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HIV+ Women's Reproductive Decision-Making: Perceiving Reproductive Choice

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Abstract

During one hour semi-structured interviews, 11 HIV+ women (age = 30 – 44 years) described 15 reproductive decision-making experiences. Using the methods of grounded theory (Strauss & Corbin, 1998), the analysis of these interviews revealed that these women's reproductive decision-making involved *Perceiving reproductive choice*. In this process, HIV+ women who received more *Support* (i.e., information, medical treatment and emotional support) displayed more *Acceptance* of the implications of their HIV for pregnancy. Women's acceptance, in turn, affected their *Response* to the implications of HIV for pregnancy in that women who accepted the implications of their HIV status proactively rather than reactively sought information regarding HIV and pregnancy and, as a result, had more *Knowledge* about HIV and pregnancy. The extent of these women's knowledge regarding HIV and pregnancy was confirmed by an analysis of their responses to a brief, quantitative, knowledge questionnaire. Finally, women with more knowledge *Perceived more choice* in whether to have a child, and their perceptions of choice determined whether they could make a decision and, if so, whether their decisions were informed. The relation of these findings to those of earlier research, the strengths and limitations of this research, and the implications of these findings for efforts to enhance HIV+ women's reproductive decision-making and future research, are discussed.

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HIV+ Women's Reproductive Decision-Making: Perceiving Reproductive Choice

By the end of 2002, approximately 56,000 people in Canada were living with HIV/AIDS, of whom 7,700 (14%) were women (Health Canada, 2005). Although fewer women than men have HIV/AIDS, the number of women living with HIV/AIDS increased 48% between 1996 and 1999 (Health Canada, 2003a). Heterosexual contact is likely the cause of this increase (Centers for Disease Control [CDC], 2002) as the proportion of HIV+ tests in women attributed to heterosexual contact increased from 46% between 1985 and 1996 to 62% in 2001 while the proportion attributed to intravenous drug use remained constant at 36% (Health Canada, 2003b). Intravenous drug use, however, plays a significant role in the heterosexual transmission of HIV because many women become infected through unprotected sex with an injection drug user (CDC, 2002).

Regardless of the mode of transmission, women are of unique concern because of the risk of an HIV+ woman transmitting HIV to her unborn child (Health Canada, 2003b; Health Canada, 2003c), a risk that becomes a reality in 2 to 25% of pregnancies (with rates varying as a function of treatment and mode of delivery; CDC, 2002; Cooper et al., 2002; European Mode of Delivery Collaboration, 1999; HIV/AIDS Treatment Information Service [HIVatis], 2002; International Perinatal HIV Group, 1999; Mofenson et al., 1999). That 80% of the women living with HIV/AIDS are between the ages of 15 and 44 (Health Canada, 2002) and that the highest proportion (44.5%) of HIV+ tests for women occurs among those between the ages of 15 and 29 (Health Canada, 2003a) makes the perinatal transmission of HIV a particularly salient concern. In Canada, the estimated national rate of HIV infection among pregnant women is 3 to 4

per 10,000 population of pregnant women (Health Canada, 2003c). Nationally, 1,384 infants have been born to HIV+ women. Of these, 375 infants have been confirmed to be HIV+ and 56 infants have undetermined serostatus (Health Canada, 2003c). Because people living with HIV remain healthier and live longer than ever before (Kelly, Otta-Salaj, Sikkema, Pinkerton, & Bloom, 1998; Kirshenbaum et al., 2004), women with HIV now have the time and opportunity to consider their reproductive options. Consistent with this, the number of infants born to HIV+ women per birth-year has been increasing from 56 in 1991 to 138 in 2001 (Health Canada, 2003c), and 163 in 2004 (Health Canada, 2005). Given this increase, the present research examined the nature of HIV+ women's reproductive decision-making. Before reviewing research that has examined the nature of HIV+ women's thoughts and decisions regarding parenthood, however, the prenatal and postnatal implications of HIV for the mother and child merit consideration.

Prenatal Implications of HIV

HIV has at least two fundamental prenatal implications, including which method of conception is chosen and the potential perinatal transmission of HIV to the infant (Bedimo Bessinger, & Kissinger, 1998; Goggin et al., 2001; Hackl, Somali, Kelly, & Kalichman, 1997; Sherr, Barnes, & Johnson, 2000; Siegel & Schrimshaw, 2001;).

HIV and modes of conception. Because heterosexual contact is one way of transmitting HIV (Health Canada, 2003a; Health Canada, 2003b), intercourse may place a woman's partner at risk for HIV infection (Healthlink Worldwide, 2000). There are, however, options for serodiscordant couples who decide to have children (Klein, Pena, Thorton, & Sauer, 2003). The risk of HIV transmission to an HIV- man can, for example, be reduced by limiting unprotected intercourse to the HIV+ woman's most

fertile time (Healthlink Worldwide, 2000; Klein et al., 2003). Couples may also choose artificial insemination (Klein et al., 2003) or adoption (Goggin et al., 2001; Klein et al., 2003).

The perinatal transmission of HIV. The physical health of an HIV+ person is defined by two measures: viral load and CD4 cell count (HIVatis, 2002; Labtests Online, 2001). Viral load refers to the number of HIV particles present in the blood (Healthlink Worldwide, 2000; HIVatis, 2002; Labtests Online, 2001), which reflects how actively the virus is reproducing (Labtest Online, 2001). A viral load between 200 and 500 indicates that HIV is not actively reproducing (Labtests Online, 2001), whereas a viral load of more than 100,000 is considered high (Healthlink Worldwide, 2000). A rising viral load indicates that the infection is getting worse, while a decreasing viral load indicates improvement (Labtest Online, 2001). People with higher viral loads usually develop AIDS more quickly (HIVatis, 2002) because the virus destroys CD4 cells, thereby impairing the immune system and making them susceptible to opportunistic infections such as pneumonia (usually pneumocystis carinii; PCP), cancer (usually Kaposi sarcoma) and chronic diarrhea with weight loss (also known as slim disease) (World Health Organization [WHO], 2000).

A CD4 count reflects the state of a person's immune system and their ability to resist infection (Healthlink Worldwide, 2000; HIVatis, 2002). A healthy, HIV- individual will have a CD4 count between 600 and 1200 while an HIV+ person is considered at risk for serious infection if his or her CD4 count drops below 200 (CDC, 1999; Healthlink Worldwide, 2000). An individual is said to have developed AIDS when they have insufficient CD4 cells to fight off existing opportunistic infections.

Antiretroviral therapy (ART) is a drug treatment designed to maintain or reduce HIV viral loads and thereby prevent or delay the progression of the disease to AIDS (Healthlink Worldwide, 2000; Lee, Solts, & Burns, 2002). For the most part, people's viral loads drop to undetectable levels within 16 to 20 weeks of commencing ART (HIVatis, 2002). Antiretroviral drugs are usually given in combination because different antiretrovirals fight HIV in different ways (Healthlink Worldwide, 2000). The most recommended drug treatment, Highly Active Antiretroviral Therapy (HAART), involves the use of three or more drugs (HIVatis, 2002).

ART may be introduced at different times and at different stages of disease progression. The HIV/AIDS Treatment Information Service (HIVatis, 2002) recommends beginning therapy on the basis of CD4 count, viral load and symptoms. People with CD4 counts below 200 are advised to begin therapy because they are at high risk for serious infection (CDC, 2002; Healthlink Worldwide, 2002). Symptom free individuals with CD4 counts between 200 and 350 are advised to begin therapy only after careful consideration with their physician. For people with CD4 counts above 350, the initiation of ART is dependent on symptoms and viral load. Monitoring is advised for symptom-free persons with viral loads below 55,000, while ART is recommended for those experiencing symptoms with viral loads above 55,000.

Because HIV+ women with lower viral loads are less likely to transmit HIV in utero and intrapartum (Dickover et al., 1996; Kliks, Wara, Landers, & Levy, 1994) and ART during pregnancy reduces the likelihood of perinatal transmission (Connor et al., 1994; Cooper et al., 2002; Mofenson et al., 1999), it is recommended that HIV+ women subscribe to ART during pregnancy regardless of their viral loads and CD4 counts (CDC,

1999; Monfenson, et al., 1999). For example, compared to a transmission rate of 20 to 25% in the absence of ART (Cooper et al., 2002), Robinson and Lee (2000) found that 86% of the infants born to women who received ART during pregnancy and intrapartum were HIV free. The use of the antiretroviral drug zidovudine (AZT) has been shown to both improve the health of HIV+ women and to reduce the risk of perinatal transmission by almost 70% (HIVatis, 2002; Mofenson et al., 1999). HAART, however, is not recommended for pregnant women or women contemplating pregnancy because the side effects of HAART on the fetus are not well understood (HIVatis, 2002).

The risk of perinatal transmission can be reduced by the earlier onset of ART (Cooper et al., 2002, Lallement et al., 2000). For instance, AZT regimens are more effective in reducing perinatal transmission when introduced at 28 rather than 35 weeks of pregnancy (Lallement et al., 2002). The risk of perinatal transmission is also reduced by the administration of more complex ART. While monotherapy, the use of one drug, reduces the transmission rate to 10.4% (Cooper et al., 2002), dual ART with zero or one highly active drug reduces the transmission rate to 3.8%, and HAART reduces the rate even further to 1.2% (Cooper et al., 2002).

Complicating matters, however, are the mixed findings concerning the effects of ART on the fetus. Culnane et al. (1999), for example, found no adverse effects in HIV-uninfected children who had up to 5.6 years of in utero and neonatal exposure to AZT. On the other hand, Blanche et al. (2003; see also Tapp-Atler, 2001) found evidence of adverse side effects in eight HIV- infants exposed to AZT monotherapy or AZT and lamivudine combination therapy. All of the children experienced respiratory difficulties. Five also displayed delayed neurological symptoms, two of whom subsequently died.

Consistent with these mixed findings, the authors of a summary of Canadian consensus guidelines for the care of HIV+ pregnant women and their children wrote, “the data currently available on the pharmacokinetics and safety of antiretroviral drugs in pregnancy are minimal” (Burdge et al., 2003, p. 1671). Nevertheless, the guidelines recommend that pregnant “women be offered combination antiretroviral therapy regardless of their viral load and CD4 count” (Burdge et al., 2003, p. 1672), that decisions be made only after full discussion of the potential benefits and risks of treatment with the patient, and that potential toxic side effects of ART be monitored carefully.

Not surprisingly, women concerned about the possible side effects of HIV medications on their child may opt to decline drug treatment. Alternatively, they may choose monotherapy or a shorter course of therapy as ways of reducing the risks of ART for the unborn child. One option is AZT monotherapy, which has been shown to reduce perinatal HIV transmission among women with minimal HIV symptoms, low viral loads and normal CD4 cell counts (Bardequez et al., 2003). Women with favourable immunologic and virologic characteristics may also delay ART until after the first trimester (Burdge et al., 2003). For example, AZT administered to women as late as 36 weeks of gestation and every three hours from the onset of labor until delivery is associated with higher CD4 cell counts in comparison to HIV+ women not receiving any form of ART (Ekpini, et al., 2002).

Unfortunately, achieving successful long-term treatment using ART requires 80 to 95% adherence in order to prevent the emergence of drug resistance that may lead to treatment failure and limit the options available for future drug therapy (Carrieri et al.,

2003). Indeed, missing a single dose in a 28-day reporting period has been found to predict treatment failure (Chesney, 2003) and adherence to ART regimens is often far from ideal (for review see Chesney, 2003). In Durante et al.'s (2003) interviews with 63 HIV+ women, 67% were regarded as adherent in that they reported taking all of the prescribed doses of their antiretroviral medications. The best predictor of these women's adherence was their ability to describe the intended effect of antiretroviral therapy on viral load, with 81% of adherent participants correctly understanding the effect of HIV medications on viral load compared to only 47% of nonadherent participants. Durante et al. (2003) identified a number of barriers to women's adherence, including the complexity of medical regimens, side effects, social relationships, medication beliefs, daily schedules and body weight.

In a qualitative study by Roberts and Mann (2000) 20 HIV+ women between the ages of 25 and 54 years also pointed to the complexity of their medical regimens as barriers to their adherence. In particular, these women regarded the number of pills, the characteristics of these pills (too big to swallow; bad smell or taste), and the special conditions for taking the pills (time of day, time intervals between pills, with or without food) as barriers to adherence. Other barriers described by these women included the negative side effects of HIV drugs, such as fatigue, nausea, diarrhea and irritability (see also Remien et al., 2003), the interference of their caregiving responsibilities (see also Tompkins, Henker, Whalen, Axelrod, & Comer, 1999), not believing in the efficacy of the antiretroviral drugs they were taking, their concern that the drugs do more damage than good (see also Durante et al., 2003; Remien et al., 2003), the fact that the drugs were

daily reminders that they were living with HIV and, for those who had not disclosed their HIV status, the inability to find a safe and private place to take their medications.

HIV drug adherence may be further compromised for HIV+ individuals with substance abuse issues (Carrerri et al., 2003; Durante et al., 2003; Power et al., 2003; Remien et al., 2003). Of the 61 HIV+ women in Durante et al.'s (2003) study, for example, 77% reported using heroin and/or cocaine in the past, two-thirds reported heavy drinking, and being too high on drugs was described as a reason for nonadherence.

Adherence levels, unfortunately, are also problematic among pregnant women, even when ART is limited to the latter part of pregnancy. In a longitudinal study of HIV+ pregnant women (Ickovics et al., 2002), adherence to ART was only 50% during the three week prenatal period ($N = 53$) and 34% during the three week postnatal period ($N = 34$). Adherence was higher for the HIV+ pregnant women who were prescribed Zidivudine (AZT) 1 to 2 times per day than it was for those prescribed Zidovudine (AZT) 3 to 5 times per day (58.1% vs. 40.3%, respectively). Thus women's ability to adhere to treatment protocols challenges the extent to which ART is likely to reduce the perinatal transmission of HIV.

Fortunately, the risk of perinatal transmission can also be reduced through elective Cesarean section (European Mode of Delivery Collaboration, 1999; International Perinatal HIV Group, 1999). Indeed, HIV+ women not receiving ART may reduce the risk of transmitting the virus by 50% with an elective cesarean section (International Perinatal HIV Group, 1999). However, the reduction in perinatal transmission risk afforded by Cesarean section is even more promising for women receiving ART (Bucceri, et al., 2002; International Perinatal HIV Group, 1999). HIV+ women receiving

ART during all stages of pregnancy have lower transmission rates of HIV to their infants with elective cesarean section (1.8 to 2.0%) compared to those who deliver with other modes (7.3 to 10.5%) (European Mode of Delivery Collaboration, 1999; International Perinatal HIV Group, 1999).

In sum, the prenatal implications of HIV are complex in that they pertain to both the current and future health of an HIV+ woman (Burdge et al., 2003) and the risks and benefits associated with the various perinatal transmission prevention strategies (Barduquez, et al., 2003; Blanche et al., 1999; Burdge et al., 2003; Tapp-Atler, 2001). Ultimately, the goal is to optimize the health of the HIV+ woman and her unborn child while minimizing fetal exposure to potentially toxic medications (Burdge et al., 2003).

The Postnatal Implications of HIV

Like the perinatal implications of HIV, the postnatal implications involve both the mother and her child. Although HIV can be transmitted from a mother to her child postnatally through breastfeeding, HIV+ women are well informed of this particular risk (Sherr et al., 2000). The primary implication of HIV for the mother revolves around her ability to parent, and for the child it involves the child's well-being.

Ability to parent. Many HIV+ parents believe their ability to parent suffers because living with HIV saps their energy and resources (Antle, Wells, Goldie, DeMatteo, & King, 2001). The physical symptoms associated with HIV may, for example, impede an HIV+ woman's ability to fulfill her caretaking role (Hackl et al., 1997; Katz, 1997; Tompkins et al., 1999). In Tompkins et al.'s (1999) study of 199 HIV+ women and the parenting challenges of being HIV+, 38% indicated their illness had limited their activities with their children. Among these mothers, 88% described

increased fatigue and 8% reported mood-related limitations such as depression and irritability as reasons for their limited activity.

Preparing for the future of their children is also a primary concern of mothers living with HIV (Antle et al., 2001; Goggin et al., 2001; Hackl et al., 1997; Tompkins et al., 1999). In this regard, HIV+ women have reported concern about finding quality guardianship for their children if they become too sick to care for their children or die from AIDS (Antle et al., 2001; Hackl et al., 1997; Mason & Linsk, 2002; Tompkins et al., 1999). Because HIV+ women may not have strong social supports to help with child care responsibilities (Antle et al., 2001; Schrimshaw, 2002), they may have little choice but to leave their children in the hands of Social Services (Antle et al., 2001).

Raising an HIV+ child also involves increased responsibility for drug adherence (for a review see Van Rossum, Fraaij, & de Groot, 2002) and complex issues regarding disclosure of the disease (Antle et al., 2001; Goggin et al., 2001; Waugh, 2003). Having a child take medicine often requires great effort on the part of the parents. Children living with HIV often do not know why they are taking the medication because their parents have not told them about their serostatus (Hackl et al., 1997), typically because they fear their children will suffer discrimination if the indiscriminately disclose this information to other people (Antle et al., 2001; Waugh, 2003). Mothers may also decide not to tell children about their own HIV+ status because they fear losing custody of their children if others become aware of their HIV status (Hackl et al., 1997) or they believe that this information will cause psychological difficulties for their children (Mellins et al., 2002; Waugh, 2003).

The health of the child may also complicate mothering (Antle et al., 2001; Goggin et al., 2001). As noted earlier, the time and energy required for parenting can detract from adherence to treatment protocols (Roberts & Mann, 2000). Moreover, nonadherence may detract from mothers' health and thereby impede their ability to parent. For example, in a two-year follow-up study, HIV+ African American women who gave birth to HIV+ children frequently reported experiencing infections, problems thinking and remembering, low energy and gynecological problems (Miles, Gillespi, & Holditch-Davis, 2001).

HIV positive mothers also face emotional challenges, particularly guilt (Antle et al., 2001; Chalfin, Grus & Tomaszkeski, 2002; Goggin et al., 2001; Hackl et al., 1997; Waugh, 2003;). Those with HIV+ children feel guilty about transmitting the virus to their child/children (Chalfin et al., 2002; Hackl et al., 1997) and women with HIV- children experience guilt because the child may lose their mother to the illness (Antle et al., 2001).

The child's well-being. Children born with HIV may also require special care because HIV affects children cognitively (e.g., delayed language acquisition), developmentally (e.g., slowed motor development), emotionally (e.g., fear of dying), psychologically (e.g., depression), behaviourally (e.g., social withdrawal) and educationally (e.g., lower IQs) (for a review see Washcler-Felder & Golden, 2001; Waugh, 2003). Moreover, the progression of HIV to AIDS is much more rapid among children than adults (Horn, 1998). Although drug treatments are available for HIV+ children, their effects are controversial and little is known about when treatment should be initiated (Horn, 1998).

In sum, the postnatal implications for mothers include the additional responsibilities of attending to their own health and drug regimens, dealing with the physical symptoms of HIV that may impede parenting, preparing for future child care and possibly guardianship, and coping with guilt about having HIV and perhaps passing the virus along to the child. HIV+ mothers whose children are also HIV+ face additional challenges to parenting because they must also attend to the health and drug regimens of the child and deal with the difficulties associated with the disclosure of both their own and their children's HIV status. HIV+ women considering pregnancy, then, would do well to consider these parenting responsibilities and complications.

Empirical Findings Regarding HIV+ Women's Reproductive Decision-Making

Many HIV+ women decide to have a child despite the complex implications of this decision. In Bedimo et al.'s study of 403 HIV+ women, 68 (approximately 17%) became pregnant subsequent to their HIV diagnosis, of whom 59% chose to carry their pregnancy to term. HIV+ women who decide to carry to term are younger (Bedimo et al., 1998; Kline, Strickler, & Kepf, 1995), less likely to have any children, more accepting of HIV drug therapy during pregnancy (Sherr et al., 2000), less educated, more sexually active, and more likely to have had previous pregnancies and abortions compared to those who choose abortion (Kline et al., 1995).

HIV+ women have many reasons for wanting to have a child, including the desire to make up for their inability to raise their other children due to their drug use (Goggin et al., 2001; Siegel & Schrimshaw, 2001), their partner's desire to have children (Siegel & Schrimshaw, 2001), and the belief that a child will make them feel complete, fulfilled and happy (Siegel & Schrimshaw, 2001). However, most HIV+ women do not want any

more children. In Kline et al.'s (1995) study, for example, 83% of 238 HIV+ women said they did not want more children. Consistent with this, HIV+ women have lower rates of pregnancy (6.32%) (Bedimo et al., 1998) in comparison to the national birth rate (10.5%) (Statistics Canada, 2004). HIV+ women who do not want children avoid pregnancy by adopting an asexual lifestyle. For example, 25% of the 140 HIV+ women in a study by Magalhaes, Amaral, Giraldo, and Simoes (2002) were sexually inactive since they learned of their seropositive status.

Choosing sterilization is also a decision made more frequently by HIV+ than HIV- women (Maghalaes et al., 2002). In Bedimo et al.'s (1998) study of the reproductive choices of 403 HIV+ women, 24% underwent sterilization after learning that they were HIV+. Women whose health was compromised by HIV, those without other children, and those not living with a family member were more likely to choose sterilization (Bedimo et al., 1998). Other research indicates that HIV+ women who choose sterilization are on average five years older than HIV+ women who make other reproductive decisions and that sterilization is more common among women who have had a child infected with HIV (Figueroa-Damian & Zestai, 2000).

The most common reproductive choice of HIV+ women who actively endeavour to avoid pregnancy is birth control. Relative to their HIV- counterparts, women with HIV are more likely to use condoms and less likely to use contraceptive methods such as the pill, an intrauterine device, the rhythm method, and withdrawal (Maghalaes et al., 2002). Nevertheless, in Kline et al.'s (1995) study of HIV+ women, only 65% used birth control consistently and only 46% regularly used condoms. Moreover, 22% of the 144 HIV+ women in Maghalaes et al.'s (2002) study said they did not use any means of

contraception and thus risked pregnancy, becoming infected with other sexually transmitted diseases, and transmitting the disease to others.

HIV+ women who do not want to have a child but become pregnant because of their inconsistent use of birth control, the failure of birth control or as a result of sexual assault may decide to terminate the pregnancy. In comparison to the national rate of 12.7% (Statistics Canada, 2004), in Bedimo et al.'s (1998) study 25% of HIV+ women who became pregnant after discovering their HIV+ serostatus chose to have an abortion. Other studies have observed that abortion is more likely to be the choice of HIV+ women who have had previous abortions (Kline et al., 1995), a history of sexual assault and those living with their sex partner (Bedimo et al., 1998).

A number of other factors may also be relevant to HIV+ women's reproductive decision-making, including women's awareness of conception methods, the effects of pregnancy on HIV, the effects of HIV on the fetus, and the need for adherence. The vast majority of women (e.g., 95%) know that HIV can be transmitted through sexual activity (Robinson, Reitan, Jones, & Gist, 2001) and are concerned about infecting their partner while attempting to conceive (Hackl et al., 1997). Not surprisingly, HIV+ women's intimate partners also play a role in the decision regarding how to become pregnant. Hunt, Myers, and Dyche (1999) asked 52 heterosexual men, 67% of whom were HIV-, about their perceived chances of becoming infected by having sex with their HIV+ partner. Half of these men (51% of HIV-men and 53% of HIV+ men) estimated their risk as relatively low, at zero to 20%. Moreover, the majority of both groups reported regular unprotected sex with their infected partner. These data suggest that HIV+ women's

partners may detract them from considering safer methods of having a child, such as limiting intercourse to periods of peak fertility, artificial insemination and adoption.

In regard to other issues relevant to pregnancy, although the evidence is not convincing (for review see CuUine et al., 1996), some HIV+ women believe that pregnancy may further compromise their health by accelerating the progression of the disease (Seigel & Schrimshaw, 2001). No research, however, has examined whether this concern affects HIV+ women's reproductive decision-making. Many HIV+ women also overestimate the risk of perinatal transmission. For example, in a self-report questionnaire study of 145 HIV+ women, 57.9% reported the transmission rate as between 50 and 100% (Visconti, Celentano, Marinaci, Scoppettuolo, & Tamburrini, 2002), a rate well above the actual rate of two to 25% (CDC, 2002; Cooper et al., 2002; European Mode of Delivery Collaboration, 1999; HIVatis, 2002; International Perinatal HIV Group, 1999; Mofenson et al., 1999). The overestimation of transmission rates may be due to HIV+ women having little knowledge of the ability of ART to decrease the risk of perinatal transmission (Robinson et al., 2001; Visconti et al., 2002). For example, 41.4% of the 145 HIV+ women in a study by Visconti et al. (2002) considered ART powerless in preventing the perinatal transmission of HIV. Similarly, in Sherr et al.'s (2000) study of 40 HIV+ women, less than a third were aware of ways of reducing the perinatal transmission of HIV.

A woman's awareness of ART's ability to reduce the risk of perinatal transmission does not guarantee her adherence to ART regimens (Lee et al., 2002; Remien et al., 2002). The literature shows that individuals who have an understanding of

their drug regimen are more adherent (Durant et al., 2003), suggesting that their awareness of adherence may be associated with their adherence behaviours.

Despite the multitude of implications of HIV for pregnancy and parenting, only three studies have explored how HIV+ women make their reproductive decisions (Kirshenbaum et al., 2004; Sherr et al., 2000; Siegel & Schrimshaw, 2001). In a questionnaire study, Sherr et al. (2000) examined how 40 HIV+ women's knowledge and beliefs about HIV interventions during pregnancy were related to their reproductive decision-making. Almost three quarters (72.5 %) of the women said that HIV played a role in their reproductive decision-making. However, these women were not well informed about interventions that reduce the risk of mother-to-child transmission. Only 34% had heard about the use of AZT during pregnancy and only 29% knew of the benefits of electing for a Cesarean section. Even fewer knew of the benefits of taking vitamin A during pregnancy (16%), taking AZT during labour (11%), and scalp and electrode avoidance during pregnancy (8%). Moreover, these women's lack of knowledge regarding existing interventions to reduce the risk of HIV transmission appeared to affect their reproductive decisions in that 58% believed they would decide to have children in the future if a partial reduction of risk could occur, only 18% had planned for future pregnancies, and 30% were still undecided.

In a qualitative study with 51 HIV+ women between the ages of 20 and 45, Siegel and Schrimshaw (2001) also examined how HIV+ women came to their decisions to have children. These women were either currently pregnant ($n = 11$), attempting to become pregnant ($n = 9$), planning on becoming pregnant within the year ($n = 6$), or still open to the possibility of attempting pregnancy in the future ($n = 25$). These women had various

reasons for wanting a child, including their partner's desire to have a child and their desire to makeup for having been unable to raise their other children. In addition, however, all of the women were concerned about the possibility of having an HIV+ child and had fears about their own and their partners' health and the implications it could have for their children in the future. Nevertheless, the women were able to justify or give explanations for why they believed their decisions to have children were acceptable and responsible choices. In fact, women's ability to justify having children stimulated their decisions to have children. One justification was that, because the use of AZT during pregnancy reduces the risk of infecting their child, pregnancy was no longer inappropriate for them to consider. Another justification was that their cessation of drug-use and their involvement in stable relationships made them better able to raise a child now, relative earlier in their lives.

In a qualitative study of 56 HIV+ women between the ages of 20 and 55, Kirshenbaum et al. (2004) explored the biomedical, individual and sociocultural themes within pregnancy decision-making for women who were and were not pregnant at the time of their HIV diagnosis. Of the 32 women not pregnant at the time of their HIV diagnosis, 27 reported not intending to have more children, primarily because of the potential risk of mother-to-child transmission and the potential guilt and responsibility bestowed upon them if they were to have an HIV+ infant. Thus, risk of transmission was the major theme for these 27 women. The five women who desired to have children after diagnosis viewed risk reduction strategies as opportunities to avoid mother-to-child transmission of HIV. Thus, risk reduction was the major theme within these women's pregnancy decision-making. Three women not pregnant at the time of their HIV

diagnosis subsequently became pregnant and all three intended not to have anymore children. Like the 27 women who did not have subsequent pregnancies, these three women reported risk of transmission as the major factor in their decisions. Unlike their counterparts who wanted to become pregnant, these three women were less aware and less trusting of risk reduction strategies. The authors suggested previous pregnancies may account for differences in pregnancy intentions given that the majority of women who did not intend to have subsequent pregnancies had children prior to their HIV diagnosis and the women who desired to have children after their HIV diagnosis did not have children prior to the diagnosis.

In sum, HIV+ women's knowledge of HIV interventions during pregnancy (Sherr et al., 2000), their ability to justify having children in a way that makes their decision appear responsible (Siegel & Schrimshaw, 2001), and their attitudes toward having children, risk assessments, and risk-reduction strategies (Kirshenbaum et al., 2004) are important to their reproductive decision-making.

The Present Study

This review of the literature suggests that many HIV+ women are unaware of the perinatal and postnatal effects of HIV. A fundamental concern regarding the reproductive decision-making of HIV+ women, then, is whether their decisions are informed. The present study was therefore designed to examine HIV+ women's reproductive decision-making in terms of which prenatal and postnatal factors they consider, their knowledge regarding the various factors that they should, ideally, consider, the factors that facilitate and impede their knowledge and decision-making, and the effects of their social context on decision-making.

The current study also sought to identify HIV+ women's needs as they contemplate whether to have a child and ways of fulfilling these needs. For example, HIV+ women have expressed their desire for social support and HIV/AIDS information from family, friends and caregivers to facilitate their reproductive decision-making (Hackl et al., 1997). One particularly relevant source of social support for an HIV+ woman contemplating pregnancy is her sexual partner, especially given that HIV+ women have identified their partner's desire to have children as a main reason for wanting to have a child (Siegel & Schrimshaw, 2001). Unfortunately, not all women living with HIV receive support from family, friends, and caregivers either because they do not have them or because they have received unsupportive responses. Given this, it is not surprising that HIV+ women fear being rejected by family, peers and society should they reach out for support. In a qualitative study of eight HIV+ women, Hackl et al. (1997) found that fear of being rejected by family, peers and society was a primary concern for these women. Further, the women in this study indicated two areas of social support concern. One was their desire for social support networks and the other was their fear of reaching out and being rejected. In the absence of social support, HIV+ women might turn to organized social support groups (Rokach, 2000). Although support groups have the potential to provide informational, emotional and practical assistance for HIV+ women, "if these organizations are primarily focused on and run by middle-class white gay men, as many are, women might receive support but might lack the subjective belonging and acceptance that comes with a more ethnically diverse or woman-focused AIDS organizations" (Schrimshaw, 2002, p. 2035). Moreover, the HIV+ women in Hackl et al. (1997) reported not knowing where to look for a support group, which means

that some women do not know how to access any groups that do exist. HIV+ women contemplating pregnancy, then, may have a need for an environment in which they can talk openly about their concerns and fears with women going through similar issues. An additional barrier to social support for HIV+ women contemplating pregnancy is their belief that their reproductive rights may be socially negated because of their serostatus (Hackl et al., 1997). The fear that their reproductive rights may be socially negated is especially important in regard to the health care practitioners on whom they rely for informational and social support.

Method

A qualitative research method was used to answer these research questions because qualitative methods are suited for the exploration of subjective experiences, personal meanings, and the development of theory or models of processes that unfold over time. A social constructionist perspective was assumed throughout the research process, meaning that I viewed “science as a form of knowledge which creates as well as describes the world” (Parker, 1994, p. 9). Also, many aspects of the design and analysis were consistent with a feminist perspective in that women’s subjective experiences and their culture and gender were considered, the women were regarded as experts of their own experiences, and I, as a researcher, acknowledge my subjectivity and endeavoured to explore it throughout the study (Harding, 1986, Letherby, 2003). The current study was not in line with aspects of feminist perspective in that class and race were not considered as they were not evident within the data. Thus, the present research gave HIV+ women an active voice in this exploration of HIV+ women’s reproductive decision-making.

Sampling and Participants

Purposive, snowball and theoretical sampling were used to recruit participants. Purposive sampling refers to intentionally selecting participants to represent certain conditions, with relatively equal numbers of participants in each of the conditions so as to enable the exploration and description of these conditions (Luborsky & Rubinstein, 1995). To facilitate the heterogeneity of the data and, thereby, the analysis and the findings, attempts were made to purposively sample at least two HIV+ women from each of three groups: women who had decided to have a child, women who had decided not to have a child, and women who were currently in the midst of trying to make this decision.

Snowball sampling, which involves using participants as referral sources (Luborsky & Rubinstein, 1995), was used in the study by asking each woman to tell other potential participants about the study. To this end, participants were given contact information cards to distribute to other HIV+ women, or were reminded of the contact information if the interviews were done over the phone. This sampling process resulted in the recruitment of at least two participants.

Theoretical sampling involved sampling for meaning with the exact nature determined by the need for particular types of information, as indicated by the evolving analysis of the data. Because I was directed by the evolving theory, sampling became more specific with time. Theoretical sampling will be discussed in more depth in the data analysis section to follow.

Table 1 presents information about the demographic characteristics of the 11 HIV+ women who took part in the study. As shown there, these women were between 30 and 44 years of age, on average 34.7 years old. Nine women were white, one of whom was French Canadian, and two were African Canadian. Their education levels ranged from grade eight to university/college graduates. Three of these women were widowed, three were single, four were in committed relationships of three to nine years, and one was separated. Five of the women had at least one child prior to being HIV+, four had children while they were HIV+, and two women had no children at the time of the study. All of their children were HIV-. These women knew they were HIV+ for an

Table 1

Participants' Background Information

Pseudonym	Age	Ethnicity	Education	Relationship status	Children	Health status	Years knowing HIV+
Cathy	36	African Canadian	University	Widow	1, before HIV+	Good	2.5
Mary	34	White	Grade nine	Widow	1, before HIV+	Compromised	14
Lisa	--	African Canadian	College	Single	1, while HIV+	Compromised	17
Glenna	30	White	Some college	Widow	1, before HIV+	Good	7
Jeannie	44	White	Grade nine	Single	2, before HIV+	Compromised	12
Linda	43	White	Some college	Single	None	Compromised	13
Sylvie	36	White (French Canadian)	Secondary Second (Quebec)	9 year partner	1, while HIV+	Good	15
Michelle	30	White	College	3 year partner	1, while HIV+	Good	8
Kristina	30	White	College, some university	Separated	1, while HIV+	Good	7
Lesley	32	White	Grade eight	7 year partner	1, before and 1 while HIV+	Compromised	9
Stacie	32	White	---	4 year partner	None	Good	15

average of 10.9 years (range = 2.5 to 17 years), and six had good health while five had compromised health.¹ Thus, this sample of women was diverse in many ways, including age, education, relationship status, motherhood experiences, length of time knowing HIV status and health status.

These women's past and present lives were also varied. As shown in Table 2, which displays a summary of women's life circumstances, these women varied in their experiences with substance abuse, living arrangements, involvement with HIV organizations, involvement in HIV+ women support groups and in their past relationships with their doctors. At present, none of the women were abusing substances, however, six women, Mary, Jeannie, Linda, Stacie, Sylvie and Lesley had substance abuse problems in the past. Most had always lived independently, with the exception of Linda who had previously lived in supportive housing and Mary who had previously been homeless and was currently living in supportive housing. Involvement with HIV organizations was part of every woman's current life circumstance, however, Lisa, Jeannie, Kristina and Lesley had not been involved with HIV organizations in the past. Involvement with HIV+ women's support groups was the most varied experience of these women. Cathy, Sylvie and Michelle were involved such support groups both in the past and at the time of the study, whereas Mary and Lesley had never been involved with such groups. Jeannie, Stacie and Kristina, on the other hand, had not been involved with HIV+ women's support groups in the past, but were at the time of their participation. Interestingly,

¹ Good health in this study referred to having CD4 counts above 200, viral loads below 55,000, and experiencing little to no HIV symptoms (HIVatis, 2002). Compromised health referred to having CD4 counts below 200, viral loads above 55,000, experiencing extreme fluctuations of viral loads, experience of HIV symptoms (HIVatis, 2002), and/or complications with other illnesses or conditions.

Table 2

Participants' Past and Present Life Circumstances.

<u>Participant</u>	<u>Substance abuse</u>		<u>Living arrangements</u>		<u>Involvement in HIV organization</u>		<u>HIV women support group</u>		<u>Relationship with doctor</u>	
	<u>Past</u>	<u>Present</u>	<u>Past</u>	<u>Present</u>	<u>Past</u>	<u>Present</u>	<u>Past</u>	<u>Present</u>	<u>Past</u>	<u>Present</u>
Cathy	No	No	Independent	Independent	Yes	Yes	Yes	Yes	+	+
Mary	Yes	Recovery	Homeless	Supportive housing	Yes	Yes	No	No	+	+
Lisa	No	No	Independent	Independent	No	Yes	No	Yes	-	+
Glenna	No	No	Independent	Independent	Yes	Yes	Yes	No	+	+
Jeannie	Yes	Recovery	Independent	Independent	No	Yes	No	Yes	+	+
Linda	Yes	Recovery	Supportive housing	Independent	Yes	Yes	Yes	No	+	+
Stacie	Yes	Recovery	Independent	Independent	Yes	Yes	No	Yes	-	+
Sylvie	Yes	Recovery	Independent	Independent	Yes	Yes	Yes	Yes	+	+
Michelle	No	No	Independent	Independent	Yes	Yes	Yes	Yes	+	+
Kristina	No	No	Independent	Independent	No	Yes	No	Yes	-	+
Lesley	Yes	Recovery	Independent	Independent	No	Yes	No	No	-	+

Note. - = negative; + = positive

Glenna and Linda, who were involved in HIV+ women's support groups in the past, were no longer involved with such groups. Glenna said she was no longer involved in HIV+ women's support groups because she had lost too many friends to the disease and did not want to be linked with somebody because of her disease. Linda said she was no longer involved because of her move from a large urban center to a smaller town where few women had HIV. Finally, although all of the women described their current relationships with their HIV doctors as positive, four women, Lisa, Stacie, Kristina and Lesley, had negative relationships with their doctors in the past.

Procedure

The 11 participants were recruited via posters inviting HIV+ women between the ages of 18 and 44 to participate in a study of HIV+ women's reproductive decision-making and by referrals from the staff and volunteers at an HIV clinic and various HIV/AIDS organizations and affiliated services. Participants who contacted the researcher via telephone were told the purpose of the study and were asked about the various criteria for eligibility (i.e., whether they had decided to have or not have a child or were currently in the midst of making this decision, whether they were of child-bearing age [i.e., 18 – 44 years], and whether their decision or decision-making processes occurred after 1994 when HIV drug interventions during pregnancy became available (CDC, 1999; Health Canada, 2003c)). At this time a mutually convenient time and place for the interview was decided upon. Two women who contacted the researcher did not meet the criteria for eligibility and therefore could not participate.

Prior to beginning the interviews the women were informed, both verbally and in writing, about the purpose of the study. Specifically, participants were told that the study

was designed to examine factors HIV+ women consider as they decided whether or not to have a child, who and/or where they go to get help with these decisions, and what has made their decision-making more or less difficult. The women were told their participation was completely voluntary, that confidentiality would be ensured, and that they could refuse to answer any question or stop participating at any time, for any reason. Participants were also asked permission to tape-record the interview to ensure an accurate account of the interview.² They were informed that the tapes would be destroyed upon completion of the study. At this point I also discussed the possibility of negative feelings arising during or after the interview. In this regard I explained that I was not qualified to offer counselling, but that they would receive a list of community resources at the end of the interview. Participants were also informed that they would be asked to complete a brief *Beliefs about HIV and Reproduction Questionnaire* after the interview was finished.

Once informed consent was obtained, the interview began. Upon completion of the interview participants were asked to provide a pseudonym, whether they would be willing to provide feedback on the interpretation of the data and how it related to their experiences, and whether they would like a summary of results. The women were then asked to complete the brief questionnaire. Finally the participants were debriefed both verbally and in writing, thanked for their participation, and given a list of resources related to HIV and reproduction (see Appendix A).

² One woman, Lisa, preferred not to have the interview recorded. For this reason, direct quotes from Lisa will not be presented. However, because she allowed notes to be taken during the interview, paraphrased versions of her responses will be presented.

Data Collection

Two types of data were collected: qualitative data from the interviews with each woman and quantitative data from the brief optional knowledge questionnaire.

Interviews. Participants were interviewed in a mutually convenient place (e.g. at the university, HIV/AIDS organization boardroom, participant's home) or over the telephone. The interviews lasted on average, 70 minutes (range = 45 to 100 minutes). The four interviews done in person lasted on average 69 minutes (range = 55 to 80 minutes) and seven interviews done over the telephone lasted on average 76 minutes (range = 45 to 100 minutes).

The interviews began by asking participants how they learned of the study and why they decided to participate. These questions were essentially designed to facilitate rapport with the participant (Rubin & Rubin, 1995; Smith, 1995). The women were then asked about their demographic characteristics (i.e., age, ethnicity, marital status, number of children, education, and when they learned about their HIV status) and about the HIV status of their children and partner/spouse, if known. These questions were deliberately asked at the outset of the interview in the hope that their ease and closed-ended nature would increase women's confidence in their ability to take part in the interviews (Rubin & Rubin, 1995). The women's answers to these questions were also used to complete the Interview Face Sheet shown in Appendix A.

The nature of the next section of the interview varied as a function of the characteristics of the women being interviewed (see Appendix A for a copy of the interview guide). Women currently deciding whether or not to have a child were asked how they were going about making their decisions. More specifically, these women were

asked about the things (factors) they were considering and any special issues, concerns or challenges they faced given their HIV status. They were asked whether any things were making the process difficult (barriers) and easier (facilitators), including who they were consulting and how these people helped or hindered them. In addition, they were asked about the sorts of services or resources they used and whether anything else might make the decision process easier or better for them. Women who had decided not to have any (or anymore) children were asked similar questions about how they came to their decisions, the factors they considered and any special issues, concerns or challenges they faced given their HIV status.

For women who had an unplanned pregnancy interview questions began with questions concerning the circumstances leading to the pregnancy, how they felt when they learned of the pregnancy, any concerns they had and why they decided to carry the child. The questions went on to ask them about their experiences during pregnancy, just before and during birth, and immediately after the birth of their children. These participants were then asked questions similar to those outlined for women trying to decide whether to have children and those who had decided not to have any(more) children, but within the context of each period of pregnancy. For the two women planning to have a child, the interview began with questions about their experiences as they came to the decision to attempt to become pregnant. These participants were then asked the questions asked of all HIV+ women, including whether they did, or were planning to do, anything special in view of their HIV status; the things they considered or were considering and any special issues, concerns or challenges they faced or were facing given their HIV status; what made/is making the process difficult (barriers) and what

made/is making it easier (facilitators), including who they consulted (e.g., partner, friends, family, organizations, GP, HIV doctor, obstetrician, other health care workers) and how these people helped/were helping or hindered/were hindering them; their thoughts about what they would do differently now that they had the benefit of hindsight and any advice they would give to other HIV+ women and others (e.g., partners, health care workers); and their thoughts about the sorts of services or resources or anything else that might have made/make the process easier or better for them.

It is important to note that the interview guide was used as a guide; it was not set in stone (Kvale, 1996; Rubin & Rubin, 1995; Smith, 1995; Straus & Corbin, 1998). Thus, the order of the questions varied, depending on participants' responses, and the nature of the questions also varied, depending on participants' realms of experience and the issues they deemed important. The goal was to have the women tell their own stories and have the questions directed by what they said, thus allowing me to explore ideas and experiences I may not have thought of asking about. The questions also changed as a result of the findings that emerged from the ongoing analyses of the data. For example, after several interviews I noticed that the participants were answering the questions with less affect than I expected. Subsequent interviews therefore included questions about women's feelings and emotions throughout the reproductive decision-making process.

After each interview, I used the Post-Interview Comment Sheet shown in Appendix A to comment on the mood/tone of the overall interview (e.g., "I feel like the interview had a good flow and that she felt comfortable talking to me. I could tell she didn't think I was judging her."); the participant's emotional reactions to each section (e.g., "She got really quiet and was sighing a lot when she was talking about how rough

her pregnancy was emotionally. She was upset in a sad and angry way to be talking about her suicidal thoughts and drug use during her pregnancy.”); my emotional reactions to the participant (e.g., “I was put off that she was so short with me at the beginning of the interview and was not willing to tell me some of the things, even the simple direct questions I was asking her. It’s a good thing I inherited my mother’s patience because the interview eventually did get rolling and she did give me some good data and also some insight into why she was protective of herself and experiences.”); my emotional reactions to what the participant said (e.g., “I’m saddened that she told me that her disease is a very lonely disease. I’m also impressed by how much she has overcome; it’s hard to understand how some people can make it through such hardships and dark times in their lives.”); the strong points of the interview (e.g., “I was still good at listening but I’m getting even better with being silent and not being uncomfortable with silences. I noticed that not automatically asking another question after she had paused lead her to elaborate more on her own without me having to ask as many probing questions.”); the weak points of the interview (e.g., “Since I’ve done some analysis and I am trying to saturate codes I may have asked too many leading questions.”); and finally, any other notable features of the interview (e.g., “She got off topic a lot even though she was informed three times about the purpose of the study – by her worker at the HIV/AIDS organization she’s involved with, at the initial phone conversation, and prior to beginning the interview today – maybe she just really needed someone to talk to.”).

The questionnaire. After completing the interview, nine of the 11 participants completed the optional 22-item *Beliefs about HIV and Reproduction Questionnaire* designed to assess their knowledge of HIV, pregnancy and parenting (see Appendix A).

Three items assessed women's knowledge of HIV transmission (e.g., "Heterosexual contact is the most common way that women become infected with HIV"). Two items assessed their knowledge of the symptoms and characteristics of HIV (e.g., "A low viral load means that the HIV virus is actively reproducing in the blood"). Three other items assessed their knowledge of HIV drugs (e.g., "Antiretroviral therapy (ART) is a drug treatment that a) reduces viral load, b) cures HIV, c) delays the onset of AIDS d) a& c, or e) all of the above"). In addition, 14 items assessed women's knowledge about mother-to-child transmission of HIV (e.g., "The antiretroviral drug Zidovudine (AZT) can be used during labour to reduce mother-to-child transmission of HIV; HIV+ pregnant women receiving antiretroviral therapy (ART) during all stages of pregnancy and who choose vaginal delivery reduce the risk of transmitting the virus to their child by approximately a) 2%, b) 7 to 10%, c) 15 to 20%, or d) 50%"). Of the 22 items, 12 had a true /false response format and 10 had a multiple-choice response format. Each of these items was developed on the basis of prior research and selected so as to provide insight into the women's knowledge about HIV transmission, drugs and reproductive interventions.

Data Analysis

Qualitative data. The analysis of qualitative data is rooted in coding (Miles & Huberman, 1994). As Charmaz (1995, p. 37) put it, "Coding is the pivotal link between collecting data and developing an emergent theory to explain these data." To facilitate the analysis, the methods of grounded theory were used to analyze the transcribed interviews. Grounded theory, a systematic and inductive approach to data analysis, has the goal of building a theory or model that is directly tied to the realities of the research

participants (Charmaz, 1995; Rennie et al., 1988). The grounded theory methods were used in the current study to build a model that was directly tied to the realities of HIV+ women as they contemplated whether to have a child.

The analysis began with me immersing myself in the data by reading the transcribed interviews several times. Two key methods were then used throughout the analysis to ensure that the emerging conceptualizations were true to what the participants said, namely making constant comparisons and questioning the data (Rennie et al., 1988). The constant comparative method initially involved comparing each piece of data with other data, and then changed to comparing data with the properties of already identified categories (Glaser & Strauss, 1967). Questions asked of the data included asking who, what, where, when, and why or how of the data. These two approaches were used throughout the three coding stages that form the essence of grounded theory, stages that are designed to take the data from the concrete to a more abstract level useful for describing processes and, for this study in particular, the processes involved in reproductive decision-making by HIV+ women.

The first systematic stage of coding, open coding, involves discovering, naming and categorizing phenomena according to their properties and dimensions (Strauss & Corbin, 1998). Open coding began with a close examination of the data, with line-by-line coding, thereby ensuring that the analysis was built from the ground up (Charmaz, 1995). This line-by-line coding helped me break the data down to discrete parts known as concepts or codes. The codes were examined and compared for similarities and differences using the constant comparison method (Glaser, 1964). Making comparison and questioning the data helped identify similar phenomenon or concepts, which were

then classified as instances of a more general category (Strauss & Corbin, 1990). As a result, categorization reduced the number of units in the analysis. Constant comparisons (Glaser, 1964) and questioning the data also helped me define the essential properties or characteristics of categories and the dimensions underlying these properties. For instance, the general category of “support” involved the grouping of family, partner, HIV organizations, other HIV+ women and healthcare professional support and was defined by its properties (e.g., type of support) and dimensions (high, medium and low support). By the end of open-coding a list of codes was generated, many of which had been grouped into larger categories, with an understanding of the characteristics of these categories.

The second stage of coding, axial coding, involved assessing the interrelations between the categories with the goal to further develop and attempt to saturate the categories and to identify relations between categories (Strauss & Corbin, 1998). Like open coding, axial coding, involved questioning the data and making constant comparisons. Questioning the data was used to expose the relations between categories, and in particular what leads to what, when and for whom, and how (e.g., What effect does relationship status have on reproductive desires? How does becoming informed about HIV and pregnancy affect the process of decision-making? What types of decisions are being made and how are those processes different from one another?). The use of constant comparisons facilitated the grouping of various categories into a larger category (Strauss & Corbin, 1990). For instance, “Proactive response” (e.g., attending support groups, seeking information from HIV organizations, seeking information from doctors and other health care professionals and becoming informed about HIV and

pregnancy, becoming informed and consideration of the future) and “Reactive response” (e.g., seeking information on a need-to-know basis, seeking information from only one source, avoidance of the implications of HIV and no consideration of the future) were grouped into to a larger category named “response.” Questioning the data in regard to knowledge and noting which women were more informed revealed that the type of “response” affected the amount of knowledge women had.

The search for negative cases (or outliers) that run contrary to the relations observed previously is key to axial coding because negative cases shed light on factors that may moderate the observed relations (i.e., the relation holds for some types of people or under certain circumstances) (Marshall & Rossman, 1995; Seale, 1999; Strauss & Corbin, 1990). Alternatively, exceptions that cannot be explained by the emerging model may indicate that the analysis has gone astray and that the relations between the categories, and possibly the categories themselves, require reconsideration. In the current study, the search for negative cases indicated that the analysis had gone astray when Linda, who was thought to have “low acceptance” of her HIV status and its implications, displayed a proactive response. However, reconsidering the categories revealed that Linda had “total acceptance” of the implications of HIV for pregnancy. Linda, who still wanted to have children, was originally coded as “low acceptance” because she did not want to pursue other reproductive options. However, reexamining the data revealed that she had “total acceptance” of her HIV status and its implications in that she accepted that, because of her compromised health and single relationship status, having children was not an option.

The primary goal of the final stage of coding, selective coding, was to integrate the various categories to form a model or theory of reproductive decision-making by HIV+ women. This process was facilitated by the identification of the “core category” that constituted the “central phenomenon around which all other categories are integrated” (Strauss & Corbin, 1990, p. 116). The core category identified in the current study was “Perceiving Reproductive Choice: Balancing facts against interpersonal and personal factors.” In effect, the core category provided the overall “story line” of the model. Having identified the core category facilitated the elimination of irrelevant categories, as well as the identification of redundant categories and categories that require additional analysis and development. For example, a category labelled “Desire” was eliminated at this point because it was redundant with the category termed “Acceptance of HIV and its implications.” For some categories, however, clarification required gathering more data (Strauss & Corbin, 1998), as was the case with “Partner Influences.” In the end, applying the methods of grounded theory to the present data resulted in a model of HIV+ women’s reproductive decision-making processes and the factors affecting these processes. As put by Strauss and Corbin (1990) concerning the development of a process through grounded theory the analyst may,

...spell out the conditions and corresponding actions that move the process forward; identify turning points; and show how the outcome of reaching, or not reaching those turning points plays into the conditions affecting the next set of actions taken to move the process forward. Added to this description, the analyst would want to account for variation in movement through these stages or phases. That is, why it is that some persons, groups and so forth lag behind and some pass through the stages or phases at an accelerated rate, while others move so far and then plateau. Or why it is

that for some persons or groups there is actually a reversal rather than forward progress, or a failure to begin at all (p.153).

In qualitative research, sampling and data analysis occur sequentially in an ongoing iterative process (Strauss & Corbin, 1998). The sampling was directed by the coding procedures used in grounded theory. During open coding, when the goal was to identify concepts and generate categories, the analysis was facilitated by collecting data from a diverse group of participants that was likely to provide information about a range of concepts (Strauss & Corbin, 1998). Here, data were initially collected from women with different experiences, including women who were amidst their decisions, women who experienced pregnancies while HIV+ and women who had decided not to have any(more) children. Data collection was immediately followed by analysis so as to enable movement on to axial coding. Because the goal of axial coding was to identify the relations between categories, as well as between subcategories and categories, existing data and new data were sampled to identify variations in concepts and their interrelations. This required theoretical sampling, which involved data collection for generating theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Data collection, coding and analysis tell the researcher what data to collect next and where to go to find them (Glaser & Strauss, 1967). For example, earlier data collection and analysis revealed that not having a stable relationship was a barrier to single HIV+ women pursuing their reproductive desires. HIV+ women in relationships were therefore sampled to examine the properties of relationship status and its effects on reproductive desires and decision-making. Sampling during selective coding, if necessary, becomes very deliberate and is referred to as discriminate sampling. This involves choosing the sites, persons, and documents that will maximize opportunities for comparative analysis. In the current study another HIV+

woman who was planning a pregnancy was sampled to maximize opportunities for comparative analysis. At the selective coding stage comparative analysis involved theoretical analysis. By comparing concepts, properties and dimensions that were not previously evident were brought out of the data. Theoretical comparisons stimulated questioning the data and thinking about properties and dimensions in different ways (e.g., differences between informed and uninformed decisions). Comparative analysis at the selective stage moved the findings from mere descriptions of incidents to more abstract thoughts about the data, thus facilitating theoretical saturation (Strauss & Corbin, 1998). Theoretical saturation, according to Strauss and Corbin (1998), occurs when no new ideas emerge regarding concepts and categories, when the categories are well developed in terms of their properties and variation, and when the relations among the categories are established (Strauss & Corbin, 1998). Theoretical saturation was approaching by the tenth interview, but further efforts were made to develop the categories, properties and dimensions in terms of planning a pregnancy. Thus, at the end of 11 interviews theoretical saturation had occurred, and the process of reproductive decision-making by HIV+ women could be described and explained in terms of categories' properties and dimensions, as well as their relations.

The second goal of the current study was to examine the needs of HIV+ women as they contemplated whether to have a child. Data coded as barriers, facilitators and needs were used to explore the needs that were and were not being met for HIV+ women contemplating their reproductive options.

Quantitative data. Given the small sample size, nonparametric measures of the descriptive characteristics of the quantitative data were considered (i.e., median and range) as well as the mean of scores.

Research Quality

Although there is a widespread belief that only quantitative data are valid (Sechrest, 1992) when done correctly, qualitative research is no less rigorous (Rice & Ezzy, 1999). In general, the quality of research is assessed using the criteria of truth value, consistency, neutrality and applicability. In quantitative and qualitative research, these concepts are referred as internal validity/credibility, reliability/dependability, objectivity/confirmability and external validity/transferability, respectively (Seale, 1999).

Credibility. Qualitative research is said to be credible when there is evidence that the findings of the research accurately reflect what the participants' said and meant. The credibility of qualitative research can be enhanced in a number of ways, including ensuring the quality of the interviews, the consideration of social context, iterative sampling and systematic analysis, the consideration of negative cases, triangulation, member validation checks, testing the emergent model with new or uncoded data, the presentation of supportive quotes, and drawing clear distinctions between data and interpretation.

The quality of interviews was facilitated through long (ranging from 45 minutes to one hour and 40 minutes), in depth, rich interviews with probes designed to gain detailed accounts of personal experiences. The consideration of social context also enhanced the credibility of the findings. Good qualitative research provides description of social context, which may include description of background information regarding the

overall structures, settings and frameworks within which participants were situated (Popay, Rogers & Williams, 1998). Popay et al. (1998) suggest that the active acknowledgement of the effect these overall structures, settings and frameworks may have on participants' actions is required in order to place the data within a wider context. In the current research, the social context of participants' lives, experiences and perspectives were considered so as to shed light on the meaning of the findings, particularly in the case of apparent contradictions, which may be rendered understandable given contextual information (Rubin & Rubin, 1995). To this end, the entire context with which decision-making occurred was considered, and not only from the context of having a positive HIV status.

Iterative sampling and systematic analysis also facilitated the credibility of the findings (Seale, 1999). The sampling of participants was directed by the systematic analysis of the data; this process directly ties the findings to the realities of the research participants (Charmaz, 1995; Rennie et al., 1988). Iterative sampling and systematic analysis were used in the present study by following the sampling and coding procedures of grounded theory.

The credibility of the research was also enhanced by the consideration of negative cases in which a relationship between categories does not hold up (Strauss & Corbin, 1990). Consideration of negative cases was achieved in the present study during the axial coding stage of analysis when the search for outliers that run contrary to previously observed relations occurs. The search for negative cases in the present analysis provided insight for where the analysis had gone astray, thus, allowing the analysis to get back on track.

Triangulation, which can involve data, investigator, theory or method, “can enhance the credibility of a research account by providing an additional way of generating evidence in support of key claims” (Seale, 1999, p.61). Data triangulation consists of collecting data from different people, settings, times and places so as to stimulate a richer description of the phenomenon of interest. To achieve data triangulation in the present study, efforts were made to collect data from women who varied in terms of their social location (i.e., education, ethnicity) and experiences (e.g., injection drug users, different lengths of time knowing of HIV status). Investigator triangulation involves having more than one researcher conduct the interviews and/or the analysis so as to bring different points of view to bear on the data and thereby reduce the impact and limits of personal world views and understandings. This was accomplished to a minor extent in the present study by getting feedback from my thesis advisor regarding coding, relationships and finally the emergent model. Methodological triangulation, the most common type of triangulation, is accomplished by the use of multiple methods to collect data, typically some combination of interviews, observations and quantitative methods. In the present study, methodological triangulation was facilitated by supplementing the interview data with participants’ responses to the quantitative measure of their knowledge regarding the factors affecting HIV+ women, childbirth and parenting. If qualitative and quantitative findings converge the credibility of findings are enhanced and failure to converge may enhance our understanding of different aspects of HIV+ women’s decision-making processes (Seale, 1999). In the present study the qualitative and quantitative findings regarding knowledge of HIV and reproduction of HIV+ women converged to some extent and gave further evidence to the credibility of

the study's findings. The converging findings are discussed later in detail in the Quantitative results section.

A member validation check is a method of assessing the researcher's understanding of the data by having participants critique the adequacy of the emergent model (Seale, 1999). Strong member checks involve getting participants' feedback on the applicability of the entire model. With moderate member checks, participants provide feedback on a small portion of the findings, and with weak member checks participants review interview transcripts are accurate (Seale, 1999). Participants' comments are then used to guide revisions of the model. Unfortunately, member checks were not possible due to time constraints.

Testing the applicability of the emergent model to uncoded or new data is another way of assessing the credibility of the findings (Seale, 1999). To the extent that the model is an accurate and complete account of the phenomenon of interest, it should apply and not be in need of revisions. In the present study, the credibility of the findings were assessed by examining the applicability of the emergent model to uncoded data from the final interview.

Efforts to enhance the credibility of the current findings also included the provision of extensive, informative and articulate quotes from the participants, quotes that provide the reader with sufficient information to assess the credibility of the researcher's understandings. As Rubin and Rubin (1995, p. 268) put it, "the text should present a comfortable interlacing of example and argument or explanation, in which the examples are vivid and anchor the more abstract arguments in understandable cases."

Following convention, two to three full quotes will be used to highlight major points and one to two quotes to highlight minor points (Rubin & Rubin, 1995).

Finally, credibility is enhanced when the reader is able to distinguish the data from the researcher's interpretation of the data (Poppay et al., 1998; Seale, 1999). This was accomplished here by making the distinction clear via the use of language (i.e. "the participant stated" or "as put by" vs. "the participant implied" or "this was interpreted as meaning").

Taken together, these techniques should facilitate the credibility of the research findings.

Dependability. The second criterion used to assess the quality of qualitative research is dependability, which refers to the ability of the study to be replicated. This is accomplished by "the provision of a fully reflexive account of procedures and methods, showing to readers in much detail as possible the lines of inquiry that have led to particular conclusions" (Seale, 1999, p.157). To keep track of their methods and methodological decisions, qualitative researchers often maintain a methodological reflexivity journal in which they document their methodological thought processes throughout the study, including their decisions and the basis of their decisions (e.g., regarding sampling, the design of interview questions). Thus, a methodological reflexivity journal was kept throughout this research to track decisions about the data, coding procedures, the relations between codes, properties and dimensions, and other thoughts about the emerging model. The following excerpts from my methodological reflexivity journal provide examples this type of tracking:

As I was writing a comment for the code 'Stable Partner' in reference to Lisa when she was outlining barriers to having a baby, she was saying in

order for her to have a baby she would want to have a stable partner – one that could look after the child if she became ill or if she died... she is looking into the future and making considerations for the future – this made me think of where some of the other women are in terms of finding someone. For some the goals of finding a partner to fulfill the desire about having a baby are not so future orientated ... Maybe this has to do with the status of the participants' health. For one, Cathy has only known about her status for two and a half years and has not been experiencing symptoms, has not been taking HIV meds and is in good health. Whereas, Lisa has known of her HIV status for 17 years, experienced ups and downs in her health and has been on HIV meds. Maybe because Lisa has experienced poor health she is aware of her own fragility and uncertain future, and therefore prepares for the worst and prepares for the best possible outcomes. With this in mind I plan on asking in more detail about finding someone/relationships and their effects on decision-making ... Also, I will ask any women who are already involved in relationships what role their partners play in the decision-making process" (November 1st, 2004).

'Achieving Stability' may be a big factor in the decision-making process ... a lot of the goals for the women who have the desire a baby but who still have not made an active decision to have a baby seem to be revolving around getting more stability in different areas (or problem areas) of their lives before pursuing pregnancy. Questions about Stability or where the participant feels they are in their lives and how that affects reproductive decision-making will be added for interviews with women trying to decide and for interviews with women who have already made decisions (November 15th, 2004).

Amount that women accept or have positive attitudes about HIV and the risks of pregnancy seems to be related to how much knowledge they have. Those women who are more accepting seem to be more informed (June 12th, 2005)

During the analysis, grounded theory dictates that the data analyst write memos in which they note their ideas and hunches, as well as the methods and processes involved in developing and clarifying categories and the relations between the categories (Charmaz, 1995; Strauss & Corbin, 1998). In effect, memos report data, tie different pieces of data together and report relationships and patterns among concepts and categories (Charmaz, 1995; Miles & Huberman, 1994). “Thus, memo-writing helps you to direct the shape and form of your emergent analysis from the very early stages of your research” (Charmaz, 1995, p. 44). The process of memoing also has the benefit of stimulating the analyst’s thoughts and keeping them on track. I used memo writing for these reasons. Take for instance the following memo that reports tying two very different codes together:

New with partner concern is the effect of testimony of others on the decision-making. Considering pregnancy often involves engaging in unprotected sex (other methods such as artificial insemination etc. not options I suspect because of financial reasons), which means there is risk of transmission to the male. Want to avoid the risk but still want to get pregnant. Although documented reproductive options suggest that HIV+ women and their partners (HIV+ or -) limit unprotected sexual intercourse until a woman's most fertile times, but that may be too simplistic of an answer for HIV+ women who are experiencing irregular menstrual cycles and can not know when their most fertile times are. In theory it sounds like a good solution but in practice/reality it is unreasonable. Kristina has heard from others that the risks of transmitting to an uninfected man would be low, but her menstrual cycles are sporadic and cannot anticipate her fertile times (February 21st, 2005).

Memos were also used to report data and hunches about relationships:

Sylvie is the first woman to talk about using specific pregnancy resources (see lines 476-492), I think she utilized this resource because of the lack of HIV+ women experiencing pregnancy and as a pregnant woman she felt like she needed the support of other pregnant women to help her through her first pregnancy especially since she did not plan to get pregnant. (January 26th, 2004).

Taken together, the methodological journal and memos provide an audit trail of the study that provided accountability for the findings of the study.

Confirmability. The third criterion used to evaluate qualitative research is confirmability (Seale, 1999). Because qualitative research is often guided by a social constructionist view of science in which the complete, detached objectivity of the researcher is regarded as unattainable, qualitative researchers stress the researcher's need to make their subjectivity apparent so as to facilitate what might be called 'subjectively informed objectivity' (Charmaz, 1995; Smith, 1995). In the present study, my subjectively informed objectivity was formed on the basis that I was a HIV- woman who had never had any reproductive experiences and that I began the study from a research perspective regarding HIV prevention. The process of subjectively informed objectivity can be facilitated by the researcher maintaining a self-reflexive journal throughout the entire project. In this journal, the researcher is encouraged to think and write about their motives for undertaking a study, their assumptions and anticipated results, and their personal and academic perspectives and how these perspectives might draw their attention toward some things and away from others, resulting in less informed understandings. Keeping a self-reflexive journal facilitates the researcher's ability to provide an "account of the researcher's personal story during the life of the project, exposing assumptions, values and theoretical perspectives for the benefit of the reader,

again in the interest of enabling critical evaluation of conclusions” (Seale, 1999, p.158). I maintained a self-reflexive journal throughout the research process. In this journal I explored my assumptions, personal biases, and personal and academic perspectives. According to Seale (1999), “once ‘assumptions’ are clear to those who hold them, they are presumably no longer ‘assumed’, since they have been brought to consciousness and acquire the status of belief, if they are held to at all any longer” (p. 164). As a result, it is hoped that my biases, assumptions and perspectives did not unduly influence the interviews, the data analysis or my interpretations. For instance, early in the analysis I assumed the HIV+ women would and should be considering certain factors as they made their reproductive decisions. This was brought to my attention during the interview with Cathy, when she said she did not think about the possibility of having a HIV+ child if she were to become pregnant. I expected the possibility of having an HIV+ baby to be a central concern of these women. By becoming aware of this and other assumptions and personal biases regarding what HIV+ women should be considering in their decision-making, I was better able to recognize the effects of these assumptions in subsequent interviews and during the data analysis. For example, I was careful not to asking leading questions regarding my preconceived ideas.

Transferability. The last criterion used to evaluate the quality of qualitative research is transferability (Seale, 1999), which refers to the extent to which the reader is able to assess the applicability of the findings to other settings or people. Transferability is achieved through a detailed and rich description of the participants and the setting. Providing such material allows the reader to know exactly to whom and in what setting

the findings may apply. Rich descriptions of participants and settings were therefore provided in the write up of the findings of the present study.

In all, the research process and analysis were systematic and evidence of the credibility, dependability, transferability and confirmability of the findings were, to at least some extent, provided.

Results

Qualitative Results

Seven of the 11 women described one decision-making experience and four described two decision-making experiences. Of these 15 decision-making experiences, six resulted in the decision to have a child, five in the decision not to have a child, and four were ongoing at the time of the interview.

The nature of women's decisions. Women's reproductive decisions were categorized as informed, uninformed-forced or ongoing, depending on the extent to which they considered and balanced interpersonal (e.g., social support), personal (i.e., acceptance of HIV status and its implications, response, desire and perceived choice) and factual factors (i.e., knowledge about HIV and pregnancy). Informed decisions were characterized by having factual knowledge regarding HIV and its implications for pregnancy and balancing this knowledge against the influence of interpersonal (e.g., their partner's desire, healthcare professionals' opinions, and HIV+ women's support) and personal factors (i.e., personal desire to have a child, attitudes toward the risk of transmitting HIV, and the ability to parent).

Three women, Stacie, Michelle and, in regard to her first decision, Sylvie, made informed decisions to have children. For instance Stacie, a 32 year-old woman trying to conceive with her HIV- partner, considered the effects of her health on pregnancy, the use of drug interventions during pregnancy, her own personal desires and concerns, her partner's desires, and her doctor's opinions and suggestions:

I've always wanted to have a baby ... My husband and I have been together for four years going on five and we're trying. He's not positive, I am. We went to the doctor and everything and they said, 'do it this way'

[unprotected sex only during fertile times], but I'm afraid of him catching it. So we do use condoms sometimes, but not all the time ... My health is great. My viral load is undetectable, because I stopped drinking. Four years and no drinking ... when I was drinking it went up high and now it's undetectable, it's under 50. My [CD4] counts, my doctor is not worried about me 'cause they jump. They don't go any lower, they go higher than low. Right now it's at 700 ... If I'm healthy the baby will be healthy. The pills that I'm on prevents the baby from catching the virus.

Michelle, a 30 year-old mother of one, spoke about her plans to have a child with her HIV- partner once they were married. Michelle was aware of her extremely good health and knew that she "wouldn't go on medication because I wouldn't need to" during pregnancy. During her decision-making, Michelle also considered her age, her desire for another child, her partner's desire for a child, and her relationship status:

Well, I mean, my boyfriend and I aren't married but I mean it [having a child] is in the future and, I mean, I am 30 and he's going to be 34. I mean, he's never had children. We've talked about it [having a baby]. You know, I basically said to myself, I will not do it again unless I'm married, 'cause I refuse to do it by myself ... I would love to have another one, but just not by myself ... I mean, it's not even an option. If we get married we're planning on having children – child, I don't want more than one.

Lisa, Glenna, Jeannie and, for their second decisions, Sylvie and Lesley, made informed decisions not to have any(more) children. Glenna, a 30 year-old single mother of one who lost her partner to AIDS, noted that she did not want any more children. Despite her awareness that interventions to reduce the risk of transmitting HIV to the fetus were both available and effective, the difficulties of being an HIV+ mother were more salient for Glenna. As Glenna said:

For me, for my own personal individual, no I wouldn't have [anymore children]. No, not being HIV+. Certainly not. It's just not, even when I wasn't, a second child was not the option ... More so now 'cause, I don't know, I'd just be in fear that oh, what if I'm taking too much of the wrong thing, or not enough of the right thing... there are a number of factors, you know. It's not just the HIV ... For me, I just don't think it would be fair. I mean, you know, you don't live forever. Well, nobody lives forever, but someone with HIV definitely has a limited time limit. And I feel like I'm already going to let down one kid. You know, I couldn't bring another one in knowing that I might not be there to see it graduate from college, or see my first grandchild or, you know, watch it buy its first house ... and that's the sorta thing that bothers me. We're a very family orientated family, and I just don't want to leave my kids ... You know, like I said, I got one and I'm going to have to face that challenge, that obstacle one day in life. One's enough. I don't want to do it to two. That's my reasoning. That's the HIV reasoning. The other reasoning is because of the world and the way it is (laughter)... just everything that is going on. The 9/11, the terrorists attacks, the bombings. It's not close to home right now, but that's not to say that the future doesn't change. You know, and to worry about one kid facing it is more than my mind can comprehend. To worry about two kids going through it would just be horrible.

Lisa, a woman in her mid-thirties, made an informed decision not to have anymore children despite her desire to have more children. Instead, Lisa considered her compromised health and being single in the course of making her decision not to have anymore children. In particular, Lisa spoke of how the instability of her health increased the risk of mother-to-child transmission and described this as contributing to her decision not to have another child. In addition, Lisa said she would not have a child because she

was not in a stable relationship and was therefore concerned about the guardianship of a child in the event of her death.

Uninformed-forced decisions about whether to have children were characterized by insufficient factual knowledge regarding HIV and its implications for pregnancy and parenting. Instead, these decisions were based solely on personal and interpersonal factors. Lesley's and Kristina's first reproductive decisions were uninformed-forced. Lesley had an unplanned pregnancy at the age of 22 when she was abusing intravenous drugs and denied her HIV positive status to both herself and others. Personally, Lesley had no desire to have a child, nor did she have any knowledge about HIV and pregnancy. Nevertheless, Lesley continued her pregnancy because her partner and her partner's family put pressure on her and she wanted to please them. As a result, Lesley felt 'forced' to continue her unplanned pregnancy.

Like [her partner] and his mother were just nuts over this baby coming because it's her first grandchild and blah-blah-blah. Everyone was happy. I was just so worried about if she [the baby] has it [HIV] ... You know, but I was thinking about myself and everybody else, really. I didn't want to rain on everybody's parade ... I know things should have been different with my pregnancy, but at the time it [going through with the pregnancy without telling anyone about her HIV status] was the best thing I could do, because everybody still liked me and, you know, at that time it was really important for people to like me.

Kristina, who also had an unplanned pregnancy at the age of 22, made an uninformed-forced decision to have her child because she was too far along in her pregnancy to consider abortion, was not well informed about HIV and pregnancy, had not had any exposure to HIV organizations and resources, and simply believed she had to

follow the directions given to her by health care professionals. Consider what Kristina said about her pregnancy experience:

I just found in my situation my doctor wasn't 100% knowledgeable about what to expect or what to suggest for me. Like they [health care professionals] automatically went by the book [in regard to her treatment] ... but at the time I was kind of put in the situation and I kind of just had to follow whatever they [health care professionals] advised me to do ... Like they [her community] had an HIV organization there too, but they [health care professionals] didn't introduce me to that at the time ... They didn't really give me any resources at the time.

Cathy, Mary and, for her second decision, Kristina were still in the process of deciding whether to have a child. Each of these women lacked knowledge regarding some aspect of HIV and its implications for parenting and pregnancy and, as a result, had yet to achieve a balance between their factual knowledge, interpersonal factors and personal factors. However, Cathy's ongoing decision-making was, at the time of the study, primarily influenced by her lack of a partner. As Cathy put it:

My decision-making? Okay, I haven't just made the decision yet. I just want to have, like, a baby. I may have one or not. It will depend on if I find the right person to make a child with. So the first thing now is to find someone. Then if I find someone, I will make it [a baby]. So the main point is to find someone.

Mary's ongoing decision-making, on the other hand, was being swayed by the state of her health:

...my viral load was really high [Interviewer: And are you experiencing any symptoms?] Yeah, just some nausea, headache. I'm tired a lot, really tired. [Are you on any kind of drug regimen?] It's colletra and comivire. I can't take them as often as I like. They make me even more nauseous...

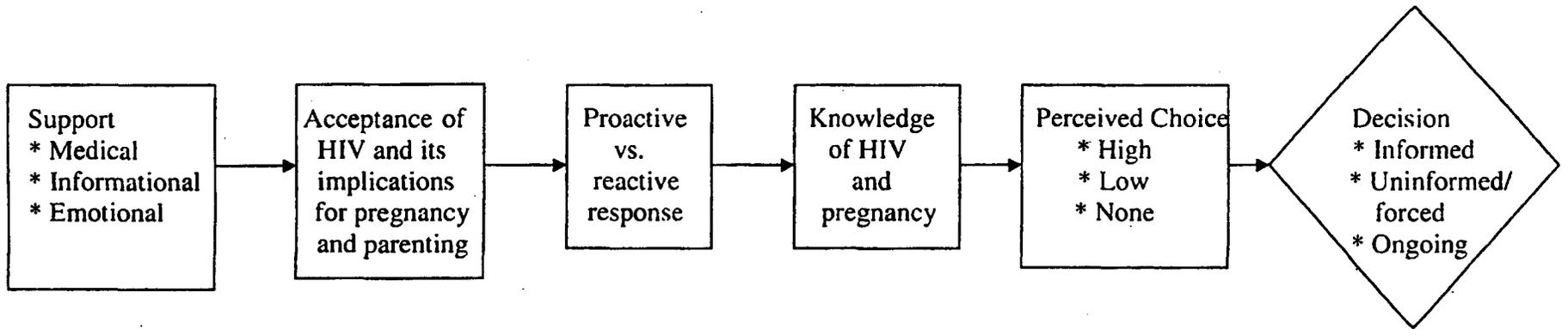
and I gotta get my health up first before I can do something like that [have a baby].

Finally, Kristina's ongoing decision-making was currently dominated by her fear of transmitting HIV to her partner and her attitudes toward HIV drug interventions during pregnancy:

For me, well I guess it is a concern for both of us [Kristina and her partner] about transmission ... Right now the concern is transmitting from me to him, because all of the research we have done and everything the chances are very minimal ... so, I mean, it looks good in that situation, but I think that it's just our main concern right now ... I know a lot of people that were on [HIV] drugs and just before [pregnancy] and everything [but] because most of them have lived in bigger cities their doctors have let them come off ... For me, I would rather, I'd like to get off of them [HIV drugs] because I'm not really sure what impact it really has on my body. I'm not even, like, they [health care professionals] say that most of them [HIV drugs] are safe enough, but I don't really know. Just because there are so many side effects already without adding pregnancy to the issue. I'm not really sure if they're 100% safe. Like nobody I know has had problems with the development of their child.

The process model depicted in Figure 1 illustrates the role of knowledge, interpersonal factors and personal factors in HIV+ women's reproductive decision-making. In this model, HIV+ women who received more *Support* in the form of information, medical treatment and emotional support from health care professionals, partners, family, HIV organizations and other HIV+ women displayed more *Acceptance of their HIV status* and the challenges it posed for pregnancy and parenting. This acceptance was important as it affected women's *Responses* to their HIV status and its

Figure 1. *Perceiving Reproductive Choice through Balancing Facts against Interpersonal and Personal factors*



implications. In particular, women who accepted their HIV status and its implications proactively sought information regarding HIV and pregnancy and, as a result, had more *Knowledge* about HIV and pregnancy and, in turn, *Perceived more choice* in whether or not to have a child. On the other hand, women who did not accept their HIV status and its implications acted reactively in that they did not seek information, had less knowledge, and believed they had less choice in their decision. Finally, women's perceptions of choice determined whether they could make a decision and, if so, whether those decisions were informed. The core category that linked these conceptual categories and summarized the nature of HIV+ women's reproductive decision-making was labeled *Perceiving reproductive choice: Balancing facts against personal and interpersonal factors*. Table 3 displays each participants' standing on these components of the decision-making process, and the characteristics of these components are described in what follows.

Support. Three types of support were crucial to these women's decision-making process, namely informational, medical treatment and emotional support. Informational support involved the provision of factual information regarding the risk of transmitting HIV to a child during pregnancy, labour and delivery, the risk of transmitting HIV to a partner during intercourse, and the availability and efficacy of interventions to reduce these risks before, during and after pregnancy. Informational support also involved the provision of information relevant to the particulars of each woman's unique situation, including information relevant to each woman's health status, the most appropriate HIV drug interventions and their possible side effects. Informational support was mainly provided by healthcare professionals, HIV organizations and other HIV+ women.

Table 3

Participants' Support, Acceptance, Response, Knowledge, Choice and Reproductive Decisions

Participant	Support	Acceptance	Response	Knowledge	Perceived choice	Decision
Cathy	Medium	Partial	Reactive	Some	Low	Ongoing
Mary	Low	Partial	Reactive	Some	Low	Ongoing
Lisa	Medium	Total	Proactive	Some	High	Informed - no
Glenna	High	Total	Proactive	Some	High	Informed - no
Jeannie	High	Total	Proactive	Some	High	Informed - no
Linda	High	Total	Proactive	Some	High	Informed - no
Stacie	High	Total	Proactive	A lot	High	Informed - yes
Sylvie 1	High	Total	Proactive	A lot	High	Informed - yes
2	High	Total	Proactive	A lot	High	Informed - no
Michelle 1	High	Total	Proactive	A lot	High	Informed - yes
2	High	Total	Proactive	A lot	High	Informed - yes
Kristina 1	Low	None	Reactive	None	Low	Uninformed/ forced
2	Medium	Partial	Proactive	Some	Low	Ongoing
Lesley 1	Low	None	Reactive	None	None	Uninformed/ forced
2	High	Total	Proactive	Some	High	Informed - no

Support in the form of medical treatment refers to health care professionals' provision of treatments or HIV drug interventions for reproductive reasons. Supportive medical treatments that were provided prior to conception to improve women's health and those provided throughout pregnancy both reduced the risk of transmitting HIV to an unborn child. The most common treatment provided to these women was AZT.

Emotional support refers to the interpersonal reassurance and comfort that reduced the uncertainty and fear these HIV+ women experienced during their reproductive decision-making and, for some, reassurance and comfort that they had made the 'right' decision. Emotional support was provided by partners, family members, HIV organizations, other HIV+ women and, for some, health care professionals.

Glenna, Jeannie, Linda, Stacie, Sylvie and Michelle had each type of support for all of their decisions, while Lesley had each type of support during her second reproductive decision. Sylvie, a 36 year-old woman living with HIV for 15 years, spoke of women's fundamental need for support and the extensive support she received during her unplanned pregnancy six years ago:

... oh the fact that I had so many people surrounding me. You know, like all this network of doctors, HARS [HIV/AIDS Regional Services], friends, and information through Voices [of Positive Women], through CATIE [Canadian AIDS Treatment Information Exchange] and all that stuff that's available ... I think that is the most important, the knowledge of all the network of things that can help the positive women with their pregnancy with their decision-making. Absolutely, you need support.

Sylvie also described the informational and emotional support she received from an HIV+ woman's support group:

I belong to Voices of Positive Women. They network women all over Ontario, because it is hard, very little of us come out. So to share experiences and things like that, with this group we get together and we exchange experiences. I really needed to know and I've gotten a lot of information from these women that already have children. That really comforted me, knowing that it wasn't for sure that it [the baby] would be positive. There was a good chance that it wouldn't [be HIV+].

Learning from these women that her unborn child would not necessarily be HIV+ comforted and reassured Sylvie. The HIV organization and other HIV+ women, then, fulfilled Sylvie's informational and emotional needs. Sylvie also received supportive informational, treatment, and emotional support from health care professionals. Sylvie's HIV specialist doctor, for example, provided her with information, medical treatment and emotional reassurance that supported her throughout her pregnancy:

... my doctor, he put me on AZT. That's the one thing I did special ... Well the AZT actually made me anemic. You know, in the first trimester you're supposed to take it, but I couldn't after the first couple of weeks because I became very tired, ill and not well. So they [health care professionals] had to stop it. What he [her doctor] decided was that it would be best to just take it at the third trimester ... So he [her doctor] figured the anemia wouldn't be so bad at that time compared to if I were to do it the whole time, and that's exactly what I did. But the doctor reassured me that everything should be fine as long as I take it in the third trimester.

Stacie, who was planning a pregnancy with her HIV- partner, also received sufficient information, medical treatment and emotional support. When asked what was helping her with her decision-making, Stacie described the information she received from the HIV organization she was involved with:

I use the HIV/AIDS Regional, where Meigan works. She's my worker. HARS is really good. They help me out with supplies and everything, like Kleenex, toothpaste, shampoo, conditioner, condoms. I even go to HARS and get condoms for my friends. I've done that a lot. They are very helpful in that way. Yeah, and I get information. If there's new information out Meigan tells me about it and she keeps it for me and I go down to see her. Usually I go once a month.

Stacie also described emotional support from her family, partner and friends:

My Mom was with me when I found out [about HIV status]. She's been there for me, but now I have my husband and he's here for me. I really don't need anybody else, but I have my family too. I've got family here in Kingston, my Mom lives in Quebec. I have some friends that are positive, and they're mainly women. Well I have a few here in Kingston and I have women that are not positive that support me. I have a lot of friends that support me and my family supports me in whatever decision I'm making [about having a child].

That Stacie also received medical treatment was evident when she said, "I'm on 5 pills in the morning and 5 pills in the night. I'm on the medication so if I do get pregnant I'm already on it."

Cathy, Lisa and, for her second decision, Kristina, had only two of the three types of support. Cathy, a 36 year-old single woman living with HIV for two and a half years who is still deciding whether to have a child, has received information from an HIV organization and other HIV+ women and emotional support from health care professionals, an HIV organization, and other HIV+ women. However, Cathy has not received supportive information or medical treatment from health care professionals. As she put it:

Okay, she [her doctor] doesn't go into detail too exact. She was telling me it was possible. I didn't ask how it was possible ... I don't discuss much. I don't go into much detail, like which medicine and which side effect. I'm not at the stage of even thinking about medication ... I just discuss it [whether to have a child] with my friends who are positive. Oh, they say that it is possible [to have a baby]. Like, all of them, they are positive. Because they are positive they are like, 'why not, it's possible.' They told me that, 'Well, you may not know how. If you can find someone who is serious and who can understand, or maybe the other good thing is maybe you could find somebody who is also positive. Because someone who is in your situation can understand better than some one who is not.' ... It's really tough because those that I know who had HIV+ babies, they got them because they didn't go through the treatment they give to women who are pregnant. Yeah, but all those who went through that, their babies are okay. [Interviewer: The ones who had treatment?] Yeah, so that gives me hope that once I get pregnant and I have that treatment my baby won't get it.

During her second reproductive decision, Kristina, a 30 year-old woman living with HIV for seven years, received information from an HIV organization and had the emotional support of her partner. Consider Kristina's description of her partner's involvement in her reproductive decision-making:

And so now it has just become that we've [Kristina and her partner] both graduated from school and now that we're getting into having real jobs and everything, now he's like, maybe now is the time to have a child. So, I don't really think the whole HIV has a big impact on having a child with him. I mean, he obviously knows the consequences and he wants to be informed and everything, and he said he would come with me to the AIDS Committee and talk to them for whatever questions he has. So he really does want to be involved.

However, health care professionals provided Kristina with insufficient information and medical treatment regarding the impact of HIV drugs on her fertility:

Because I think one of my other concerns is that, I'd say over the past 18 months to a year, I haven't had like a regular period. And so that kind of, well they [health care professionals] are not really sure why that is being caused. Is it because of something drug-related that it is happening or is it just the natural course of my system? Because I haven't really seen anything about that either. Like I've never seen that as a side effect, so I'm not sure if it's a side effect of the meds, or once you've been taking something for too long, like how it starts to influence other factors in your body ... I think even for medical professionals – I don't think they are even 100% sure either at this point. Like I've talked to my doctor in Sudbury, I've talked to two doctors here [in Ottawa] and I think nobody is 100% sure of what meds have what side effects, because with everyone it is different.

Mary and, for their first reproductive decisions, Kristina and Lesley, did not receive at least two of the three types of support. For instance, Lesley did not have any support because she did not tell anyone about her HIV status. As she explained:

My doctor didn't know [about her status] like when I was pregnant with [daughter]. He didn't know and I didn't tell him. Like no tests were done or anything like that to see if I was [HIV+], even though he [doctor] knew I was using intravenous needles. I should have told my doctor, but you know hindsight is 20-20 ... I had my whole family and [her partner] and [her partner's] family, but they were not there. I was all alone then. It [her HIV status] was a big secret ... Oh, it [her pregnancy] would have been so much easier to tell [about her HIV status], 'cause then, you know, I would have got support for my own self and maybe if I had gotten some help then I may be a little better now.

Mary, a 34 year-old recovering drug addict living with HIV for 14 years, only has emotional support as she currently contemplates having a child. This emotional support is provided by health care professionals:

Like she's [her doctor] great. I get along with her, and I can talk to her like a friend. Usually I go about an hour or hour and a half every time I go. She's more like my psychiatrist than my doctor. [Interviewer: So you get the emotional support?] Yeah, that I could use. I can go there not even for a doctor's appointment. Drop in, if she's not busy, if I'm emotionally distraught and I need somebody to talk to. Yeah, my doctor is really good. There's a couple of nurses that I feel the same way about.

Unfortunately, because her doctor is unaware of Mary's desire to have a child, she has not been provided with supportive medical treatment to reduce the risk of HIV transmission during pregnancy. That Mary also lacked information regarding HIV and pregnancy was implied by her statement, "Oh, I think there's lots of medical information out there. I just don't know how to obtain it." In addition, Mary does not have the emotional support of her family:

No, I can't talk to my family about it because they would be dead against it. Well, they already brought up one kid of mine and he went wayward. They would just be afraid of having to bring this one up. [Interviewer: How's that make you feel?] Not good, because I could probably use all the help I could get ... I know they wouldn't be supportive of me having a child, especially with me being sick and stuff. They don't feel like I should be doing that to a child, yeah, because it could die and why bring a child into the world if it could die.

Women's access to information, medical treatment and emotional support was important to their decision-making because of its impact on whether they accepted their HIV status and/or its implications for pregnancy and parenting.

Acceptance of their HIV status and its implications. Women varied in the extent to which they accepted their HIV status and/or its implications, implications that included the risk of transmitting HIV to their partner and child, their health status, drug interventions, stigma, and parenting. All of the women were concerned about the risk of transmitting HIV to their child during pregnancy. In this regard Sylvie said: "Well, my main concern was will he [her baby] be healthy, and will he get this disease." Several women also expressed their concern regarding the risk of transmitting HIV to their partners during intercourse. As Kristina put it, "For me, well I guess a concern for both of us [Kristina and her partner], is about transmission ... Right now the concern is transmitting from me to him." Although many of the women were confident in the efficacy of interventions designed to reduce the risk of transmission during pregnancy, labour and delivery, some viewed these interventions with uncertainty. Stacie, for example, was sure of the benefits of the intervention she used: "The pills that I'm on prevents the baby from catching the virus." Glenna, on the other hand, was uncertain: "I'd just be in fear [during a pregnancy] that what if I'm taking too much of the wrong thing [medication], or not enough of the right thing?" All of the women said they considered their health status during their decision-making, often regarding their health status as a reason for pursuing or not pursuing having any(more) children. For instance, Michelle said, "I am very healthy ...the whole transmission thing is pretty much zero." Lisa, on the other hand, believed her health was "not steady enough" to consider having a

baby. Several women also expressed their concern regarding the stigma of HIV for themselves and/or their children. In this regard Lesley said:

Nobody even knew about me [being HIV+] let alone a baby, so like what kind of a person does that [becomes pregnant]? ... I was only thinking negatively. Thinking everybody is going to hate me, you know? And if I do tell are they going to take my baby away from me?

Kristina, on the other hand, was concerned about the stigma her daughter might experience as a result of her mother's HIV status:

I don't want her to have to carry around a big secret. I think if she were to know [about Kristina's HIV] it would just be a burden on her. Just knowing how society is, if she [daughter] were to say 'by the way' or if it were to slip out, I think that she in her own little world would be chastised.

Finally, these women considered a number of parenting issues, such as whether they would have the energy and good health to raise their children and concerns for future guardianship. Consider Linda's statements about raising a child as an HIV+ parent:

I mean, even if I could go and adopt a child ... I mean, do you want to adopt a child and not have the energy to go and take the child to the park? You know, that's not fair. You know, part of me thinks that having a baby when you're HIV+ is a very selfish thing to do. You might get sick and die on the child.

Although all of the women considered the implications of their HIV status for a number of aspects of pregnancy and parenting, they varied in the extent to which they accepted these implications. Glenna, Lisa, Jeannie, Linda and Stacie, as well as Lesley during her second reproductive decision and Sylvie and Michelle during both of their reproductive decisions, totally accepted their HIV status and its implications. For

example, Michelle, who was in extremely good health and living with HIV for eight years, accepted her HIV status, safer sex practices, and the risk of transmitting HIV to her partner and an unborn child:

Yeah well, when I finally told him [her partner] I was positive years ago we literally went and sat down with my doctor. I didn't even know but this is the statistic, he gave my boyfriend a one in ten-something [risk of transmission to him], so that just killed all suspicions of anything. Safer sex, or having children, or starting a family, or just everything. It just killed it all.

Jeannie, a single 44 year-old woman living with HIV for 12 years, completely accepted the implications of her HIV status, age, relationship status and experiences within relationships for having anymore children:

Being older now, that would be a whole different story. It's just my life. Even if I didn't have HIV I couldn't because I just don't know how to treat somebody else in a tight relationship like that properly, I don't think. And I don't want to hurt anybody and I don't want to have my feelings hurt no more, eh? So I just leave it alone.

Linda, a 43 year-old single woman with compromised health, also accepted the implications of her age, health and the use of interventions for having children.

Well, I always wanted to have babies but, now that I'm 43 its kind of. I was talking to my sister just the other day about it [having children] and I guess its kind of, I guess the ship sailed on that one. I guess even if I found someone that I wanted to have children with and wanted to get pregnant. I mean, I'm 43. Plus I would think that I would have to stop all of my prescriptions. You know you can't get pregnant and be on all these drugs. And I stopped menstruating in 1998 ... I don't know if it is because of the medicine, but I definitely been on a lot of retreats with HIV+ women and a

lot of women there had stopped getting their periods. And I always thought, you know, I was really grateful that I had my period and that it was really regular. Then when it stopped it was like, 'Oh no!' I always looked at it as a sign of being real healthy and now that I don't have it ... Now I know I feel like I've been through menopause.

In contrast, Cathy, Mary and, during her second reproductive decision, Kristina, accepted some, but not all, of the implications of HIV for pregnancy and parenting. Cathy accepted her HIV status, her good health and that she would need to take medication to reduce the risk of transmitting HIV to an unborn child during pregnancy:

The health, I was wondering about that, but when I talk to my doctor she says my health is good. The chance is high [for me] to have a healthy baby ... there's some kind of treatment to give women who are pregnant and who are positive so that they may protect the baby.

Cathy did not, however, accept the possibility of having an HIV+ child. When asked whether she had considered the possibility of having a HIV+ child, Cathy replied, "No. I never thought about it." Kristina accepted the risk of transmitting HIV to her partner during intercourse, that she may need to change her medical treatment for the health of an unborn child, and that the medication she was currently taking may be the reason she was having irregular periods and her concern that, because of her irregular periods, she may be putting her partner at risk unnecessarily. However, Kristina did not accept the possibility that her medical regimen made her infertile and unable to bear children. Instead, Kristina talked about the effect of her medical regimen on her fertility in the following way:

I think that one of my other concerns is that I'd say over the past maybe 18 months to a year, I haven't had a regular period ... and that's the whole

thing with taking medication at this point because they're not really sure why that is being caused. Is it because of something drug related that it is happening or is it just the course of my system? ... it [her period] started coming back regularly and now its gone again for like three months. So that's another thing for a concern for myself, like, how would I even know when is a time for me to even try to get pregnant?

The two women who did not accept their HIV status and/or the challenges it posed for pregnancy and parenting, Kristina and Lesley, either learned of their HIV status during pregnancy or denied their HIV+ status throughout their pregnancy. Kristina had insufficient time to accept her HIV status and its implications for her pregnancy because she learned she was HIV+ late during her unplanned pregnancy:

I was like really, really hesitant [to be tested for HIV] because, first of all, I was pregnant and I really, I thought this was going to be the worst time in my life because at the time I really didn't know much about HIV and AIDS and everything. And I thought this was going to be the worst thing that could ever happen. So I hesitated and hesitated and I finally went and it came back positive. I didn't know much then, but now I know quite a lot, but at the time I was kind of put into the situation and I kind of just had to follow whatever they [the doctors] advised me to do. ... because everything happened so suddenly and I was going to give birth in like a month. I just didn't really have the time to research anything myself and they weren't as knowledgeable as maybe they could have been. Maybe the information was just not available at the time. Like, I'm not sure. They were pretty much like, 'You have to take this drug cocktail because you're going to have a baby in a month,' and that was pretty much it. They didn't really give me any more resources at the time.

Lesley, on the other hand, could not accept the challenges of HIV for her unplanned pregnancy because she denied her HIV status:

The first five years I denied it [being HIV+]. I totally denied it, like put other people at risk knowing I had HIV, went and had sex, did drugs with other people knowing I had it. You know, I was in such denial that I didn't see myself as having it. But then when I did, I lied a lot. I couldn't help it. I'm being honest with you now because I'm hoping that some of this information will help somebody else ... When you first find out about it, it is hard to admit to yourself and you just lie a lot. Just two years ago I told people and up until then nobody knew. And even when, you know, she [daughter] was conceived nobody knew. ... Look, it took me seven years to tell even my partner, so like that's a long time. You know, I know things should have been different with my pregnancy, but now. At the time it was the best thing I could do because everybody still liked me and, you know, at that time it was really important for people to like me I guess, or to just think that I was just a nice person.

Women's acceptance of their HIV status and its implications for pregnancy and parenting was fundamental to their reproductive decision-making because women with more acceptance acted proactively in response to the challenges of HIV for pregnancy and parenting. Women who could not accept their HIV status and/or its implications, in contrast, reacted to the challenges of HIV for pregnancy and parenting.

Proactive and reactive responses. Proactive responses to the challenges of HIV for pregnancy and parenting included seeking resources and information, considering the long-term effects of being HIV+ and having children on themselves, others and their potential children, and future considerations in general (i.e., illness, guardianship) as related to HIV and reproduction. Lisa, Glenna, Jeannie, Linda, Stacie, Sylvie and Michelle were proactive in their responses to the challenges of HIV, as were Kristina and Lesley during their second reproductive decisions. Although Sylvie experienced an unplanned pregnancy at the age of 30, she was very proactive in her response to being

HIV+ and pregnant. She discussed the risks and interventions with her doctor, sought information from several other resources, and considered her own health, her future and the future possibilities for her unborn child, partner and family. As Sylvie explained:

I consulted with my HIV specialist, went and got a bit of information at HARS, actually through whatever they had in the library to see if other women had children. Then I consulted with other women and with my family. I talked with my family and people at HARS of course . . . I needed to know if my partner would be okay, you know, and my family if they could take care of my child lets say if I pass away and stuff like that . . . I went to these Better Beginnings and everything, but I was the only one that was positive. And I was the first one ever to go to that place who was positive and I told them who I was first 'cause I wanted to make sure that they were comfortable that I was there and that it was me. And I wanted to teach them, you know, about anything if they had any questions for me, so the next time anybody goes through they could help her.

Michelle and Stacie were proactive as they planned their pregnancies, making special efforts to learn about the risks and appropriate interventions for themselves. Stacie, who never had any children, outlined her preparations for pregnancy:

About four years we've been trying. I got checked to see if I can reproduce and I can. I'm fine. I'm ovulating and everything. It hasn't happened yet. Yeah, I'm on five pills in the morning and five pills in the night. I'm on the medication so if I do get pregnant I'm already on it ... virapine or something. A new pill that they have out for women trying to get pregnant. If they get pregnant then they can take that medication.

Lisa, whose health was compromised by the HIV she had lived with for 17 years, consulted several resources for support and information about the implications of

HIV for reproduction and how they applied to her particular situation. During the interview, Lisa described how she actively sought the information, attended HIV/AIDS conferences, and was involved in HIV/AIDS organizations and HIV+ women's support groups (e.g., Voices of Positive Women). In her words, "you just need to look and read and get involved."

Women who did not accept their HIV status and/or the challenges it posed for pregnancy and parenting were reactive in their responses to the implications of HIV for reproduction in that they only sought information on a need-to-know basis and gave little consideration to the future and the effects of their decisions on their interpersonal relationships. Women who responded reactively included Cathy, Mary and, for their first reproductive decisions, Kristina and Lesley. For instance, Mary answered questions about her ongoing decision-making with statements like, "Well right now I'm single, so as soon as I find somebody who is agreeable with it [having a child]," and "Yeah, I gotta get my health up before I do something like that." Further, when asked about the risks involved, Mary responded:

About the risks, I haven't really deeply thought about them. I thought about having a child. I haven't gone that deep into it. I'm not that close yet, especially not having someone to have a child with.

Also, when asked whether she had discussed the possibility of having another child with her doctor, Mary said, "No, not yet. I don't want to do that until I find somebody, you know." Similarly, although Mary discussed wanting to become more adherent to HIV drugs to improve her health, taking a parenting course, getting counseling and doing more research about HIV and pregnancy, she had not yet pursued these things. Thus,

Mary's responses were reactive in that she only sought information on a need-to-know basis and did not consider the implications of HIV for pregnancy and parenting.

Lesley also responded reactively throughout the unplanned pregnancy during which she denied her HIV status:

You know, all that its [the baby] going to be positive, but I didn't do that [think about it] at all through my pregnancy because whenever I did think of that [having a HIV+ baby], the AIDS or the HIV, I just went and got high. And for me getting high was the easiest thing to do. I know that might not sound nice to you or anybody else, but they're not in my shoes either ... speed, cocaine, heroin, you name it. Yeah, I'm not proud to say it now, believe me, but I did it in smooth, small amounts. You know, I know any amount is bad, terrible, but I think I did help by not doing a lot. I would do half the amount I would regularly... I tried to convince myself that I was helping my baby by only doing this much. I know it's stupid, but I was convincing myself and it worked for me at the time. You know what I mean? That was a big coping mechanism that worked. You know, I had nobody to talk to, like nobody except for one girl and she wasn't, you know, there all the time. So, you know, when I could get a hold of her it was great because then I wouldn't do it [get high]. I wouldn't do nothing. But when I couldn't get a hold of her, which was 90% of the time because she works with other people too, I'd just go get high and then I wouldn't think of it. And you know what, I didn't really care. Because then, you know, ... that shit makes you think you are king of the world anyways. So I just thought, you know, it [having an HIV+ baby] won't happen to me, you know, it does to everyone else but it won't happen to me.

Not surprisingly, how these women responded to the implications of HIV for pregnancy and parenting affected their knowledge.

Knowledge. These HIV+ women knew that there was a risk of transmitting HIV to an unborn child, that interventions to reduce that risk were available, that a baby born to an HIV+ woman would not necessarily be HIV+, and that their health status affected the risk of transmission. For example, Stacie acknowledged the effect of her health on the risk of transmitting HIV to a baby when she said: “If I’m healthy, the baby will be healthy.” Mary knew of the benefits of interventions during pregnancy, stating, “Yeah, I do [have concerns], but with technology and medicine these days I think that we could [pause] ... I know you have to take AZT when you’re pregnant.” Glenna, who did not want anymore children, had general knowledge of HIV and reproduction: “I know now that they have lots of medications ... So I know that the eradication and stuff is possible. You know there are many better drugs out there now than there was ten years ago even.”

However, these women’s knowledge about the specific details of the challenges of HIV for pregnancy and parenting, particularly as it applied to their unique situations, was more variable. Women who proactively sought information were more informed about the implications of HIV for pregnancy and parenting and how those implications applied to their own situations. These women included Glenna, Jeannie, Linda, Sylvie, Michelle, Stacie and, in regard to their second reproductive decisions, Kristina and Lesley. When Kristina talked about her current decision-making with an HIV- partner, she discussed the knowledge she and her partner had regarding the risk of transmitting HIV during intercourse:

We have gotten information mostly from the AIDS Committee. For me, well I guess it is a concern for both of us [Kristina and her partner] is about transmission. Like we don't really have any concerns about the whole pregnancy or about becoming pregnant or like transmitting to the

child. Right now the concern is transmitting from me to him, because of all the research we have done and everything the chances are very minimal and because we know a couple of people that have had children where the women is positive and the man is negative and all of them have been able to have a child who is negative and the man is still negative. So, I mean, it looks very good in that situation, but I think that is just our main concern right now.

Michelle, who was in a three-year relationship with an HIV- man, acted proactively to get herself and her partner informed about the risks of having children. Because her doctor told her excellent health made her an extremely “rare case,” she knew her situation was unique:

Technically, I wouldn't go on medication because I wouldn't need to. I know that now. I didn't know that years ago. Um, the whole transmission [risk] thing it's pretty much zero, and for him [her partner] too. I know more now eight years later than I knew back then [when she was pregnant with her daughter].

Women who reacted to the implications of HIV for pregnancy and parenting, in contrast, had less knowledge about the particular implications of HIV for reproduction. Cathy, for example, was unsure about the risks involved, asking, “If I'm positive and I find someone who is positive, what is the chance of getting a healthy baby when both of you, you're positive?” Cathy was also unsure about medications, “But that medicine would be for the sake of the baby, right? If you're pregnant, basically they'll put you on the medication until - they'll stop when you give birth. Or you continue taking the medication? I don't know.” Even Linda, who was well informed about HIV and pregnancy and decided not to have children due to her compromised health, lacked knowledge concerning her

reproductive options: “I always thought it would be nice to go and adopt a little HIV+ baby, but then how do you?”

Women’s knowledge, however, was essential to the reproductive decision-making because it affected their perceptions of choice.

Perceived choice. HIV+ women who accepted their HIV status and proactively became informed about HIV and its implications for pregnancy and parenting believed they had reproductive choices. As shown in Table 3, Lisa, Glenna, Linda, Jeannie, Stacie, Sylvie, Michelle and, for her second reproductive decision, Lesley, believed they had choices. Some women chose not to have any(more) children. For example, Sylvie’s discussion of her current reproductive decision-making suggested that she was aware that her health made it possible for her to have another child but, given her health scare after her first pregnancy and her desire to ‘have fun,’ she chose not to:

Oh no, I'm scared. I don't know, I'm still healthy and everything but the infection scared me to death and I don't know if I could pull it off. I'm 36 now ... and I would like to enjoy my life, not that children stop you from that, its beautiful. But, you know, I want to be able to not have to change diapers at 40 years old. I want to be able to go on vacations and, you know, before my life is over have some time to have some time for me now 'cause I've donated so much of myself and helped out everywhere and I want to look out for me a little bit. Not that I'm selfish, but I'd like to have some fun.

Glenna, Jeannie and, for her second reproductive decision, Lesley, also believed they had chosen not to have children. Lesley, for example, chose to have her tubes tied:

No, I could never be pregnant again, like my tubes are tied, so I can't ... I would love to have another baby myself, but just the thought of [daughter] is enough to make me change my mind ... You just constantly worry

about this little baby inside of you ... It is so hard because, because you're not thinking about yourself, you're thinking, you know, if the baby comes out not normal.

Other women, including Stacie, Michelle, and Sylvie with her first pregnancy, believed they had the choice to have children. Stacie's perception of choice was evident from her consideration of other reproductive options: "I wanted to get artificial insemination, but it costs money. It costs a lot of money to get artificially inseminated ... My husband said if we can't have a baby, then we will adopt." Similarly, Sylvie's perception of choice to have her child was evident from the time she took to consider her options, "It wasn't too long, a few days after I, you know, knew everything [about HIV and pregnancy] and then I just had to make the decision and that took another couple of weeks."

Cathy, Mary and, for both of her decision experiences, Kristina, believed they had choice in regard to some, but not all, aspects related to HIV and pregnancy. Cathy, for instance, believed she had the choice to take treatment to reduce the risk of transmitting HIV to a potential child during pregnancy but, because she was single and given the stigma surrounding HIV, thought she did not have any choice in getting pregnant. Cathy said:

... there's some kind of treatment to give to women who are positive so that they may protect the baby ... the difficult thing is to find someone to make a baby with. Okay, to find someone is not difficult but to disclose your status [is] because you don't know the reaction of the other one [man]. It is difficult to tell somebody because you don't trust people ... and you are scared. You may not even try [to find someone] because you are afraid of what will be their reaction. ... If I find someone, I will make it [a baby].

Kristina described having only some choice during her unplanned pregnancy because she found out about her pregnancy so late:

So, first it was like a really big shock that I was pregnant because I was six months along ... it was like a whole situation, because at that point I obviously knew that I had to have the child. In my own mind I wasn't really 100% sure if I actually wanted to have a child but it was actually too late not to have a child, like to go through the abortion or anything ... Like, I was going to school at the time and I really – like it was just something really, really unexpected and I kind of had to rearrange my life. So it was just a whole – like everything just happened at once. It was very overwhelming to just deal with everything. I think the only thing that I wish would have happened was if I would have found out earlier, so that I would have had the choice of if I actually wanted to follow through with the pregnancy because by the time I realized it, it had to happen. Like it wasn't something I really had the decision to make. And I would have preferred to decide whether or not to have a child.

Kristina also believed she had little choice in the type of treatment she received during the final stages of her pregnancy. Kristina explained,

So automatically when they [health care professionals] found out in February they put me on like a combination therapy for the last month of my pregnancy ... and I actually had my daughter like naturally, which I hear now is not the best situation to go. Like, normally they [health care professionals] should have given me a Cesarean to reduce the risk.

However, Kristina did feel she had some choice because, although she considered giving her child up for adoption, she chose to keep her child instead: “at one point, even before I knew I was positive, I was thinking, ‘Well, maybe I should give the baby up for adoption and everything’ and for myself I couldn't do it.”

Lesley was the only woman who, during her first pregnancy, believed she had absolutely no reproductive options. Instead, Lesley described her decision-making during her unplanned pregnancy as being made “around everybody else:”

It was a big surprise and it was like, ‘Oh my God! What am I going to do?’ but we decided to stay together. So, he was happy and so I was kind of stuck. I felt really stuck because it was the first grandchild for his mom and oh it was just, it was easier for everyone else to just keep going. Like there was nothing going on with me, do you know what I mean? It was just easier to make everybody else happy. [Interviewer: So your decision to keep going with the pregnancy and everything like that was], was more, like, I know it was my decision, but it was more around everybody else. It really was. I had a choice but I didn’t really have a choice.

In sum, women who believed they had reproductive options made informed decisions to have or not have a child. Women who believed they had some but not complete choice remained undecided or, in the case of Kristina’s first pregnancy, chose to follow a particular course of action because of the constraints of the situation. The sole woman who believed she had absolutely no choice, Lesley, made an uninformed-forced decision to have her child.

Needs Assessment

A second goal of the current study was to identify HIV+ women’s needs as they contemplated whether to have a child and ways of fulfilling these needs. The analyses of women’s responses to questions about their needs revealed that they had needs related to healthcare, information and social support.

Healthcare needs. All 11 women had an HIV specialist doctor at the time of the study. Further, all of the women commented on the positive relationships they had with their doctors. Jeannie described her HIV doctor in this way:

This guy here he has a way of, 'Come on, lets see what we can get you started on.' Oh, he just made it so easy to talk and to get started on whatever medication I needed to get started on. He just made it so that, he's just a nice man. He's just a beautiful man."

The specialized HIV clinics and on site pharmacies available to these HIV+ women were also regarded positively. For example, Linda said, "my prescriptions are all filled at the HIV clinic, which is nice. They have a pharmacy right at the HIV clinic, so when you see your doctor you can get your prescription filled and they don't cost a thing."

However, the level of health care available to these HIV+ women appeared to depend on whether the women lived in an urban or rural location. Ten of the 11 women lived in urban areas at the time of the study, but three women (Kristina, Linda and Cathy) had lived in a rural area at one time. Kristina talked about how her experience with health care in a smaller town was not up to par with the health care she expected and latter received in a larger urban area:

And because I was actually living in [small town] at the time, I don't know if they're as educated. Like there's only like one doctor there. He's a specialist, but I don't think, like he does a lot of other stuff. He's more of a GP with a specialization, he's not like an HIV specialist. They weren't really like 100% sure of what to do with my whole situation. So automatically when they found out [about her HIV+ status] in February they put me on like combination therapy for the last month of my pregnancy. And they didn't really, well they kinda knew what to do, but they weren't really 100% sure. And I actually had my daughter like

naturally, which I hear now is not the best situation to go. Like normally they should have given me a Cesarean to reduce the risk.

Linda described the negligent blood taking practices at the rural HIV clinic she attended:

I know that recently there were some people complaining about the nurses at the lab where we go to get our blood drawn, because they were not being very discreet. Like they were saying 'No, we don't do viral loads today.' And that's a pretty well known test. You know, you only get viral loads done if you're HIV+, and they had to take these people aside and have a talk with them about being more discreet, more confidential about people's blood work ... I did notice that they don't use gloves when they take our blood.

Sylvie suggested that making research findings and up-to-date information about HIV, transmission, pregnancy and HIV drugs more readily available to all health care professionals working with HIV+ women might help reduce the gap between the knowledge of HIV specialists and that of other health care professionals and thereby enhance the healthcare provided to HIV+ women in rural areas. As she put it, "So yes, make it more available for anybody, even for obstetricians to have that. Not all of them, lets say, but for at least the ones who would be treating women like us, to have that information."

Informational needs. On the whole, the women were positive about the amount of information available to them. In this regard Mary said, "Oh, I think there's lots of medical information out there." Similarly, Lesley commented, "I was looking at some prenatal stuff down at Street Health, and oh my God, they got so much stuff out now than they did seven years ago. It's like, oh my God, there's just so much more information now." These women received information from a number of resources, including

HIV/AIDS organizations, their doctors, other HIV+ women, retreats for HIV+ women, and the internet. Despite the availability of information regarding HIV generally, these women encountered informational barriers as they contemplated having a child. One prominent barrier to their reproductive decision-making was the lack of available information, research and statistics regarding the implications of HIV for pregnancy, reproductive options, HIV drugs and their effects, and fertility as it pertains to HIV+ women. This made it difficult for them to make informed decisions about what was right for them. Sylvie, for example, was concerned that she did not know the best and worst case scenarios for being HIV+ and having children:

Well, you know, there's not enough. You know, like research on, like to reassure people on pregnancies. For people to know how many pregnancies were good, how many were bad, and what some of the outcomes were, you know. That's missing, and what was the worst case scenarios and what were the good case scenarios. I mean, the fact that ... you can't talk to any of the other positive women that are pregnant it makes it difficult. 'Cause we're one in a million kind of thing, we're so far apart. It is hard to, you know, like when you are pregnant you can talk to other pregnant women about blah, blah, blah to reassure you. And you know there are no other positive women to do that with and that can be hard ... That is why I want more research so that you can make your own judgments. Like 80% are not okay? Well, I'll go this way. It is kinda hard if you don't see these stats anywhere, and its really hard to [to make an informed decision].

Sylvie's suggestion that all healthcare professionals working with HIV+ women be provided with up-to-date information to provide to their HIV+ patients might help remedy this informational lack.

Information concerning the reproductive options for HIV+ women contemplating having a child was also unavailable to some of these women. Indeed, when asked about their reproductive options, these women's first responses referred to sexual intercourse. Moreover, they seemed to have given little consideration to other reproductive options or believed that other options, such as artificial insemination and adoption, were not possible for them. As Stacie said, "It costs a lot of money to get artificially inseminated. That's one thing that maybe the government should look in on, who are HIV and want to get pregnant, to get artificially inseminated." Other women did not consider or ruled out adoption because they mistakenly believed they would not be allowed to adopt because of their HIV status. In this regard Stacie said, "Well, my husband said if we can't have a baby then we will adopt, but can I adopt if I am HIV?"

Some women also had insufficient information about the side effects of HIV drugs and fertility remained unclear for the women of the study. As Cathy put it:

No, I don't like taking medication. I just want to live positively, to keep my health. I won't take medication for ... I don't know for how many years. I don't like taking medication because people say that it has side effects. Some, they don't have those side effects, but many they have side effects – it shows. You see somebody with all these side effects because of their medication. Yeah, it is helpful because it gets you fit, but at the same time it has the side effects.

Kristina expressed her uncertainty about side effects on fertility:

I mean some people haven't been able to get pregnant and I don't really know if it is related to the regimen that they are on. You know, if it has caused any fertility problems or if it's just a natural problem. I don't know and I really haven't been able to find much research on that because I don't think either a lot of women aren't able to speak out about it or there

isn't enough research being done in that area.

In summary, although these women were well aware of the possibility of taking HIV drugs such as AZT during pregnancy, labour and delivery to reduce the risk of transmitting HIV to the fetus, they were relatively unaware of the alternative reproductive options available to them and the implications of HIV drugs for health and fertility.

Support needs. These women's need for social support was fulfilled through a combination of family, friends, partners, doctors and, most notably, HIV/AIDS organizations. All eleven women were involved with some type of HIV/AIDS organization, including the AIDS Committees of Ottawa, Toronto and Windsor, HIV/AIDS Regional Services, Voices of Positive Women, People with AIDS Support Action Network, CATIE, and Street Health). These organization provided the women with counselling services, support workers, HIV+ women's support groups, links to other HIV+ women (e.g., through Voices of Positive Women's 'Talk Time'), retreats and information. Some organizations also provided the women with basic necessities such as shampoo, conditioner, toothpaste, condoms, vitamins, financial support and housing. Nevertheless, these HIV+ women spoke of their need for public support rather than discrimination, emotional support, and prenatal and postnatal support.

These women believed that the general public provided little support to HIV+ women contemplating having a child. Indeed, five of the 11 women voluntarily spoke of their concern about stigma and their fear of disclosing their status to others, particularly potential partners, because of the rejection and discrimination they might encounter. Cathy described how discrimination made it difficult for her to develop romantic relationships, "...to find someone is not difficult, but to disclose your status, because you

don't know what will be the reaction of the other one." Linda also described how the stigma surrounding HIV makes it difficult for her to find a partner:

Oh yeah, well I mean that's why I feel like I'm not going to, like, it's pretty hard to find a partner. You know, how am I ever going to find a man in Windsor? I just feel like when they find out that I'm HIV+ they're going to – why would they want to be with me when they could be with a healthy woman that could give them children? ... I also hate people who ask you how you got it. I hate it 'cause I feel like that when they start to ... they want to know whether you got it from a blood transfusion 'cause then they can feel you're an innocent victim, but if you get it through sex then you asked for it. I don't care how sexually active you are, you don't deserve to die for it. And it's like I'm not dead, but my social life is, that's for sure.

Women's familiarity with the stigma surrounding HIV was also evident in Lesley's fear that her baby would be taken away from her if she told people she was HIV+ and Stacie's erroneous belief that people with HIV were ineligible to adopt children.

Many women described their need for emotional support. Being able to talk to similar others and hear their testimonies about coping with reproductive issues was especially important. Lisa spoke about importance of getting support from similar others. She belonged to a women's support group that provided links to other HIV+ women to talk about "anything that is going on in their lives, ask questions, get responses." Lisa described the HIV+ women's support group she attended as very important because she believed the women in this group understood her better than others, that she could trust them not to disclose what was discussed during these groups to outsiders, she was not judged there and because the group gave her the opportunity to learn what other HIV+

women were doing and experiencing. Cathy also described the importance of talking to other HIV+ women,

At the meetings [HIV+ women's support group meetings] we share experiences. Sometimes it's like, it's good to really have someone who's talking about something that is really happening. Not only reading, but to have testimony.

The support these women received from HIV/AIDS organizations also helped some women overcome emotional problems, such as low self-esteem, anxiety, depression and suicide risk. Jeannie, for instance, overcame her depression and suicidal thoughts and behaviours with the help of the members of of the HIV organization she was involved with:

I ended up in the hospital and HARS was there for me the whole way through this suicide attempt ... so then when I went home from the hospital I had a little bit of strength from somewhere. HARS was really supportive. Oh they backed me up all the way. Like they, always reminding me that I'm not as bad as I'm thinking I am. You know, that if I would just give myself a break then I would see it for myself And like they have never stopped. I volunteer here now two days a week. If it wasn't for totally strangers and my one cousin I would have never made it. I know it ... I was just so depressed. I just couldn't imagine, finally I just, and I don't want to kill myself and I've come to that realization that I don't want to kill myself ... You have no idea. This place has done an amazing job on me. They have been there. In everything that I have a problem with, they're there.

Lesley, who experienced extreme stress, loneliness and suicidal thoughts throughout her pregnancy, believed she used drugs during her pregnancy because she had nobody to talk to about how to cope being an HIV+ pregnant woman:

You know I had no one to talk to, like nobody except for that one girl and she wasn't, you know, there all the time. So, you know, when I could get a hold of her it was great because then I wouldn't do it [get high], but when I couldn't get a hold of her ... I'd just go get high and then I wouldn't think of it [being HIV+ and pregnant].

Lesley suggested that a health center that openly invites HIV+ women and emergency phone lines would facilitate the well-being of women in situations similar to hers:

Like, you know what I mean, like a center where if you think you're pregnant, or want to become pregnant or by accident got pregnant – come in HIV+ or not. Or just put 'HIV persons more than welcome' and once you get the person in there tell them, you know, 'You see HIV on the window, so we do an HIV test.' Do something like that. And phone numbers. Like there are so many times even right now there's so many times I'm thinking, 'Fuck, it's 4 o'clock in the morning and who am I going to call?' Like I'd like to see more numbers to call. Like I don't have a computer, so I can't get on the internet.

Prenatal and postnatal needs. Although some of these women's prenatal and needs were met, others were not. One prenatal need that was satisfied was the ready availability of HIV drugs to reduce the risk of transmitting HIV to the baby. However, Sylvie described women's need for nutritious food during pregnancy:

Some kind of a disability cheques, like some kind of pregnancy fund for the woman so she could get the fresh fruit and vegetables that she could take during the pregnancy. Cause low income doesn't help very much for ... fresh food and whatever.

Similarly, some but not all of these women's postnatal needs were met. Kristina, for example, noted how postnatal medication and HIV testing were readily available for the children of HIV+ mothers:

... just after my daughter was born they gave her, I think it was AZT. They gave her something and I had to give it to her like four times a day for the first six weeks or something like that. ... It [HIV test] was negative. She goes every six months and that's with her doctor now because you never know, it could stay in your body for half your life.

Sylvie also commented on a program that provides formula to replace the breast of HIV+ mothers, saying, "Well there's another thing, well its for afterwards, because we can't breast feed. I was told about this program. It is the Toronto's Hospital for Sick Children provides the baby formula."

However, Sylvie drew attention to women's need for help after the baby was born if something happened to the mother. Sylvie, who experienced postnatal complications and had to go back into hospital without her child, provided insight into the difficulty getting help for a newborn baby:

... just to have some people available for a week to a month, you know, for after the delivery, because that was getting difficult at the end to find the people. But I'm sure even if you had a set-up it would be difficult. You know, people work. But I mean, even extend the home care, home nursing or something because it was very difficult.

Overall, then, while some of these women's needs were satisfied, others were not. These unmet needs included the need for competent healthcare for HIV+ women in rural locations and the need for various types of information, including statistical information about the outcomes of HIV+ women's pregnancies, information about the side effects of HIV drugs as they pertain to women's health and fertility, and information about the alternative reproduction options available to HIV+ women. In addition, these women expressed their need for public support rather than discrimination and described their

need for more readily accessible emotional support that would help them cope with the complexity of their social circumstances (e.g., substance abuse) and emotions (e.g., stress and suicidal thoughts).

Quantitative Results

The *Beliefs about HIV and Pregnancy* questionnaire assessed women's general knowledge of HIV and their knowledge specific to HIV and pregnancy. On the whole, the 9 women who completed this measure appeared to be well-informed about the general aspects of HIV ($M = 75\%$, median = 83.3%). The vast majority knew that that highly active antiretroviral therapy (HAART) reduces viral loads and delays the onset of AIDS (83.3% answered correctly), that a low viral load means the HIV virus is not actively reproducing in the blood (88.9% answered correctly), that the physical health of a person living with HIV is measured by their CD4 cell counts, viral load and symptoms experienced (83.3% answered correctly), and that antiretroviral therapy (ART) is an HIV drug treatment that reduces viral load and delays the onset of AIDS (72.2% answered correctly). However, fewer women knew that heterosexual context is the most common way that women become infected with HIV (66.7% answered correctly), and that HAART involves taking more than two HIV drugs (55.6% answered correctly).

These women had even better knowledge about HIV and pregnancy ($M = 84.9\%$, median = 90.9%). All of the women knew that that HIV+ women can transmit HIV to their child during pregnancy and via breastfeeding, and the vast majority knew that women with higher viral loads and lower CD4 cell counts are more likely to transmit HIV to their child during pregnancy (88.9% answered correctly), that being pregnant is not bad for an HIV+ woman's health (88.9% answered correctly), that women with low

viral loads are less likely to transmit HIV to their child during pregnancy (88.9% answered correctly), that infants born to HIV+ mothers can receive HIV drug treatment to reduce the risk of transmission (88.9% answered correctly), that drugs are available to reduce the risk of mother-to-child transmission of HIV during pregnancy, labour and delivery (88.9% answered correctly), that antiretroviral (ART) drugs are not powerless in preventing mother-to-child transmission of HIV (88.9% answered correctly), that Zidovudine (AZT) can be used during labour to reduce mother-to-child transmission (77.8% answered correctly), and that taking ART earlier (28 weeks) rather than later (36 weeks) in pregnancy reduces the risk of mother-to-child transmission (77.8% answered correctly). Far fewer women, however, were informed that children living with HIV progress to AIDS more quickly than adults (44.4% answered correctly).

However, these women were far less informed about the specific statistics associated with HIV and pregnancy ($M = 51.1\%$, median = 40%). Specifically, although most knew that zidovudine (AZT) reduces the risk of mother-to-child transmission by 70% (77.8% answered correctly), far fewer women knew that HIV+ women who do not receive antiretroviral therapy (ART) during pregnancy, labour or delivery have a 20 to 25% chance of transmitting to their child (55.6% answered correctly), that women who receive antiretroviral therapy (ART) through their pregnancies transmit HIV to their infant 7 to 10% of the time (44.4% answered correctly), that women who choose to receive ART during all stages of pregnancy and who choose to have a Cesarean section reduce the mother-to-child transmission rate to 2 to 5% (44.4% answered correctly), and that women who choose to have a Cesarean section, but who had not received

antiretroviral therapy (ART), reduce the risk of transmitting to their child by 50% (33.3% answered correctly).

On the whole, these quantitative findings converge with those of the qualitative analyses in that both indicated that these HIV+ women were well informed about HIV in general and HIV as it relates to pregnancy in general, but were less aware of the specific statistics as they related to the issues associated with HIV and pregnancy. For example, while these women were aware of the availability of interventions to reduce the risk of transmitting HIV to a child during pregnancy, they were less aware of the extent of the risk reduction afforded by various strategies.

Moreover, as shown by the women's scores listed in Table 4, the five women who were classified as having made informed decisions not to have a child in the qualitative analysis, Lisa, Jeannie, Linda, Sylvie and Lesley, had high scores regarding HIV as it relates to pregnancy in general ranging from 82 - 100%. However, their scores of specific statistics of HIV and pregnancy were more varied and, with the exceptions of Lesley who scored the same, the scores were lower³. Not surprisingly, Lisa, Jeannie, and Linda were found to have "some" knowledge in the qualitative analysis and Sylvie was found to have "a lot" of knowledge. A finding that was not reflected in both the quantitative and qualitative findings was Lesley's knowledge about HIV and pregnancy. Although Lesley scored perfectly on the questionnaire, she was found to only have "some" knowledge within the qualitative analysis of the interviews.

³ There may have been a data collection limitation in regard to Lesley's questionnaire given that the questionnaire was mailed directly to her and returned to the researcher at a later date, where as in other data collection procedures with participants the questionnaires were done in person with the researcher or at an HIV organization and sent back to the researcher from the organization.

Table 4

Participants' Scores Regarding General HIV, HIV as it Relates to Pregnancy in General, and Specific Statistics of HIV and Pregnancy Knowledge

Participants	General HIV	HIV as it relates to pregnancy	Specific statistics of HIV and pregnancy
Cathy	67%	73%	0%
Mary	83%	27%	40%
Lisa	83%	82%	20%
Jeannie	58%	91%	40%
Linda	67%	91%	20%
Stacie	83%	100%	100%
Sylvie	50%	100%	60%
Kristina	83%	100%	80%
Lesley	100%	100%	100%

Cathy and Mary, who scored 73% and 27% on HIV as it relates to pregnancy in general and 0% and 40% on specific statistics of HIV and pregnancy, respectively, were two of the women who remained in ongoing decision-making about whether to have children. Their low scores appeared to lend support to the qualitative findings that some knowledge led to perceived low choice when reactive response was used. Kristina, who was also within an ongoing decision process and had some knowledge, scored higher on HIV as it relates to pregnancy in general (100% correct) and specific statistics of HIV and pregnancy (80% correct) than Cathy and Mary. Kristina was found to have proactively responded in the qualitative findings. Her higher scores on the questionnaire lend support for the link between response and knowledge.

Stacie scored perfectly on both the general and specific questions about HIV and pregnancy, and had made the informed decision to have a child. The quantitative finding that Stacie was very well informed converges with the qualitative finding that she had “a lot” of knowledge about HIV and pregnancy. It appeared that this convergence lends support to the link between knowledge and high choice.

Discussion

The analysis of these 11 HIV+ women's discussions of their 15 reproductive decisions suggested that their decisions whether to have children involved a process of perceiving reproductive choice by balancing facts (i.e., knowledge about HIV and its implications for pregnancy) against personal (i.e., personal desire to have a child, attitudes toward the risk of transmitting HIV, and the ability to parent) and interpersonal factors (e.g., their partner's desire, healthcare professionals' opinions, and HIV+ women's support). In this process, HIV+ women who received more *Support* (i.e., information, medical treatment and emotional support from health care professionals, partners, family, HIV organizations and other HIV+ women) displayed more *Acceptance of their HIV status* and the challenges it posed for pregnancy and parenting. Women's acceptance, in turn, affected their *Responses* to their HIV status and its implications. In particular, women who accepted their HIV status and its implications proactively sought information regarding HIV and pregnancy and, as a result, had more *Knowledge* about HIV and pregnancy and, in turn, *Perceived more choice* in whether or not to have a child. On the other hand, women who did not accept their HIV status and its implications acted reactively in that they did not seek information, had less knowledge, and believed they had less choice in their decision. Finally, women's perceptions of choice determined whether they could make a decision and, if so, whether those decisions were informed.

These findings are consistent with the findings of some studies, but not others. In Siegel and Schrimshaw's (2001) qualitative study, for example, HIV+ women decided to have children when they were able to justify having children in the face of their HIV status. These reasons and justifications for having children included their partners' desire

for children, not having been able to parent their other children, the use of AZT to reduce the risk of mother-to-child transmission and the cessation of their drug-use. The HIV+ women in the present study gave similar reasons and justifications for pursuing pregnancy despite living with HIV, including their partner's desires to have a child, their own desires to experience motherhood, knowing that other HIV+ women had healthy children and the use of AZT and other risk reduction strategies (e.g., Cesarean section) to reduce the risk of transmission. However, the current findings also suggest that informed decision-making on the part of HIV+ women requires balancing factual factors against interpersonal and personal reasons, and that an imbalance of factual, interpersonal and personal factors may result in uninformed-forced reproductive decisions or indecision. The present study also went beyond that of Seigel and Schrimshaw (2001) in that it included women not open to the possibility of becoming pregnant in the future and women who had past pregnancies. As a result, the process model that emerged from this study applies to a broader range of HIV+ women.

That "support" was integral in the reproductive decision-making processes of the women in the current study was not surprising given that previous studies have revealed support to be important to women living with HIV (e.g., Hackl et al., 1997; Schrimshaw, 2002; Siegel & Schrimshaw, 2001). In this regard, the current findings suggest that HIV+ women contemplating pregnancy require several types of support, specifically support pertaining to medical treatment, informational support and emotional support. Further, in the absence of these supports, these women were less able to accept their HIV status and/or its implications for pregnancy and parenting and, as a result, perceived little choice in their reproductive decision-making and ultimately made an uninformed-forced

decision or remained undecided. That some of the women in this study lacked certain types of support is not surprising in view of earlier findings suggesting that HIV+ women do not receive the types of support essential to this unique subgroup of persons living with HIV (e.g., Blanche et al., 2003; Burdge et al., 2003; Culnane et al., 1999; Schrimshaw, 2002; Sherr et al., 2000). For example, and as observed by Hackl et al. (1997) and Schrimshaw (2002), unsupportive reactions and rejection by family members and partners was a concern for the women in this study. Moreover, five of these women did not know where to go for emotional support. Also consistent with previous research findings (Siegel & Schrimshaw, 2001), the support of other HIV+ women was extremely important to these HIV+ women contemplating reproductive options. However, unlike the women in Schrimshaw's (2002) study, all of the 11 women in the present study belonged to HIV+ women's support groups at some point.

A lack of informational support was also evident among the women still deciding whether to have children and those who had made an uninformed-forced decision to have a child. These women were confused by the mixed findings regarding the safety of HIV drugs and the uncertainty of their side effects (e.g., Blanche et al., 2003; Burdge et al., 2003; Culnane et al., 1999; Tapp-Atler, 2001), confusion that spilled over into their reproductive decision-making processes. In line with these qualitative findings, the analyses of women's responses to the *Beliefs about HIV and Pregnancy Questionnaire* suggested that many of the women were not fully informed about important factual matters concerning HIV and pregnancy. Nevertheless, some women in the present study did have informational support, support that they received from several sources, including HIV organizations, other HIV+ women, and healthcare professionals. That

these women had to go to several sources to obtain the information they needed, however, speaks to the difficulty in obtaining informational support.

These women's uncertainty regarding the side effects of HIV drugs and their long term effects on children (Burdge et al., 2003) also suggested these HIV+ women lacked medical treatment support and medical informational support. On the surface, this lack of medical support is surprising given that all 11 women described positive relationships with their doctors and other healthcare professionals. Conceivably, some of these women may not have known what to ask their physicians or simply assumed that their reproductive desires were not possible to pursue. If so, physicians attending to HIV+ women of childbearing age may need to be more proactive in their provision of information and suggestions for treatment concerning HIV and pregnancy. That some women received all types of support (medical treatment, informational and emotional), however, suggests that it is possible for HIV+ women to find high levels of support during their reproductive decision-making.

To date, no studies have considered the impact of women's acceptance of their HIV status and/or its implications for pregnancy and parenting on their reproductive decision-making. Studies have, however, documented the reproductive and parenting issues that concern HIV+ women and, as observed in this study, report that HIV+ women are concerned with a multitude of issues. These issues include the risk of mother-to-child transmission of HIV, the impact of their health on mother-to-child transmission, the risk of transmitting HIV to their partner (e.g., Hackl et al., 1997; Kirshenbaum et al., 2004; Kline et al., 1995; Seigel & Schrimshaw, 2001), the use of drug interventions during pregnancy (Kirshenbaum et al., 2004; Seigel & Schrimshaw, 2001; Visconti et al, 2002),

the potential side effects of HIV drug interventions (Visconti et al., 2002), their ability to parent (Antle et al., 2001; Goggin et al., 2001; Hackl et al., 1997; Seigel & Schrimshaw, 2001; Tompkins et al., 1999), their ability to raise an HIV+ child (Antle et al., 2001), the stigma their children may face, and potential guardianship in the event of their death (Antle et al., 2001; Hackl et al., 1997; Kirshenaum et al., 2004). That women's ability to accept these implications was pivotal to their reproductive decision-making is congruent with the findings of Kirshenbaum et al. (2004), where HIV+ women with more positive views of the risk of mother-to-child transmission and risk reduction strategies intended or had subsequent pregnancies because they believed they could avoid the risk of transmission, while women with more negative views of the risk of mother-to-child transmission and risk reduction strategies did not intend to have subsequent pregnancies because they believed the risk of transmitting HIV was too great.

To date, no studies of HIV+ women's reproductive decision-making have documented or examined the proactive versus reactive nature of women's responses to the implications of HIV for pregnancy and parenting. In the present study, women who accepted the implications of HIV for pregnancy and parenting were proactive in their responses to the challenges of HIV for pregnancy and parenting in that they actively sought support and information, considered the long-term effects of being HIV+ and having children on themselves, others and their potential children, and considered more distal or future concerns, such as illness and guardianship. On the other hand, women who did not accept their HIV status and/or the challenges it posed for pregnancy and parenting were reactive in their responses to the implications of HIV for reproduction in that they only sought information on a need-to-know basis and gave little consideration to

the effects of their decisions on their interpersonal relationships and the future.

Consistent with these findings, albeit indirectly, Goggin et al. (2001) found that some reacted proactively to their HIV+ status by making positive changes in their lives, such as recovering from substance abuse, increasing their self-esteem and enhancing their personal relationships. Other women, however, responded reactively by avoiding new personal relationships, particularly love relationships, because of their HIV status.

Otherwise comparison to this study is limited.

While all of the women were well informed about issues relevant to HIV in general and were reasonably well informed about issues relevant to HIV and pregnancy, their knowledge of the statistics associated with issues relevant to HIV and pregnancy was more varied. Consistent with other studies (e.g., Kirshenbaum et al., 2004; Siegel & Schrimshaw, 2001; Visconti et al., 2002), all of the HIV+ women in the present study were aware of interventions that reduce the risk of mother-to-child transmission of HIV, including the use of AZT during pregnancy. Although this finding is contrary to those observed in Sherr et al.'s (2001) study of 40 HIV+ women, where surprisingly few women had heard of using AZT during pregnancy (34%) and labour (11%), it is consistent with the more frequent discussion and use of such interventions now compared to the time of Sherr et al.'s study. That these women were relatively well informed about the general issues regarding HIV and pregnancy may also stem from the fact that they all had an HIV specialist physician and attended HIV/AIDS organizations. Nevertheless, although these HIV+ women were aware of interventions that reduce the risk of transmission to an unborn child, they were still unaware of the extent of the risk associated with various risk factors and the extent to which interventions actually reduce

the risk of transmission. Moreover, women's awareness of various interventions does not necessarily mean they believe in the efficacy of these interventions (Kirshenbaum et al., 2004; Visconti et al., 2002). For example, Visconti et al. (2002), who also documented HIV+ women's awareness of interventions that reduce the risk of HIV transmission to the fetus, found that 41.4% of 145 HIV+ women considered ART powerless in preventing the mother-to-child transmission of HIV. Not surprisingly, in the present study women's lack of knowledge about the efficacy of various interventions affected their reproductive decision-making. In particular, women who overestimated the positive effects of HIV drug interventions were in ongoing decisions, whereas women who believed the negative side effects of drug interventions presented too much risk were either also undecided or had made the decision not to have children. That the decision-making process was ongoing among women with only some knowledge is similar to the findings of Sherr et al. (2001) where, in a sample of uninformed women, 30% were undecided about whether to have children.

Ultimately, these women's knowledge affected their perceptions of choice, and perceived choice determined whether their reproductive decisions were informed, uninformed-forced, or ongoing. In a sense, then, for these women knowledge was empowering in that knowing more about the implications of HIV for pregnancy and parenting allowed them to believe that they had the freedom to choose among a number of reproductive options. The central role of choice in these women's reproductive decision-making is in line with a number of theories of health behaviour. For instance, in Ajzen and Madden's (1986) Theory of Planned Behaviour, the extent to which an individual perceives a behaviour to be under his/her own control directly effects their

behavioural intentions and, thereby, their behaviour. Accordingly, Leganger and Kraft (2003) found that women with higher education had higher perceived control and more often participated in a positive health behaviour. Similarly, the extent to which the women of the current study perceived reproductive choice (i.e., believed they had control over their own decision) directly affected their decision.

Like all research, the present study has a number of strengths and weaknesses. Among the strengths is the fact that the emergent model was developed on the basis of HIV+ women's own lived experiences. The inclusion of women who had decided not to have a child, as opposed to simply studying those who had decided to have a child or were still in midst of deciding, also goes beyond the types of women studied in previous research. In addition, the four criteria for assessing the quality of qualitative research were satisfied in the present research. Credibility was ensured through good quality interviews, consideration of social context, use of iterative sampling and systematic analysis, consideration of negative cases, data and methodological triangulation, testing the emergent model with new data, provision of good quality quotes from participants and through the distinction of data from interpretation. Dependability of the research was satisfied by the maintenance of a methodological reflexivity journal and memo writing which provided an audit trail for research decisions. Maintenance of the personal reflexivity journal ensured satisfying confirmability in that expectations, biases and emotional reactions were monitored. Finally, transferability was ensured by providing rich description of participants and settings.

Nevertheless, the present study also has a number of potential weaknesses, most notably those stemming from restrictions in the characteristics of the participants, their

decisions and their life circumstances. For example, because the participants in this study were between the ages of 30 and 44, the findings may not be applicable to HIV+ women between the ages of 18 and 29. That some of the participants described reproductive decisions that they made earlier, when they were between the ages of 21 and 22, may go some way to overcoming this limitation. Similarly, because these women were recruited from urban centers, the findings may not be applicable to HIV+ women living in rural areas. Again, however, a number of the women spoke of their experiences when they did live in rural areas. Nevertheless, future research might usefully study the reproductive decision-making of younger HIV+ women and those living in rural areas.

More worrisome is the fact that none of the women in this study had terminated a pregnancy since they learned of their HIV status. In addition, none of the participants had given birth to an HIV+ infant. The latter point is not surprising given that, in all of Canada, only 375 infants have been confirmed HIV+ and another 56 infants have undetermined serostatus (Health Canada, 2003c). Because these and other potentially important perspectives (e.g., the experiences of women never affiliated with an HIV/AIDS organization) were not considered in this study, some of the factors involved in HIV+ women's reproductive decision-making may not have been documented or fully understood. The fact that only two women made uninformed-forced decisions is similarly problematic. Future research examining HIV+ women's reproductive decision-making would therefore be wise to ensure that women with these experiences are sampled.

To the extent that the findings of this study are valid and reliable, they have a number of applied and research implications. In particular, each of the factors in the

reproductive decision-making model that emerged from this study might usefully be considered as a potential target for efforts to improve the quality of HIV+ women's reproductive decision-making. These factors include the extent of women's *support* (i.e., information, medical treatment and emotional), their *acceptance of their HIV status* and the challenges it poses for pregnancy and parenting, their *reactive versus proactive responses* to the challenges of HIV for pregnancy, their *knowledge about HIV and pregnancy*, and their *perceptions of choice* or control over their decision. For example, just as increasing HIV+ women's sense of control may enhance their quality of life (e.g., Goggin et al., 2001), increasing HIV+ women's control over their reproductive decision-making may enhance the quality of their decisions (i.e., whether decisions are informed, uninformed-forced or ongoing). Unfortunately, the findings from the needs assessment portion of this research suggest that the resources available to some HIV+ women are limited in ways that detract from the perceptions of control. In particular, these women spoke of their lack of support, their need for information, their health care needs, and their prenatal and postnatal needs. However, they also suggested ways of remedying these deficiencies.

Support was integral within the emergent process model and specifically, emotional, informational and medical treatment support were found to be essential within decision-making. Similarly, these women discussed public and emotional support as unmet needs. There was a lack of public support in that some women experienced discrimination in establishing relationships and in their right and ability to raise children. Unfortunately, no remedy was provided by the women of the current study to overcome this unmet need. In regard to remedying unmet emotional supports, it was suggested that

health clinics and emergency phone lines be available to HIV+ women and women at risk for HIV to help them deal with emotional problems that may arise in response to a positive status diagnosis and/or unexpected pregnancy. Likely, continued provision and support to HIV organizations and outreach programs would facilitate the fulfillment of public and emotional support.

Further, these women's need for informational and health care link with the lack of informational and medical treatment support found within the emergent model. To remedy these unmet informational and health care needs, it was suggested that up-to-date information about HIV and pregnancy be available to those who work with HIV+ women including doctors and other healthcare professionals, support workers, counselors, staff and volunteers from HIV organizations. This may be facilitated by educating those who work with HIV+ women about HIV and its implications for pregnancy and parenting. Particularly, by making research and statistics of pregnancy outcomes of HIV+ women more easily available to those working with HIV+ women, as well as HIV+ women in general, including those who do not live in larger urban areas, could help women become more informed. Additionally, it is conceivable that the lack of informational needs discussed by these HIV+ women would also link to the lack of knowledge found for some of the women in the emergent model. Thus further education for HIV+ women of childbearing age would be useful. This may be accomplished through continued provision and support of alternative supports such as HIV organizations, HIV+ women's support groups, and credible HIV information websites.

The findings of this research also have a number of implications for future research, including those mentioned earlier. Most fundamentally, quantitative methods

might be used to test the model, or components of the model, that emerged from these qualitative data. Future research might also examine the applicability of the model to the reproductive decision-making of HIV+ men, HIV- women with HIV+ male partners, and HIV- men with HIV+ female partners. Indeed, research might be designed to assess the extent to which HIV+ women's reproductive decision-making is the same as and/or different from that of women with other diseases that can be transmitted to their children, such as the variety of genetically conveyed diseases. Given the paucity of research in this area, there is a need for research examining any of a countless number of issues related to HIV+ women's reproductive decision-making. Moreover, given the fundamental implications of such decisions, such research is clearly merited.

Personal Endnote

This research began as an extension to my past research interests in HIV prevention. Given that I am a HIV- woman who has never made a reproductive decision, I expected that my perspectives would differ from the women of the study. At the onset of the study I was not sure of my stance or biases regarding reproductive decision-making by HIV+ women because I had never had that experience. With that in mind, I kept a personal reflexivity journal to document any biases or expectations that arose throughout the research process. Due to my inexperience and research oriented knowledge about the topic, I had the early expectation that decisions about whether to have a child would be quite rational and take into consideration most of the prenatal and postnatal factors. I quickly learned, however, that not all women considered the same factors to the same degree. For instance, I had expected women to be extremely considerate of future concerns such as, the possibility of having an HIV+ child or parenting complications that

could arise. This expectation was not met as I found that for some women these were not immediate concerns and therefore did not influence heavily on decisions. I also expected the seriousness and impact of HIV upon reproductive decision-making would trump the desire to experience motherhood. Again, this bias was unmet and I learned that it was the balance of personal factors including desire for motherhood (also interpersonal factors such as partner's desire for fatherhood) and knowledge based factors about HIV and reproduction that were essential within an informed decision about whether to have a child. Obviously, tracking my personal expectations and biases throughout the research process was valuable in enhancing my subjectively informed objectivity toward the data and findings.

In line with the methods of grounded theory, I immersed myself in the data (Strauss & Corbin, 1998). Future researchers should do the same to ensure close examination of the data. They should, however, be prepared for the emotional and consuming nature of such a research process. As the researcher, I at times found it difficult to remain subjectively objective about the data because of the emotional closeness to the data. Maintenance of the personal reflexivity journal thus, was effective in making apparent my own emotional reactions. Indeed, it is recommended that researchers get close to the data and equally recommended that they keep a personal reflexivity journal.

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Appendix A
Research Materials

Interview Guide

“Perhaps the easiest way to begin is to ask you how you learned about this study?”

“Why did you want to participate?”

BACKGROUND

“O.k., I’d like to move on to ask you some simple questions about your background”

Date of birth

Ethnicity/immigration

Length of time knowing about HIV

Education history

Relationship status

Employment history (self and spouse/partner)

Spouse/Partner’s HIV status (negative, positive, unknown)

Number of children

Children’s HIV status (negative, positive, unknown)

Status of current health (last known CD4 count, viral load, and symptoms)

Current drug regimen

For women who had a planned child, go through events in chronological order:

- Pre-pregnancy
- Getting pregnant
- During pregnancy
- Just before and during birth
- Immediately and later after birth

For each period, ask:

- whether they did anything special in view of their HIV status, the things they considered and any special issues, concerns or challenges they faced given their HIV status
- what made the process difficult (barriers) and what made it easier (facilitators), including who they consulted and how these people helped or hindered them (people may include partner, friends, family, organizations, GP, HIV doctor, obstetrician, other health care workers).
- any thoughts about what they would do differently now that they have the benefit of hindsight
- any advice they would give to other HIV+ women; and
- any thoughts about the sorts of services or resources or anything else that might make the process easier or better for HIV+ women

For women who had an unplanned pregnancy: ask about:

- the circumstances leading to pregnancy;
- how they felt when they learned of their pregnancy
- any concerns they had;
- why they decided to carry or abort the child.

If they decided to abort explore the factors contributing to this decision (e.g., information, input and reactions of other people, etc.), barriers and facilitators to making the decision; etc. as outlined above

If they decided to carry the child, go thru the above from during pregnancy to after the birth.

For women currently deciding whether or not to have a child: Ask how they are going about making their decision:

- the things they are considering and any special issues, concerns or challenges they face given their HIV status
- what is making the process difficult (barriers) and what is making it easier (facilitators), including who they are consulting and how these people help or hinder them
- what sorts of services or resources or anything else that might make the process easier or better for them?

Closing

Is there anything else you think I should know about how you went about making your decision regarding having children? Anything I missed?

Before we stop, I'd like to ask you if you'd be willing to complete this questionnaire. basically it asks you about some of the issues we've already discussed. (If she doesn't want to do it that is fine). Have the participant complete the questionnaire.

Do you know any other HIV+ women who might want to participate? If so, would you contact them and ask if they'd be interested? Give her a contact information sheet.

Can I call in 1-2 days to see if you want to add anything or take away anything? Can call you if I want to clarify anything you've said?

Would you be willing to go over the results to check if I have a valid account of your experiences? Would like me to mail a copy of the final results once they are done? (If yes get mailing address). Is there a particular pseudonym you'd like me to use when I write this up? Go through debriefing. Make sure she knows she can contact you if she wants to clarify or add anything

One or Two Days Later

Give the post-interview follow-up call to ask if she has anything to add to the interview and if there's anything she wants to take back.

Interview Face Sheet

Participant name

Chosen Pseudonym:

Address:

Ethnicity:

Age:

How they learned of study:

Reproductive Decision: wants a baby Does not want a baby Undecided has children; wants more Adoption has children; no more

Mode of conception: Adoption etc

Artificial

Intercourse with partner

Willing to do validity check? (circle) Yes No

Wants a summary of the findings mailed? Yes No

Follow-up check up call completed? Yes No

Interview

Date:

Location:

Total duration (hrs. and mins):

Any notable features/comments:

Post-Interview Comment Sheet

Participant No.: ____

Feeling/Mood/Tone of the Overall Interview

Participants Emotional Reactions During Interview

Your Emotional Reactions to the Participant

Your Emotional Reaction to What the Participant Said

Strong Points of the Interview

Weak Points of the Interview

Other Comments

Beliefs about HIV/AIDS and Reproduction

Instructions: The following questions ask about what you believe about HIV transmission, HIV symptoms and characteristics, mother-to-child transmission, HIV drugs and children and HIV. For each statement, please circle True or False.

1. Heterosexual contact is the most common way that women become infected with HIV. True or False
2. A low viral load means that the HIV virus is actively reproducing in the blood. True or False
3. HIV+ women can transmit HIV to their unborn child during pregnancy. True or False
4. HAART (Highly Active Antiretroviral Therapy) involves taking 2 HIV drugs. True or False
5. Drugs are available for HIV+ women to take to reduce mother-to-child transmission of HIV during pregnancy, labour and delivery True or False
6. HIV+ women with lower viral loads are more likely to transmit HIV to their child during pregnancy. True or False
7. Antiretroviral (ART) drugs are powerless in preventing mother-to-child transmission of HIV. True or False
8. Taking ART earlier (28 weeks) rather than later (36 weeks) in a pregnancy will decrease the risk of mother-to-child transmission . True or False
9. Being pregnant has a bad effect an HIV+ woman's health. True or False
10. The antiretroviral drug, Zidovudine (AZT), can be used during labour to reduce mother-to-child transmission of HIV. True or False
11. Infants born to HIV+ mothers can receive HIV drug treatment to reduce the risk of developing HIV. True or False
12. HIV+ women cannot transmit HIV to their child through breastfeeding. True or False

Instructions: Please answer the following multiple choice questions by circling the one answer that seems most correct.

13. The physical health of a person living with HIV is measured by:

- a) Symptoms experienced
- b) CD4 cell count
- c) Viral load
- d) a) & c)
- e) All of the above

14. Antiretroviral therapy (ART) is a HIV drug treatment that,

- a) Reduces viral load
- b) Cures HIV
- c) Delays the onset of AIDS
- d) a) & c)
- e) All of the above

15. HIV+ women who do not receive antiretroviral therapy (ART) during pregnancy, labour or delivery have a _____ chance of transmitting the virus to their child.

- a) 0 to 10%
- b) 20 to 25%
- c) 45 to 50%
- d) 80 to 100%

16. Women who receive the antiretroviral drug, zidovudine (AZT), reduce the risk of mother-to-child transmission by,

- a) 0%
- b) 30%
- c) 50%
- d) 70%

17. HIV+ women who choose to have a Cesarean section prior to labour and delivery, but who have not received antiretroviral therapy (ART) reduce the risk of transmitting HIV to their child by,

- a) 0%
- b) 20%
- c) 50%
- d) 85%

18. What percentage of women who receive antiretroviral therapy (ART) through their pregnancies transmit HIV to their infant?
- a) 2%
 - b) 7 to 10%
 - c) 15 to 20%
 - d) 50%
19. HIV+ pregnant women receiving ART during all stages of pregnancy and who choose to have a Cesarean section reduce the mother-to-child transmission rate to
- a) 2%
 - b) 7 to 10%
 - c) 15 to 20%
 - d) 50%
20. An HIV+ woman is more likely to transmit HIV to her child during pregnancy if she has a
- a) low viral load and high CD4 cell count
 - b) high viral load and high CD4 cell count
 - c) high viral load and low CD4 cell count
 - d) low viral load and low CD4 cell count
21. HAART (Highly Active Antiretroviral Therapy) is a drug treatment that,
- a) Reduces viral load
 - b) Cures HIV
 - c) Delays the onset of AIDS
 - d) a) & c)
 - e) All of the above
22. Children living with HIV progress to AIDS
- a) more slowly than adults
 - b) more quickly than adults
 - c) at the same rate as adults

Resource List

Hotlines

- * HIV/AIDS Hotline:
1-800-668-2437
- * AIDS/Sexual Health Information Hotline:
(613) 563-AIDS, or toll free at 1-800-267-7432
 - City of Ottawa public health nurses provide bilingual information and referral services to callers from across the province.
 - Hours: 10:00 am – 8:00 pm

Regional and Provincial

- * AIDS Committee of Ottawa (provided for Ottawa participants only)
 - A community-based , non-profit organization providing free, confidential services for people infected with HIV and others affected by HIV/AIDS. Services provided include advocacy, education, counseling, and support.
 - Location: 251 Bank Street, Suite 700, Ottawa
 - Hours: Monday –Friday, 9:00 am – 5:00pm
 - Website: www.aco-cso.ca
 - Phone: (613) 238-5014
- * Oasis (provided for Ottawa participants only)
 - A health promotion centre for people at risk of or living with HIV. Services provided include advocacy, drop-in centre, health promotion programs/outreach, alternative therapies, treatment information, volunteer/volunteer development/buddy teams, and women's programs/outreach.
 - Location: 116 Lisgar, Suite 200
 - Website: www.sandyhillchc.on.ca
- * Planned Parenthood Federation of Canada (Ottawa Affiliate)
 - An organization that provides services, information and counseling on sexual and reproductive health.
 - Location: 701-331 Cooper Street, Ottawa
 - Website: www.ppottawa.on.ca
 - Phone: (613) 226-3234
 - *For information about pregnancy, being HIV+, preventing mother-to-child transmission of HIV, your baby's health and other related issues see "HIV Women and Youth" at www.ppfca.ca/HIV/index.html*

* HIV/AIDS Regional Services (provided for Kingston participants only)

- A community-based , non-profit organization providing free, confidential services for people infected with HIV and others affected by HIV/AIDS. Services provided include advocacy, education, counseling, and support.
- Location: 844a Princess Street, Kingston
- Website: <http://www1.kingston.net/~hars/index.html>
- Phone: (613) 545-3698
Toll free: 1-800-565-2209 (for those in 613 area)

* AIDS Committee of Toronto (provided for Toronto participants only)

- A community-based , non-profit organization providing free, confidential services for people infected with HIV and others affected by HIV/AIDS. Services provided include advocacy, education, counseling, and support.
- Location: 399 Church Street, 4th floor
- Website: <http://www.actoronto.org/>
- Phone: 416-340-2437 (AIDS); Main Switchboard; 416-340-8484: Voicemail

* AIDS Committee of Windsor (for the participant from Windsor only)

- A community-based , non-profit organization providing free, confidential services for people infected with HIV and others affected by HIV/AIDS. Services provided include advocacy, education, counseling, and support.
- Location: 1168 Drouillard Road, Suite B, Windsor
- Website: <http://www.mnsi.net/~aidscw/index.htm>
- Phone: 519/973-0222 or 1-800-265-4858

* Voices of Positive Women (VOPW)

- A provincial, community-based, non-profit organization directed by and for women infected with HIV/AIDS. It provides free and confidential support and advocacy for HIV+ women throughout Ontario.
- Website: www.vopw.ca

National and International

* *Canadian AIDS Society*

- Provides access to many documents including guides, reports and fact sheets related to HIV/AIDS, and information about events related to HIV/AIDS.
- Location: 309 Cooper Street, 4th Floor, Ottawa
- Website: www.cdnaids.ca
- Phone: (613) 230-3580

* Canadian HIV/AIDS Information Centre

- The largest information centre on HIV/AIDS in Canada that provides information resources on HIV prevention, care and treatment.
 - Location: 400-1565 Carling Avenue, Ottawa
 - Website: www.clearinghouse.cpha.ca
 - Phone: (toll free) 1-877-999-7740 or (613) 735-3434
- * Canadian AIDS Treatment Information Exchange (CATIE)
- A source for HIV/AIDS treatment information.
 - Website: www.catie.ca
- * Canadian HIV/AIDS Legal Network (CHLN)
- An organization that promotes policy and legal responses to HIV/AIDS that respect the human rights of people living with HIV and those affected by the disease.
 - Website: www.aidslaw.ca
- * Canadian Treatment Action Council (CTAC)
- A national organization directed by people living with HIV/AIDS that promotes informed public policy and public education. It also promotes awareness on issues that impact on access to treatment and healthcare for people living with HIV/AIDS.
 - Website: www.ctac.ca
- * Canadian Aboriginal AIDS Network
- Provides advocacy, counselling programs/support groups, health promotion programs, peer support, spirituality and wellness.
 - Location: 251 Bank Street, Suite 602, Ottawa
 - Website: www.caan.ca
 - Phone: (613) 567-1817
- * AIDSmap
- A website dedicated to accurate and up-to-date information about HIV/AIDS.
 - Website: www.aidsmap.com