and smaller, firms will make a similar cost-benefit analysis and conclusions.

It is clear that mixed signals are still coming from the South African struggle to contain AIDS. On the one hand, the society is grappling with the after-effects of past racist policies with huge problems on all fronts, not least of which is a climate of violence. Fran's aunt and uncle were murdered in Gauteng just before our visit and a staff member of the Africa Centre was killed by hijackers after our return. On the other

hand, the country is rich in natural and human resources, with the coexistence of first- and third-world facilities.

In the absence of an effective vaccine, prevention has to depend on hopes to change attitudes and increased communal responsibility. It is widely acknowledged that peer education is a powerful force for influencing human behavior. One concern foremost in our minds throughout was to help people help themselves.

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2. Dorrington, R., Bourne, D., Bradshaw, D., Laubscher, R. & Timaeus, I. M. The Impact of HIV/AIDS on Adult Mortality in South Africa. (South African MRC, 2002) Available at www.mrc.ac.za/bod.



Children at Zevenfontein immersed in *Staying Alive*.