

BIOETHICS MATTERS ENJEUX BIOÉTHIQUES

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Changing Bioethics:

The HIV/AIDS Epidemic in North America and Sub-Saharan Africa

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HIV stands for Human Immunodeficiency Virus, which attacks and weakens the immune system. When the body reaches the point where the immune system is too compromised to ward off infection, the patient has AIDS, Acquired Immunodeficiency Syndrome, a fatal disease. As yet, there is no cure for AIDS and no vaccine to prevent HIV. Current treatment includes HAART, or “highly active retroviral therapy”. Formulated in the late 1990s, it “involves using a combination of three or more antiretroviral medicines that work together to slow the rate at which HIV multiplies in the body, thus allowing the immune system to stay healthy and delaying the progression of the disease to AIDS.”¹

First diagnosed in 1981,² HIV/AIDS has influenced the development of health care ethics, first as the epidemic was experienced in North America and now as it is being experienced in Sub Saharan Africa.

HIV/AIDS IN CANADA: STATISTICS

The first AIDS diagnosis in Canada was made in 1982 and the first death from AIDS occurred in Canada in 1983.³ Reporting began in 1985. Initially in Canada, HIV/AIDS was most widespread in the male homosexual population, and in hemophiliacs and others who had been transfused with tainted blood. Needle sharing injectable drug

users also accounted for a large proportion of those infected with HIV/AIDS.

From 1985 to the end of 2008, 67,442 people in Canada were reported to be HIV positive.⁴ From the beginning of the epidemic until the end of 2008, there have been 21,300 reported AIDS cases in Canada⁵ and 13,458 people have died of AIDS.⁶ Until 1994, 7% of AIDS cases were women; in 2007, 20% were women.⁷ By 2008, 246 children had been diagnosed with AIDS.⁸

ETHICAL ISSUES IN NORTH AMERICA

In North America, the onset of the HIV/AIDS epidemic coincided with the turn from paternalism in health care, “where physicians were able to rely almost exclusively on their own judgements about their patients’ needs for treatment, information and consultation”⁹ to an emphasis on patient autonomy and patient-driven treatment decisions. Many of the ethical issues raised by the epidemic as it was experienced in North America coincided with and contributed to this development.

For instance, patient populations hit hardest by the epidemic included homosexual men. Then socially marginalized and fearing further stigmatization because of the disease, patients insisted on rights to privacy and confidentiality, including the right to anonymous testing. At that time, universal bodily substance precautions—the use of gloves, masks and protective eyewear donned by health care professionals in the treatment of patients—were adopted. With all patients being treated with the same precautions, there was no need to distinguish

between those who were HIV positive and those who were not. With AIDS taking them in the prime of their lives, patients wanted a greater say in treatment decisions, including end-of-life care. Advance directives, particularly living wills, were being developed at that time. Knowing that there was no cure for AIDS, patients nevertheless agitated to be enrolled in clinical trials and otherwise have access to experimental drugs that might prolong their lives. This raised issues of rationing (who should be enrolled in trials when enrollment was limited), informed consent (did desperation obscure freedom in decision making), and a patient's right to risk.¹⁰

The focus of many of these issues was on patients as individuals and their rights to privacy and protection from discrimination, as well as to their right to participate in and even direct decisions around their treatment and care. This emphasis on individual rights and patient participation in treatment decisions was deeply influential in shaping health care ethics in which respect for patient autonomy became a driving principle.

SUB-SAHARAN AFRICA: STATISTICS

According to UNAIDS, "Sub-Saharan Africa remains the region most heavily affected by HIV world wide, accounting for over two thirds (67%) of all people living with HIV and for nearly three quarters (72%) of AIDS-related deaths in 2008."¹¹ By 2008, an estimated 22.4 million people in Sub-Saharan Africa were HIV positive; of these an estimated 1,800,000 were children.¹² Since the beginning of the epidemic, an estimated fifteen million people in Sub-Saharan Africa have died of AIDS, 1.4 million in 2008 alone.¹³ The epidemic has left nearly fourteen million children orphaned.¹⁴ In Swaziland, an estimated 26.1% of all adults are HIV positive; in Botswana, 23.9%; in Lesotho, 23.2%; in South Africa, 18.1%.¹⁵

In Sub-Saharan Africa, HIV/AIDS is primarily spread through heterosexual sexual activity¹⁶ and "the vast majority of people living with HIV in Africa are between the ages of 15 and 49 – in the prime of their working lives."¹⁷ In South Africa, 21% of teachers aged 25-34 are HIV positive.¹⁸ Botswana lost 17% of its health care workers between 1999-2005 to AIDS.¹⁹ In Zambia, 40% of midwives are HIV positive.²⁰ Of all AIDS deaths in Sub-Saharan Africa, 60% are in the 20-49 year old age group.²¹ In Swaziland, the average life expectancy is now 31 years of age.²²

HIV/AIDS: THE ETHICAL ISSUES IN SUB-SAHARAN AFRICA

Perhaps the most pressing issue initially was that HIV/AIDS patients in Sub-Saharan Africa did not have access to the same medicines and medical care that are available to their counterparts in North America. HAART has been proven to delay the onset of AIDS and thus prolong the lives of those who are HIV positive. AZT taken by pregnant women can help prevent the transmission of HIV to their children during pregnancy and childbirth. While the cost of these drugs became more affordable for patients in North America, they were simply beyond the means of patients in Sub-Saharan Africa.²³ Furthermore, while HAART can be a complex "cocktail" of drugs in North America because of drug interaction and the possible side effects for patients, in Sub-Saharan Africa, the regimen is simplified out of necessity. In part this is because, as HIV/AIDS has had a devastating impact on the professional classes, there simply aren't enough practitioners to oversee complicated regimens or technicians to do ongoing diagnostic testing.²⁴

HIV/AIDS is also threatening the social fabric of much of Sub-Saharan Africa. Traditionally orphanages have not been a part of African society; instead, orphaned children would be taken in by members of

their large extended families. HIV/AIDS and the sheer numbers of children who have lost one or both parents to the disease have changed this. Even before they are orphaned, children find themselves caring for sick parents—parents who may be unable to work and no longer bring money into the household. Once their parents have died, the children may join other cousins who are also in the care of an aunt who may also be ill. Many, many children are taken in by grandmothers, older and who have few economic resources. And many children simply assume the duties of their parents, raising siblings without help. School is out of the question for them and these children who need parenting themselves become open to exploitation.²⁵

In Sub-Saharan Africa, HIV/AIDS has created vulnerable populations open to discrimination, particularly women. HIV/AIDS is associated with promiscuity and, even though a woman may have been infected by her husband, she often risks violence, abandonment, even death if she discloses her HIV status. The woman and her children also risk being ostracized by families and neighbours. This discrimination and the cult of secrecy and silence it engenders can become an obstacle to education, treatment and prevention of further spread of HIV/AIDS.²⁶

While it would be wrong to lose sight of the individual in the experience of HIV/AIDS in Sub-Saharan Africa, many of the issues identified point to the importance of adopting a social justice perspective in health care. One can ask, for instance, what fairness requires when such a gap exists between the medical care available to HIV positive Africans and HIV positive North Americans. It is clear that poverty plays a large role in this discrepancy, affecting the health of millions of people. Furthermore, the situation in Sub-Saharan Africa raises issues of what “health” means. A child orphaned by AIDS

may herself be infection-free but, at age eleven, is unable to go to school because she has cared for her dying parents and now is in charge of three younger siblings, one of whom might be infected, and has no way of bringing money or food into the household except through unregulated menial labour and, eventually, prostitution. For her, health means more than the absence of disease or infirmity. As well, given the effects of HIV/AIDS on the social and economic fabric of Sub-Saharan Africa and on the world’s consciousness, health becomes more than the state of an individual; it becomes a community—a global—matter.

CONCLUSION

Bioethics is an evolving discipline and the HIV/AIDS epidemic, as it has been experienced in North America and Sub-Saharan Africa, has had a profound effect on this evolution. Out of the crisis in North America came an emphasis on safeguarding the dignity of individuals, protecting persons from discrimination, involving patients in treatment decisions, and protecting individual rights and interests. HIV/AIDS as it is being experienced in Sub-Saharan Africa continues to shape health care ethics. Without abandoning respect for patient autonomy, it has nevertheless raised issues of justice and points to the necessity of moving to a more comprehensive understanding of health and the realization that the wellbeing of our global community matters.

From a Catholic point of view, all of these developments have been consistent with our life ethic: that all persons are valuable no matter what their stage of existence or state of health and that we must work to protect and uphold their dignity as persons. As members of the Body of Christ, we are connected to one another; the wellbeing—or lack of wellbeing—of one member of the Body will affect the overall health of the rest of the members. And, as the parable of the Good Samaritan teaches, we must move

beyond a narrow understanding of who our neighbour is to adopt a much broader and more inclusive perspective. ■

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IN THE NEXT ISSUE OF BIOETHICS
MATTERS: THE AFRICAN CHURCH
RESPONDS TO THE HIV/AIDS CRISIS.

¹ Public Health Agency of Canada, "More About Highly Active Antiretroviral Treatments," <http://www.phac-aspc.gc.ca/aids-sida/info/5-eng.php#antiretroviral> (accessed November 2009).

² Public Health Agency of Canada. "A Brief History of HIV/AIDS in Canada," <http://www.phac-aspc.gc.ca/aids-sida/info/1-eng.php> (accessed November 2009).

³ Ibid.

⁴ Public Health Agency of Canada. *HIV and AIDS in Canada: Surveillance Report to December 31, 2008*, http://www.phac-aspc.gc.ca/aids-sida/publication/survreport/2008/dec/surveillance_2008_3-eng.php#Section_1_2 (accessed May 2010).

⁵ See endnote 4: 7-eng.php#Section_3_14.

⁶ See endnote 4: 10-eng.php#Section_4_22.

⁷ "Canada Statistics by Year and Age. Trends in AIDS diagnoses," <http://www.avert.org/canada-aids.htm> (accessed November 2009).

⁸ See endnote 4: Section_3_14.

⁹ Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, fifth edition (Oxford: Oxford University Press, Inc., 2001), p. 176.

¹⁰ For further discussion of these and other issues raised by the HIV/AIDS epidemic in North America, see: David J. Roy, John R. Williams and Bernard M. Dickens, *Bioethics in Canada* (Scarborough, Ont.: Prentice Hall Canada Inc., 1994), pp. 235-262; Benedict M. Ashley and Kevin D. O'Rourke, *Health Care Ethics: A Theological Analysis*, fourth edition (Washington: Georgetown Press, 1997), pp. 61-62, 73-74, 102; Thomas M. Garrett, Harold E. Baillie and Rosellen M. Garrett, *Health Care Ethics*, fifth edition (Boston: Prentice Hall, 2010), pp. 125-126.

¹¹ UNAIDS, "Fact Sheet Sub-Saharan Africa," http://www.unaids.org/pub/FactSheet/2009/20091124_FS_SSA_en.pdf (accessed May 2010).

¹² "Sub-Saharan Africa HIV & AIDS Statistics," <http://www.avert.org/africa-hiv-aids-statistics.htm> (accessed May 2010).

¹³ "The Impact of HIV & AIDS in Africa," <http://www.avert.org/aids-impact-africa.htm> (accessed May 2010).

¹⁴ See endnote 11.

¹⁵ See endnote 12.

¹⁶ See endnote 11.

¹⁷ See endnote 1.

¹⁸ Ibid.

¹⁹ Ibid

²⁰ Ibid.

²¹ Ibid.

²² Ibid.

²³ As Rosemary Tong noted, the AZT regimen for pregnant women in the U.S. costs about \$800. Even when this treatment is modified to comprise only 10% of the dosage used by American women, at \$80 it was still too costly when "about U.S. \$10.00 constitutes the annual per capita health care expenditure in the poorest of the poor developing nations." See: Rosemary Tong, *New Perspectives in Healthcare Ethics: An Interdisciplinary and Crosscultural Approach* (Upper Saddle River, N.J.: Pearson, 2007), p. 97.

²⁴ Stephanie Nolen, "Deaths rob Malawi of warriors in its assault against AIDS," *The Globe and Mail*, November 21, 2005, A 12.

²⁵ For a more detailed discussion of the plight of African children orphaned by AIDS, see: Andre Picard, "AIDS epidemic creates generation of orphans," *The Globe and Mail*, July 14, 2000, A11; Doug Saunders, "AIDS orphan tells of horror in homeland," *The Globe and Mail*, May 9, 2002, A9; Estanislao Oziewicz, "HIV-AIDS newest stalker of children, UNICEF says," *The Globe and Mail*, December 9, 2004, A20; Stephanie Nolen, "Africa's AIDS orphans grow up fast," *The Globe and Mail*, December 1, 2003, A9. According to a UNICEF report cited by Nolen, "the orphans are poorer, sicker, and less likely to go to school than children with parents. They dream less, play less, and they frequently fall prey to abuse, theft and exploitation by relatives and other adults in their communities."

²⁶ See, for instance: UNAIDS, "Sub-Saharan Africa," <http://www.unaids.org/en/CountryResponses/Regions/SubSaharanAfrica.asp> (accessed May 2010); World Health Organization, "Gender inequalities and HIV," http://www.who.int/gender/hiv_aids/ed/ (accessed May 2010); Stephanie Nolen, "Continent's educated can no longer run things: They're dead or can't cope," *The Globe and Mail*, June 19, 2002, A13.