Doing HIV medicine in southern Africa – what does the epidemic teach us?

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As my grandmother used to say, 'There are only two families in the world, the haves and the have-nots.'[1] (Cervantes)

In the last analysis it is not so much their subjects that the great teachers teach us as it is they themselves.[2] (Frederich Buechner)

If the HIV epidemic has done Africa any good, it has been to emphasise the fragile health of the continent's peoples and the urgent need to do something about it. Currently 700 - 800 South Africans die daily from HIV and between 11% and 19% (approx. 5.54 million) are living with the disease.[3] This is a region where few know their status and where only 65% of South Africans sampled in a 2004 survey consented to being tested.[4] Yet being HIV-positive has significant consequences for the individual and his/her family. Wealth is lost. A 23% decline in household expenditure over a 3-year period was documented in South African homes where an AIDS death had occurred.[5] A country's health can be jeopardised. Average life expectancy in Zimbabwe has fallen to 33.9 years.[6] South Africa, Botswana, Zimbabwe, Zambia and Uganda all have current life expectancy levels lower than in 1960, 1980 or 1990.[7] Prevention is possible. This gap can be closed. Those who know their status are less likely to transmit the virus.[8,9] Being HIV-positive frequently brings shame, fear and guilt: dealing with this for some will begin a process of coming to terms with oneself, taking responsibility – and learning to value life and health.

Can this epidemic be brought under control? The South African government's current initiative, the new 5-year strategic plan, attempts to answer this question[3] (Table I). This initiative will require the co-operation of a demoralised state health sector. The implementation of the public antiretroviral (ARV) roll-out plan has been slow and remains well below target.[10] Eligibility for enrolment requires a diagnosis of advanced disease or a CD4 level of ≤200/µl. But many die before clinical infection is diagnosed and at CD4 levels above 200/µl.[11]

The new strategic plan reads well. However, looking back on two decades of AIDS in this country, it is clear that we have made several mistakes. Although we were dealing with a fatal and transmissible infection, a thorough-going public health approach to its control was not adopted.[12,13] We believed that notification would 'force the epidemic underground' and unfairly stigmatise the infected and their families. Today the epidemic remains underground and denied. Stigma persists. Protecting personal rights – confidentiality, limiting testing to the consenting patient, the promotion of medical secrecy, litigation for those who transgressed this code – has been laudable but its corollary, the prevention of spread and the protection of the uninfected, has been notably unsuccessful.[14]

Furthermore, our failure to take the virus seriously has been echoed in the highest and the lowest strata of society. The link between the virus and AIDS is queried. A shower is presumed to protect against risk-taking. A diet of beetroot, garlic and olive oil is expected to promote the health of the sick.[15,16] Surveys indicate that South Africa's youth have excellent knowledge of the virus and know how to prevent transmission. Yet this group of respondents – who thought they were uninfected – had a high HIV prevalence when tested.[17]

Something more is needed. 'Rationality', writes Amartya Sen, 'is the discipline of subjecting one's choices – of actions as well as of objectives, values and priorities – to reasoned scrutiny.'[18] Remarking on effective counselling, Scott Peck notes that 'if the patient is to be healed, he/she must learn that the entirety of one's adult life is a series of personal choices, decisions'.[19] Making the right choice is not always easy. But the process can be learnt. Children learn from their parents, their teachers and from peers. HIV transmission does at times occur apart from choice – through sexual assault, perinatal and accidental exposure. In the main, however, the prevention of HIV remains a choice. What then blunts reason and the will?

Poverty, the 'haves and the have-nots'

Poverty has been linked to increased HIV transmission. Nevertheless many poor remain HIV negative.[20,21] But somewhat surprisingly, Africa's middle-class and wealthy are also at risk. Sexual 'networking' – the overlapping of sexual partnerships beyond a primary relationship, across the rural and urban divide and beyond the borders of countries – occurs throughout sub-Saharan Africa.[22,23] Poverty and prostitution are unlikely determinants of this phenomenon. However, the impotence and inertia that accompany poverty and unemployment will fuel risk-taking behaviour. And while poverty, social and gender inequity persist, women will remain vulnerable. The new 5-year strategic plan provides for social

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Table I. The main goals of South Africa's new 5-year strategic HIV/AIDS plan[3]

1. Reduce the number of new HIV infections by 50%.
2. Scale up the prevention of mother-to-child transmission (PMTCT) to reach a target of fewer than 5% of perinatal transmissions. Included in this is 'special support' for women who chose to exclusively breastfeed.
3. Provide 'appropriate' treatment, care and support to 80% of those infected and their families by 2011, thus reducing AIDS-related morbidity and mortality.
4. Offering routine HIV testing within and without the health service – thereby promoting a culture of testing and counselling.
5. Greater use of trained lay personnel and primary care nurses to do the tasks of doctors and other more skilled health care professionals. The nurses would initiate antiretroviral therapy.
6. Greater partnership between government and private sector institutions and services.
7. Enhance the measurement of monitoring and evaluation systems.

assistance to the HIV needy. But more is needed than a grant and a food parcel. How do attitudes change? How are the empowering choices made?

Leadership

Intervention by politicians and community leaders in Uganda and Thailand was decisive in bringing their epidemics under control in the early 1990s.[24] This leadership has been absent during the growth and expansion of South Africa's epidemic. Reinhold Niebuhr's comment might still apply today: 'As individuals, men believe that they ought to love and serve each other and establish justice between each other. As racial, economic and national groups they take for themselves, whatever their power can command.'[25]

'AZT treatment will have a limited effect on the epidemic, as we are targeting individuals already infected' – the reply in 1998 of a past South African minister of health to a question on the prevention of mother-to-child transmission.[26] 'That mother is going to die and that HIV-negative child will be an orphan. That child must be brought up. Who is going to bring that child up? It's the state. The state. That's the resources you see' (Parks Mankahlana, 2000, quoted in *Science* and reported in the *Mail and Guardian*[27]). While it is indeed the state that has to find the resources, the state is made up of individual people. The utilitarian position must find a balance somewhere between altruism and self-interest ('state-interest' versus individual rights). Leadership here came from the people themselves – the Treatment Action Campaign (TAC) who forced the government to provide antiretrovirals (ARVs) to South Africans in 2004.[28]

South Africa needs to find a wide array of voices – not just the TAC or the government – that will provide informed and appropriate leadership to the nation. The new national strategy suggests the need for this. It has to happen.

Culture

Culture informs the choices we make. But the cultures of Africa are in transition. 'Urbanisation and a cash economy have smashed the intricate balance of dependence and obligation within the family, and Western education has undermined its sanctions. In the face of this destruction of its outward forms can the primal concept of Man survive?'[29] The reference to primal here is not intended to imply 'inferior', but refers to the ancient cultures found throughout Africa where individuals have a place within society and experience belonging. HIV destroys the family and 'belonging'. 'The most basic culture in which we develop is the culture of our family. Our parents are its culture "leaders". The most significant aspect of that culture is … how our parents behave toward each other, toward our siblings and above all, toward ourselves.'[30] African governments need to invest in the family if the child is to be reached and given a future.

What should be the response of the medical community to traditional healing systems that refuse to confront the virus? 'In the African context, writes a local healer, illness always has a reason … It follows therefore that a detailed biomedical explanation based on the germ theory is foreign and irrelevant to African concepts of illness.'[31] At its best science uncovers and enshrines truth. Where truth and non-truth coexist, one will have to give way to the other. Nevertheless a bridgehead must be created across which evidence-based medicine and traditional healing practices can find and uphold common truth(s). Patients will make up their own minds. Cultural beliefs must be informed with evidence-based practice.

Stigma, denial and prejudice

'Doc, your blood keeps you alive. But mine's killing me.'
'I can't take my pills to work. The guys will ask too many questions.'[32] These responses identify those with a 'spoiled' identity, who feel 'tainted' and believe that they constitute an affront to the moral order or have in some way, 'violated' the norm.[33] Stigma – relinquishing personal control: allowing others to make the decisions that control my life. It is ironic that a society that only a few years ago fought for freedom, should face again the issue of freedom but this time acquiesce so silently. The only way to neutralise stigma is to own it. Embrace the shame and bring it into the light of day. Few can do this alone (Table II).

Stigma and prejudice require that the scientist and the community talk to one another. Discrimination is less of a

Table II. Interventions to reduce stigma in society[34]

Public health fear	Prevention emphasised Reduce public fear with appropriate public health measures Identify the infected early, e.g. 'opt-out' testing, routine testing, promote counselling Control infection with ARVs as appropriate
Stigmatisers	Provide education, information to deal with fear Communicate with the general public Social awareness to enhance compassion, reduce guilt and blame Correct false beliefs about degree of risk and danger to the community
Emotional impact of stigma on the infected	Provide counselling Create support groups in every practice and clinic Create patient-to-patient mentorship groups
Social and legal	Advocacy groups, e.g. TAC, SA National AIDS Council (SANAC) Legal support, e.g. Aids Law Project Faith-based organisations and other NGOs

problem to the wealthy and independent. But the poor are vulnerable. 'If medicine is to fulfil her great task,' says Virchow, 'then she must enter the political and social life. Do we not always find the diseases of the populace traceable to defects in society? If disease is an expression of individual life under unfavourable circumstances, then epidemics must be indicative of mass disturbances. Since disease so often results from poverty, physicians are the natural attorneys of the poor and social problems should be largely solved by them' (quoted in Marmot[35]).

Conclusion

What have we learnt from the epidemic and how do we deal with the choices that are presented to us? The fields of science and medicine have developed in response to the virus and to the needs of sick patients. We practise HIV medicine better today. But the virus and the infected are still among us. Daily every South African will face choices that will affect their health and possibly their role in this epidemic. What of the 'defects in society' to which Virchow alludes? Have we learnt to listen to what this virus has to say about us, our society, our values and how we practise medicine? And have we, the physicians of this epidemic, become the 'natural attorneys of the poor'?

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