Birth Rights

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We know how to help HIV-positive people get pregnant safely, yet those exploring the idea of having children still too often encounter ignorance and fear. Diane Peters reports on fertility options for PHAs and the drive to improve access to fertility services.

Two years ago, Marie-Josée and her husband, Luc, decided to set aside the condoms and make a baby. She's HIV positive, he's not—but they were willing to take the risk. "This is really high on our list of things we want to do," says Marie-Josée, who's 38 and concerned she's running out of time to become a mother.

But after 18 months of trying, no baby was on the way. Then, last fall, Luc got some upsetting news: Tests showed a sperm count so low that he's unlikely to be able to father a child. International adoption was out for the Quebec couple—it was too expensive. Besides, they quickly learned that Marie-Josée's status could make international adoption challenging, as many countries require medical examination of the parents and discriminate against people with HIV. A fertility clinic and the use of donor sperm seemed the best alternative.

Marie-Josée called all the clinics in the Montreal area, and heard a string of no's. "We don't deal with HIV-positive women for safety and security reasons," one secretary told her. Marie-Josée knew these reasons had little scientific basis, but meanwhile, she was getting little support. Her HIV specialist did not want to be involved in her quest to become a mom, saying that reproductive health issues were beyond his expertise. He also told her: "I'm not supposed to know you're having unprotected sex. I don't want to have this conversation with you."

But Marie-Josée knows that for the past decade it has been both possible and safe for PHAs (people living with HIV) to have children. Doctors know how to dramatically reduce the risk of the virus passing from mothers to newborns (this is called perinatal, mother-to-child or vertical transmission). Preventing HIV transmission between partners ofen also requires medical help, but unfortunately in Canada that help can be hard to find—services are few and education among medical practitioners and the general population is lagging. However, a push for change is gaining momentum—community members and healthcare professionals, including obstetrician/gynecologists and infectious disease specialists, are joining forces to improve access to services for PHAs like Marie-Josée who want to get pregnant.

Baby boom

The desire to procreate among PHAs is on the rise. "I think it's really growing. I'm getting more and more referrals for couples who want to conceive," says Dr. Mona Loutfy, an infectious disease specialist and the director of the Women and HIV Research Program at the Women's College Research Institute in Toronto. Women in particular are keen. A recent survey found that 30 percent of young HIV-positive women in British Columbia hoped to become pregnant in the future. Researcher Gina Ogilvie, the associate director of the division of STI-HIV prevention for the BC Centre for Disease Control, says these intentions are just seven percent lower than those of women in the HIV-negative population. "We can no longer assume that just because women have HIV they are not interested in having children," she says.

Medical innovations have triggered this growth in a desire for kids. Thanks to a decade of experience and research—and resulting new protocols—the transmission rate of HIV to babies during pregnancy, childbirth and breastfeeding has dropped dramatically since the early 1990s, when rates were around 25 percent. "The risk is not zero, but with the right care it can be less than 1 percent—a risk that couples are usually willing to take," says Dr. Deborah Money, an obstetrician/gynecologist who heads up the prenatal program at Oak Tree Clinic in Vancouver, which specializes in treating HIV-positive women.

Now doctors are seeing PHAs go through with their fertility plans. Money says that one-third of the HIV-positive pregnant women she treats have planned their pregnancies. Not that prospective parents are making the decision lightly. Like Marie-Josée and Luc, many educate themselves on the risks to both themselves and the baby before setting aside birth control. They worry about transmission, the impact of a pregnancy on their health and how their illness or a shortened lifespan might affect a child.

As well, many of the young HIV-positive people in Canada are recent immigrants from countries where the disease is endemic, and cultural issues affect their fertility needs. "Some cultures place a huge weight on motherhood—it's a pinnacle to achieve," Ogilvie says. In many cultures, particularly African cultures, becoming a mother is equated with being a woman. If these couples haven't

disclosed their status to other family members, they must often cope with strong social pressures to have a baby and prying questions about why it's taking so long or why the couple is using fertility services.

Safe options

Infertility is not the underlying reason why most PHAs come to a fertility clinic, according to Dr. Mathias Gysler of the Isis Regional Fertility Centre in Mississauga, Ontario. Instead, they are looking to prevent transmission of the virus between partners. "So, at a fertility clinic, these couples should do well," he says.

However, infertility does affect about 10 percent of the general population, and people with HIV might be at higher risk. The reasons for this are not clear but might include previous genital tract infections (in either sex) and sperm problems in men. Couples with fertility difficulties have various options. They may need ovulatory drugs, which stimulate a woman to release an egg. Or perhaps they'll undergo intrauterine insemination (IUI)—where sperm is placed inside the woman's uterus using a thin tube inserted into the vagina. They may even undergo in vitro fertilization (IVF)—in which the woman's eggs are fertilized in the lab and then inserted into her uterus.

When it's the woman who's HIV positive, a couple can often get pregnant at home. But, doctors do not recommend unprotected sex. For a safer option, these couples can try IUI at home by inserting semen into the vagina. Dr. Mark Yudin, an obstetrician/gynecologist at St. Michael's Hospital in Toronto who has a special interest in HIV, gives his patients empty syringes and helps them map out their menstrual cycles to determine when they are most fertile. "They don't need assistance," he says. "They maybe just need advice." With IUI, there is about a 15 percent chance of pregnancy per cycle for all women, which is roughly the same or a little lower than it is for couples having regular intercourse.

When it's the man who has HIV, a couple does require a doctor's help: The virus transmits twice as easily from men to women, and unprotected sex carries on average a 1 in 1,000 chance of male to female infection per sex act. The best approach is IUI using washed sperm in a fertility clinic. This process involves a lab removing all the seminal fluid—where most of the virus lives—from around live sperm before insemination. Sperm washing costs about $400 per procedure and IUI costs a similar amount, taking the total per try to $800. If this fails, doctors can try IVF with washed sperm, which costs about $6,000 per cycle. However, since sperm washing reduces the effectiveness of sperm, many clinics recommend using intracytoplasmic sperm injection (ICSI) during IVF. In this process, sperm is injected directly into a woman's egg in a lab dish using a microscopic needle, so fewer healthy sperm are needed. ICSI adds an additional $1,200 to the cost of IVF.

While washed sperm has been used for the past decade thousands of times around the world with no incidents of HIV transmission to women or infants, there is still a theoretical concern. "I don't think you can eliminate the risk," Gysler says. To minimize the risk, doctors perform IUI with washed sperm just once every cycle.

For couples in which both partners are HIV positive, having safer sex is still important, as is possible for them to reinfect each other during unprotected sex. The woman is more likely to become reinfected, and if reinfection occurs at the same time the woman becomes pregnant, her body would face these two health issues at the same time. Yudin says these couples might feel the risk is worth it. A safer but costlier choice is sperm washing and insemination at a fertility clinic.

While not recommended by doctors, couples who choose to forgo condoms often take other precautions to reduce the risk of infection. One of the most important is suppressing HIV in the positive partner. Research has shown that having an undetectable level of virus in the blood generally, but not always, means a lower level of virus in the semen and vaginal fluids. Lower levels of virus generally mean a lower risk of infection.

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First steps

While the science already exists to help people with HIV have a baby, few Canadian clinics actually offer these services to PHAs. In a first step toward addressing this situation, Yudin and Loutfy recently surveyed fertility clinics across the country. Of the 23 that responded, only four offered a full range of services to HIV-positive people (many clinics don't offer sperm washing) and five said they do not help PHAs at all. "There's a big disconnect here," Yudin says. "It isn't right." The survey also found that HIV fertility services are not equally dispersed across the country. "We're doing well in Ontario and Alberta, but provinces like BC, Quebec, Manitoba and Nova Scotia aren't," Loutfy says. PEI, Newfoundland and the territories have no fertility clinics.

This patchwork of coverage is largely due to the fact that it has been the choice of individual doctors and clinics to offer their services to people with HIV. At Isis in Mississauga, Gysler and his colleagues began helping HIV-positive women and men about two years ago because they believed that ignoring the need could do harm—something that goes against their mandate as doctors. "If an HIV-discordant couple decides to have unprotected intercourse, that presents a greater risk than us helping them," Gysler says. Isis brought in an infectious disease expert to ensure that the clinic was being extra safe with its protocols. So far, the clinic has assisted in more than a dozen successful pregnancies, some of them in people who had been trying for nearly a decade.

Labour of love

As has been the tradition in HIV activism, the community is fully involved in the effort to raise awareness and demand access to fertility treatments. Along with Loutfy, Yudin and Gysler, PHA and longtime community member Shari Margolese has been spearheading several initiatives aimed at addressing the gaps in understanding and the lack of services. Most pivotal is the National HIV Pregnancy Planning Guidelines Initiative, which is consulting with community and medical experts across the country to develop guidelines for healthcare professionals around safe practices for dealing with HIV during pregnancy planning and fertility treatments "They will be the first comprehensive guidelines of their kind in the world," says Margolese, who is co-lead on the initiative. "And they will be for all HIV-positive people, not just for women with HIV."

In Quebec, community members are also taking the lead in ensuring that PHAs are able to become parents in that province. In the winter of 2008, HIV-positive women joined forces with healthcare professionals to create a committee to investigate the current state of policy, law and practice related to reproductive health and adoption for PHAs in Quebec. The committee, supported by provincial HIV organization COCQ-Sida, expects that its research will highlight where the most urgent changes need to be made.

What's motivating everyone in taking on this new work is a shared sense that the current situation is simply not fair and that access to fertility services should be offered to everyone, no matter what their HIV status.

Cautious optimism

Fortunately for Marie-Josée, in January the fertility clinic at the Royal Victoria Hospital in Montreal accepted her as a client. (The clinic, however, can't help HIV-positive men, as it doesn't offer sperm washing.) Her new fertility doctor told her and Luc that their case—female seropositivity and male infertility—was not as complex as they might think.

Now Marie-Josée is getting needles and ultrasounds as part of a fertility work-up and is facing the reality of fertility treatment. "The medicalization bothers me," she admits. "I'm already at the doctor more than I ever was in my previous life before HIV." As well, getting fertility help is costly—and there's no guarantee she'll have a baby in the end. "We're cautiously optimistic," she says. "We're not elated." When will she get excited? The day she holds a healthy baby in her arms. +

For more info about HIV and pregnancy, check out *You can have a healthy pregnancy if you are HIV positive*, published by Voices of Positive Women and CATIE and available through the CATIE Ordering Centre at www.catie.ca or 1.800.263.1638.

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