TRENDS & DEVELOPMENTS

THE EMPTY PROMISE OF PRIVACY:

pregnancy and HIV testing

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Until recently there was no known way to prevent some babies of HIV-infected mothers from also being born with the virus linked to AIDS (acquired immune deficiency syndrome). But in the spring of 1994, the results of a major U.S. clinical trial (see sidebar entitled "Known Benefits, Unknown Risks" on page 37) offered the possibility of controlling maternal-foetal transmission of the human immunodeficiency virus.[1] The possibility of a somewhat effective means to prevent the transmission of the virus to foetuses in the womb has added steam to efforts to test and identify HIV positive women before they give birth. Such testing may put women at risk of discrimination and interference with their reproductive and parenting decisions.

In the United States there has been significant pressure to institute mandatory testing for all pregnant women. However, mandatory testing has been linked both to eugenic[2] efforts to stop HIV positive women from having babies at all, and to efforts to criminalize HIV positive women who infect their "innocent" foetuses.[3] Needless to say, such an approach has met with some resistance from women's rights and AIDS activists. This resistance reflects the ongoing problem of how to adequately protect women's individual interests while assuring access to a treatment that may prove very beneficial to many women and their foetuses.

In Canada, the approach to identifying HIV positive women during pregnancy has been quite different than in the U.S. The government is not proposing mandatory testing. Instead, there has been a strong public emphasis on attaining consent to testing and maintaining confidentiality of test results.[4] One example of the approach to testing in Canada is British Columbia's policy of recommending that all pregnant women have an HIV test as part of their routine prenatal care.[5] Nevertheless, this policy does not include adequate protection for the privacy of HIV positive women nor for their reproductive

decision-making more generally. However, it is far from clear that it would be possible to provide such protection in the context of an HIV diagnosis during pregnancy. Acting on a positive diagnosis necessarily involves significant compromises of a woman's privacy, even though there are other highly valued social interests which may "justify" overriding it. In fact it seems that the promise of confidentiality may primarily work to pacify critics rather than to protect HIV positive women.

Promising privacy is a particularly effective means of mollifying those who might otherwise object to the policy as interference with reproductive rights. "Privacy" is the American constitutional doctrine under which women's reproductive rights are protected, so protection of privacy tends to imply, by association, acceptance of reproductive freedom and women's decision-making.[6] Although Canadian constitutional doctrine is less explicit in its deference to individual privacy, the convergence of privacy rhetoric with notions of individual liberty is, in general, characteristic of rights documents such as the Canadian Charter of Rights and Freedoms. Privacy's importance as a core value in our society is based on a visceral sentiment that holds opposition to government authority as a central part of individual liberty, while remaining fundamentally abstract. The unstable, appealing and contradictory nature of the value tends to displace critical thinking about the potential negative effects of a policy intended to be helpful.

Testing all pregnant women for HIV is a policy which seems to offer the irresistible possibility of "preserving life and preventing suffering"[7] of foetuses which might otherwise be born with HIV. However, although test results seem very hopeful, positive trial results do not necessarily mean that any routine testing program is appropriate or justified. As well, there may be some risks to pregnant women who test positive which are overlooked in a policy that is geared almost exclusively towards foetal health. The failure to examine the policy's negative effects for pregnant women may be rooted in the assumption that women will welcome the testing since they themselves want their children to be healthy, and, in pursuit of that end, "good mothers" should be willing to put aside their own concerns.[8]

One might expect that affected women's distinct interests will be safeguarded by the protection of their right to privacy. This may be misleading. The government neither does, nor promises to do, much more than protect confidentiality in official contexts. At the same time, there is a presumption that confidentiality protection will be an effective means to prevent unwanted disclosure of women's health status and any resulting loss of control by the women. As such, the promise of confidentiality relies on our broader notions of privacy without providing much content for that promise.

KNOWN BENEFIT, UNKNOWN RISKS

The National Institute of Allergy and Infectious Diseases conducted a clinical trial among a group of six hundred HIV positive women who had taken a drug called zidovudine, better known as AZT, during pregnancy and labour. In that group, the statistical average of births of infected babies was reduced by two-thirds. Without this medical treatment, an HIV positive woman has about a 25 per cent chance of giving birth to an infected baby. With AZT the rate of transmission was reduced to about eight per cent.

Although the test results seem very hopeful, some critics have urged a cautious approach to the results. The trial was relatively limited. For ethical reasons, women on the placebo were given the genuine medication before the end of the trial, so there was no control group. None of the women who participated in the trial were at a sufficiently advanced stage in their HIV illness to show the symptoms of AIDS. For these reasons, medical authorities and health activists have criticized the trial. Health Canada, for example, urged caution in any recommendations about treating pregnant women with AZT to prevent transmission of HIV to their foetuses.

Possible risks of AZT treatment to women include:

- **Will women who use AZT during pregnancy – before they are themselves ill with AIDS – develop increased resistance to the drug?**
- **Will there be presence of "viral strain", that is, will the progress of the women's own disease be accelerated by taking the drugs during pregnancy?**
- **U.S. Food and Drug Administration studies produced some evidence of the presence of vaginal tumours and "developmental malformations" when rodents received heavy dosages of AZT during pregnancy.**
- **Women who took AZT during the clinical trial did not seem to have suffered from side effects (ranging from anemia to liver chemistry abnormalities) at any greater rate than women who took the placebo.**

Sources: M.J. Oxtoby, "Perinatally acquired human immunodeficiency virus infection" (1990) 9 Paediatric Infectious Diseases Journal 690; Health Canada, (1994) 20:12 Canada Communicable Disease Report 97; Centre for Disease Control and Prevention, "Recommendations for the use of zidovudine to reduce perinatal transmission of human immunodeficiency virus" (1994) 43 M.M.W.R. RR-11; "Zidovudine for mother, foetus and child: hope or poison?" (editorial) (1994) 344 The Lancet 207, Brenda Macevicius, "Women and AIDS Project: Routine HIV Testing for Pregnant Women" in AIDS Vancouver Island Update (Fall, 1994).

Despite the promise of confidentiality, HIV positive women may be subject to unwanted intervention as a result of testing and diagnosis. It is important to recognize that confidentiality protections do nothing to help an HIV positive woman deal with the extreme personal stress, depression and crisis that often follow diagnosis. Privacy protection is useless to prevent a loss of control over the timing of one's illness and dealing with it.

Furthermore, in an intimate context, a woman's need or desire to keep her health status confidential is seen to be in direct conflict with her partner's right to know his or her own status. Whether or not women tell their partners directly of their condition, their actions will make any kind of privacy within their household almost impossible, exacerbating the feelings and real experience of loss of control. If women choose to act on their HIV diagnosis to get medical care, they will likely face changes in diet, regular medical visits and a course of medication, none of which are easy to conceal and all of which may increase the significant risk of violence in these women's lives. A recent American study shows HIV diagnosis in women is often followed by abuse or the end of significant relationships.[9] A British Columbia study found that more than half (54%) of the HIV positive women surveyed had been sexually assaulted or abused as adults.[10] It cannot be safely assumed that women's need for confidentiality is only in relation to the government, employers or members of the general public. Their safety may be significantly jeopardized within the family, an area where an assumption of privacy operates and which is consequently often ignored by legislators and policy makers.

There are a number of reasons, in addition to concerns about safety within their familial relationships, why HIV positive women might refuse treatment. AZT and the related family of drugs (called retrovirals) are controversial as a means of treating HIV, despite their widespread support in the medical community.[11] The AZT treatment during pregnancy is highly intrusive (medication five times a day and intravenously during labour) and may increase the woman's resistance to the drug during her own treatment when (presumptively) she develops AIDS. In practice, more than half of the women with AIDS in the B.C. study of HIV positive women were not taking retrovirals for their illness, contrary to their doctor's orders. Because women may be pressured by medical and child protection authorities, there is clearly a need for rigorous safeguards to ensure that they are not forced into treatments they do not want.

Legislative protection for women's medical decisions in the context of treatment for HIV may also be inadequate. The confidentiality provisions in Canada's Privacy Act,[12] B.C.'s Freedom of Information and Protection of Privacy Act[13] and the Communicable Disease Regulations under B.C.'s Health Act,[14] when read together, seem to offer comprehensive protection against the use of medical information, particularly voluntary test results, without permission of the individual. However, in contrast, the Child and Family Services Act explicitly overrides every confidentiality obligation (except solicitor-client privilege) when a person suspects that a child may be being abused or neglected. Doctors routinely report to the director of Family and Children's Services when they think a child may be at any degree of risk.[15] If her physician had recommended the AZT treatment for the benefit of the foetus, and the woman declined it, it is highly likely that child welfare authorities would be informed at the time of birth, if not earlier.[16] There are no reported cases specifically on HIV illness; however, where parents' (usually single mother's) mental or physical illness is in question as a factor in reported Canadian child protection cases, extensive use is made of medical and psychiatric records.[17] In the overwhelming number of these contested cases guardianship is awarded to the child welfare agency, foster parents, or adoptive parents.

The collapse of mothers' privacy protection to ensure adequacy in reporting child abuse seems to be only the first step in the ideological separation of the interests of mother and child. Allowing state

FACTS & FIGURES

Several studies of HIV positive women have revealed the precarious social position of people with HIV.

Lack of Support: Numerous studies of HIV positive women report loneliness and isolation as the most important problem these women face in dealing with their illness. In an Ontario study of nearly seven hundred women with HIV about sixty percent of the women had children, while only one third were married or cohabiting.

Poverty: Only about 16% of the women in the Ontario study were working full time in the paid employment market; a further 13% characterized themselves as full time home-makers. The rest, whether or not "disabled" by their illness, were unemployed or working part time. Since disability payments under GAIN (Guaranteed Available Income for Need Act) are only available to individuals with AIDS symptoms, it is significant that only 27% of people who are HIV positive have been diagnosed with AIDS. A B.C. study of sixty HIV positive women showed that well over half of them, including those with children, had annual incomes under $20,000; 45% did not have high school education. Drug Use: More women than men contract HIV through dirty needles. In 11% of reported Canadian cases, women's use of injection drugs is listed as the cause of infection.

Sources: Strathdee, "A Sociodemographic Profile of Known HIV Positive Women in Ontario, Canada" HIV Infection in Women Conference Abstracts (Washington: 1995); Lobb & Kirkham, "Measuring the Impact: Sociodemographic Characteristics of Women with HIV/AIDS" (8th Annual British Columbia HIV/AIDS Conference Syllabus, 1994); Health Canada, Laboratory Centre for Disease Control, "Risk Factors for Reported AIDS Cases, Females, all ages (n=586)" (June 1994).

authorities to keep a preventative eye on a potentially needy child seems eminently justifiable, but it is not always clear what the consequences will be. It should be remembered that the higher level of scrutiny these women's parenting can be subject to may be a direct result of the breach of the confidentiality promised as a part of the earlier testing regime.

As a general rule, women with HIV are already precariously situated socially (see sidebar entitled "Facts and Figures" on page 38). They may or may not have had positive interactions with social welfare agencies and may already object to state interference in their lives and decision-making. "Help" from social welfare agencies can be interpreted as threatening, undermining, or directly antagonistic. In many cases, the women may be worried that their children will be taken away from them if they do not follow the directions of their doctors or social workers. In such a context, women may be forced into accepting treatment and services that are intrusive and/or unwanted.[18]

Fear alone may affect treatment decisions and dealings with social service agencies if women are worried about losing their children. In fact, such anxieties are not unreasonable. It is highly unlikely that a woman's HIV status alone would form the basis of a child protection decision: all child protection cases apply the same standard, the best interest of the child.[19] But one effect of a program to test all pregnant women for HIV might be to institute a standard that presumes treatment is in the best interest of the child. For a woman to refuse the AZT treatment may be seen to represent a significant departure from that standard, especially if in caring for a child her actions are coupled with other problems that may accompany poverty and illness.[20]

PROMISE OF PRIVACY: DISARMING CRITICS

If it is accepted that women's privacy is not — and perhaps cannot be — protected where a routine testing program is set in place, then one may wonder why privacy would be a heavily emphasized part of a health policy. It can be argued that privacy functions in a complex way to assure potential critics that the testing program is not going to be oppressive or coercive for the women who are its subjects. To some extent, this succeeds because of the ambivalent nature of privacy as a value in our society. The value of privacy is at once instrumental – seen as a *pre-condition* to the development of the self – and an end in itself. As an end in itself, privacy seems to offer the promise of state non-interference and the scope to make fundamental personal decisions. In particular, privacy is linked to an idea of moral agency that suggests responsible people need not be accountable to authorities for their life decisions. Furthermore, as an end in itself, privacy is characterized both in the highly abstract terms of autonomy, self-hood and liberty as well as in the visceral and concrete imagery of a locked door, a man's moated castle, or escape from Big Brother. In its former manifestation, as an abstraction, privacy presents itself as an obvious and fundamental component of liberal democracy. In its latter manifestation, as an image, it presents itself as a personal necessity. Due to its unique character as an abstraction that we can easily visualize as well as personalize, the promise of privacy may displace accountability for the consequences of a policy that could otherwise be considered highly intrusive.

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In the area of reproduction, privacy is a particularly powerful way to displace alarm. Without the "reassurances" of privacy the testing policy can easily be conceived as a major interference with women's reproductive rights. The promotion of AZT treatment for the "baby's good" must be placed in the context of wider patterns of foetal health movements and medicalization of pregnancies — both trends which take women's health decisions out of their hands. Furthermore, there are problems with defining "fit" mothers. HIV positive women are often counselled by their physicians and others to have abortions.[21] This "advice" is based on the notion that the women are sick and therefore unfit to be mothers or, perhaps more fundamentally, that they represent the source of their babies' illness rather than the giver of life.

In the United States, the rhetoric of privacy has played a central role in the development of constitutional and political protections for women's

reproductive rights. Most importantly, constitutional protection is based on the fourteenth amendment, where decisions relating to family and reproduction have been characterized as a part of the individual right to privacy. However, feminists in the United States have criticized privacy as a way of protecting women's reproductive rights. First, it is unequally distributed in a country riven by class, race and gender privilege or disadvantage. Second, it provides no positive guarantee of the material conditions that will allow the exercise of the rights protected. (Though privacy protects the right to abortion it does not mandate state funding of the service.) Third, it individualizes issues of reproductive choice, presenting them as women's personal decisions and thus ignoring the way that women's "choices" may be structured for them by their position in society. For example, compare the history of the 1960s where black women were fighting a battle for reproductive freedom against forced sterilization while white middle class women were fighting to have the right to terminate a pregnancy.[22]

These criticisms are very relevant to the effectiveness of privacy protection as a way of ensuring HIV testing does not put women at risk. The array of social disadvantages faced by most HIV positive women means that their privacy is more difficult to protect and more often overridden in the name of public interests associated with the various social and medical services they may use. In addition, protection of women's privacy with respect to their test results will have no effect on their health, nor on their control of their treatment. An HIV diagnosis does not guarantee them access to social support systems such as family benefits,[23] nor would a program change the widespread pattern of underestimating the HIV risk of women who are not pregnant.[24]

The American criticisms of constructing women's equality issues in terms of women's privacy are particularly important in the context of HIV positive pregnant women. The emphasis on the private choices of women with respect to treatment ignores the circumstances which may limit those choices and the conflicting expectations the women may face.[25] Pressures to abort or to participate in a health program that is difficult to maintain without the necessary material and emotional support will certainly have an effect on women's "choices" in this situation. Despite, or because of, the anti-government appeal of privacy rhetoric, these constraints are more likely to remain unaddressed where responsibility and decision-making is individualized. Nor is privacy a satisfactory answer to the problems faced by HIV positive people — gay and straight, pregnant or not — in terms of social stigma. People with HIV diagnoses face discrimination whether attempting to buy insurance, seeking to rent or maintain housing, or using public services. The promise of confidentiality is meant to address the legitimate fear that being diagnosed with HIV means a life of isolation. Arguably, while privacy may be viewed as a requirement for the personal security of affected individuals, more often it is a way out for governments which have failed to deal effectively with embedded prejudices.

ENDNOTES

1 Centre for Disease Control and Prevention, "Recommendations of the U.S. Public Health Service Task Force on the use of Zidovudine to reduce Perinatal Transmission of Human Immunodeficiency Virus" (1994) 43 M.M.W.R. RR-11 at 1-4.

2 "Eugenic" is a term that generally applies to attempts to control reproduction in order to select for or against certain genetically-carried traits (e.g., race, sex selection, Down's Syndrome). HIV is a virus and is not part of the genetic material passed from mother to foetus; however, the principle of selecting for "healthy" or "normal" children based on a pre-natal diagnosis makes the use of the term appropriate in this context.

3 Working Group on HIV Testing of Pregnant Women and Newborns, "HIV Infection, Pregnant Women and Newborns: A Policy Proposal for Information and Testing" (1990) 264C J. Am. Medical Assoc. at 2416; J. Terry, "The Body Invaded: Medical Surveillance of Women as Reproducers" (1989) 3 Socialist Review at 131-38.

4 See, for example, Health Canada, (1994) 20:12 Canada Communicable Disease Report 97 at 100; British Columbia Centre for Disease Control - C.D.C. Advisory Committee on HIV in Pregnancy, "Bulletin #1" (1994); Canadian Medical Association, *Counselling Guidelines for Human Immunodeficiency Virus Serologic Testing* (Ottawa: 1993).

5 B.C. Center for Disease Control, see note 4.

6 Particularly in conjunction with a promise of consent to treatment, which will not be the subject of this paper.

7 Office of the Provincial Health Officer, Press Release 1994/109 (28 June 1994).

8 See C. Smart, *Feminism and the Power of Law* (London: Routledge, 1990) at 99-100.

9 Working Group on HIV Testing of Pregnant Women and Newborns, see note 3 at 2418.

[10] D. Lobb and C. Kirkham, "Measuring the Impact: Sociodemographic Characteristics of Women with HIV/AIDS" (8th Annual British Columbia HIV/AIDS Conference Syllabus, 1994) at 63.

[11] Zidovudine is the drug most frequently prescribed to AIDS patients. For more information see *The AIDS Practice Manual: A Legal and Educational Guide*, 3rd ed. (New York: National Lawyers Guild AIDS Network, 1992).

[12] R.S.C. 1985, c. P-21, s. 2.3(a)(viii).

[13] S.B.C. 1992, c. 61.

[14] B.C.Reg. 4/83, s. 4.3(a)(i).

[15] *New Brunswick (Minister of Health and Community Services)* v. *L.(D.M.)* (1987), 78 N.B.R. (2d) 151 (Q.B.).

[16] *Re: Baby R* (1988), 53 D.L.R. (4th) 69 (B.C.S.C.).

[17] See, for example, *Catholic Children's Aid Society of Metro Toronto* v. *M. (C.)*, [1994] 2 S.C.R. 165; *Superintendent of Child Welfare for British Columbia* v. *P.(J.)* (1988), 15 R.F.L. (3d) 216 (B.C.C.A.); *New Brunswick (Minister of Health and Community Services)* v. *L.(S.) and R.L.* (1988), 81 N.B.R. (2d) 13 (Q.B.).

[18] See the article "No Lock on the Door" in this volume of Appeal – Review of Current Law & Law Reform.

[19] In the United States, courts have found that HIV infection, AIDS illness, or even AIDS dementia were not in themselves relevant to determinations of parental fitness or the child's best interests. See L.O. Gostin, "The AIDS Litigation Project: A National Review of Court and Human Rights Commission Decisions, Part 1: The Social Impact of AIDS" (1990) 264B J. Am. Medical Assoc. 1961 at 1965.

[20] National Council on Welfare, *In the Best Interests of the Child* (Ottawa: 1979) at 4.

[21] See C. Levine and N.N. Dubler, "HIV and Childbearing: Uncertain Risks and Bitter Realities: the reproductive choices of HIV infected women" 68 Millbank Quarterly 300 at 321.

[22] See A. Davis, "Racism, Birth Control and Reproductive Rights," in M. Gerber-Fried, *From Abortion to Reproductive Freedom: Transforming a Movement* (Boston: South End Press, 1990) at 15.

[23] See K. Bastow, "Women, AIDS and Family Benefits: A Case Study" (1994) 7 C.J.W.L. at 173.

[24] C.Devine, "The Epidemiology of HIV/AIDS in Women" (1993) 13:3 Canadian Woman Studies/Les Cahiers de la Femme at 17.

[25] J. Williams, "Selfless Women in the Republic of Choice" (1991) 66 N.Y.U. L.Rev. at 1559.