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Breaking the Chains of Silence and Shame

Stephanie Nolen 2007, *28 Stories of AIDS in Africa*. New York: Walker & Comp., 2 maps, glossary, 'How you can help', bibliography, index, 375 pp., ISBN 13: 978-0-8027-1598-2, US\$25,95 (hbk); Ontario: Vintage Canada, 416 pp., ISBN 13: 978-0-676-97823-0, US\$15.95 (pbk).

This moving book tells the real life stories of 28 men and women in Africa who live, or lived, with HIV or AIDS,¹ one for each of the 28 millions Africans that according to UNAIDS were infected with the *Human Immunodeficiency Virus* (HIV) in 2006.² In addition, it has an introduction (1-17) and an epilogue (347-352). In the latter, Nolen relates briefly how the 28 she had interviewed since 1997 were doing in 2006 at the time the book went into production: four had died, three she could not reach; of the remaining 21, only one was in poor health. The others were in good health, thanks to the ARVs (*antiretroviral* drugs), and most were active in movements that try to break the chains of silence and shame that keep Sub-Saharan Africa in the grip of this pandemic which had already killed 22 million Africans by 2006. Infection rates had begun to decline by then, in part due to ARV treatment, in part because death had already wiped out those most likely to spread the virus. Death rates, however, had not yet declined, because only one in four of those

¹ All but two of her cases are from East and Southern Africa, reflecting the much higher incidence of HIV/AIDS in those parts than in West Africa. Five of her histories are from Zambia; four from South Africa; three from Uganda; two each from Swaziland, Ethiopia, Kenya, Zimbabwe, Mozambique and Nigeria; and one each from Burundi, DR-Congo, Botswana and Lesotho.

² Nolen 2007: 15. She finds this figure 'conservative'. She suspects that the number of infected is higher, and will be still higher when accurate survey methods finally reach into rural areas (16).

in need of treatment were as yet on ARVs (350). And she argues that it is unlikely that the G8 goal of universal access to ARVs by 2010 (253) will be reached, for one reason because of corruption and inefficiency, for another because only half of the funds needed to fight HIV/AIDS effectively is available (350-352).³

In her introduction, 'Why 28', she explains how long it took her to become truly aware what a savage silent killer HIV/AIDS is in Africa. It sunk into her only in 2002 when, in a village in Malawi, 'I had a sense of a community quietly evaporating around me' (2) and then wandered, a few days later, through an overcrowded hospital in Lilongwe 'in a state of growing horror' searching for 'the lone doctor who had agreed to speak to me about the country's HIV epidemic':

'There were people everywhere: three to a bed, lying head-to-foot-to-head; under the beds, lying on grass mats in the stairwells and in the verandas off the wards. They were bone thin and covered with lesions and abscesses. As I stepped gingerly among them, they shifted their heads slightly to look up at me through eyes grown huge in sunken faces. I could not find the doctor; I did find a nurse – perhaps the only nurse – who was stout and slovenly and clearly drunk, her hairpiece of copper curls askew. Looking around the ward, I couldn't blame her: it was barely 8 a.m., but I felt in desperate need of a stiff drink myself' (2).⁴

This awareness of the slow, almost incalculable devastation HIV/AIDS was wreaking in Africa made her persuade the editors of the Toronto *The Globe and Mail* news-paper, for which she was stationed in Africa as reporter, that she must uncover the stories of the thousands of villages on the verge of disappearing. Whereas in North America, people with HIV were kept in good health for decades with ARVs, in Africa people could only sit and watch its inexorable progress to death, almost entirely unremarked by the world at large. Covered up by the silence of shame, it was wiping out the sexually active generation, leaving a host of orphans in the care of the elderly (67-71, 186-195, 223), or to fend for themselves

³ In 2005, the UN Global Fund to Fight AIDS, Tuberculosis and Malaria was short more than \$8 billion (327-328).

⁴ Cf also 155-159, 162, 164-165, 245, 247-248 on the 400% overtaxed hospitals critically short of doctors, nurses, pharmacists and other staff in Malawi and other parts of Africa due to HIV/AIDS and emigration.

(3-4, 31-40), if they did not die early, having contracted HIV at birth and/or through breastfeeding (190-192, 231).⁵

Nolen explains what kind of ‘retrovirus’ HIV is. It invades the lymphocytes that normally fight infections and turns them into factories that churn out tens thousands of new HIV viruses. In ten days’ time, a drop of blood of an infected person contains 100 million HIV viruses. By that time, they have spread to the brain and other major organs. Then a long battle between the body responding with new killer T cells⁶ and the HIV virus begins which the virus inevitably wins after a few years. A brilliant strategy, says Nolen, because by that time the person infected has spread the virus to plenty of other people.⁷ In addition, HIV is able to resist the toughest barrage of drugs by burrowing itself in the lymph nodes and to pop out and begin to reproduce again years later (4-5, 200, 310-312).

The other asset of HIV is cultural in kind: HIV is transmitted through blood, sexual fluids, and breast milk, in the moments of intimacy of sex, birth giving, breastfeeding, and drug injection, licit and illicit. Their discussion is heavily tabooed, especially in imbalances of power, as between male and female, and in the margins of society, among prostitutes, drug addicts, gay and migrants. So is also the discussion of HIV-transmission (328-329): ‘an illness no one likes to name’ (333), that ‘preys on our moments of weakness, and on our least manageable emotions of shame, fear and denial’ (274). It is this silence from shame that has pro-

⁵ 700.000 babies contract HIV/AIDS in Africa each year, and only 300 in all rich nations combined. HIV-transmission at birth is easily prevented (190). HIV/AIDS treatment of babies and young children is, however, much more difficult and underdeveloped than that of adults (190-192).

⁶ The so-called ‘sero-conversion’: flulike symptoms signalling that the body begins to produce antibodies to HIV. They pass by after a couple of days and then it can be years before any other symptoms become noticeable (338, 357).

⁷ HIV-1[M-]C, the strain most common in Southern Africa, typically progresses slowly from infection to illness. During Mandela’s presidency, 1994-1999, HIV-infection rates in South Africa rose from 8% of adults to nearly 25%, but the first large wave of deaths did not begin until about 1999 (320, 321). Cf. also 196-210 on Pontianu Kaleebu, researcher at the Uganda Virus Research Institute, and the hunt for a vaccine against HIV. On the various strains, esp. HIV-1M that causes the vast majority of infections globally, and its nine sub-classes, HIV-1M-A to HIV-1M-I, cf. 201. Infections in Europe and North America are virtually all HIV-1M-B; in East Africa HIV-1M-A and HIV-1M-B, and HIV-1M-C in Southern Africa. Most research focussed on HIV-1M-B until recently when it swung to HIV-1M-C, the biggest killer (201-202, 206, 209, 283-284).

vided HIV with very potent silent carriers ('vectors') for ultrarapid diffusion in African societies until now (5-6).⁸

By the time HIV was discovered and identified in the gay communities in the West in the mid-1980s, it had already been devastating rural areas in Uganda, Zambia and Zaire for over a decade as the 'slim' disease of young adults that responded to no treatment (cf. also 198). In 1983, HIV was first attested in Kigali and Kinshasha, in heterosexuals, not in gay. In 1986, in the first national survey in Africa, a staggering 17.8% of the urban population of Rwanda proved HIV-positive (6-7). By examining frozen blood samples stored in hospitals, it was shown soon that HIV/AIDS had spread in Central Africa from as early as 1959. Genetic investigations have established recently that HIV is a modification of SIV, *Simian Immunodeficiency Virus*, in chimpanzees and mangabeys. It 'jumped' to humans in South-East Cameroon some seventy years ago, and 'travelled' to Kinshasa where it spread through the use of unsterilized needles in mass vaccination campaigns in the next two decades. From there it radiated to other parts of Africa in the 1960s, and through Haiti to the gay communities in the Western world (6, 8). By 1990, one in five adults in Uganda was infected. By 2005, at least twenty million Africans had died from HIV/AIDS, and in parts of Southern Africa, infection rates in adults had risen to over 30% in 2006 (8-11).⁹ Nolen indicates poverty as a key factor in the spread of HIV/AIDS in Africa: 'millions of Africa [...] might easily have been protected if they had had access to education about it, or to the means of defending

⁸ Key vectors are labour migration, especially of miners (119, 122-123); long distance haulage of truckers (41-51); the armies (143, 148-151); men 'going around', more especially the wealthy and educated men 'who ought to know better' (159-161, 326); and bar girls (280-281).

⁹ 'Swaziland now has the highest adult HIV prevalence in the world: 33.4%' (UNAIDS 2006, *AIDS Epidemic Update: December 2006*, p. 13, at:

http://data.unaids.org/pub/EpiReport/2006/04-Sub_Saharan_Africa_2006_EpiUpdate_eng.pdf.

In KwaZuluNatal, 'adult infection rate is about 40%' (285). But Nolen cautiously notes the 'extreme weakness' of data collection with respect to HIV/AIDS infection in Africa and the numbers of deaths it has caused (15-17). Figures are unreliable because national governments tend to push them down for fear of scaring off tourists and foreign investors (231), while international agencies may inflate them to attract attention and funding'. On HIV/AIDS in Swaziland, cf. also the stories of Siphilwe Hlophe (19-30, esp. 27-29) and Mfanipela Thlabatse (136-139, 348).

themselves'. And the Sub-Saharan states were too weak and destitute to take effective measures against it (11).

That was a legacy of colonialism, Cold War global politics and IMF structural adjustment. 'More than a century of foreign meddling had reduced much of the continent to a corrupt, conflict-torn, impoverished mess' (12, 246-255). Rich donor nations refused to put adequate funding into it for combating AIDS. When in 1999 the UN requested \$6.6 billion, donor nations gave \$560 million (also 254). Another factor is ineffective, kleptocratic (250-251), repressive (288-304) African leadership that resorts to stigmatizing and ostracizing people with HIV/AIDS rather than coming to their rescue. A third are cultural and social practices: eschewing condoms while having multiple concurrent sexual partners¹⁰ (12-13).¹¹

Nolen does note a change for the better since 2000: ARVs are now dispensed to 1 million patients; African AIDS activists forced the pharmaceutical industry to allow the production of cheap generic drugs;¹² the HIV/AIDS pandemic became a political and media issue and has begun to attract serious funding through the rock star Bono, Bill Clinton (cf. also 206, 327), Bill and Melinda Gates (cf. also 206-207, 285) and Stephen Lewis, UN's Special Envoy for AIDS in Africa from 2002 to 2007, and Bush announcing his five-year, \$15 billion President's Emergency Plan for AIDS Relief (PEPFAR) in 2003. Even so, it is hard for people unaffected by Africa's plight to be aware of the epic drama – medical, demographic, econom-

¹⁰ Nolen is careful to stress that 'years of research have made it clear that Africans do not, in the course of their lives, have a greater number of sexual partners than North Americans or Europeans. But where people in the West follow patterns of serial monogamy, moving from one partner to the next in relationships of varying lengths with limited overlap, many sub-Saharan Africans have the same number of partners in what are called concurrent sexual networks, where some or all the partners overlap. Because of the way HIV works, those networks greatly increase the odds of infection' (161, 334).

¹¹ Key factors, other than the three named by Nolen, are silence from shame and for fear of stigmatisation and ostracization (23-24, 65, 162, 320); and ignorance through misguided notions about HIV/AIDS as a disease that would strike promiscuous whites only, or gay, or prostitutes, i.e. 'sinners' (23, 143). A new misguided notion since ARVs began to be distributed, is that you need not worry about contracting HIV: 'they can "fix it" with a pill' (334).

¹² Cf. 167-185 on Zackie Achmat ('gay, atheist, full-time rabble-rouser and one-time sex worker') and the Treatment Action Campaign (TAC), 1998-2006, Mbeki's role in it (173-176, 217-219, 323, 344), and the support Mandela gave him (178, 324-325, 327) and Winston Zulu (211-224, 224).

ic, social, cultural – HIV/AIDS has caused and is causing in African communities and in the lives of Africans.

The 28 biographies gathered in her book are meant to bring that drama home, and to explain how the disease works, spreads and kills, and is tied to conflict, famine and the collapse of states. But also how treatment works, when people can get the drugs, and how those who cannot get them, fight to stay alive with virtually no help and no support (14-15). Her 28 real life stories bring this home extremely well. They show, on the one hand, how many HIV/AIDS patients were betrayed by their lovers, families, neighbours and government, and lost much more than only their health. On the other hand she shows how some people cared for their sick families and neighbours, fought the drug companies and their governments, sheltered orphans (66-71, 239, 245) and overcame fear and shame (17).

Let me summarise one: that of an Anglican priest in Uganda, Gideon Byamugisha (257-268), who, as early as 1992, was the first clergyman to declare publicly that he was HIV-positive. He dedicated his life to breaking the stigma, shame, denial, discrimination, in-action and mis-action with respect to HIV and AIDS.¹³ His story is briefly as follows. In April 1991, a few months after their first baby daughter Patience had been born, Gideon, then a lecturer at a theological college and in charge of a parish fifteen miles outside Kampala, and his wife Kellen were poised for departure to Britain for graduate studies, when Kellen had suddenly to be rushed into hospital with severe chest pains. She died a week later. Devastated by her sudden death, Gideon abandoned his studies abroad to care for Patience. In late 1991, however, his sister Eunice, who as a nurse had attended to Kellen in hospital, came to tell him what she had kept as a closely guarded secret since Kellen's death, to wit that Kellen had been tested for HIV/AIDS during her final week and had been found positive. Gideon went to hospital at once for a test on himself and was found positive also. His daughter, however, was not found infected. Though he was well aware that he stood to lose his job and his parish if people knew he had tested

¹³ Quoted from <http://www.engagehivaids.com/cm/news/54>. Cf. also:

http://www.biblenetworknews.com/africa/112802_uganda.html ,

<http://www.pressureworks.org/focus/hiv/players/gideon.html>

<http://www.abc.net.au/rn/religionreport/stories/2006/1697057.htm>

http://sw.wikipedia.org/wiki/Gideon_Byamugisha

HIV-positive, Gideon decided that he could not and should not lead a ‘double’ life. He did not feel guilty about his status, which he attributed to lack of information rather than to a moral fault on his, Kellen’s or someone else’s part.¹⁴ He immediately informed his family, his in-laws,¹⁵ the staff and students of his college, and the wider church community about his condition. He rejected the request of the staff that he inform no one else. Though many people were uneasy about his public confession, he eventually did not lose his job and parish, not even when he remarried in 1995 to Pamela, who had lost her husband to AIDS and like him was HIV-positive (267). Rather, as the only openly HIV-positive priest in Africa for a decade, he became a speaker much in demand, e.g. during the pan-African AIDS conference held in Uganda in 1995 (260, 263).

In 1996, Gideon fell ill himself. His CD4 count dropped to below 100.¹⁶ Unless he was put on ARVs, he had fewer than six months to live, doctors told him. ARVs,

¹⁴ Neither Kellen nor Gideon had taken the test before their marriage. Gideon had, however, had blood transfusions in 1988 when he suffered a serious cycling accident. The blood was donated by a person who later died of HIV/AIDS. He also had had many injections for malaria at a time when sterilisation was not practised rigidly (260, http://www.anglican.ca/news/news.php?newsItem=2002-11-29_xx.news). Cf. the similar case of Noé Sebisaba and his wife Agrippine (82-98). When Noé volunteered to donate blood in 1995 in the refugee camp in Tanzania to which they fled in 1993 to escape from the Tutsi-Hutu troubles in Burundi, a routine test showed that he was HIV-positive. When Agrippine eventually took the test too, she proved HIV-positive also. They agreed they could not throw stones (90), for they had not taken the test before getting married; and Agrippine had been raped by a soldier before they fled from Burundi (86). Agrippine refused to have their status made public. As a result, when their baby daughter Lina died from AIDS in early 2003, and a few months later Agrippine herself also, people began to accuse a childless neighbour of having caused their deaths by witchcraft. To forestall that his in-laws killed her, Noé disclosed the true cause of their deaths and his own condition. The pastor at once publicly condemned him as a sinner, his friends deserted him, and his brother took his children away from his house. And when the news of Noé’s confession reached the local Tanzanians, they began to harass the refugee Burundians for spreading HIV/AIDS among them. From Noé’s confession, however, a ‘Stop SIDA [the French acronym for HIV/AIDS]’ movement started among the refugees in 2003 for spreading knowledge about HIV, and for caring for AIDS victims and orphans (92-98). Thokozani Mthiyane (329-345), who was careful never to have unprotected sex, contracted HIV when he was stabbed during a burglary of the house of a neighbour (336-340).

¹⁵ See http://www.anglican.ca/news/news.php?newsItem=2002-11-29_xx.news

¹⁶ The number of T-helper lymphocytes with CD4 cell surface marker should average between 500 and 1500 per cubic centimetre blood; cf. also 354.

however, were not available in Uganda. Gideon was saved, however, by the Anglican bishop of Kampala. He launched a crusade to keep him alive in 1997 and found two 'Good Samaritans', one in Singapore and one in the US. They sent Gideon the ARVs he needed. He recovered fully. Gideon and Pamela even decided to have children when drugs to forestall HIV-transmission from mother to child became available in Uganda. In 2000, their daughter Love was born, and 2002 another daughter, Gift. Like Patience, they were HIV-negative.

In 2002, his break-through came. By then he served on the [Anglican] Church of Uganda's AIDS programme, travelled abroad often as the representative of the Ugandan organisation People Living with HIV/AIDS (PLHA), the AIDS NGOs' Network in East Africa, the International Alliance for Religious Responses Against AIDS, and as the FBO¹⁷ Specialist for Africa in 'Hope Initiative' AIDS program of World Vision, a Canadian Christian relief organization.¹⁸ In December 2002, he was invited to the White House by the US President Bill Clinton for a meeting on faith-based responses to the pandemic (264).

More importantly, however, Gideon secured funds in 2002 to bring forty-two of the many clergymen, who had privately disclosed to him during his travels in Africa that they too were HIV-positive, together in Harare in a retreat in order that they might feel safe to speak freely about their condition. At this meeting, 'it took them only one day to decide that they wanted to organize into a continent-wide network – to support and care for each other, and to influence the policies of their churches'.

As a result, the African Network of Religious Leaders Living with, or Affected by, HIV/AIDS (ANERELA+) was founded.¹⁹ It was officially launched in October 2004, with Gideon as its first President and with Jape Heath,²⁰ an Anglican priest in Johannesburg, South Africa, as its General Secretary, during the 11th In-

¹⁷ Faith Based Organisation

¹⁸ Cf. <http://www.worldvision.ca/About-Us/Pages/AboutUs.aspx>

¹⁹ At <http://www.anerela.org/INERELA+%20-%20International%20expansion.htm> it is, however, reported that ANERELA+ was founded during a working retreat at Mukono in Uganda in November 2002.

²⁰ Cf. <http://www.pressureworks.org/focus/hiv/players/japeheath.html>

ternational Conference of the Global Network of People Living with HIV/AIDS (GNP+) held in Kampala, Uganda. It had a membership of 1.372 on 1st January 2006 in Africa.²¹ It included not only Christian but also a few Muslim and Hindu, and several Bahai religious leaders.²² The concept of ANERELA+ was in addition introduced to religious leaders outside Africa during the International AIDS Conference in Toronto-Canada in 2006, by the speech that Gideon delivered before the United Nations in June 2006,²³ and by his publications.²⁴ To accommodate religious leaders living with HIV/AIDS outside Africa, ANERELA+ was transformed in 2006 into INERELA+, the International Network of Religious Leaders Living with, or Affected by, HIV/AIDS. Its membership in Africa stood at 2.700 in 2007.²⁵

Gideon's honesty, perseverance, patience and achievements show how much HIV-positive religious leaders can contribute towards breaking the chains of silence and shame if their communities and institutions do not automatically stigmatize them as sinners and ostracize them by their moralizing theologies of damnation, but instead attempt to understand the complexities and scale of HIV/AIDS pandemic, spread knowledge about it, and support the infected and affected. Gideon was lucky to serve in a church, college and parish that did not silence or

²¹ In Uganda, Kenya, Malawi, Tanzania, Zambia, South Africa, Mozambique, Namibia, Nigeria, the Democratic Republic of Congo, Rwanda, Lesotho and Zimbabwe, and most recently in Botswana. There 'a stigma eradication for Botswana religious leaders was held from the 9th to the 13th July 2007 at Desert Sands Motel in Palapye' that was attended by 23 religious leaders from various Christian churches, the Baha'i faith and traditional healers. They elected a committee, chaired by Bishop John Phillip, to organise BONERELA+, the Botswana Network of Religious Leaders Living with, or Affected by, HIV/AIDS. Cf. <http://www.anerela.org/Botswana.htm>.

²² http://www.anerela.org/Report_2005.doc, p. 7

²³ For the text of the speech, cf. <http://www.engagehivaids.com/cm/news/54>

²⁴ Gideon Byamugisha & Lucy I. Steinitz 2002, *Journeys of Faith: Church-based Responses to HIV and AIDS in Three Southern African Countries*. Oxford: Strategies for Hope Trust, 116 pp., ISBN-10: 0954306007 (pbk); Gideon Byamugisha & Glen Williams (eds.), 2005, *Positive Voices: Religious Leaders Living with, or Personally Affected by, HIV and AIDS*. Oxford: Strategies for Hope Trust, 39 pp., ISBN-10: 095490513X (pbk).

²⁵ <http://www.anerela.org/INERELA+%20-%20International%20expansion.htm>

oust him, even though they were troubled by his ‘confession’. Instead it stood by him and even rescued him from impending death.

Gideon was heartened by certain signs of change such as the public apology for having shunned people with HIV/-AIDS issued by Kenya’s Anglican Church in March 2006; the Catholic church mitigating its rigid anti-condom position a bit, also in 2006, in respect of married couples in which one partner is HIV-positive; and individual priests and nuns in Zambia and South Africa defying the ban of the Vatican on the distribution of condoms.

Moralisation, stigmatisation, testing before marriage, insistence on abstinence as the only pillar of prevention and recourse to the numerous kinds of spiritual healing rather than medical, educational and political ones, however, continue to constitute predominantly the approaches of religious institutions in Africa. The chains of silence and shame keep most of them in bondage as yet.

That is also mostly true for other institutions, especially families and workplaces, as the stories told by Nolen make clear abundantly.²⁶ Silence from shame is, with ignorance, probably the major reason why HIV/AIDS has been so devastatingly successful in Africa.

Departments of Religious Studies in Africa may use Nolen’s book therefore with great profit in their teaching for confronting themselves and their students with the grassroots realities of HIV/AIDS in contemporary Africa. And for shouldering their part in the huge task of breaking the chains of silence and shame, as did Nelson Mandela publicly in 2002 (178) and 2005 (313, 322-330); as had done his wife, Graça Machel, before him, in 1999 (319), Joshua Nkomo in 1996, and Kenneth Kaunda, and Uganda’s president, Museveni, as early as the mid-1980s (319-320).

²⁶ Like Prisca Mhlolo, in Mabvuku, Harare, who was severely maltreated by her sister and brothers in 1997 at the burial of her son for revealing that she was HIV-positive, that her youngest daughter and her husband had died of AIDS in 1995, and that her son had killed himself for fear of dying from AIDS after he had been raped by a teacher at his secondary school (52-65). By 2004, all her brothers and sisters had died, of AIDS (64). Gugu Dlamini was beaten to death by a mob near Durban, South Africa, in 1998 for revealing on a radio programme that she was HIV-positive (171).

So did and do the HIV/AIDS-infected heroes of Nolen's book. Its 'impact could shape public opinion as never before', says Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa. It will certainly shape that of students of religions, if they read it.