

**AFFIRMING LIFE DESPITE A POISONED FATE:**

**A GROUNDED THEORY**

**OF REPRODUCTIVE DECISION-MAKING**

**AMONG WOMEN LIVING WITH HIV**

**by**

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ABSTRACT

AFFIRMING LIFE DESPITE A POISONED FATE:  
A GROUNDED THEORY OF  
REPRODUCTIVE DECISION-MAKING AMONG WOMEN LIVING WITH HIV

The purpose of this qualitative research study was to investigate the cultural, psychological, and social processes of reproductive decision-making among women living with HIV. In using grounded theory method, the primary objective of this study was to generate a substantive theory.

Audiotaped interviews were completed with 29 women living with HIV and nine of their primary support persons. Other sources of data included field notes about each interview, non-fictional literature, and articles in the popular press that described the experiences of reproductive decision-making for women living with HIV. Data were analyzed by using techniques of constant comparison for qualitative data.

'Affirming life despite a poisoned fate' was identified as the core process in reproductive decision-making by women living with HIV. This process consisted of two competing elements: 'struggling with vulnerability' and 'striving for longevity.' These elements interacted dialectically so that change in a woman's sense of her own vulnerability affected her capacity to strive to live longer. This interaction depended on the woman's experience of 'wanting to live,' 'managing fears of HIV,' 'awakening personal spirituality,' and 'yearning for connection.' A woman's sense of balance in 'struggling while striving' contributed to decisions about 'risking deadly connections,' i.e., whether she would risk possibly giving others HIV when having sex or giving birth. The women considered a range of practical, romantic, intellectual, and ethical determinants in deciding "how risky is risky?" This personal calculation of risk accounted for the diverse and sometimes contradictory feelings and thoughts described by women as they made these decisions, and allowed each woman consciously or

unconsciously to justify their choices.

Throughout the overarching process of 'affirming life despite a poisoned fate,' each turning point in the women's decision-making depended on their life context including their own sense of 'mothering capacity' and 'mothering anxiety,' and how they saw themselves in terms of the struggle with vulnerability and the striving for longevity. For these women, reproductive decision-making involved making sexual decisions about whether to protect others from getting HIV and to protect themselves from the potentially traumatic result of getting pregnant. Such decisions were heartbreaking emotionally as each woman confronted deep convictions about spirituality and morality, her many contradictory, changing desires, and the powerful, social forces that shape perceptions about motherhood. These decisions were not always well-informed because of the gaps in knowledge about the most effective treatments and best prevention practices for HIV-seropositive women.

This grounded theory provides some insights about the realities of reproductive decision-making of women living with HIV. Health professionals must be sensitive to the effects of HIV stigma and be prepared to set aside their personal values, and encourage women to reflect on "what matters most" when faced with pregnancy decisions. Health professionals have a crucial role in assisting women living with HIV to optimize their health, by knowing available HIV prevention technologies, and informing them about current treatment options. Efforts must also be made to involve the primary support persons or sex partners and to assist couples in talking about sexual issues. Other important implications included new research directions to address the unique concerns of women living with HIV and policies to ensure the provision and accessibility of comprehensive health services for all those who must endure the terrible reality of this disease.



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In gratitude,

A. L. H.

## DEDICATION

To women living with HIV  
who thrive  
through the caring and understanding  
of  
many people

## CHAPTER I

### INTRODUCTION

Research about reproductive decision-making of women living with Human Immunodeficiency Virus (HIV) has focused on their potential role as vessels or vectors in spreading the disease. Little is known about HIV-seropositive women's experiences of reproductive decision-making, the influence of contextual effects, and how they arrive at their reproductive decisions. This qualitative study addresses a critical gap in understanding about the multiple factors affecting reproductive decisions and the ways in which these factors influence a HIV-seropositive woman's decision about having a child. This study provides knowledge which may be valuable in creating services and health policies that promote and improve the quality of life for women living with HIV and their families in Canada.

The dissertation is divided into six chapters. Chapter I introduces background information about the research topic. Chapter II reviews pertinent literature related to the reproductive decision-making of women living with HIV. Chapter III describes the study design and discusses the way in which the grounded theory method was applied in this study. Chapter IV introduces briefly the substantive theory derived from the data and presents in detail the life context in which the women in the study made their reproductive decisions. Chapter V details the theory developed regarding the process of reproductive decision-making for these women. Chapter VI locates the contribution of this project in relation to other knowledge about the impact of HIV in women's lives, particularly their sexuality and reproduction, and presents conclusions and implications for practice, research, and policy.

### Background

The grief of not having a child has always been greater than the grief of having HIV.

(Denison, 1995, p. 1)

For most people, particularly for heterosexual men and women, having children and being a parent symbolize maturity and are considered natural parts of adult life. Some religious doctrines view procreativity as an expression of the marital bond between husband and wife (Rumbold, 1986). Like most other people, HIV-seropositive women are eager to have children (Allen, 1996; McCarthy, Norman, Studd & Johnson, 1993; Rudin, Laubereau, Lauper & The Swiss HIV and Pregnancy Collaborative Study Group, 1998). However, they often experience social condemnation regarding their decisions to get pregnant or to continue with pregnancy (Berer & Ray, 1993; Denison, 1995; Mitchell, 1994; O'Sullivan & Thomson, 1992; Women's Health Resource Collective, 1992).

The risk of transmission to others by infants infected with HIV from their mothers, the costs of health care services, and the probability of transmitting HIV from mother-to-child is theoretically no greater than for some genetically transmitted diseases, such as cystic fibrosis (Kass, 1991; Nolan, 1989). Yet public fear of HIV infection and related stigma to Acquired Immune Deficiency Syndrome (AIDS) contribute to a moral panic that raises doubts about the rights of women living with HIV to have children (Levine & Dubler, 1990). Questions about the limits of reproductive autonomy, rights of privacy, and the public health imperative to prevent further spread of HIV infection serve to challenge the legitimacy of these women making their own reproductive decisions (Amaro, 1993; Arras, 1990; Bayer, 1990).

According to Kass (1991), HIV is distinct from other perinatally transmitted conditions in the following ways: (1) eventually the mother becomes fatally ill from HIV infection; (2) HIV in pregnancy disproportionately affects disadvantaged populations; and (3) stigma and preconceptions create a greater gulf between health care providers and



patients than is true within the context of other conditions (such as genetic conditions including Huntington's Chorea and Tay-Sachs disease). These differences may contribute to a prejudice that women living with HIV are irresponsible or ignorant and thus unable to make reasonable reproductive decisions on their own (Nolan, 1989).

Women of childbearing age are the most rapidly growing group of people being diagnosed with HIV throughout the world (Vermund, 1997). As a result of early diagnosis and appropriate medical treatment, more women of childbearing age live longer with HIV and more of them choose to have children. The use of Zidovudine (ZDV) to reduce perinatal transmission of HIV from 30 to eight percent (Connor et al., 1994) means that fewer babies are likely to be infected with HIV; nevertheless, the fact remains that some women living with HIV will infect their infants and will not live long enough to watch their children grow up. Such harsh realities make this decision fraught with ambivalence.

Reproductive decisions are perceived by many to be the individual woman's choice because it is women who bear children and, for the most part, are responsible for their care (Currie, 1988; Ruddick, 1988). In the case of women living with HIV, social pressure to remain childless, pressure from health professionals to postpone pregnancy, at least until better HIV treatment is available, and a perceived moral responsibility may influence this choice. Some women do decide to remain childless. Others risk ostracism and choose to have babies, knowing the risks of perinatal transmission, of having a child while living with HIV, or having a child die from an HIV-related condition (Holman et al., 1989; Selwyn, Carter et al., 1989; Selwyn, Schoenbaum et al., 1989).

### Purpose and Specific Aims

The purpose of the study was to investigate the cultural, psychological, and social processes of reproductive decision-making among women living with HIV. The specific aims were:

1. To identify the factors that influence reproductive decisions for HIV-seropositive women;
2. To describe how living with HIV affects women's experiences of reproductive decision-making; and
3. To generate theory which explains how women living with HIV make decisions in regard to childbearing.

### Significance

In each minute of the past year (1998), an estimated 11 men, women, and children acquired HIV, thus increasing global HIV infections to 33.4 million (Joint United Nations Programme on HIV/AIDS (UNAIDS), 1998). By the year 2000, it is estimated that the number of women will equal the number of men infected with HIV (Siporen, 1998). Since mother-to-child transmission represents the major source of pediatric HIV infection, female seroprevalence rates will significantly influence the distribution of pediatric AIDS (Auer, 1996; de Bruyn, 1992; Melvin, 1996). With no cure, millions of adults and children will continue to die of AIDS. This horrendous outcome has huge economic and social implications, particularly for families as they care for orphaned children following the death of an infected mother, father, or both (Melvin, 1996).

In Canada, the number of known women living with AIDS remains small compared to the number of men (Health Canada, 1997). Heterosexual activity is most often reported as the source of infection for these women (Health Canada, 1997). With more men living with HIV/AIDS (Health Canada, 1997), and since heterosexual transmission is more efficient from man to woman (Gorna, 1996; Long, 1996), increasing numbers of women are likely to acquire this disease. As more childbearing women live longer from early diagnosis and advances in treatment, they face decisions about whether or not to have children.

Currently, little is known about the effects of psychological, social, and cultural factors on the reproductive decision-making process for women living with HIV, or the way in which HIV affects women's experiences of that process. Even less is known about the complex process of reproductive decision-making by women with HIV as a result of their diverse life experiences. Such decisions are personal and individual, yet require accessibility to a full range of women's health services including family planning, abortion, perinatal care, education, and drug treatment. A better understanding is needed about the rationale of the reproductive decisions made by HIV-seropositive women. Effective interventions could then be developed to support these women in making choices that affect themselves and their social and family relationships. Appropriate health policies could also be developed to further support women's health and reproductive rights.

#### Rationale for Selecting This Research Topic

I chose to conduct this study based on knowledge that more women than ever before of childbearing age are being infected with HIV in British Columbia (Wong, MacDougall, Patrick, & Rekart, 1996), and worldwide (Vermund, 1997). Also, more women are living longer with HIV following early diagnosis (Steben, Mensah, Bally, & Taylor, 1994), and despite having a life-threatening condition that can be transmitted perinatally, more of these women are having children (Selwyn & Antoniello, 1993). Furthermore, while I have a number of close friends who are living with HIV, the few who are mothers had never discussed with me what it was like for them to make reproductive decisions. When I mentioned to these friends that I wanted to hear their stories, to let their stories be known, so that not only the perspectives of injection drug users, sex trade workers, or middle-class, educated women would be heard, but those of a wide range of women living with HIV, they were very excited. Most of all, they were filled with hope because this study would address an issue of such importance in their lives.

I chose to use the grounded theory method to approach this study. In using this method, as with other qualitative methods, the researcher is an integral part of the research process (Carpenter, 1995; Stern, 1980). During in-depth interviews, the researcher interacts on a personal level with study participants. The researcher observes non-verbal behavior, listens carefully, and creates a relaxed, trusting atmosphere that facilitates honest and comprehensive responses. During data analysis, the researcher interacts with the data by constantly comparing themes and following hunches about possible linkages between themes to create a higher level of abstraction. Intuition, creativity, and rigorous methodology are used to gain insights from the data (May, 1994). Since the researcher brings a unique perspective to the investigation, I provide here a brief personal background statement.

#### Background of the Researcher

I am a middle-aged mother of two school-age daughters. I am HIV-seronegative and a third-generation, Chinese Canadian. For the past 15 years I have worked as a community health nurse, preventing the spread of HIV in Gitksan and Wet'Suwet'en First Nation communities in rural, northwest British Columbia, and caring for families infected and affected by HIV in Vancouver. From 1992 to 1994, I was a volunteer for the Women and HIV/AIDS Network in Edinburgh, Scotland, and from 1997 to 1998, the vice-chairperson for the Hummingbird Kids Society, a non-profit organization for children living with and affected by HIV and their families. Currently, I am the elected British Columbia and Yukon board of director for Canadian Nurses in AIDS Care. As a result of my volunteer work and clinical experiences, I am keen to learn more about the impact of HIV on families, particularly on women's lives. My interest has been further piqued by the need for more research focusing on women living with HIV.

## CHAPTER II

### LITERATURE REVIEW

The literature presented in this chapter provides the initial background and starting point for conducting this project. As is commonly practiced in doing a grounded theory study, I initially familiarized myself with pertinent literature to ensure that I was knowledgeable and sensitized theoretically to the field. Simultaneously, I tried to avoid an excessive reliance on existing literature so that I could remain open to the process of discovery in this project. This chapter includes work reviewed prior to and in early phases of data collection and analysis. The reader will note that literature reviewed subsequently has been incorporated in two later chapters: in Chapter IV, as work which supported or contrasted with my own analysis or findings; and in Chapter VI, as current developments in the field presented in relation to the theoretical and clinical implications of this project.

#### Motherhood

The concept and experience of motherhood is complex, and this complexity is reflected in its extensive treatment in both the popular press and academic writing. Further, the woman's individual experience and her perception of herself as a childbearer and mother is influenced by factors such as personal history, position held in society, and socioeconomic status (Williams, Watkins, & Risby, 1996). This experience is also influenced by the mother's health and everyday life, and particularly by the quality of relationships with her children, family, friends, and others. The images of the 'good' mother at the societal or cultural level contrast sharply with the diversity of maternal experience and realities of childrearing.

### Images of Motherhood

I measure my life in experiences. To hold my baby just once would be to live an entire lifetime in a single beat of a heart.

(Denison, 1995, p. 1)

This image of the mother holding her infant captures the maternal feelings of love and protection, similar to the Madonna and Child image of Christianity. In many cultures motherhood is idealized and often romanticized, and is regarded an essential role for women. According to Rabuzzi (1988), Christianity's Virgin Mary or Madonna supports motherhood as the biological destiny of women, and as such is assumed to lead to psychological and spiritual fulfillment.

Another image of the sacred nature of motherhood is expressed by a female Ojibway elder:

It was a privilege to have children, it was not a right. The elders, the women, they used to determine who could have children. Had abortion medicines. And if somebody was abusing a child, they took that child, and the woman couldn't have children anymore. They determined that. Children are sacred. They are living treasures, gifts from the Great Spirit. You always treated them as if they didn't belong to you; they belonged to the Creator.

(Laverdure, as cited in Wall, 1993, p. 130)

These images portray motherhood in the context of the primacy of relations to sustain life of the vulnerable baby, of others, and of the community. Motherhood is presented as a privileged role for the development of self and others. Hidden from these images is the burden of motherhood that is conveyed in the 17th century by an unknown French poet:

Was there anything less charming  
Than a heap of wailing babies?  
One says papa, the other mama,  
And the other cries for his darling.  
And if you take this on  
You're treated like a dog.

(Badinter, 1981, p. 71)

Historically, a woman's identity was defined by the roles of wife and mother, and because of the belief in innate maternal instinct, childbearing was considered essential to a woman's fulfillment (Badinter, 1981; Thurer, 1994). Women were expected to produce children, particularly sons, to maintain and sustain a family legacy. Lack of recognition for mother's work led upper class women to accept their childbearing role but to seek other women to do the childrearing (Badinter, 1981; Thurer, 1994). Despite the passage of time, there is still the idealization and romanticization of motherhood and little recognition for mother's work in western society (Graham, 1993; Richardson, 1993). Thus, for many women, motherhood remains both a fulfilling and oppressive experience, as noted by American feminist Annette Muir:

We are bombarded on all sides with the image of motherhood as a radiant mother who has achieved her ultimate fulfillment by holding a sweet-smelling, sleeping baby in her arms. The reality is more likely to be a harassed, disheveled mum with a foul-smelling yelling baby. I think the shock effect of this gap between the myth and the reality is underestimated and not discussed enough.

(Muir, 1970, p. 6)

### Theories of Motherhood

Theories of motherhood are validated by empirical research to support assumptions about how to be a 'good' mother. Birns and Hay (1988) discuss two prominent and popular myths of motherhood: first, that the well-being of children depends unequivocally on mother's enduring love, and secondly, that a good mother is an unselfish person who always puts the needs of her children before her own. These myths are "formalized" into theories which in turn ignore the realities of motherhood, but of themselves have the power to affect women's lives (Birns & Hay, 1988, p. 3). When mothers are unable to conform to the myths of a 'good' mother, or follow advice based either on theory or research from experts or childrearing handbooks, they may experience anxiety, guilt or even despair (Birns & Hay, 1988; Phoenix & Woollett, 1991). This gap between myth and reality, theory and practice is not, as suggested by Muir (1970), a "conspiracy of silence" (p. 6).

Rather, it reflects the historical and social contexts about existing expectations, norms, and symbols that define 'good' motherhood in society. To date, the extent to which a woman's strong desire to have children is a natural instinct and characteristic of the female identity, or one constructed from societal expectations about appropriate roles and behavior, remains an unresolved issue.

When motherhood is deemed a biological consequence of a woman's femininity, it is assumed that womanhood equals motherhood (de Beauvoir, 1953; Rich, 1976). The blending of these two different roles results in making motherhood a norm for women (Collins, 1994). In psychological and ethological theories, it is assumed that women want to have children and that the maternal-child relationship motivates and enables mothering behavior. These physical and psychological processes presumably bring about motherhood. However, similarities within groups and existing differences between groups of women, including culture, ethnicity, or socioeconomic class are ignored when accounting for the individual experience of motherhood. Instead, "personality organization, ego functions, and personal biographies" (Boulton, 1983, p. 8) are typically used. For example, according to psychoanalytical theory, personal dissatisfaction in being a mother indicates an inadequately developed feminine psychosexual identity (Phoenix & Woollett, 1991).

Ethological theory claims that mothering is essentially rewarding and that the bonding or attachment between mother and child compels mothers to enjoy caring for their children (Bowlby, 1969). Richardson (1993) noted that this emphasis on mother-child interactions excludes other aspects of a woman's life that contribute to motherhood and ignores the possibility that maternal love may be experienced independently from mothering.

Sociological theory in this area shifts from a focus on the individual to the conditions in which women experience motherhood. It is assumed that the desire and capacity to care for children is mainly socially constructed (Van Buren, 1989).



Motherhood is a social role, specifically a work role that is influenced by the organization and conditions of the job. According to Richardson (1993), it is a “labor of love” (p. 2) with mothers assumed to have a duty to care for their children and expected not to receive wages for taking on the responsibility and work of childcare. Many feminists claim that motherhood is a gender-based institution that constitutes opportunity costs (Glenn, 1994; Rich, 1976; Richardson, 1993; Wearing, 1984). It may prevent women from getting an education, getting a full-time job, or having personal leisure time (Glenn, 1994; Richardson, 1993).

Research on mothering has focused mainly on its usefulness in terms of child development or psychopathology among white middle-class women (Boulton, 1983; Gerson, Alpert, & Richardson, 1990; Richardson, 1993). Little attention is paid to the different ways women think about and experience their lives as mothers. Therefore, little is known about what ‘good’ mothering is from the perspective of mothers, and even less is known about the different cultural contexts and conditions under which mothering is carried out. Existing research implicitly supports normative assumptions about the circumstances in which motherhood should occur and how mothers should interact with their young children when a model of ‘good’ motherhood is used to compare the experiences of mothers who do not fit the norm or dominant, white middle-class view of motherhood. As a result, single, teenage, or African-American mothers are considered deviant (Phoenix, & Woollett, 1991).

By ignoring differences between mothers that include, but are not limited to, social class, race, marital status, sexual orientation, disability, and age, research insufficiently addresses the diversity of motherhood and the impact of the contexts in which mothering occurs. In studies that recognize these differences [e.g., the concerns of lesbian mothers (Harvey, Carr, & Bernheime, 1989; Olesker & Walsh, 1984), motherhood in women less than 20 years of age (Phoenix, 1991; Schofield, 1994), and women living with disability (Shaul, Dowling, & Laden, 1985)], the generalizability of results is often limited because

of small sample size, qualitative research design, or the use of retrospective in-depth interviews. Other studies, even fewer in number, seek to explain the ambivalence, contradictions, and conflict often experienced by mothers in terms of structural factors, such as women's isolation in individual households (Graham, 1993) or conflicts with employment outside the home (Fabe & Wikler, 1979; Gerson, 1985), rather than the emotional or psychological state of individual women.

In the literature, motherhood has been defined and examined as an identity, a source of emotional commitment and romantic attachment, a social position, and as the practice of childrearing. Boulton (1983) argued that motherhood is neither naturally nor inherently rewarding. Rather, it is the product of a complex but poorly understood set of social, psychological, and cultural factors. The reality of motherhood, its joys and privations, will vary among women as a function of their personal and cultural history, as well as their position held in society. In this context, the decision about having a child and becoming a mother may be difficult even in the best situation. For women living with HIV, such decisions are even more difficult due to the uncertainty about risks of perinatal transmission and the harsh reality of living with a life-threatening, stigmatized disease.

### Reproductive Decision-Making

The personal significance of the decision of whether or not to have children  
[makes it] the most irrevocable and important one that most of us will make.  
(Dowrick & Grundberg, 1980, p. 8)

Reproductive decision-making refers to the process of deciding whether or not to have children. The term implies that it is a rational process whereby women consider the pros and cons in getting pregnant and becoming mothers. In reality, many pregnancies are unintended and the decision to continue with pregnancy is contextually dependent.

Most research about reproductive decision-making is based on the dominant (white, middle-class) view that motherhood is an important source of identity: to be a 'good' woman and to be like other women (Barr, Pope, & Wyer, 1990; Glenn, 1994).

Differences in motivation between women who desire to become mothers and those who do not have been examined extensively to identify and evaluate the importance of various biological, psychological, and social phenomena that influence this kind of decision-making (Gerson et al., 1990). However, little is known either about the interaction and relationship between these phenomena (Boulton, 1983), or about the different ways in which the social norms of childbearing affect women who are lesbian, single, infertile, or those who choose not to have children (Richardson, 1993; Royal Commission on New Reproductive Technologies (RCNRT), 1993). Even less is known about the influence of contextual effects and the actual process of deciding whether or not to become a mother.

The question, "why are some women mothers and others not?" implies that "there is some choice in the matter" (Richardson, 1993, p. 62). The prevalence of infertility [e.g., in Canada it ranges from 7 to 8.5 percent among couples following 1-2 years of cohabitation (RCNRT, 1993, p. 188)] and the substantial number of unplanned pregnancies that result from failure of contraceptive methods, risk-taking behavior, or violence suggests that choice is not necessarily the case (Borysenko, 1996; Holmgren & Uddenberg, 1993)). The extent to which mothering is considered an option will also vary with the circumstances of the women's lives. When a woman does have a choice about her childbearing role, it is important to distinguish between becoming pregnant and becoming a mother (Schofield, 1994). These two separate but related questions reveal other issues, such as the choice of contraceptive method to prevent pregnancy or the decision to continue or terminate a planned or unplanned pregnancy. On the one hand, there is the promise of fulfillment through the intimacy of heterosexual relationships or the relational aspect of mothering. On the other hand, there is the culturally and historically specific institution of motherhood that forces women into economic or emotional dependency, isolation, and the primacy of others' needs before one's own.

Results from the few studies that examine the process of deciding about having children (Bergum, 1989; Currie, 1988; McMahon, 1995) seem to reinforce the importance

of motherhood as a primary source of identity for women. Decisions are seen to be based on questions about the potential of motherhood or the practicality of being a mother (Currie, 1988). A series of interrelated questions may be asked about the impact of a child on employment or career, financial future, personal life, and/or relationships (Currie, 1988; Fabe & Wikler, 1979; Gerson, 1985; McMahon, 1995; O'Donnell, 1985). This deliberation may typify traditional approaches of decision-making such as "cost-benefit analysis" (Currie, 1988, p. 233). However, the fact that the decision itself is not rational is underscored by a new mother:

I don't think I could think of any 'reasons' for going ahead with motherhood, really. I've always maintained actually that if it were a rational decision there is no really good reason to have a child. It costs you money, so it's not financially advantageous. It restricts your freedom. It's damaging to your career. If you look at it rationally, there's no good reason.

(Currie, 1988, p. 238)

Bergum (1989) proposed that this decision requires a "leap of faith" (p. 45), recognizing that in choosing to have a child, there are no guarantees and one needs to be receptive to the unknown. Therefore, such a decision cannot be fully understood until after the child is born, until, paradoxically, a woman becomes a mother (Bergum, 1989; McMahon, 1995).

These studies involved samples of working or middle-class white women, and thus, the findings have limited generalizability. Unanswered questions remain regarding the different contexts in which reproductive decisions are made, why most women choose to become mothers, and in far fewer cases why others choose to remain childless. Even more attention is needed to understand fully the ambivalence experienced by women in making reproductive decisions, particularly for the many women who remain undecided (Currie, 1988).

### Reproductive Decision-Making of Women Living With HIV

Much of the literature about reproductive decision-making in women living with HIV has focused on their potential role as “vessels” or “vectors” in spreading HIV disease (Amaro, 1993; Rosser, 1991; Sherr, 1993; Smeltzer & Whipple, 1991). The majority of studies recently reviewed by Selwyn & Antonello (1993) have considered perinatal transmission, the effect of HIV on pregnancy, fetal and infant health, and the effect of pregnancy on the progress of HIV in women. Little attention has been paid to the general health needs of women living with HIV (Richardson, 1992; Smeltzer & Whipple, 1991).

Research about the reproductive behavior of women living with HIV has concentrated on their decisions to continue or terminate pregnancy. Eleven of these studies were longitudinal and sample size varied from 22 to 2,023 (Barbacci, Chaisson, Anderson, & Horn, 1989; Bedimo, Bessinger, & Kissinger, 1998; Cowan, Kotloff, Alger, Watkins, & Johnson, 1990; Henrion, Henrion-Geant, Mandelbrot, & Cremieux, 1991; Holman et al., 1989; Johnstone et al., 1990; Kaplan et al., 1989; Kline, Strickler, & Kempf, 1995; Pivnik, 1994; Schneck et al., 1989; Selwyn, Carter et al., 1989; Selwyn, Schoenbaum et al., 1989; Sowell & Misener, 1997; Stephenson, Griffioen, & The Study Group for the Medical Research Council Collaborative Study of Women with HIV, 1996; Sunderland, Minkoff, Handte, Moroso, & Landesman, 1992; Temmerman et al., 1990; Wiznia, Buetti, Douglas, Cabat, & Rubinstein, 1989).

In these studies, it was generally assumed that a high proportion of HIV-seropositive women would terminate their pregnancy because of the health risk to the fetus and themselves (Johnstone et al., 1990). This outcome was observed in the United States for women living with HIV from urban cities (Bedimo et al., 1998; Cowan et al., 1990; Kaplan et al., 1989; Schneck et al., 1989), and in Britain and Ireland (Stephenson et al., 1996). However the majority showed that the presence of HIV disease was not a significant factor in making reproductive decisions. Neither the presence of a previous child living with HIV/AIDS (Holman et al., 1989; Wiznia et al., 1989) nor of HIV-related

symptoms deterred women from continuing pregnancy (Schneck et al., 1989; Wiznia et al., 1989). Most women, when told that they were HIV-seropositive at the same time pregnancy was confirmed, chose to continue their pregnancy (Selwyn, Carter et al., 1989; Selwyn, Schoenbaum et al., 1989; Stephenson et al., 1996; Sunderland et al., 1992). However, Sherr, Jefferies, Victory, & Chase (1996) showed that “negatively framed information concerning transmission risks is taken as a stronger indicator for termination than is positively framed information” (p. 109). Pivnik et al. (1991) showed that the longer a woman had been living with HIV before getting pregnant, the more likely the pregnancy would be terminated, possibly due to the woman’s declining health. Knowledge of HIV serostatus does not seem to affect decisions about becoming pregnant (Cowan et al., 1990; Selwyn, Carter et al., 1989; Selwyn, Schoenbaum et al., 1989; Sunderland et al., 1992). All of these studies suggest that decisions about pregnancy are highly complex in the context of living with HIV/AIDS.

According to Bracken, Klerman, & Bracken (1978), decisions about adoption, abortion, and motherhood are context-specific rather than related to the characteristics of women. Green (1994) and Kline et al. (1995) suggested that the partner’s desire for a child may influence whether or not a woman living with HIV will try to get pregnant. In contrast, Fogarty et al. (1997), Kline et al. (1995), and Sowell & Misener (1997) found that the decision to continue or terminate pregnancy was considered by women living with HIV to be their own. Whatever the decision, it was accompanied by feelings of guilt or ambivalence for a variety of reasons: ignoring the wishes of the partner (Kline et al., 1995; Selwyn, Carter et al., 1989; Selwyn, Schoenbaum et al., 1989), not knowing whether the fetus was free of HIV infection and therefore wrongfully killed (James, 1988; Scott et al., 1989), ignoring religious beliefs about abortion (Borysenko, 1996), or acting on a strong desire to be a mother (Johnstone et al., 1990; Scott et al., 1989).

Factors associated with decisions to continue or terminate pregnancies by women living with HIV have been identified (Henrion et al., 1991; Holman et al., 1989; Johnstone

et al., 1990; Kline et al., 1995; Selwyn, Carter et al., 1989; Sunderland et al., 1992).

Some factors are unique to the condition of HIV infection; HIV serostatus may be denied or used as a coping strategy because the women have no AIDS-related conditions. Perception of risk is based on information about perinatal transmission, the impact of HIV on pregnancy, and the impact of pregnancy on disease progression. Knowledge that other women living with HIV have healthy children, and a desire to produce a child for someone they love, or to replace the loss of other children from HIV-related condition or foster care may motivate women to have children. Other factors are common to all women in making a decision about a pregnancy: the desire to have a child, the meaning of pregnancy, religious and ethical beliefs about abortion, health, and reproductive history. Since many of these factors in the case of women living with HIV were identified either through retrospective interviews or qualitative analysis of women's pregnancy decisions, the complexity and relative importance of each factor, and how they interconnect remain unknown (Selwyn & Antonello, 1993).

Several studies in the last ten years suggest that women of color are disproportionately affected by HIV disease [i.e., mainly African-American, Latino, and Haitian women from inner-cities in the United States (Boyd-Franklin, Aleman, Jean-Gilles, & Lewis, 1995), immigrant women from a country in which HIV is endemic (e.g., Haiti and countries in Central, East, and West Africa) in Canada (Center for Disease Control (CDC), 1993; Remis, Eason, Palmer, Najjar, & Label, 1995)] and for them the cultural meaning of childbearing cannot be ignored. In these cultures, the traditional roles of women are mother and family "caretaker" (Boyd-Franklin et al., 1995, p. 55). Studies suggest that in the absence of an alternative social or personal identity because of high unemployment and little opportunity for an education in the inner-city, motherhood is a primary source of status, security, and validation for Latino, African-American, and/or Haitian women (Holman et al., 1989; Hutchison & Kurth, 1991; Pivnik, 1994; Rose, 1993; Sunderland et al., 1992).

Only one study examined the process of reproductive decision-making in HIV-seropositive women who were mainly injection drug users from diverse ethnic backgrounds (Hutchison & Kurth, 1991). Since injection drug users may not use contraception (because amenorrhea, attributed to drug use, is interpreted as infertility) (Ralph & Spigner, 1986), and reproductive behavior is affected by injection drug use (Densen-Gerber, Werner, & Hochstedler, 1972), this cohort of HIV-seropositive women is not representative in general of most women living with HIV. Nonetheless, it was shown that reproductive decisions involve processes of articulating and coping with affective or emotional responses and complex, contextual factors. Similar to other studies that investigate the reproductive concerns of drug using, HIV-seropositive women (Pivnik, 1994; Williams, 1990), it appears that the decision to have a child may motivate women to change their lives. Pregnancy may be one of the few ways in which they may feel good about themselves, may feel accepted as being like other women (Pivnik, 1994; Sunderlund et al., 1992).

With the exception of Green (1994) and Jason, Evatt, & The Hemophilia -AIDS Collaborative Study Group (1990), investigation about HIV-seropositive, heterosexual men's reproductive decision-making has been ignored. Small sample size limits the generalizability of published results; nonetheless, findings suggest that men and women face similar dilemmas when making reproductive decisions. First, decisions about having children often occurred in the context of a long-term, relatively committed relationship based on assumptions about normative behavior for heterosexual couples. Second, perception of risk was the crux of reproductive choice. 'Acceptable odds' were context-specific, depending on life circumstances and whether the demands to sustain the relationship or desire to have a child overcame fears of transmitting to partner and/or child. Third, because HIV infection evokes strong negative feelings in our society and fuels the risk of discrimination and stigma for persons living with HIV/AIDS (Arras, 1990; Bayer, 1990; Sherr, 1993), and because reproductive decisions in the context of HIV disease raise



profound moral issues about individual rights and social interests (Amaro, 1993; Arras, 1990; Bayer, 1990; Levine & Dubler, 1990), persons living with HIV are reluctant to seek information regarding the effect of HIV on reproduction from health professionals. As a result, choices about having children may be based on inaccurate knowledge.

### Summary of Literature Review

This review shows that reproductive decisions for women are intrinsically linked to the cultural meaning of childbearing, and despite the burden of childrearing, motherhood is often a woman's primary source of self-worth, identity, and status. To date, little research has explored the influence of contextual effects and how women arrive at their reproductive decisions. Even less is known about why women living with HIV, a stigmatized, life-threatening disease would choose to become pregnant, or to continue pregnancy.

The paucity of research about HIV and reproductive decision-making suggests that much more information is needed about the way childbearing choices are made effectively, safely, and without fear of judgment. Lack of knowledge about the factors considered in reproductive decision-making by women (and men) living with HIV leaves health professionals largely ignorant about how to best meet their clients' needs when discussing their reproductive options. This critical gap in our understanding about reproductive decision-making, particularly for women living with HIV, needs to be addressed.

Chapter III describes the study design and discusses the use of grounded theory method in this study.

## CHAPTER III

### METHOD

#### Study Design: Grounded Theory

A study to examine the way in which women living with HIV make reproductive decisions required a research design that would provide an “emic” perspective and capture fully the point of view of the study participants (Leininger, 1985, p. 5). The grounded theory method, a method which is mainly an inductive approach to generate theory about social and psychological phenomena rather than other interpretive qualitative methods such as ethnography or phenomenology was chosen. Through this method, the data were analysed to produce abstract concepts and to hypothesize conceptual relationships and possible theory. As analysis progressed, hypotheses were integrated and a substantive theory that explained as much of the data as possible was developed.

The methodology of grounded theory is informed by the sociological perspective of symbolic interactionism. Symbolic interactionism conceptualizes individuals as creative social actors whose behavior always occurs in social contexts that include other people and social structures (emergent processes dependent on social interaction) such as family, friends, culture, and society (Blumer, 1969). Human behavior is oriented towards situations and objects based on the meanings these have for individuals. Meanings are thus conceived as being neither private or psychological, but as social constructions that are derived through relationships and processes. Identity is seen as a central dimension of meaning involved in social interactions.

Since meanings are constantly recreated through social interaction and the grounded theory method focuses on interaction, patterns of behavior, and its consequences or processes rather than on static situations, this method is particularly suited to study how women living with HIV make reproductive decisions in everyday life. Analysis is based on the experiences of women rather than on a preconceived theoretical model. This method

is also well-suited for areas where little empirical evidence exists, as is the case in this study.

In using grounded theory method, the processes by which women living with HIV choose to have a child despite knowing the risks of perinatal transmission, perceiving a moral responsibility, and experiencing social pressure to remain childless could be examined. This method allows the researcher to “discover what is going on, rather than assuming what should be going on” (Glaser, 1978, p. 159).

## Sampling

### Initial Sample Selection

Initial sampling was based on locating individuals who were the most informed about the phenomenon of interest, in this case, HIV-seropositive childbearing women who were willing and able to share their reproductive decision-making stories. Women under the age of 18 and older than 40 have unique childbearing issues contributing to substantially different experiences about reproduction. Therefore, the sample selection criteria of women living with HIV consisted of the following: women aged 20 to 40, who were able to understand and speak English or provide their own interpreter in order to communicate their experiences in reproductive decision-making, who differed in ethnicity, and stages of the decision-making process (i.e., childless, pregnant, or new mothers), and who lived in the Vancouver area in British Columbia. ‘Living with HIV’ was based on the presence of the HIV antibody as measured by enzyme-linked immunosorbent assay (ELISA), and confirmed by a Western blot test that identifies the individual viral components to which the detective antibodies are reactive (Barrick & Vogel, 1996). Women living with HIV excluded from the study were those with a history of major mental illness, including mood, anxiety, organic mental, and psychotic disorders, schizophrenia, and delusional paranoia (American Psychiatric Association, 1987). The exclusion of these

women was intended to limit the effects of these extraneous conditions on reproductive decision-making.

Primary support persons were included in the study for several reasons. First, little is known about who, if anyone, is involved when women make reproductive decisions (Sowell & Misener, 1997). Second, the perspective of the primary support person might reveal factors that facilitated or hindered the decision-making process but were unrecognized by the women living with HIV. Thus, this data source would enrich conceptual development and theory construction. Inclusion criteria for primary support persons were that they were able to participate in interviews and that they were identified by the women in the study as the single other person most involved in the decision to prevent, terminate, or carry on with pregnancy.

### Theoretical Sampling

Theoretical or purposive sampling is used to ensure the appropriateness of the sample for the purposes of rich description and/or concept or theory development (Morse, 1991). This form of non-probability sampling is driven by the need to collect as much data as necessary to investigate theoretical linkages or categories, and to ensure that the generated theory is representative of the data. Data collection continues until the categories are saturated, or when no new data are obtained and the phenomena are richly described. Sampling continues until the emerging theory provides a credible explanation about the process of reproductive decision-making for women living with HIV. Saturation of categories for descriptive or theoretical purposes rather than for representativeness thus determines sample size. In this way, some limitations inherent in retrospective studies are reduced; for example, contraceptive risk-taking that results in unintended pregnancy can be examined as a characteristic of reproductive decision-making rather than a characteristic of the women themselves.

### Ethical Considerations

The nature of this research required ethical consideration to ensure a balance between the potential benefits of this study and the potential risks to study participants. To ensure that rights of privacy and confidentiality for informants were respected, a multilevel approach was used in recruitment. First, potential informants either contacted me by phone or asked a contact person in the community to give me their name. Second, when I contacted these individuals by telephone to arrange interviews, they could refuse to meet with me if they so desired after questions and concerns were clarified (Appendix A). Third, the study participants chose the date, time, and location of the interviews. After I informed the potential study participants about their role, I asked whether they were still interested in being interviewed. One woman declined because she did not realize that interviews would be audiotaped and transcribed. Fourth, potential informants were assured that their decision about participation would not affect the services they receive from any health care agency. Fifth, an informed written consent was obtained before starting interviews.

Potential risks to informants were that interviews would raise disturbing issues, could lead to the disclosure of many intimate details, or evoke vulnerability for some study participants. For example, one study participant was extremely anxious lest her identity become known despite the use of a code name, even though I reassured her that the transcriptionist understood the importance of confidentiality, and that contact information about informants was stored in a locked filing cabinet. However, after she spoke to a close friend who had participated in the study and was confident that anonymity was secure, she agreed to do a follow-up interview. Ultimately, all the study participants reported that the benefits outweighed the risks in volunteering to be in the study. They appreciated having a safe and non-judgmental environment in which to express their anxieties, fears, and hopes about having or not having children. When conducting interviews, I emphasized that they

could end them at anytime, refuse to respond to question(s), ask for audiotaped information to be erased in their presence, or ask that sensitive information not be reported.

Every study participant's right of privacy was protected by maintaining confidentiality and anonymity in the following ways. Each participant chose a code name for the purpose of interviews. Only I could access field notes, transcripts, and audiotapes that were stored in a locked filing cabinet. Biographical details have been altered as necessary to conceal identifying characteristics of the informants. All data will be destroyed five years after the end of the study, unless the study participants are consulted and agree to its further use.

### Sample Recruitment

Before I began sample recruitment, this research project was approved by the University of British Columbia Behavioral Research Ethics Board to recruit study participants from St. Paul's Hospital, British Columbia's Children's and Women's Hospital, and Health Science Center in Vancouver (Appendix B). In October 1997, five women were identified through the local representative of the International Community for Women Living with HIV/AIDS. These women spoke to their friends who then contacted me about being a potential participant. This strategy, known as "nominated, network, or snowball sampling" (Morse, 1991, p. 130), is a well-established sociological sampling method particularly suitable for this study because people living with HIV usually disclose their status to a select group of trusted individuals because of HIV-related stigma.

One month after the study began, recruitment expansion was requested from the University of British Columbia Behavioral Research Ethics Board because it was not proving possible to access women through institutions previously approved. Permission was sought to include women who had been using injection drugs for the past three months, because they had information and knowledge that would contribute significantly to the study. Different strategies to recruit study participants were used that respected rights

of privacy and ensured that a contact person who provides outreach HIV support in the community was available when necessary to support study participants.

One informant assisted in recruitment by approaching the Vancouver Native Health Society located in the downtown eastside of Vancouver. This organization provides an outreach program for HIV-seropositive First Nation peoples. The staff posted a notice describing the study on their bulletin board. Women living with HIV interested in participating in the study told the outreach coordinator who then contacted me and gave me their names.

I approached general practitioners recognized as experts in caring for persons living with HIV to assist in recruiting study participants. Some of them refused to be involved or did not have suitable candidates for the study while others approached their clients; unfortunately only one woman was recruited through this strategy. Clients who refused to participate were typically women of color. They feared that if their HIV serostatus was known, they or their family members would be stigmatized within respective local ethnic communities or back home in their country of origin.

Contact persons for various community based organizations including: AIDS Vancouver, Prostitution Alternative Counseling and Education (PACE), Youth CO, Drug and Alcohol Meeting Support for Women (DAMS), the Immigrant and Refugee Women's Project, Atish Network Society, and Asian Society for the Intervention for AIDS (ASIA) were receptive about recruiting study participants. However, no participant was recruited through these agencies.

Four months after the study began, further recruitment expansion was approved by the University of British Columbia Behavioral Research Ethics Board in order to access women whose income was greater than \$20,000 and who were not using services provided by HIV community-based organizations or specialists in HIV/AIDS care (Appendix C). Articles describing emerging study findings and to advertise recruitment of participants were published in local papers including The Courier (Appendix D) and UBC Reports

(Appendix E) that are distributed in the west side of Vancouver. Other advertisements were published in The Province and in a publication of the British Columbia Persons with AIDS Society, BCPWA News (Appendix F). Both publications are distributed throughout the province. I was also interviewed on the Rafe Mair Radio Show on March 12, 1998 to discuss and further advertise the study.

The majority of participants heard about the study by word of mouth from other study participants or read notices that were posted on bulletin boards at the Vancouver Native Health Outreach Centre and the Dr. Peter Daycare Centre or published in the BCPWA News. This approach to recruit participants was used as it was assumed that women who suffered when making their reproductive decisions or preferred to keep their experiences private would not want to be involved in the study. Only women who were motivated or wanted to share their stories identified themselves as potential participants. An honorarium of \$15 for each completed interview was given to facilitate recruitment and to express gratitude for the valuable contribution of each informant.

### Description of Study Sample

In total, 29 women living with HIV and nine primary support persons volunteered to be interviewed. Of the women in this study, 13 were Caucasian, 13 First Nation or Native Indian, two Metis (half Native Indian and half Caucasian), and one was Spanish Sicilian. The average age of the women was 31 years, ranging from 21 to 40 years old. These women had been living with HIV for an average four years, ranging from two months to 13 years. In terms of antiretroviral treatment, 17 of them had either refused or did not need it. A history of substance abuse was reported by 22 women and a history of violence including emotional, sexual, and physical abuse that started as young as five years of age was reported by 21 women. The source of infection for 14 women was a combination of sharing dirty needles and not using condoms when having vaginal intercourse and for six women was unprotected heterosexual contact.



In terms of reproductive history, five of the women in the study had never been pregnant. Of the remaining 24 women, 17 had been pregnant while living with HIV and five of these women terminated a pregnancy. Inconsistent contraceptive use was reported as the source of 84 unintended pregnancies out of 93 pregnancies. There were five women who did not know they were infected with HIV at the time of conception and subsequently transmitted perinatally HIV to their infants. Three of these infants have since died from a HIV-related condition.

Boyfriends, common-law partners, or husbands were identified by 16 of the women in the study as primary support persons. The rest of the women claimed that they might have sought the advice of their general practitioner, sister, mother, or grandmother but ultimately they were on their own when making their reproductive decisions.

Of the 16 primary support persons identified, nine volunteered to be interviewed and had known the woman living with HIV for an average of five years, ranging from one to seven years. The average age of the primary support persons was 34 years, ranging from 23 to 43 years old. Of the nine primary support persons, six were Caucasian and the rest were First Nation or Native Indian, Metis, or Turkish; five reported having a history of substance abuse; and three experienced physical abuse when they were children. One of them reported being a drug dealer and another had been a sex trade worker to support past drug addiction.

The source of income for the majority (31 participants) was government-approved disability insurance if HIV-seropositive, or social assistance for those with an annual income below \$20,000. Of the nine primary support persons interviewed, three had not completed high school, whereas the others had some college or university education. Of the 29 women interviewed, one had only elementary school education, 15 had some high school education, 11 had some post-secondary education or had graduated, and two had baccalaureate degrees. More than half of the sample (20 participants) were not affiliated with a church. However a majority (34 participants) believed that a "higher force" existed

as the source of their spirituality (see Appendix G for tables that describe sample characteristics).

## Data Collection

### Interviewing Procedure

Interviews were done from October 1997 through October 1998. Before starting an interview, I gave each participant a copy of the Information Letter that briefly introduced the study and described what was involved as a study participant (Appendices H and I). Next, I gave a copy of the consent form to study participants, instructed them to read it thoroughly and to feel free to ask any questions, and told them that a copy of the signed consent form would be given to them (Appendices J and K ). To ensure each potential informant fully understood his or her role in the study, I reviewed the consent orally before obtaining permission to audiotape the interview for subsequent transcription. The signed consents are stored in a locked filing cabinet to protect the identity of informants.

Study participants were encouraged to choose a code name to maintain confidentiality and privacy for interviews, records, and any documentation that pertains to them. Demographic, HIV health status, HIV risk behavior, and history of substance abuse was obtained from the Background Information Interview Guide for women living with HIV (Appendix L) and for primary support person (Appendix M). Reproductive history was asked only from the women in the study.

The use of a question and answer dialogue at the beginning of the interview helped each study participant gain self-confidence about being able to answer questions and to reflect on their lives in terms of reproduction. Responses to questions sometimes triggered the informant to elaborate on the circumstances in which, for example, a decision was made to terminate or carry on with a pregnancy. In such an instance, I began to audiotape the interview while completing the Background Information Interview Guide. I was able to

capture information that was important for the participant without breaking the momentum of the evolving interview.

All interviews were informal, audiotaped, and lasted from one to two hours. In contrast to predetermined questions of survey interviews, this data collection technique allowed study participants to express their thoughts freely about motherhood, childbearing, and reproductive decision-making (Wilson, 1989). There was enough structure so that the interview neither jeopardized rapport nor deprived participants from the opportunity to make sense of their experiences and to communicate their views about the phenomenon of interest (Braithwaite, 1990).

Early in data collection, responses about reproductive history were used to begin the audiotaped portion of the interview. In this way, the depth and breadth of the interview depended on the level of comfort each participant had in sharing information about intimate aspects of their lives such as sexuality and sexual practices. Open-ended questions such as: "Tell me about how you decided whether or not to have a child?" "Tell me about a time or incident that you felt was a problem, important, or meaningful when considering your reproductive choices with (name of primary support person)." "What role did 'becoming a mother' play in your decision-making as a woman living with HIV?" helped elicit the informants' perspective with as few prompts as possible.

Each woman was asked whether she would like to be present when her primary support person was interviewed. One interview was done when the woman was present with her spouse. However, the subsequent interview was done separately because the woman felt she kept interrupting her spouse or the spouse kept deferring to her when responding to questions. The rest of the women chose not to be present because they did not want to influence their primary support persons who were asked about their role in making or not making reproductive decisions with them and the experience of this role.

I encountered few problems in establishing rapport with participants as I assured them that they were free to stop the interview at any time and that I was grateful to hear

whatever they wanted to tell me. After several interviews were completed, I was able to reassure participants that they were not alone when voicing their fears, concerns, and anxieties about having or not having children. It was important for them to hear this information because for the majority of participants, I was the only person to whom they spoke openly about their thoughts and emotions regarding what they perceived as a critical aspect of living with HIV. At the same time, I was able to draw on my clinical expertise gained from working with First Nation families in rural northwest British Columbia and with persons living with HIV and their families in Edinburgh, Scotland and in Vancouver for the past 15 years. My counseling and communication skills were particularly useful when a sensitive topic was raised.

As the study progressed, I continued to start each interview by asking for information about demographic background and reproduction. In so doing I maintained consistency in data collection. Questions gradually became more specific as more information was gathered and analysis proceeded. Ideas from previous interviews were introduced, identified concepts were explored, and linkages between concepts were hypothesized through questions and to which participants responded. Follow-up interviews were opportunities to clarify information shared by the study participants and to focus on any change in perceptions or different thoughts about their reproductive decision-making since the first interview. There were 11 participants who completed three interviews and 23 participants who completed two interviews. There were four participants unavailable to do a follow-up interview for the following reasons: (1) whereabouts unknown because of a relapse in cocaine use; (2) personal choice by two individuals from having a different job or new family commitments; and (3) re-location to another city in the province.

Follow-up contact was an integral aspect of data collection because reproductive decision-making is an emotionally laden issue for women living with HIV. Contact varied from a visit by the study participant to a selected, appropriate support agency to a phone

call by a mutually agreed outreach worker within one week after the interview. Thereafter, every one to two months, I would either arrange follow-up interviews or give updates about the study. All informants emphasized that they appreciated having “someone taking the time to listen, to really listen and not judge their experiences.” For many of them, the interviews were like “counseling sessions” helping them “pique their memories” and “know their priorities.”

### A Personal Journal

As part of the ongoing process of data collection and analysis, I kept a journal to document the problems, mistakes, and frustrations that occurred during the study. For example, after doing a few interviews, I found I was unable to carry on with the research. I felt overwhelmed by the study participants’ candid disclosures about the violence in their life that ranged from child sexual abuse and sexual assault to repeated beatings from boyfriends and “johns” or clients refusing to wear condoms when paying for sex. I knew that violence was likely an integral part of their lives, but I had not anticipated my difficulties in witnessing this harsh reality. I found myself dwelling on their past pain and abuse, while being in awe of the resilience that resulted from desensitizing themselves to their situations. I needed to learn how to contain my emotions such as anger and grief that were evoked from hearing about their suffering during interviews or when doing data analysis. This was accomplished by taking a two-week break from the research and creating a separate section in the journal to chronicle the ways in which my responses may have influenced data collection, as well as the ways in which biases, or even personal experiences may have influenced theoretical coding. In this way, I documented my subjectivity as a researcher and examined carefully the extent to which this subjectivity impacted on the research process.

Other field notes were made regarding the interview process itself, including but not limited to the interview environment, study participant characteristics, observed non-verbal

behaviors, the dynamics of an interview including affect, presence/absence of rapport, and eye contact. To ensure accuracy and consistency of data collection, field notes were transcribed within one day following each interview.

### Anecdotal Materials

I collected non-fictional literature and articles in the popular press that described experiences of reproductive decision-making for women living with HIV (Appendix N). I analyzed these materials in the same way as the interview data. This information was useful particularly to help me focus on the research topic. For example, the hurt and trauma arising from violence and substance abuse for the majority of women in the study was confusing and sometimes distracting when I was trying to distinguish the context of living with HIV from unique life experiences. This source of data was also helpful to explore new ideas or to verify different linkages between categories with participants.

### Data Analysis

Field notes and interview transcripts were analyzed by using the well-established techniques of constant comparison (Glaser & Strauss, 1967; Strauss & Corbin, 1990). This method of analysis requires that the coded responses of each participant be compared constantly to others until conceptual categories emerge inductively. As data collection proceeds, these categories are integrated and are further developed through analysis. In this way, a description of the process of reproductive decision-making was developed into a theory that accounts for much of the observed "action" in the participants' accounts.

Initially I read each transcript to get an overall impression of the interview or a sense of the story shared by the participant. Next I open-coded transcripts, a process of naming of data points that aroused interest or revealed an idea or a theme. During open coding, I asked "what is happening here?" to discover its analytical potential and to discern whether the content of the coded piece of data related to reproductive decision-making. I

often used the participant's own words to label each code. Some examples of codes that emerged during the study are: "me being positive," "kick in the pants," "afraid to be alone, to die alone," "I'm toxic."

After completing open coding of five transcripts, I began substantive coding to subsume data into categories. A category refers to a process, pattern of behavior, or theme that was distinguished from the data. 'Having a poisoned life' was a category that emerged in relation to the previously described codes. This category captured the way in which the lives of the women had changed following HIV diagnosis. To avoid premature closure of categories, all transcripts were initially open-coded. This approach to coding was tedious but it allowed me to remain sensitive to the data and to be open for new directions in collecting and analyzing data.

When open coding transcripts, I wrote memos or documented my thoughts about a code or category. Initially my memos were short and stimulated me to ask more questions about what was happening in the data. As data collection and analysis progressed, my memos became more substantive as I started to see common themes or processes shared by study participants when making reproductive decisions. I compared hunches and questions from previous memos with new thoughts that occurred in response to open coding. I discarded some categories, found new categories, or built categories by combining and recoding them as broader ones. For example, when the following categories were combined together: 'challenges in feeling good about self,' 'trying to build a positive female identity,' 'wanting sexual fulfillment,' and 'adapting to a life conditioned by HIV,' the category labeled as 'having a poisoned life' was recoded as 'struggling with a poisoned life.'

Categories were constantly compared with newly coded data. If a category no longer made sense in relation to new codes, I examined that category to determine whether the data was appropriately grouped together and whether a new category had emerged by reviewing transcripts that I had open coded previously and reading past memos that

elaborated the development of a category. I also compared categories with each other to determine whether there were changes in the relationships between categories. Further verification and deduction was used as each category was compared based on its respective properties. Properties of the categories were identified and located along dimensions as I posed questions about possible causes for reproductive issues, contexts within which reproductive behavior occurs, contingencies and consequences of reproductive decisions and conditions in which reproductive behavior occur (Glaser, 1978).

The process of building connections between categories and looking for causal links between concepts that emerged from the categories is referred to as “theoretical or axial coding” (Strauss, 1987, p. 34). At this level of coding, I focused on categories that fit well with new data and connected in a way that pointed towards a credible explanation about the way in which women living with HIV make reproductive decisions. I observed that certain categories such as ‘protecting against killing others,’ ‘wanting to have a kid,’ and ‘becoming pregnant’ were necessary to build the emerging theory. Other categories such as ‘damaging love’ and ‘caring grandmothers’ seemed increasingly irrelevant as data analysis progressed and were eventually dropped from analysis.

As I grouped categories together and compared each category for fit with new data, the categories became more abstract but remained grounded in data. Defining the limits of each category was accomplished by reviewing all the coded data that pertained to it. In this way, I identified the properties or characteristics of a category that distinguished it from others, and also considered the conditions or circumstances in which a category emerged. Saturation of categories occurred “when additional analysis no longer contribute[d] to developing anything new about a category” (Strauss, 1987, p. 21).

By identifying the conditions, properties, and dimensions of each category, I was able to define concepts that contributed to the emerging theory. Concepts are analytic notions, sufficiently generalized to identify characteristics of entities but not the entities themselves; they constituted meanings that explained much of the behavior under study



(Glaser & Strauss, 1967). A core process was then sought to explain the overall relationship among the concepts. For example, towards the end of the study, I sought to refine the theory by searching for larger-order categories by integrating smaller categories. 'Struggling with a poisoned life' was integrated with other categories to become 'struggling with vulnerability while striving for longevity.' This category was then isolated and identified as the major aspect of 'affirming life despite a poisoned fate.' A closer examination of all the data revealed that 'affirming life despite a poisoned fate' emerged as the core process of the study.

### Criteria for Judging Rigor

Generating theory is a process that requires careful judgment about the significance and meaning of data. Inherent in the process are questions about when category development should cease and when a theory is sufficiently developed. These issues could only be resolved by the analyst, the person most familiar with the data. I had to be convinced that the theory generated provided a credible explanation about the reproductive decision-making process of women living with HIV. One strategy I used to determine this was to explain the major aspects of the grounded theory to a few women living with HIV who had not participated in the study and to several individuals who were not living with HIV. These people concurred that the reported theory made sense and resonated with the real-life experiences of those living with HIV.

Because intersubjectivity is an integral feature of grounded theory, the canons of reliability and validity used to demonstrate rigor in scientific research are important but, while important, must be adjusted somewhat (due to the nature of qualitative research). Reliability (the replicability of scientific findings) and validity (the accuracy of scientific findings) have been redefined to better fit the complexity and uniqueness of the qualitative paradigm (Wilson, 1989). Credibility, fittingness of the data, and auditability are considered more appropriate criteria to demonstrate the reliability and validity or rigor in

qualitative research (Patton, 1990; Sandelowski, 1986). As is customary, all phases of the research process in this project were scrutinized by the dissertation committee chairperson, who is an expert in the grounded theory method.

Credibility refers to the 'truthfulness' of the theory or the extent the description of the theory reflects the multiple realities of those who participated in the study (Patton, 1990; Sandelowski, 1986). I validated with participants whether or not concepts and the connections between concepts were faithful to their experiences of reproductive decision-making. They were also asked whether the substantive theory represented the intended meaning of their shared experiences and what changes might be needed.

Notes describing my self-awareness about the research process were documented in my personal journal to further enhance the credibility of the generated theory. The journal documented the different rationale used in decisions about data analysis and collection, personal biases or idiosyncrasies relevant to the study, and any strategies done to minimize research subjectivity (Rodgers & Cowles, 1993). The following reflexive questions were also asked and documented: in what ways did I identify or not identify with the study participant(s)? To what extent do these similarities and differences, for example in personality, experience, or character, affect the interview(s)? How does this interaction affect the research process? By minimizing researcher subjectivity and validating interpretations of the data with participants, the criterion of credibility was demonstrated.

Auditability refers to consistency of the research process. Careful documentation of observations, events, and other factors related to the context of the data collection and the actual data collection process ensured transferability of the study. Memos to explain decisions were written to account for the research process and to ensure dependability of the study. In this way, an audit trail was established that demonstrated the criterion of auditability.

Fittingness of the data refers to the extent that the concepts, categories, and ultimately, the generated theory reflect the experiences of the study participants. A

discriminant sample consisted of two couples (one primary support person is living with HIV and the other is not), a counsellor, and a nurse who worked with HIV-seropositive women who faced reproductive decisions. These individuals were asked to assess how closely the interpretations of data reflected their own experiences. Additionally, my supervisory dissertation committee were asked to judge whether the study had meaning and relevance (Sandelowski, 1986). In this way, the criterion of fittingness of data was demonstrated.

The study findings are reported in the next two chapters. Chapter IV describes how women's interpretation of their reproductive choices evolves based on the personal meaning of their situations that change over time. In this chapter, comparisons will be drawn with already published works to delineate how current thinking in reproductive decision-making does and does not fit for women living with HIV. The inclusion of this literature will also show how knowledge affected women's experiences of reproductive decision-making in the following ways: (1) how experiences of the women in the study resonated with existing knowledge; (2) how evolving knowledge about HIV pathogenesis and treatment impacted on their lives; and (3) how this knowledge is interpreted by the women in light of their experiences. Chapter V presents the substantive theory that helps explain the complex reproductive decision-making process of women living with HIV.

## CHAPTER IV

### STUDY FINDINGS

This chapter is the first of two chapters which presents a theory regarding reproductive decision-making among women living with HIV. An overview of the theory is presented first (refer to Appendix O), followed by a detailed presentation of the theory as it reflects, and is rooted in, the life context of women living with HIV. With permission from the study participants, who are identified by code names, quotes from their interview transcripts are used to let the women and their primary support persons “speak for themselves” about their experiences. Quotes were selected to illustrate aspects of the theory and to express the concerns of the study participants in their own words. Participant quotes in the text are distinguished by double quotation marks or indented. The codes and processes that emerged from the study are first presented in single quotes and then merely incorporated in the text.

#### Reproductive Decision-Making of Women Living With HIV:

##### A Grounded Theory

In this theory, ‘living with HIV from a woman’s perspective’ refers to the life context in which women living with HIV make their reproductive decisions. ‘Affirming life despite a poisoned fate’ emerged as the core process in making reproductive decisions. ‘Struggling with vulnerability while striving for longevity’ are the two halves of this core process that interact dialectically and contribute to emotionally-laden decisions about childbearing.

For the purposes of this investigation, reproductive decision-making is viewed as a process that occurs in stages and changes over time. It is marked by ‘turning points’ in the reproductive lives of the study participants. Turning points are defined as moments in their everyday lives in which the processes of ‘struggling with vulnerability while striving for

longevity' interact to set up a specific decision or action in terms of preventing, terminating, and carrying on with pregnancy. Each turning point exposes the tension in the reproductive decision-making process experienced by the women in the study as a result of their life-threatening, infectious, stigmatized disease. This tension relates to the possibility of infecting others with HIV through heterosexual exposure or childbearing and is referred to as 'risking deadly connections.' The process of 'risking or not risking deadly connections' repeats over and over again as a woman's potential to conceive continues and conditions in her life shift. Decisions about risking or not risking deadly connections may be conscious, or even beyond conscious awareness as a woman confronts deep convictions including her many contradictory changing desires, values and beliefs about spirituality, and the powerful social forces that shape perceptions about motherhood. As a result, the reproductive decision-making process of women living with HIV unfolds in relation to everyday life, something true for all women, but is influenced by having a disease that will likely kill them and could potentially kill others with whom they share their lives.

In this theory, the life context describes how women with HIV are alike and yet different from other women who face reproductive decisions. Women struggled with the vulnerability inherent in living as a woman of childbearing age with HIV by dealing with their fears, reflecting on spirituality, and suppressing or yearning for connection in their lives. Whether or not these women eventually risked deadly connections (i.e., having vaginal intercourse without a condom or becoming pregnant and having a baby) depended on how vulnerable they felt and how they viewed their prospects for living. Variables that affected a sense of well-being (i.e., feeling strong or weak and optimistic or pessimistic about their situation) contributed to individual differences in how they went about the process of affirming life despite a poisoned fate.

### Living With HIV From a Woman's Perspective: Life Context

The reality in which women living with HIV make reproductive decisions involves an ambivalence about having a baby, even when a baby is desired. This ambivalence is linked to each woman's 'mothering capacity' and 'mothering anxiety,' a woman's perceived ability to give birth and to mother a child, and the anxiety that accompanies such activities. The "biological clock," her stage of HIV disease, and her desire to give life, have a child, and experience motherhood are other important characteristics of the life context. All the women in this study reported that each turning point in their lives was subject to the highly variable experiences of living as a woman, living as a woman with HIV, and living as a mother with HIV. A description of these experiences and pertinent information culled from the literature is presented to distinguish the salient aspects of their lives that shape the reproductive decision-making process.

#### Living as a Woman

I'm not greedy. I'm not asking for the world. Ever since I was a kid, I wanted a nice home and a family that's all I've ever wanted. You know. And if I could get a career in there too, that's fine. But as long as I have a nice home that's mine and a family that's mine, and just that we're happy, that's all I ever wanted. That's all I ever asked for.

- Cindy

All the women in the study agreed that motherhood is central in women's lives. For some it was the best thing they ever did, and, for others, it was delayed or completely avoided. Like women in general, they perceived and defined themselves in terms of this gender role (Barr et al., 1990; Boulton, 1983; Gerson et al., 1990; Phoenix & Woollett, 1991; Richardson, 1993). Collins (1994) suggests that linking these two different roles contributes to making motherhood a gender norm for women. In this study, the 'motherhood imperative' refers to the woman's views of the primacy of motherhood, an essential social role for women based on the dominant, patriarchal model of the family. Regardless of gender, class, or race, all the study participants recognized that the mother is

central in nurturing family members and the family as a unit. The majority (22/29) of the women in the study assumed that they would follow their mothers' footsteps in having children, who will grow up to have their own children. Having a baby was seen as naturally part of being a woman, and being a mother is a natural outcome of giving birth. In this way femininity and motherhood are seen as interconnected as discussed elsewhere (de Beauvoir, 1953; Rich, 1976).

Most informants as young girls fantasized about being mothers to fulfill both a societal expectation and personal desire. Like many other women, they imagined that any love lacking in their lives could be replaced, replenished, or completely filled by having their own babies who depend on them and love them unconditionally (Allen, 1996; Sobo, 1995; Williams, 1990). Some of them even believed that motherhood would bring them middle-class security as previously described by Cindy. Consequently, being a mother fulfills "girl dreams" and satisfies a psychological need to be like other women.

For most women, as it was with 22 out of 29 women in this study, motherhood is a welcomed identity believed to give purpose and meaning in their lives (Barr et al., 1990; Phoenix & Woollett, 1991). Some women in the study agreed that it was the duty of daughters and wives from African and Asian cultures to produce babies in part to ensure family survival and in part to leave a bit of themselves after they die as has been reported elsewhere (Carovano, 1991; Orubuloye, Caldwell, & Caldwell, 1993; Osakue & Martin-Hilbur, 1998; Petchesky, 1998). In this regard, a woman's worth may be seen to depend greatly on her reproductive capacity (Osakue & Martin-Hilbur, 1998; Fabros, Paguntalan, Arches, & Guia-Padilla, 1998; Dawla, Hadi, & Wahab, 1998). This view was more intense among low socio-economic class women as it was for 25 women in this study whose annual income was below \$20,000 (Farmer, Connors, & Simmons, 1996; Petchesky, 1998). The promise of comfort and security from motherhood was shared by all but one women in the study, a perception supported by gendered social norms

(Carovano, 1991; Collins, 1994; Phoenix & Woollett, 1991; Richardson, 1993). This promise helped diminish any fears about childbearing and childrearing.

Women in the study regarded the unrelenting burden of mothering as a significant element of the motherhood imperative. It consisted of tremendous demands upon the mother's time, energy, and emotions. In the literature, this aspect of motherhood is discussed extensively by feminists as a source of oppression for women (Muir, 1970; Collins, 1994; Glenn, 1994; Richardson, 1993). For the mothers in the study, it was perceived as an inevitable consequence of motherhood. Like many other mothers, they claimed that the burden was lightened by the love received in caring for and caring about their growing children (Bergum, 1989; McMahon, 1995; Rich, 1976). For these women their happiness was maintained and sustained from knowing that their children were happy and thriving as a result of love and care provided by themselves or other trusted caregivers.

In the literature, when women experience poverty, racism, and discrimination, motherhood is reported to be especially difficult (Farmer et al., 1996; Petchesky, 1998; Ward, 1993). For 18 women in the study who were from visible, minority groups or had a history of substance abuse, they wondered whether the color of their skin and their present or past drug addiction contributed to their being treated badly by health care providers and the public. These social barriers created varying degrees of hardship, intensifying the demands of mothering and threatening their coping capacity. In light of this predicament, high levels of stress could contribute to women "slipping out," i.e., using alcohol, crack, heroin, or cocaine to escape from violence in their lives or simply to feed an addiction, as described by Cindy:

My drinking led me into more drinking and then came the drugs. It just got so bad to the point where like I was putting her to bed just so I could do my drugs and drink. And then I started feeling guilt around that because I yell at her and I'd get mad at her for no reason, you know. Just so I could drink and stuff. This is really bothering me (weeps). So that's where I'm not a good mother. When my babies get taken from me, instead of me fighting back, I go fuck up on drugs because I can't handle the pressure. But just because I'm a drug addict, it doesn't mean I beat my kids or did anything to



hurt them. It's just got to the point I couldn't take care of them anymore [because of my drug addiction].

Without the prospect of positive change in their lives, these women feared an inevitable, downward spiral deeper into substance abuse, and further from what they saw as being "good mothers," who do their best to be responsible for meeting their children's needs. When their children were placed in protective custody, or died, like many mothers who are injection drug users described in the literature, they experienced guilt from being "bad mothers" and despair from losing their children, and from losing their means to lead normal lives with a sense of belonging in the community (Pivnik, 1994; Williams, 1990). In this instance, the motherhood imperative acts both as a social structure and as a psychological pressure that exacerbates the anguish experienced by women who lose their children from separation or death.

For seven women in the study, motherhood was delayed or avoided completely. Using contraception or abstaining from sexual relations, some women in the study (before being diagnosed with HIV) pursued their search for happiness by having a career or being self-sufficient, educated women. If happiness failed to materialize from being a successful professional or being in a committed, caring relationship, like many other women, they assumed "there is always motherhood" (Barr et al., 1990; Glenn, 1994). Provided a woman's capacity to conceive and childbear exists, she has a chance to give life and to nurture a loving relation with her offspring. In so doing, a woman's lifelong quest for happiness is satisfied paradoxically through a social role critiqued by feminists as the greatest source of oppression for women (Glenn, 1994; Richardson, 1993). In the minds of the majority of the study participants, the motherhood imperative creates an opportunity to have fulfilling, happy lives.

### Living With HIV

Like my mom would say I had every kind of disease. The only one word that wouldn't come out of her mouth was HIV. That's the only one that wouldn't come out. I had every kind of disease but not that one.

- Elmo

HIV as a disease in women has been mainly invisible. In 1981, the first cases of AIDS were diagnosed in men (Kurth, 1993). Eleven years later, the case definition of AIDS by the CDC in the United States was amended to include, for example, invasive cervical cancer and pulmonary tuberculosis that tend to affect or are only seen in women living with HIV (CDC, 1992). Despite advances in medical treatment, women living with HIV continue to have shorter survival times than men (Denenberg, 1997). Studies largely from developed countries such as the United States and England show that gender differences exist in the utilization of medical care (Gorna, 1996; Squire, 1993). In contrast, Hogg et al. (1995) reviewed hospitalization of 735 HIV-seropositive men and 30 HIV-seropositive women in Vancouver, Canada, and found that more HIV-seropositive women were hospitalized than men. In comparison to the men, these women were likely to be receiving less than optimal antiretroviral therapy from inexperienced physicians and to be receiving care in rural communities. In this case, these women received a lower standard of care than did men, and as a result, experienced more health problems.

Sociocultural norms as opposed to sex contribute significantly to gender differences in survival (Clark, Hankins, Hein, Mitchell, & Williams, 1993; Denenberg, 1997; Lea, 1994; Mitchell, Tucker, Loftman, & Williams, 1992). Women who are the primary family caregivers and often the sole supporter of their families tend to come later for treatment or do not access care at all (Bury, 1992; Denenberg, 1997; Long, 1996; Ward, 1993). When HIV-seropositive women seek medical care, it has been reported that they may refuse antiretroviral therapy because their problems of everyday living prevent them from adhering

to the demanding treatment regimes (Denenberg, 1997). Like many of the women in this study, women in general do not have enough time to take care of themselves when caring for family members (Denenberg, 1997; Rose, 1993; Ward, 1993). Like a few women in this study, some question the safety of HIV medications because research about HIV is mostly done on men (Bury, 1992; International Community for Women Living with HIV/AIDS (ICW), 1998); Women Alive, 1997). Lack of research about how HIV and treatments affect women (Bury, 1992; Gorna, 1996; Kurth, 1993; Smeltzer & Whipple, 1991; Stevens, 1995) and lack of information on and the inaccessibility of affordable conventional and alternative therapies (e.g., the use of acupuncture, massage therapy, herbs, vitamins, and homeopathic remedies) leave women confused and ignorant about the best way(s) to preserve their health (ICW, 1998).

Women in the study who were diagnosed in the 1980s, and even in the early 1990s, reported experiencing shock and denial when diagnosed with HIV. Like the general public, they assumed only homosexuals and other people who were promiscuous (i.e., prostitutes and injection drug users) got the disease (Bunting, 1996; Carovano, 1991; Gorna, 1996; Kurth, 1993; Lather & Smithies, 1997; Levine & Dubler, 1990). Similar to women studied in England, they often were ignorant about the risk of HIV when having heterosexual intercourse without a condom (Positively Women, 1994). They knew that sexual activity could lead to pregnancy or sexually transmitted diseases, but did not worry about these possible consequences because they saw abortion and antibiotics as readily available.

Societal beliefs, such as "nice women do not get HIV" and "any woman living with HIV deserves it" (Siversides, 1998, p. 96) contribute to the shame that many women feel about their disease. This stigmatization is cruel in light of the following facts: first, more men than women are living with HIV in Canada (Health Canada, 1998); second, heterosexual HIV transmission is more efficient from man to woman, particularly through unprotected anal intercourse (Clark et al., 1993; Gorna, 1996; Padian, Shiboski, & Jewell,

1991); and third, unprotected heterosexual activity is most often reported as the source of infection for women in Canada (Health Canada, 1997) and throughout the world (UNAIDS, 1998).

Like women in general, many of the women in the study felt they had little control over their sexual decision-making (Petchesky, 1998; Tallis, 1998) or bodies (Farmer et al., 1996; Ortigas, Amuchastegui, & Rivas, 1998; Islas et al., 1998). Their lack of education, social status, or economic freedom, as well as powerful cultural and gendered norms, often prevented them from avoiding the risky sexual practices that made them and other women vulnerable to HIV exposure (Barbosa et al., 1998; de Bruyn, 1992; Farmer et al., 1996; Hylton, Delapenha, & Frederick, 1998; Kagawa et al., 1998; Mullick, Karim, & Morar, 1998; Petchesky, 1998; Shrestha, Thompson, & Weeden, 1998; Worth, 1989). In contrast to study findings from three northern New Jersey cities, Hispanic and African American HIV-seropositive women claimed that they had substantial power over their male partners in light of their sexual decision-making (Kline, Kline, & Oken, 1992). Since most of these women were in their early 30s, their experiences and views were probably different from those of most teen-aged or younger women. Because they shared their stories during focus groups, they also might have been influenced to share socially acceptable information or to conform to peer pressure. Nevertheless, as suggested by Kline et al. (1992), this finding implies that women should not be stereotyped by traditional, gender roles, and that each woman's sexual decision-making is influenced differently by her ethnicity, socioeconomic background, and acculturation.

All the study participants, like other women living with HIV, quickly learned that their diagnosis cannot be shared freely with others, not even with their friends or kin due to HIV-related stigma (Auer, 1996; Kimberly, Serovich, & Greene, 1995; Lather & Smithies, 1997; O'Sullivan & Thomson, 1992). Reported repercussions from disclosing their diagnosis ranged from social ostracism, verbal abuse, psychological torment to physical assault. These repercussions made existing domestic violence worse. Spring shares her

experience, one that was similar for three other women in the study who stayed in abusive relationships:

I couldn't find somebody serious to stay with me and I loved this guy. I mean, I thought I loved this guy. My mom was pushing me too. You [are] lucky you have him. You gonna end up alone. [But] he was mentally abusive, abusive in his words. He was making me feel that anyway, I was lucky to have him. I wouldn't get better and with that fuckin' disease I wouldn't get nobody, and you know, he used that a lot.

It was clearly wiser for study participants, particularly the women, to keep their HIV serostatus to themselves, at least until they could trust that they were in a safe situation and that their rights of privacy and confidentiality would be respected. As noted by Spring:

This guy came and put his knife on my throat, telling me you gave me a disease [chlamydia]. I says I didn't even know it. This guy made me so afraid after that I couldn't tell nobody about me being HIV.

Keeping their HIV status secret was draining psychologically and emotionally, and in the long term, this added stress may threaten their health. In the literature, women's self-disclosure has been examined mainly in relation to mothering, and little attention has been paid to disclosure to sex partners. A number of Canadian women reported having disclosure "policies" ranging from "depending on the situation" to "must tell the person" (Colterjohn, 1997, p. 9). Similar to other HIV-seropositive women, the majority of the women in the study preferred "honesty is the best policy." But if they were not ready to disclose, they would insist on condoms to protect against pregnancy (Sobo, 1995).

Like other men and women, all the study participants living with HIV claimed that in being silent about their disease, they could feel normal (Sobo, 1995). However, this silence currently has criminal implications in Canada. In 1998, the Supreme Court, Canada's highest court, determined that failure to inform a sex partner of HIV serostatus constituted assault (Kandro, 1998). The ruling was based on the potentially fatal consequences of unprotected sexual intercourse. Although this court decision seeks to safeguard those who are uninfected, it also further stigmatizes people living with HIV.

There is a tyranny resulting from this decision, in that, to escape the legal duty to disclose, more people may refuse or avoid HIV testing. Such a potential public response may sabotage this judicial attempt to protect the rights of uninfected individuals.

Given that public knowledge about an individual's HIV serostatus means potential harm for those infected and affected, HIV is not "just another disease." Women are more profoundly affected by this cruel predicament. Because of their diverse lives, and fears of rejection and abandonment following disclosure, HIV paradoxically isolates and unites them in their invisibility (Gorna, 1996; Lather and Smithies, 1997; Positively Women, 1994; Smeltzer & Whipple, 1991). The complex conditions of living as a women with HIV are further underscored by decisions about childbearing and motherhood.

#### Living as a Mother With HIV

I respect women who make the decision to have children. A lot of people look down on women who are HIV positive and have children. But I know some amazing mothers who are [HIV] positive and they chose to bring a child into this world, even when being [HIV] positive. They're great mothers. And you know, their children aren't [HIV] positive.

- Nancy

Women living with HIV learned quickly that the comfort and security sought from motherhood is elusive for them because of a widespread belief that it is wrong for women with HIV to bring children into this world to suffer and die (Arras, 1990; Bayer, 1990). There is a popular belief, even among HIV-seropositive women, that mother-to-child transmission is 50 percent (Lai, 1994). In fact, recent research indicates that several preventive measures have substantially decreased the risk of mother-to-child transmission: the perinatal use of Zidovudine (ZDV) has reduced this risk from 30 to eight percent (Connor et al., 1994) or less (Fiscus, Adimora, Schoenback, Wilfert & Johnson, 1998; Paul et al., 1998; Pinto et al., 1998; Rakusan et al., 1998; Ramos et al., 1998). Further, combination antiretroviral therapy has improved maternal health (Beckerman, Benson, Dahud, & Shannon, 1998; Dorenbum-Kracer et al., 1998; Money, Burdge, & Forbes,

1998); and other medical interventions including elective cesarean section (Deveikis, Towers, Asrat, Major, & Nageotte, 1998; Firlag-Burlacka, Piasek, Horban, Niemiec, & Kryzywdzinski, 1998; Kind et al., 1998; Lutz-Friedrich et al., 1998; Mandelbrot et al., 1998; Read, 1998), particularly within one hour of ruptured membranes, (Gomez-Martin, De Souza, Mitchell, O'Sullivan, & Scott, 1998), and bottle feeding instead of breastfeeding (Izazola-Liceajo et al., 1998; Leroy, Newell, Dabis, & Peckham, 1998; Taha et al., 1998) have reduced mother-to-child HIV transmission. Other findings indicate that giving pregnant women multiple vitamins (Fawzi & Hunter, 1998) and more effective antibacterial agents during labour enhanced the health of both mother and infant and might further reduce vertical transmission ("Program Aims," 1998), while a combination of elective cesarean section and ZDV considerably diminished the risk of infection for the newborn to below one per cent in the United States (Picard, 1998).

Despite the fact that HIV perinatal transmission can approach zero, public opinion continues to question the legitimacy in women with HIV having children. This reflects a societal double standard for pregnant women. Women in their late 30s with hereditary diseases or other life-threatening conditions such as cancer, who have high risk pregnancies usually experience no social condemnation (Nolan, 1989). In contrast, pregnant women living with HIV who have high risk pregnancies are considered selfish not just by others, but also by many women in the study, who voiced concerns about "bringing orphans into the world" (Nolan, 1989; Kass, 1991). As a result, HIV-seropositive childbearing rights are challenged in light of the public health imperative to prevent the spread of HIV (Kass, 1991; Levine, 1993; Levine & Dubler, 1990). For example, three women reported that physicians recommended sterilization to prevent any chance of pregnancy and abortion when pregnancy occurred. Although these recommendations were based on concerns about the woman's health status, these women thought their right to choose was being usurped by physicians, as voiced by LK,

I'd gone to see a specialist in Victoria and he told me that I should have my tubes tied. I was livid. After he told me that I just left. I thought, no you wanna cut my body up. I'm sorry. Like I may not have children but you're not taking part of my body because you don't think it's right. Because I'm HIV positive. That's the message that was very loud and clear to me from the beginning, women who are HIV positive don't have kids. It's a big, no, no.

The motherhood imperative for some women in the study was viewed as a "curse that never goes away." This interpretation was based on the powerful social and cultural norm that defines a woman's worth by her reproductive capacity described elsewhere (Osakue & Martin-Hilbur, 1998; Fabros et al., 1998; Dawla et al., 1998). Perceiving motherhood in this way potentially harms women living with HIV who are too afraid to have children, as in the case of a few women in the study. In a qualitative study about motherhood and HIV, nine Brazilian women feared giving their disease to "an innocent baby" (Cabral, 1998). Immense psychological and emotional suffering results from shattered "girl dreams" of cradling their own babies and being good mothers (Cabral, 1998; Positively Women, 1994). Their plight is further exacerbated by not being able to adopt or foster children because of their life-threatening, contagious disease.

Grieving from the loss of (potential) motherhood, and scared to death, women living with HIV report feeling alone and afraid (Landau, 1990; Positively Women, 1994). They feel alienated in themselves and in the world (Cooper, 1998; Lather & Smithies, 1997; Positively Women, 1994). To overcome such alienation, the motherhood imperative sometimes motivates and supports women, as a few women in the study reported, to dare to fulfill "a burning desire to have kids," to "be like other [heterosexual] women," and have a child or family. Whether or not a woman living with HIV pursues motherhood depends on a number of factors, which, when taken together, constitute what women regard as their mothering capacity.



### Mothering Capacity

In this study, 'mothering capacity' refers to a woman's perceived ability to give birth and be a mother. Her "biological clock," stage of HIV disease, and desire to give life and have a child/family are identified as factors that affect in varying degrees a woman's perception of her mothering capacity. These factors influence separately, or collectively, the reproductive decision-making process of women living with HIV.

Biological clock. In this study, biological clock is defined as the physiological aspects of childbearing, including fertility and energy level of a woman, and emotional aspects of mothering that women see as being age-related. Since the biological clock determines mothering capacity, it is present throughout the reproductive decision-making process. For example, all the women in the study reported that the older they became, the more cautious they were about having a family because they knew that they had less patience and energy for meeting the constant demands of parenting. This caution could motivate them at any point in time to be more careful in contraceptive use, to have a tubal sterilization, or to terminate an unplanned pregnancy.

Women who were mothers in their late teens to early 20's reported having idealistic and romantic ideas about motherhood, like Sky, who shared these thoughts: "It was just a cool thing to do, to get pregnant and have a child. Being cool meant-- oh she's experienced, you know, had sex, she's got a child." Fertility is highest in the teen years. However, contraceptive use among those reported to be sexually active in late teens was inconsistent or non-existent. Teen pregnancy was reported by six mothers in the study as "a rebellious act" or fulfilled "a need for unconditional love in their lives," reasons similar to those found in research reported elsewhere [e.g., among African-American teen mothers (Dickerson, 1995; Kaplan, 1997; Polakow, 1993)]. Lack of maturity and substance abuse interfered with their mothering capacity at that point in their lives so that sometimes the grandmothers or foster mothers raised their children. A few women in the study recognized in retrospect that the past kindness of their mothers or foster mothers was

harmful in the long term. These women reported that co-dependency had evolved in the mother-daughter relationship, preventing them from experiencing motherhood fully and being more responsible about family planning.

Women in the study in their mid-20s to mid-30s reported that at this age they were most ready to have a child. The decision to delay having the first child reflects the continuing trend towards older mothers with the average age of new mothers currently reported as 27.3 years (Miriabelli, 1998 cited in Laucius, 1998). By this age, they had witnessed and reflected on the realities of motherhood, particularly as one woman put it, the "awesome responsibility of being a parent." This responsibility intimidated some women in the study to the point that they would not consider having a child until they were in their 30s.

As was true for 26 of the women in the study, there is a societal tendency to view motherhood for women aged 35 and over in terms of biological risks, such as decreased fertility, increased pregnancy complications, and the overall chance of having a healthy baby (Berryman, 1991). The possibility of having a baby with a chromosomal abnormality like Down Syndrome prevailed in the minds of women who were in the mid-30s in the study. Amniocentesis, available to most women, was considered by many of the women in the study as too risky for HIV transmission, and thus was not considered as something to alleviate their fears (Berryman, 1991). HIV mother-to-child transmission was an added concern, but potential HIV risk was minimized by knowledge that the perinatal use of antiretroviral medications could reduce it.

Stage of HIV Disease. Stage of HIV disease is another factor of mothering capacity that is constant throughout the reproductive decision-making process of these women. HIV is a retrovirus that replicates in the lymph system by infecting and destroying healthy CD4 T-lymphocytes (CD4 cells). As the disease progresses, the immune system deteriorates from the constant destruction of CD4 cells and viral replication exceeding CD4 cell production (Ho et al., 1995; Wei et al., 1995). The lymph nodes eventually become

dysfunctional, freeing more HIV into the blood (Ho et al., 1995; Wei et al., 1995). This destruction leads to a greater likelihood of opportunistic infections and certain malignancies (Andrews, 1998). As more HIV circulates in the blood, the central nervous system degenerates, contributing to mental disorders, seizures, and declining sensory and motor function (Andrews, 1998).

Little is known about whether HIV progresses differently in women than men (Gorna, 1996; Wofsy, 1995). This lack of knowledge is partly due to past research policies discriminating against childbearing women (i.e., to prevent harming a woman's reproductive capacity) (Roth et al., 1998) and lack of scientific attention to gynecological conditions or the impact of HIV treatments on women (Gorna, 1996; Women Alive, 1997). For example, in the United States, the first clinical trial regarding gynecological concerns was not conducted until 1992 (Kurth, 1993), and when women were included in studies, there were often not enough of them to determine the statistical significance of observed outcomes (Wofsy, 1995).

As emphasized by Gorna (1996), Lather and Smithies (1997), and Women Alive (1997), many basic questions about HIV in women remain unanswered. What are the differences between women and men regarding treatment and pathogenesis? How does HIV impact on a woman's reproductive system? For example, do the endocrine and immune systems interact with each other? If so, what are the effects? The past few studies reviewed by Gilden (1997) revealed contradictory findings about sex differences in metabolism and accompanying fat and protein loss. According to Project Inform (1998), plasma concentrations of Indinavir (a protease inhibitor) fluctuate in relation to hormonal changes in the menstrual cycle, raising concerns about regimen efficacy and resistance. All women, like those in this study, report being frustrated by this lack of knowledge about gender differences and their causes (ICW, 1998).

In this study, stage of HIV disease refers to the natural history of HIV from primary infection, asymptomatic to symptomatic phases, and other time-related aspects of

HIV disease, including timing of diagnosis and medical advances in treating HIV disease and reducing HIV perinatal transmission. The time-related aspects of HIV disease particularly influenced women when faced with a decision about whether or not it was the “right time” to have a child. Stage of HIV disease contributes to the risk of having a HIV-seropositive baby and the health status of the woman living with HIV. Timing of diagnosis exemplifies the way in which the reproductive decision-making of women living with HIV is marked by turning points that depend on life context and shifts over time because of new medical knowledge about HIV and personal knowledge about living with this disease.

Susan describes how her reproductive decisions changed over time:

[Following HIV diagnosis] the first thing on my mind was not, I'll have a child real fast [be]cause I only have three years to live. It was sort of like I needed to concentrate on my own health. Suddenly, you live your three years and you're still in quite good health and you're not gonna croak anytime soon. And the question of kids comes up again. Well, because I am by myself, I choose not to be a single parent, so I'm not gonna have kids for now.

Women in the study reported that when they felt “healthy,” they were optimistic about the future and might contemplate or plan to get pregnant. When they felt “very tired” and had a HIV-related condition like thrush, vaginal yeast infection, or shingles, they were pessimistic about the future and re-thought their desire to childbear and delay pregnancy or have a tubal sterilization. Their view of their mothering capacity changed as did the personal experience of living with HIV in response to the changing status of the immune system.

Nevertheless, sometimes pregnancy occurs despite the proper use of contraception (Hutchison & Shannon, 1993). Inconsistent contraceptive use was reported as the source of the majority of pregnancies in this study. All the study participants believed that being diagnosed with HIV and a pregnancy simultaneously is the worst possible situation in reproductive decision-making. This perceived catastrophe was based partly on the persistent myth that “HIV equals AIDS equals death” and partly on fears about pregnancy

shared by other women (Colterjohn, 1997; Silbiger, 1997). These fears included doubts about their mothering capacity, and whether the baby would be healthy and normal “with five fingers and five toes.” The fear experienced in response to being diagnosed with a life-threatening, infectious, stigmatized disease and the guilt experienced from not protecting against HIV, particularly against pregnancy, were much more pronounced than reported by those in the study who were diagnosed with only HIV. These experiences resonate with those of other women, as described by James (1988) and Pivnik et al. (1991).

The seven women in the study who were caught in this situation reported that the most frightening aspect was having no experience in living with this disease and being forced to make a decision about pregnancy, as voiced by Recovery:

I needed time to think about I was HIV. I was scared. I didn't know what to do. I was pregnant. I wasn't ready to deal with the abortion part yet. I just found out I was HIV. I didn't wanna give it [HIV] to my baby. I had nobody to talk to. What if I had this baby and I pass it [HIV] to my kid. Nobody will wanna play with my kid. Nobody will wanna touch my kid. My kid will be dirty too [like me]. That's about it.

These fears were exacerbated by physicians who recommended to three of these women that elected abortion was the best option for HIV seropositive pregnant women, a belief still widely held by physicians (Stringer et al., 1998).

For most women living with HIV, like 16 women in this study, pregnancy and childbearing is a way to feel normal and be like other heterosexual women (Allen, 1996; Hutchison & Kurth, 1991; Lather & Smithies, 1997; Sowell & Misener, 1997). In this instance, the motherhood imperative motivated and sustained them in deciding to continue with an unplanned pregnancy. A majority (33/38) of study participants in this study were very critical of other women living with HIV who abused substances and neglected their mothering duty and yet continued to have children that ended up in foster care. Among these study participants, and as reported elsewhere by Arras (1990) and Kass and Faden (1996b), such women are seen as selfish and irresponsible or bad mothers. A negative

attitude towards HIV-seropositive mothers in general was greatly influenced by witnessing other mothers die and abandon their children, as in the case of Brenda and Elmo, two women in the study. This attitude is consistent with those who believe it is wrong to knowingly bring children into the world to die or become orphans (Arras, 1990; Bayer, 1990).

At the same time, all the study participants recognized, as observed by Joe that,

having a child might settle them [women] down, give them a reason to live. And if they are treated like a leper [outcast], a child will help them [be]cause your child is not gonna treat you that way. Especially if they've had one or two before [HIV diagnosis]. They'll know that their child will never ever do that to them. Children need their mother and want their mother.

Similar thoughts and beliefs are voiced by other women living with HIV, and supported by those who appreciated the widely held significance of motherhood for women (Allen, 1996; Kass & Faden, 1996b; Pivnik, 1994; Williams, 1990).

The stage of pregnancy at the time of the woman's HIV diagnosis further influenced this turning point in reproductive decision-making. Based on past information provided by nurses or their experience with previous abortions, women in the study assumed that if they were more than 12 weeks pregnant, abortion was not an option. Only Louie reported that she knew that she could have a second trimester (beyond 12 weeks) abortion. Her experience exposes the way in which physicians are gatekeepers in accessing abortion services:

They gave me two dates. Normally abortions are up to this date. But because it was considered for a medical reason, it can go up to this date. And I felt like (exhales loudly) it didn't make sense to me. I felt like if this is the date for ordinary people, then that is the date you should go by. Like maybe if you found out something between those two dates I can understand why you might consider it a medical problem and make that exception. But I wasn't going to find out until after my baby was born. Whatever the second date was, I chose to ignore that. I didn't think that was appropriate. Considering I found out when I was like three weeks pregnant. I felt that by three months it was decided.

Sometimes the magnitude of childbearing was too daunting because of enormous fears about living with HIV, living as a mother with HIV, possibly infecting a baby with HIV who will “go through a painful death,” and dying and abandoning their children. If a pregnant woman newly diagnosed with HIV was overwhelmed by these fears, she was likely to doubt her ‘mothering capacity’ and to choose to have an abortion.

To illustrate the impact of the time-related aspects of HIV disease on decisions about pregnancy, the following section outlines significant shifts in medical opinion in recent years about women living with HIV and childbearing. For the women in the study there were time lags between new information relative to risks of treatment and their knowledge about it. Based on the women’s reported experiences in the study, medical knowledge about HIV offered little solace when making reproductive decisions. This kind of knowledge exacerbated the confusion and ambivalence experienced in their reproductive lives. Like other women living with HIV, they faced an uncertain future from not knowing what would happen in years to come (Lather & Smithies, 1997). The personal meaning of such uncertainty changed over time and in relation to their life circumstances.

In 1989, animal studies linked ZDV, an antiretroviral medication, to cervical cancer (Lucey, 1997). Despite this known risk, in 1991 a clinical controlled study (ACTG 076) was initiated in the United States to test the use of ZDV to reduce HIV perinatal transmission (Connor et al., 1994). At that time, Lori was five months pregnant and diagnosed with HIV. She describes her experience:

The week before I’d seen the ultrasound and everything was fine. [when told] all I remember is you’re [HIV] positive. I said pardon? He [the doctor] says you’re [HIV] positive, you have 24 hours to decide whether you want to abort or not. . . [One doctor told her] I didn’t have that long to live. Everybody [the doctors] who I talked to said I should abort. It was the right thing to do. They said it would be 50-50 that the baby would have it. They didn’t tell me anything else. And to this day I don’t think I’ve ever dealt with it [the abortion]. . . I always wonder if I did the right thing. Just not knowing was the baby [HIV] positive or not.

Semba et al. (1994) examined the impact of Vitamin A, a micronutrient essential for good immune function, on HIV perinatal transmission in 474 HIV-seropositive pregnant women in Malawi. Results indicated that maternal Vitamin A deficiency contributed to infants acquiring HIV and doubled the risk of death for HIV-seropositive mothers. In Canada, Vitamin A deficiency is uncommon because this micronutrient is added to many food products (e.g., milk and cereal). Therefore caution was justified in the prenatal use of Vitamin A because it is toxic in high doses and a known teratogen.

That same year, results from ACTG 076 demonstrated that ZDV effectively reduced the risk of HIV perinatal transmission from 25.5 to 8.3 percent (Connor et al., 1994). Based on this information, HIV testing was recommended for every pregnant woman in British Columbia (Wong et al., 1996), in Canada, (Tobin, Chow, & Bowmer, 1996; Canadian Medical Association, 1995; Maternal/Fetal Medicine Committee, 1997) and throughout the world (Maldonado, Hill, Castro, Sullivan, & Ruiz, 1998). Louie describes her experience that exemplifies the significance of this new information:

I was fairly fortunate that the study had just been released like that January I believe. . . It made a difference in the way doctors talked to me. In their attitude. It seemed that way when 6 months prior another doctor told me to get sterilized. Anyways, I couldn't imagine how it was possible for someone who's positive to have a child that wasn't. They were saying even without drugs it's only 25 -30 per cent of kids who are. I couldn't stretch my brain around that. It didn't make sense to me. It still doesn't make sense to me. I've never had it explained.

Interestingly enough, according to the women in the study who were offered ZDV perinatally, they were only told that this treatment lowered vertical transmission. Vitamin A deficiency was not mentioned. In the United States, Vitamin A deficiency was found among HIV-seropositive women with CD4 cell counts less than 200 and especially those who used cocaine (Greenberg, Semba, Schoenbaum, & Klein, 1995). This information highlights the potential harm in assuming that a woman is not vitamin deficient because she lives in a developed country like Canada. For the women in the study, knowledge of the



importance of Vitamin A in prenatal care might have further motivated them to maintain good nutrition.

Despite the availability of voluntary HIV testing with pre- and post-test counseling and treatments for pregnant women living with HIV, women are still not accessing these services because they are uninformed (Rubini et al., 1998), do not receive adequate prenatal care (Frederick et al., 1998; Wortley et al., 1998) and/or are afraid that the stigma associated with HIV will be attached to them and their babies if they are diagnosed with HIV (Kissinger, Fuchs, Herwehe, Groft, & Gruber, 1998). Lapointe et al. (1998) reported that in British Columbia from 1995 to 1996, 75 percent of pregnant HIV-seropositive women received antiretroviral therapy, compared with only 59 percent in Ontario and 15 percent in Alberta. It was determined by these researchers that the proportion of women receiving therapy was not influenced by risk group or maternal race and that women who identified heterosexual exposure as their HIV risk behaviour were less likely to be diagnosed with HIV during pregnancy and therefore less likely to use antiretroviral therapy perinatally. In the United States, Hertz, Parham, Soto-Torres, & Trent-Adams (1998) reported that many health care providers still do not offer HIV testing to pregnant women and are ignorant or skeptical about the perinatal use of antiretrovirals, particularly ZDV in reducing mother-to-child transmission.

The decision whether or not to take ZDV perinatally by the women in the study was experienced and described by other women as a critical one in their lives (Richter, Sowell, & Harris, 1998). Complete adherence in the ZDV regime is necessary to prevent mother-to-child HIV transmission (Bertolli et al., 1998; Peralta et al., 1998). To date, the possible long term effects of ZDV on the fetus are unknown (Rogers, Mofenson, & Moseley, 1995). There is also no research regarding experiences of pregnant women living with HIV using ZDV or any other antiretrovirals. Women, including a few in this study, have no idea what to expect or must rely on limited anecdotal information to determine what it is

like to take this medication [i.e., managing pregnancy with ZDV side effects like kidney problems, headaches, and stomach aches (Women Alive, 1997; Silbiger, 1997)].

Mouse chose not to take ZDV perinatally for the following reasons:

It [ZDV] was available. But I didn't wanna give it as a supplement. She's just a baby. I didn't wanna give her something that's so toxic. Like why would I give it to a little baby that's not even into the world yet?

Of the four women in the study who wanted to have future children and contemplated this decision, only Susan reported that she would not use ZDV perinatally:

Just by chance, I saw the bottle of ZDV that the pharmacist gets, you know what it says on the label? Toxic if swallowed by mouth. Has a skull and cross-bones on it, too. So like I wanna give this to me if I'm pregnant? The other thing is I looked up the action of it [ZDV]. Well, it caps off DNA from reproducing. It stops cellular growth. And what do you have happening inside of ya when you're pregnant? Growth. And I thought if something goes wrong, you're gonna have problems let's say 20 years from now. And then I realized that in Africa, they don't have ZDV over there. They reduced transmission down to 7% with multi-vites. So that solidified what I was feeling before, my gut instinct was telling me, no. Stay away from ZDV.

The 12 women who faced or anticipated this decision felt they had to take ZDV perinatally if they wanted their infants to be free of HIV disease. Hansen (1997) reported that some pregnant HIV-seropositive women were even threatened that they would lose their children if they did not take ZDV perinatally. Louie describes the various thoughts and feelings shared by the eight women who took ZDV perinatally and gave it to their babies:

For me I really hated taking ZDV. I didn't really feel like I had a choice. I just felt if I didn't take it, I'd be a bad person. But I believed taking that drug was bad. Obviously, I don't know anything about the study, but I'd heard it makes people sick. Nobody in the [HIV] positive community seemed to support that drug. I felt judgements. Like there's no way I couldn't take it. Even my family judged me. Taking ZDV was just what I had to do. . . I threw up everyday. If this [ZDV] was making me sick, what's it gonna do to my child? They didn't know what's going to happen.

Reports by Gorna (1996) and Lucey (1997) echoed similar concerns. These AIDS activists disputed whether the ACTG 076 protocol should have been recommended to pregnant HIV-seropositive women because gaps in knowledge still remain regarding long term effects on women and children, the best time to give ZDV to reduce transmission (i.e., prenatally, during labor and delivery or to the newborn for six weeks), the efficacy of the regimen for women with CD4 counts less than 200 cells per cubic millimeter, and prior ZDV therapy. Other research has indicated that ZDV use does not consistently reduce vertical transmission (Sperling et al., 1996; Weiser, 1995). For example, Weiser (1995) reported no associated link between ZDV use and HIV transmission, nor a link between ZDV use and viral load among 30 HIV-seropositive pregnant women. In a follow-up report of the ACTG 076 findings, Sperling et al. (1996) confirmed ZDV only modestly decreased the HIV RNA level and HIV transmission occurred both among women who used and who did not use ZDV perinatally.

In 1997, there were concerns that the use of ZDV might cause cancer because it was originally developed as an anti-cancer drug and if a person treated with anti-cancer drugs lives long enough, he or she often develops secondary cancers (Lucey, 1997). High level ZDV resistance can occur from using ZDV during pregnancy, persist for many years, and can affect the use of other antiretroviral therapy (King, 1995). Based on this new information, it was recommended by the British Columbia Centre for Excellence in HIV/AIDS Care (1997), for example, that pregnant women living with HIV should be offered appropriate counseling and discussion about their choices regarding pregnancy, antiretroviral therapy, and the known and unknown benefits and risks of such therapy during pregnancy. Hankins, Tran, Lapointe, and The Canadian Women's HIV Study Group (1998) reported that following the use of antiretrovirals in 1994 to reduce mother-to-child transmission, there has been no increased pregnancy incidence in Canada. There is, however, a decreased incidence of therapeutic abortions as more women living with HIV

choose to carry on with their pregnancies. A similar trend was observed in France (Meyer, Fourquet, Chenadel, & Nayaux, 1998).

Mofenson (1998) cautioned that all nucleoside analogues [e.g., ZDV and Lamivudine (3TC)] pose potential risks for the developing baby, and the use of protease inhibitors to reduce perinatal transmission is unknown. Despite these risks, the use of more than one antiretroviral medication or combination therapy is increasing, as reported by Beckerman et al. (1998). Further, there is an emerging trend to give ZDV and 3TC to pregnant HIV-seropositive women living with HIV, as in the case of Heather and Samantha, two women in the study (Dorenbum-Kracer et al., 1998). Unfortunately, high level 3TC resistance is common and the long term benefits in using this combination and other combinations of antiretroviral therapy remain unknown (Lucey, 1997). No information exists about how combination therapy affects fetal development, whether these drugs cross the placenta, and if doses need to be changed during pregnancy (Cadman, 1997).

Currently, a pregnant woman on combination therapy must decide whether to stop taking her medication during the first trimester (Cadman, 1997). When faced with this decision, one woman in the study chose not to stop treatment because it meant potential resistance, or a rapid return to a high viral load leading to disease progression. Nor did she want to harm a future baby, or dare to transmit HIV, if she took no medication. Regretfully, she had an abortion and consoled herself that she was blessed with two children free of HIV.

New studies using shorter versions of the ACTG 076 regimen [e.g., during just delivery and to the newborn or only to the newborn within 48 hours following birth (Wade et al., 1998)] show significant reduction in babies acquiring HIV (McIntosh, 1998). These outcomes raise more questions about the mechanisms of vertical transmission and the efficacy of ZDV. They underscore the controversy in using antiretrovirals perinatally, particularly ZDV. For example, Schüklenk (1998) challenges the ethics of using ZDV

when it is known that 80 percent of pregnant HIV-seropositive women will not infect their babies without using ZDV. Likewise two neurobiologists voice similar dissent. Pert (1997) emphasizes that ZDV destroys both the virus and healthy cells, particularly those of the immune system. Murrain (1997) reminds us that ZDV interferes with replicating rapidly dividing cells, such as those of the central nervous system. In light of these concerns, pregnant women living with HIV struggle to understand their options about using antiretroviral therapy, as voiced by Susan:

I've talked to a lot of women and none of them heard about the action of ZDV. I just said okay, this is information you need to know. Because I think it's part of informed consent. And if a woman looks at that and in her gut it's telling her it is fine, then that's her decision. She's made that decision. And . . . I think the worst thing in the world would be a woman feeling cheated afterwards. You know, we find out 15 years down the road that we have all these children that are now with organic brain problems because of some chromosomal feature that was checked and not allowed to develop in fetus because of this bloody ZDV. We don't know. I'm just thinking anything that is hindering, and solely goes to stop cell reproduction [or] cell growth is scary.

Ironically, advances in the perinatal use of antiretroviral therapy leave many questions unanswered in the search to eliminate mother-to-child transmission. Powerful medications are being taken with little knowledge about potential harm, particularly about long term effects on a developing fetus. In light of these risks, it is important that a pregnant woman living with HIV is informed of her options regarding the use antiretroviral therapy (Kass & Faden, 1996b). In seeking to act in the best interests of their future babies, most women take this medication. However some of them may suffer extreme emotional distress, as did one woman in the study who agonized about whether she had made the right decision, and whether her child would grow up hating her for what she did if there are future health problems.

Desire to give life and have children. 'Desire to give life and have children' is another factor of mothering capacity that is constant throughout the reproductive decision-making process. This factor identified in the study refers to motherhood as both a natural

biological function and an important social identity for the women. Women in the study who sought motherhood, like other women living with HIV described in the literature, claimed that there was “something really powerful” about the capacity to reproduce (Allen, 1996; Rudin et al., 1998). In having a child and becoming a family, the woman fulfilled her “girl dreams” and societal expectations. This yearning for children was influenced psychologically, as observed by DJ:

I think sometimes too. You don't even know if you want something until it's taken away. And sometimes when you're told that you have HIV you may interpret it that you can never have children, so it's like taken away from you, and then you want it more.

According to research, the lure of motherhood for women with HIV was particularly strong in cases of low socioeconomic status and lack of education (Farmer et al., 1996; Petchesky, 1998). In these situations, women had limited options for creating productive, happy lives. Social support provided by family, friends, and others, including physicians, social workers, and nurses, further enhanced the prospect of motherhood or having more children (Richter et al., 1998).

For women in the study, a desire to give life and have children was based on the perceived benefits of motherhood such as: saving a failing marital relationship, expressing their love in an intimate, committed relationship, fantasizing to be a better mother than their own, seeking the promise of unconditional love, or having a chance to feel needed and valued. Similar benefits are echoed by other women as reported elsewhere (Allen, 1996; Pivnik et al., 1991; Williams, 1990). Any urgency experienced in having children was associated with the potential to have a healthy infant as determined by the biological clock and stage of HIV disease, as described by Susan:

When I got married we talked about it but I didn't have the longing and the need to have children so we chose to be a family of two, my spouse and I. Recently I felt pressure. Now with all the things about the potential of having a healthy and well baby and the fact that I'm getting closer to forty. . . Then my viral load went from 300 to 700,000. Everything I knew about at that time was, this is bad news. I've a fair bit of medical knowledge, and that knowledge wasn't friendly to me. It's kind of a hopeless situation. So

I am hoping against hope that I'm gonna be healthy and there's a way out of this . . . After three months of being on supplements and off anti-retrovirals my viral load went down to 120,000. Even my doctor said this is significant. Of course, it's not detectable yet. So about having children. I don't have a long time to fool around. It'll either happen or it won't in the next couple years.

In addition, as reported by local physicians, and in the literature, some women from African and Asian countries suffer greater stigma in being a childless couple than being a HIV-seropositive couple with children (Shariff, 1995). One woman from Zimbabwe was reported to have kept trying to get pregnant after her son died from HIV in order to maintain the family lineage. Women living with HIV feel compelled to give life and have children because, as noted by Bill and others in the study, "they are forced to live up to society's standards, not 'cause they yearn to do it."

In contrast, when women delayed childbearing, their decision was based on the biological clock and perceived burden of motherhood on the individual woman, as voiced by women in the study like Nancy:

I want to keep my life spontaneous. My whole life would change with a child. I'm twenty-six and I still don't feel like I'm old enough to have to take that responsibility or take care of another life and bring a child into this world. I'm not financially stable, I'm just definitely not at a place in my life where I could do that.

Only Diana, one woman in the study, spoke about having the freedom of not defining her life through motherhood. Diana's comments are consistent with a qualitative study about white, middle-class women who chose not to have children (Bartlett, 1994). Diana's rejection of motherhood was influenced partly by the biological clock and her concern about global overpopulation:

I'm only 27. This [motherhood] is not something that has been going through my mind. Who knows how I will feel when I'm 35, 40. For now, there's enough people in the world. M. [her spouse] grew up in India and he was around a lot of poverty. M's sister is adopted from India and M's sister adopted a child from Haiti. That to me seems so much more appealing. So I'll do my little small part by not putting one out [childbearing].

All mothers in the study reported questioning their mothering capacity when faced with turning points in their reproductive lives. This doubt was related partly to the uncertainty in living with a life-threatening disease and partly to a woman's perception of her mothering capacity that changed over time and in relation to her life. As long as a woman had the potential to conceive and childbear, mothering capacity was a factor in her reproductive decision-making. The motherhood imperative was reported by all study participants as a factor which motivated women living with HIV to become mothers and sustained mothers who were diagnosed with HIV. Each mother in the study was like other mothers in complaining about the burden of mothering (Allen, 1996; Andrews, Williams, & Neil, 1993). The challenges of living with HIV and mothering reveal how mothers in this study are alike and yet different from other mothers who face reproductive decisions.

### Living With HIV and Mothering

I survived my pregnancy as most women do. And I gave birth to a very healthy, nine pound nine ounce baby in the year of 1993. And it seemed the hardest part was over but really it just begun because I had no idea what it was like to be a mother. All of sudden this thing is outside of you and you're going, "What do I do now?"

- LK

No mother in the study regretted experiencing motherhood. All of them cherished their children, even if they had "poor mother-child relations," because they were grateful for childbearing and nurturing life through mothering. Their faces beamed with pride when they talked about the accomplishments of their children. They claimed, like other HIV-seropositive mothers, that the only thing that truly mattered in their lives was knowing that their children were happy and healthy (Corby, Shedlin, & Wood, 1998; Williams, 1990). At the same time, motherhood was a source of personal suffering. All the mothers in the study knew that without a cure for HIV, they would eventually die and abandon their children like other mothers living with HIV (Andrews et al., 1993; Echeverria et al., 1998; Lather & Smithies, 1997). In light of this predicament, their experience of mothering anxiety exacerbated the burden of motherhood.



### Mothering Anxiety

'Mothering anxiety' defined in the context of this study refers to women's worries, fears, and losses in being a mother living with HIV. Deciding about breastfeeding, discussing their HIV serostatus, "testing for my baby's fate," and mothering my "miracle/unlucky" baby were identified as factors that influenced mothering anxiety. Each of these factors was considered a "painful" reminder of living with a stigmatized, life-threatening, infectious disease. Once a mother is living with HIV, mothering anxiety influences women positively or negatively in varying degrees when making reproductive decisions.

The 13 mothers in the study who faced decisions about breastfeeding, disclosing living with HIV, and testing their baby's HIV serostatus reported fretting about wanting to be 'good mothers' who act in the best interests of their children. These women reported experiencing denial, guilt, depression, and worry when facing these situations. Each situation involved the intertwining of emotion, cognition, and action as the women grappled with their choices. The majority of these women relied mostly on information from health care professionals, such as physicians, nurses, and social workers, to weigh the risks and benefits in breastfeeding and HIV testing of child/ren.

Deciding about breastfeeding. To date the mechanism of transmitting HIV through breastfeeding remains unknown (Mitchell, Fennoy, Tucker, Loftman, & Williams, 1993; O'Gara & Martin, 1996). Rates of transmission from HIV-seropositive mothers range from 18 to 52 percent for breastfed babies and 25 to 33 percent for bottle-fed babies (O'Gara & Martin, 1996). Biological factors contributing to transmission include: HIV in the breastmilk, especially high in the colostrum and early milk (Ruff et al., 1994) and in blood from cracked or bleeding nipples, and breast abscesses (Van de Perre et al., 1992). Research indicates that if the mother becomes infected with HIV during pregnancy, there is an increased risk in transmission through breastmilk ranging from 16 to 60 percent (Shariff, 1995). Ruff et al. (1994) reported that breastfeeding for less than six months

could delay disease progression in HIV-infected babies, and breastfeeding for more than six months contributed to increased transmission. Nishimoto, Gibbons, Segall-Correa, Teruya, & Hayden (1998) observed a greater survival among Brazilian breastfed babies even if both mothers and babies were living with HIV. The findings of these studies confirmed the benefits of breastfeeding resulting from the unique nutrient composition of breastmilk. For example, the bifidus factor in colostrum enhances the baby's developing epithelial lining in the digestive system, decreasing susceptibility to intestinal infections (O'Gara & Martin, 1996). More extensive research is needed examining the impact of specific infant feeding practices (i.e., frequency and duration of breastfeeding and infant formula feeding) on HIV transmission and infant health. In light of this information, the World Health Organization and UNAIDS (1998) recommended that pregnant women understand the HIV risks of breastfeeding and infant formula feeding.

In the study, 12 out of 13 women chose not to breastfeed to protect against giving HIV to their newborns. Only Mouse chose to breastfeed:

I was told I couldn't breastfeed. I was told not to. [But] I still did. Like I breastfed all my others [2 sets of twins and a son]. And I didn't wanna treat this baby any different than my others. Like I knew she was gonna be [HIV] positive. Even before the doctors told me. I knew she was gonna have the exact same thing as me. So that didn't scare me. I just wanna treat her like my others.

Two mothers in the study believed that "when you breastfeed your babies, then they really know their mothers." As a result, they reported having a less intimate bond with their bottle fed babies. In light of the cultural norm that "breast is best" (Maposphere, 1998), the five mothers in the study who "wanted to give their babies every chance to be healthy" reported that they mourned that they were not being like other mothers who suckle their babies and not able "to give some of themselves, breastmilk's life-giving sustenance to their babies." Following childbirth, their distress was intensified by being afraid of the responses of hospital nurses who might judge them as "selfish women" for having a baby

due to stigma about HIV-seropositive mothers. Louie describes her experience of being a new mother in the hospital that captures the feelings shared by others in the study:

It was horrible. There were a few nurses that bugged me about it. You know, that breastfeeding is better. My doctor may be, tried to protect me by not telling people I was HIV. Still they [the nurses] shouldn't be harassing women. Like if someone's already made a choice. The bottle's already in the kid's mouth. You shouldn't be saying anything. It was enough for me. I'm a wreck right? I'm totally depressed about this [not breastfeeding] . . . To this day, I still can't handle it [sobbing].

Discussing my HIV serostatus. 'Discussing my HIV serostatus' refers to the decision mothers living with HIV face in telling their children about their disease and is another factor of 'mothering anxiety.' Like mothers in general, all the mothers in the study wanted their children to be happy, feel safe, and secure (Bergum, 1989; McMahon, 1995; Rich, 1976). All the mothers in the study were particularly cautious about talking about their disease to protect their children from being fearful that their mother could die anytime, or, as reported by Kalyanasundaram (1998), to avoid harm and discrimination by others that may contribute to financial hardship.

Each mother in the study knew that at some point in her life she had to decide when to disclose her HIV-serostatus to her family. Like other mothers living with HIV, those in this study agreed that there is "no easy way to disclose, no best time, and no ideal circumstance" (Damson, 1997, p. 29). According to Wiener, Battles, & Heilman (1998), parents' decision to explain their HIV-serostatus to children may be as emotionally charged as learning their own diagnosis. Parents struggle with the fear that their children will hate them, reject, or abandon them once they are told (Damson, 1997; Wiener et al., 1998). In this study the mothers struggled with a desire to maintain an open, honest mother-to-child relationship and a need to shield their children from unnecessary stress, as voiced by CJ:

You know I have mixed feelings about it. One I wouldn't want them to live with the thought that their mother might die and they lose out on being a kid and have a childhood [be]cause they're always worrying. Then again, may be it's better [to tell]. [Be]cause then they know things are not their fault, they understand why Mom needs to rest.

It was agreed by all study participants that it was important to answer questions from their children with accurate information about HIV (disease, process, and treatment) at an age-appropriate level of understanding. They wanted to answer questions truthfully but, like other parents living with HIV, they feared their children would be psychologically harmed from this information (Damson, 1997; Wiener et al., 1998). Despite fears of the impact of HIV disclosure on their children's well-being, HIV disclosure decreased mothering anxiety. The burden from keeping HIV-serostatus a secret was reported by 13 mothers in the study to exacerbate mothering anxiety. Only one mother, Spring, reported that this was not the case for her. When Spring was pregnant, she decided to tell her four year old about living with HIV in case his future sibling was HIV infected perinatally. In retrospect, she regretted the timing of her disclosure:

He started being afraid of losing me and he started being aware that some people were dying of this disease and everything. After I told him and I saw all the support we didn't have and all the problems it brought in his life, I started feeling, now I could never tell a woman to tell her child because of the lack of support. My son started to have deeper behavior problem especially when my daughter died [of a HIV-related condition when he was six and half years old] and he started to go down, down, down. [He was] even prevented from coming to school because of his problems.

Testing for my baby's fate. In this study 'testing for my baby's fate' refers to the decision women face in regard to HIV testing of their children. In the minds of these mothers, their children, regardless of age, were "babies" who depended on them for nurturance and protection. The term 'fate' acknowledges the reality that whether or not the test result is negative or positive for HIV, the result impacts directly on the children's lives. Testing for my baby's fate was reported by 12 mothers in the study as a "horrible" experience that paradoxically ends fears about the fate of their children and initiates fears about a fate that has an uncertain future. Their fears are summarized by Elmo:

All kids that I've seen or heard of didn't live very long. To have my own kid go before me that would be too hard. To watch my kid die in front of me be much harder. I don't think I could really handle it if I found out that my kids were [HIV] positive. Watch my kids go through pain, the pain and suffering and all that.

Mothering anxiety was reportedly increased by feeling vulnerable and helpless when doing these blood tests and waiting for confirmatory test results, as voiced by Crystal:

From 12 months on, I was literally holding her down to do the test. I felt like the meanest person on the world as she kicked and screamed while they took the blood. It was horrible! Like I just didn't know what was happening. And the doctors they can't tell you anything to make you feel better. Because they don't even know until later on. It's the not knowing that was the hardest part. Then again, the doctors did say her growth and development was fine. So that was a little reassuring.

Before the early 1990s, HIV-seropositive mothers could not know their baby's fate in regard to HIV infection until the age when infants lose maternal antibodies (15 to 18 months old) (O'Hara, 1995). Spring describes her mothering anxiety when she was diagnosed with HIV and her son was eight months old:

She [the female doctor] didn't do much, gave me a bunch of statistics and sent me back home. She said I had about two and half years to live and it's almost sure your child will have it or it's 50 percent. You know the only thing I could see is that I won't see him grow up. I won't see him walk, to hear him talk. I was really afraid. When he was two years he wasn't [HIV] positive and I was still healthy.

Currently, infants who acquire HIV during pregnancy and in the first weeks of life may be identified by the detection of the virus (i.e., p24 antigenemia), viral culture, and HIV polymerase chain reactions (PCR) or culture assay tests (Borkowsky et al., 1992; Burgard et al., 1992; Miles et al., 1993). The health of these infants can be protected by using specific antiretroviral and prophylactic therapies. Caution is needed with negative results because of variable test sensitivity (O'Hara, 1995), or, as reported by Buchholz et al. (1998), infants treated with ZDV perinatally may have HIV viral loads that are below the limit of PCR detection. Further caution is needed in interpreting positive results in light of a European Collaborative Study that reported nine out of 264 children were positive by virus culture or PCR and subsequently seroreverted (Newell et al., 1996). Repeat testing and monitoring of infant development is thus needed to rule out HIV infection (Boaland &

Czarniecki, 1995). Cindy describes anxiety similar to what was reported by eight other mothers in the study who knew they were living with HIV during pregnancy:

I went through my whole pregnancy wondering to myself, what if the baby is negative? Is he gonna be born with HIV? It was a horrible feeling. My nerves were just shot. And then when the baby was born negative that was great but then the doctor said, hey don't get your hopes up too high because it takes eighteen months before we can really tell you if the baby is HIV or not. So it was like, oh my God. So then another 18 months. After that I had to really think about it, like do I wanna ever go through that again?

Advances in HIV testing of children and timing of HIV diagnosis are time-related aspects that affected the mother's anxiety. All the study participants agreed that there is no "best time" for a mother or child to be diagnosed with HIV. Young mothers under 25 years of age at time of diagnosis in the study experienced more anxiety in light of inexperience and greater burden in mothering young children infected or affected by HIV. In contrast, mothers in the study of 25 years or more with school age or older children at time of diagnosis experienced less anxiety. These mothers had already created "lots of happy memories for their children to remember them" and had an increased likelihood that their children would be old enough to understand what happened when they eventually died of a HIV-related condition. They concurred that having children free of HIV greatly decreased their anxiety.

'Testing for my baby's fate' may bring a negative result where the child will outlive the mother and therefore decisions will need to be made about the future life of the child. Alternatively, testing may bring a positive result where decisions need to be made about specific antiretroviral and prophylactic treatments and who will be informed about the HIV serostatus of the child. As a result, the HIV test of a child leads to decisions about caring for their children.

Mothering my miracle/unlucky baby. The term "miracle" baby was used by the seven mothers in the study who chose to carry on with pregnancy following a diagnosis of HIV and their infants tested negative for HIV. In their minds "miracle" was the only way

to describe and explain their children's well-being. For these mothers, it did not make sense that only a few infants ended up infected, when every newborn is exposed in the womb to HIV infected blood of the mother. Even if research showed that the perinatal use of antiretroviral medications ensured "the odds" were in their favor to have a healthy infant, these mothers felt "blessed" by being "spared of the unfortunate consequences in pushing chance to the limit," an outcome that seemed unfathomable to face, as described by Cindy:

I don't know how I'd deal with it. I really don't. You have to be almost in that position to be able to answer the question. But you know, I'd cry. I'd be very devastated and I'd feel horrible. Everyday I'd look at the baby and think it's my fault. I'd be totally blaming myself. I don't know if I could forgive myself for doing this [giving my baby HIV]. But I would never give up. I would never put my baby up for adoption. No matter what. Just because he had a disease. It doesn't mean he's unloved and unwanted. I'm the one that gave it to him. Like it's my fault, not his fault, right? I have the responsibility.

Despite the relief these women in the study experienced in having children not infected with HIV, their mothering anxiety was increased by on-going worries and uncertainty about living with a life-threatening, incurable disease. These issues included not being there to raise their family, having their children watch them be sick, or being sick all the time so that their children must look after them. It bothered them immensely that, if they were not careful in preserving their own health, their children could end up being their caretakers (as also reported by Williams, Shahryarinejad, Andrews, & Alcabes, 1997).

The term "unlucky baby" was used by six women in the study who knowingly or unknowingly gave their children HIV. Like other mothers living with HIV, they did not understand how a few infants ended up being HIV infected (Williams, 1990). Therefore, "being unlucky" was the only reasonable explanation for this painful situation, and for losing a chance to be like other mothers who had healthy babies. Anxiety for these mothers was intensified, and more excruciating than for mothers living with HIV whose children were not HIV infected, as observed by Jane:

(takes a deep breath) I'd say the only thing was, it's hard to carry on with your life when the baby is [HIV] positive. Carry on with it in a normal way

because you are so protective. You're scared of people having colds around your baby. You're scared of people and what they are going to say or do. So you don't really have a normal life afterwards. Even if the baby was healthy for a moment, it's hard to go on with regular life afterwards.

Two of the six affected mothers did not blame themselves, or feel guilty for their child's predicament. Mouse claimed that her unlucky baby's HIV diagnosis was fate, a natural consequence of being pregnant and living with HIV. Spring remarked, "it's like any decision. You make anything of it. There's a good side, a bad side, and I just did my best with what happened."

These mothers hoped for a cure, particularly to give their children infected with HIV a chance to grow up and be adults. In this way, they could avoid watching their children get sick, suffer pain, and die from an HIV-related condition. After being diagnosed with HIV, Sky recalled the moment when she learned that her son, who was two years old and always having colds and a runny nose, was HIV infected:

They said we've got to talk to you about one of your child's blood tests, and then I just flipped. I screamed and they said it's D. They looked at me and I just said, Why? Why is God punishing me? (crying) I thought he was going to die because he has AIDS. That was the worst day of my life was finding that out. (crying). And I know that he got it from me because he came out of me... And then I just looked at him out there playing and he looked so healthy and normal. That's when I stopped [drinking and using cocaine]. I said he's got to be put on meds. I've got to stay alive to make sure he's healthy so I can keep him alive.

Research has provided some optimism for mothers of children living with HIV with improved survival following early diagnosis and appropriate medical treatment. In Canada, Singer et al. (1998) reported that children identified as HIV infected, at birth or shortly after, had 67 percent or greater cumulative survival rate at eight years of age than those diagnosed much later in age. In the United States, Pliner et al. (1998) reported that in the past 12 years, the survival of perinatally HIV-infected children has significantly increased through the use of prophylactic treatments and antiretroviral medications. In Gambia, Ota et al. (1998) observed that maternal death significantly increased child mortality. This



finding demonstrated the importance of the health of the mother living with HIV in nurturing their HIV-infected children. Such research findings were consistent with the views of the mothers in the study who endeavored to remain healthy, based on a personal belief that the survival of themselves and of their children depended on their mothering, as voiced by Rain:

There is no other mother that will be like me. It's like I need to be with my children too. Like if they need me, I need them. I want to be with them. Uhm. That's hard like to leave them and I think that's why I'm still here because of my children. I am responsible for them. I love them and they love me and nothing can replace that.

Despite advances in the treatment of pediatric AIDS, children still die from HIV. Reigada et al. (1998) determined that in Valencia, Spain, 68 percent of infected children died during their first year of life. At present, HIV-infected children will die inevitably from a HIV-related condition. This knowledge affected their mothering, as reported by Spring and Jane. To buffer the future loss of her child or to prevent a "close attachment," Spring used to send her daughter who was HIV infected perinatally to a babysitter who would give her the love and comfort that she could not give at that time. This action helped temporarily decrease her anxiety about mothering her unlucky baby. When Jane's daughter was diagnosed with HIV at six months of age, Jane describes how she attempted to decrease her anxiety:

The doctor told me that she'd live a maximum of two years. Right off the bat. Because she was a rapid progresser, and by looking at her CD4 count, they knew she'd die pretty quickly. So right there I didn't feel I had much hope. They were going to try some drugs on her, but they didn't feel they were going to do much good. And she looked so sick. I just thought no. They're wrong. She's not gonna make it to her first birthday. There's no way. I thought about praying and I thought there's no point. It's not gonna do any good. So I prayed for strength, but there was no way I'd pray for her to get better 'cause I didn't feel she would.

Furthermore, Spring and Jane talked about being "helpless and powerless," about being able to do "absolutely nothing" to comfort their dying children. Like other mothers, Jane

sought inner strength and solace from spirituality (Regan-Kubinski & Sharts-Hopko, 1995).

The grief experienced following the death of a child is immense. Of the six mothers who had an HIV-seropositive child, four of them experienced grief from anticipating or facing this maternal loss. Their grief was worsened by self-blame or guilt: in giving life these mothers knew they had simultaneously “destroyed life” by infecting what they cherished so much, their beloved children. Three mothers had minimal to no contact with their children who were in foster care. This may have contributed to not experiencing the same maternal loss as the other three mothers.

Spring and Jane reported that after their children died, their lives seemed worthless. In response to a “loss that pierced her heart and never healed,” Spring confessed that she was promiscuous because she felt “nothing mattered anymore.” At the same time, these particular mothers spoke about a wish to fill up the emptiness that grew stronger over time. The yearning for children was further supported by other people, such as social workers and physicians, who consoled them with words like “people do have more children and it’s not a bad thing.”

Maternal grief from losing a child is a factor of ‘mothering an unlucky baby.’ Unresolved emotions from this loss may increase mothering anxiety and compel a woman living with HIV to question her mothering capacity and, as a result, choose never to childbear again. Alternatively, these same emotions or grief may “blind” a woman to her past experience; as a result, high levels of grief may paradoxically strengthen her desire to give life and have children, leading her to conceive again. A similar response has been reported for other HIV-seropositive mothers with a history of substance abuse (Pivnik et al., 1991; Williams, 1990) and among women who use crack cocaine in the United States (Kearney, Murphy, Rosenbaum, 1994). This response further supports the significance of motherhood in giving purpose and meaning to otherwise chaotic lives.

The prospect of dying from a HIV-related condition and abandoning one's children also affects mothering anxiety. None of the mothers wanted to talk about her own death, partly because of denial about the inevitable outcome of living with HIV, and partly because of fear of dying. Concerned about the welfare of the children, future planning about child custody may increase mothering anxiety, as noted by DJ.:

One thing I know about HIV and AIDS is if I get sick I'm not gonna die tomorrow. So I have a chance to make those decisions. Right now that's something I'm facing because I'm not comfortable with anyone raising my daughter. My mom and dad would be wonderful, but they're too old. They're sixty-four years old. I don't think that's appropriate for a young child. So I keep asking who is there to take care my of daughter? Will they be the kind of parents I want her to have?

Others, like women in Kenya, reported "having peace of mind" from knowing their children could be taken care of by an older sibling, a sister, or another suitable family member (Phillips & Njorge, 1998).

A few mothers worried about their children having to experience or watch them die and/or not being able to express their feelings or problems with friends, the teacher, or neighbor because of HIV-related stigma. Similar concerns about the social isolation of their children are voiced by mothers in the literature (Williams et al., 1997). There were four mothers in the study who did not want to be remembered as being sickly and dying, or being "drugged up" because they were in pain. Two of these mothers were torn mentally and emotionally about whether to have another child because they were single. In these instances, having another child meant the children would not be left alone when the mother died. At the same time, another child could end up HIV infected, and, as a result, the sibling would likely witness a little brother or sister as well as the mother suffer and die. In response to this possible scenario, the acuity of mothering anxiety may compel a mother living with HIV to permanently forego childbearing as did two women in the study who had a tubal sterilization after giving birth to HIV-seronegative babies.

Like other mothers living with HIV described in the literature, every mother in the study reported being at times overwhelmed by the burden of motherhood, a burden related partly to living with a stigmatized, life-threatening, infectious disease and partly to being a parent (Andrews et al., 1993). For the mothers in the study, their mothering anxiety changed over time, and in tandem with life circumstances. As long as a mother living with HIV continues to be responsible for nurturing and protecting her children, mothering anxiety is a real-life factor.

In summary, reproductive decision-making of women living with HIV is marked by turning points in their lives that are subject to the highly variable experiences of living as a woman, living as a woman with HIV, and living as mothers with HIV. Each turning point is influenced particularly by a woman's perceptions and experiences of motherhood that include mothering capacity and mothering anxiety. Each turning point may result in a different reproductive decision. These decisions not only affect cognition and reproductive behavior but also impact on living with HIV. Reproductive decision-making is a dynamic, on-going process that interacts with a woman's evolving life. As each woman experiences the consequences of her decisions, she makes personal meaning of these experiences. These meanings further shape her reproductive behavior and contribute to future decisions about having children.

The next chapter details the components of a theory that explains the process of the reproductive decision-making of women living with HIV, a process of balancing the prospect of a better life against the realities of HIV disease.

## CHAPTER V

### THE REPRODUCTIVE DECISION-MAKING PROCESS

This chapter presents a theoretical explanation of the reproductive decision-making by women living with HIV as depicted in Appendix O. For the women in the study, 'affirming life despite a poisoned fate' described their personal experiences of making reproductive decisions. Factors that contributed to specific decisions reached by the participants are described, reflecting the experience of women living with HIV as they ponder the consequences that may occur from sexual relations and childbearing.

#### Affirming Life Despite A Poisoned Fate

I think the urge to procreate [through sex] is probably the single deepest human urge. And in the last 100 years we've been able to satisfy the urge without actually having children.

- Michael

All study participants spoke about being confused, perplexed, or even overwhelmed about sexuality and parenthood. The source of their ambivalence came from wanting to fulfill fantasies, feelings, and physical urges spontaneously while avoiding the consequences of their actions. For women in this study, multiple forces were present in the singular acts of having sex, preventing conception, terminating pregnancy, and childbearing. These conditions and factors were difficult to articulate because of the confusion of emotions, thoughts, and morals when making pregnancy choices. Their decision-making was further complicated by the potential of transmitting HIV through sexual intimacy and childbearing.

In this study, 'affirming life' refers to the emotional component of reproduction and human behaviors that affirm again and again the power of life, a manifestation of existence and expression of the mysterious universe based on the collective view of the study participants. 'A poisoned fate' refers to the emotional reality of living with uncertainty,

immense loss, and the immediacy of death, the triple burden of living with HIV. The following discussion elaborates the way in which these concepts resonated in the participants' lives.

### Affirming Life

All the women in the study emphasized that after being diagnosed with HIV, they no longer took sex for granted; satisfying sexual needs and desires required adapting and making the most of their tragic situation. In addition, they all wanted to feel loved and lovable, and in this regard sexual intimacy that was respectful and sensitive to each other's needs most often achieved such a sense of love. Becoming mothers was another way of being loved, and creating even greater love for self and others by giving life and having a child. However, in light of living with HIV, for the women in the study who chose to carry on with pregnancy, childbearing was double edged: "both heaven and hell" because of the possible danger in giving HIV to their future child.

Faced with the horror of potentially infecting their sex partners and offspring, the women in the study reported being tormented about simultaneously satisfying themselves as loving, sexual persons and protecting others from HIV. Their anguish was further exacerbated by the fact that, to prevent heterosexual transmission of HIV, they ultimately required their sex partners to co-operate in either consistent condom use or abstinence. Destiny, a partner of one participant, expressed an opinion shared by seven other primary support persons and captured the way in which reproduction and sexuality for a couple with a partner infected with HIV was about embracing love and life:

We use condoms most of the time, but when we don't it's to get closer, it's more a sense of oneness, of closeness. Plus the fact, I'm just stubborn and I refuse to be frightened of my wife or what she has. Like I watched various people I know pass away and die, including my mother and the only thing that kept them strong was having a good connection with their partner. Some people might call it ignorance but I refuse to be frightened of the situation. You take the proper respect, the proper protection most of the time. But there are those times when you wanna feel a bond. And I think that goes [when] using barriers like condoms.

In affirming life, each reproductive decision marked a turning point in which the woman both strived to stay alive and thrived from being alive. Such was the case of Christina, 32 years old, who did sex trade work to feed her cocaine and heroin addiction for more than five years and was diagnosed with HIV in 1995:

I always used condoms [be]cause I didn't wanna catch HIV. You know to protect from other diseases. It was more my ass than theirs [the men]. Now [diagnosed with HIV] I don't have sex. I don't desire sex. I've had all my sex before the age of 25. I've had more than enough. And I don't need it anymore. My ex-husband beat the crap out of me. To me men aren't worth it. My kids are. And that's what I live for. My kids and my cats.

### A Poisoned Fate

Although it may seem obvious, it is important to recognize that nobody in the study deliberately got infected with HIV. Those who were injection drug users agreed with Bill that if "you're gonna play you gotta pay." Elmo also admitted that "I was stupid for a couple of minutes and look what happened." A diagnosis of HIV marked a fate that meant all the practical details of everyday living from that point would always be conditioned by the presence of the disease. Such a fate meant being treated differently, either as a victim of bad luck, an object of pity, or a medical challenge. It meant facing a destiny in which life could no longer be taken for granted nor things delayed until tomorrow. There was now a need to learn to live with this disease and to take advantage of the remaining good days, or months, or years.

Faced with the triple burden of living with life-threatening, stigmatized, infectious disease, it was vitally important for the 32 HIV-seropositive study participants to assert that HIV is only a part of their life, a disease that does not change the essence of who they are, as observed by Crystal who shared her experience of being diagnosed with HIV in 1995:

I guess the counsellors expected me to cry or something and all I wanted was for them to get outa my face, away from me and just let it [being diagnosed with HIV] to sink in, you know. [The doctors and social worker asked] How do you feel about it and this and that? And I was like, well I don't know. You just told me. Could you please go away. Get away from

me. [Then] I just went and looked in the mirror [be]cause I thought I'd be able to tell. Couldn't figure it out. It was really weird. I just looked like I did a couple minutes before. (laughs). But now I was being treated differently.

However, for all the women in the study an HIV diagnosis severely damaged their perception of self. They "feel poisoned and are poison," having been contaminated by an invisible virus that conquers the immune system, and having become a toxic vector with the potential to infect others with HIV. Nancy, a 26-year-old Caucasian woman who had known her common-law spouse for more than eight years and was diagnosed with HIV in 1992, described the trauma of feeling poisoned that was shared by all but one woman in the study:

In the beginning when I was first tested [HIV] positive, I felt like the opposite to sexual. Extremely unsexual. I didn't wanna have sex, never want it. The thought of it was repulsive and everytime I did have sex I just couldn't enjoy it. All I could think about was I'm going to infect this person. (laughs) So that sort of destroyed any beauty in having sex (sighs).

As poisoned persons, they sometimes felt like "present day lepers" who did not belong and were marginalized because of the social stigma of HIV:

I just remember this one biblical story when anybody going by a leper had to yell unclean, unclean! Well, sometimes I feel like that 'cause of the HIV and I shut down sexually for quite a while. . . because I felt anytime a male came near me or even when having a hug, I had to scream unclean, unclean!  
- Susan

For a majority (27/29) of the women in the study, being poisoned resulted in feeling ashamed that they were infected and feeling ashamed of even being alive because of the societal belief that "good women do not get infected" with HIV, let alone mothers who are responsible for the well-being of their children. Spring emphasized that feeling poisoned was not just a perception of self, but also about fear and loss associated with this fate:

When you just learn [you're HIV positive], no matter how much information you have...the only thing you have close, right under your skin



is the sensation and the feelings of the imminence of death, of being a potential killing instrument. If you have a partner, it's all those feelings about am I going to end up alone? Does my relationship end? You know, my life is over.

In addition to the women's experience of feeling poisoned and that they themselves are poison after being diagnosed with HIV, participants were aware of societal judgements about childbearing for HIV-seropositive women. Such judgements supported that living with HIV was being not only a poisoned person, but also someone with a tainted fate, as described by LK:

To understand where that came from. You know, saying you can't have what other people have because you're different. You shouldn't have kids. And how dare you? What it really translated to is that you have no rights now. You have no rights whatsoever. You have no right to have sex. You have no right to have a relationship. You have no right to have a family. You have no right to give birth to a child. You have no right to do that. All because of HIV.

'A poisoned fate' was described and experienced by the women in the study as a sense of profound loss in their lives from the impact of being HIV seropositive. In regards to sexuality and childbearing, there was loss of their previous sex lives, as bemoaned by Spring, "wanting to feel normal when you don't have to protect yourself and don't want to think that danger is at every corner," and loss of a guilt-free pregnancy because of the prevailing opinion that it is wrong for HIV-seropositive women to childbear. If mothers, they mourned the time when they would no longer be around to share their children's lives and joys, as voiced by Samantha,

I was scared for my children. Because I probably won't see them grow up, you know. And watch my grandchildren, watching them get married. Things like that, miss out on my children's lives and their children's lives.

The greatest source of despair from this poisoned fate (voiced by 23 of the 29 women) was that sex was forever tainted, as voiced passionately by Diana:

... sex isn't just for lust and love. Sex is a potential to kill others. It's an ugly thing now. There's some psychological part that feels poisonous and

toxic. It's not a beautiful thing alone and there's part of me that wants sex to be a beautiful thing. I know sex can be a horrible, ugly thing too, like if it's rape. But the whole other side, you know, this is what you want and the need to feel special and wanting to feel normal. Just wanting to be like I used to be. All that is lost, no longer achievable because of the HIV. I envy the people who can be there. [Be]cause I would like to have it back. I'm just wanting to be like I used to be [not poisoned]. But I don't think you can really get it again unless you're in total denial. I just envy people who can be there. I can't. Personally.

All of the women experienced varying degrees of fears of sex that spoiled the pleasure of sexual relations, and even intimidated four women in the study to abstain from heterosexual intercourse. To diminish the burden of difference and isolation experienced in their sex lives, two women in the study vowed to date only HIV-seropositive men. They believed that there would be less rejection by potential sex partners if they both had the same disease, less risk of physical harm in response to HIV disclosure, and less hassle in using condoms.

Only Susan rejected the notion of 'a poisoned fate' to describe her situation. She found that the term 'poisoned' evoked feelings of disgust and repulsiveness that she could not relate to. Susan was a professionally-trained Caucasian woman with a middle-class socioeconomic background, who appeared to experience greater loss as a result of being HIV seropositive compared to the rest of the women in the study in terms of being employed and keeping employment, maintaining her lifestyle, and quality of life. In addition, Susan experienced the most drastic changes in health compared to the rest of the women during the one-year period of the study. Differences in her life context may have contributed to her feeling this way about a concept which was true for the majority of study participants.

### Struggling with Vulnerability While Striving for Longevity

In this study, affirming life despite a poisoned fate is the core process for making reproductive decisions that involved facing dangers from being HIV infected while satisfying personal needs and desires of being a heterosexual woman. This core process

consists of two competing elements: 'struggling with vulnerability' and 'striving for longevity.' They interact dialectically with each other (i.e., any change in one element affects the other) to set up a specific decision or action as women decided about preventing, terminating, and continuing with pregnancy. 'Struggling with vulnerability' is about dealing with fears of living with HIV and is defined in the context of the study as the on-going battle of living with uncertainty, immense loss, and the immediacy of death. Based on the study participants' point of view, 'vulnerability' refers to the anxiety of one's own mortality and feeling unsafe in the world. Diana described her experience of struggling with vulnerability and how acting in a drama group provided a temporary escape:

When you're acting the character plays you, right. As you're saying the lines, the body reacts from memory, how those emotions feel and so it's very spontaneous. And it's cleaning. You know, it feels really good to get it out, letting all these emotions out and no one knows where they're coming from. And it's safe. A safe environment. There's no judgment. And there's absolutely showing of yourself. You're truly exposed and people are accepting of that. I don't have to say I'm HIV positive, feel sorry for me. I can show my feelings of living with HIV, like the feeling of isolation or whatever. I'm freed without having to identify where it's coming from to explore feelings creatively like [about] the physical debilitation stuff and societal stigma.

Fears of the disease and of an uncertain life were reported by all 32 of the study participants living with HIV as the two major elements of vulnerability. Separately or in combination, these fears threatened the health of a woman, her femininity, and aspirations to be a good mother. In the short term, when women feel vulnerable they may become pregnant as a means to be like other women and to forget about being HIV infected. In the long term, the notion of giving life and having a family enables a lonely HIV-seropositive woman to gain an identity and social role for the rest of her life. Thus struggling with vulnerability is an aspect of affirming life despite a poisoned fate.

'Striving for longevity' is about getting beyond fears of living with HIV and acting in the best ways for staying alive and realizing hopes and dreams. 'Staying alive' means doing everything possible to prevent dying and death. Motherhood was identified by all

the study participants as a means and an end in striving for longevity. In being or becoming mothers, 22 women in the study fulfilled their "girl dreams" and found a purpose and meaning for surviving, striving, and thriving while living with a life-threatening stigmatized disease. For the women in the study, childbearing or having children was interpreted in two ways with regards to their future. In the short term, their children could replace them so that their spouses were not alone after they died. As their children grew up, the spouse would be reminded of the mother in the different ways they resembled her. In the long term, their children represented the next generation who would pass on the lessons learned from them. In this way, childbearing was about creating potentially better lives and making life worth the effort involved. This point of view was shared by all but two study participants and is described by Susan:

For me having a child is sort of creating a legacy and making a contribution to the world, by having a part of yourself stay once you're dead. And then potentially your child will procreate and they'll procreate and you know you'll be part of the world a hundred years from now. So if there's a legacy about me that goes on, let it be something I've done like have a kid.

Together, struggling with vulnerability, while striving for longevity are two halves of the reproductive decision-making process for the women in the study. As these women focused on their vulnerability they were simultaneously striving to stay alive. Conversely, as they concentrated on living longer, they were simultaneously struggling with their own vulnerability. In this way, the dialectical interaction of their own vulnerability and hopes for longevity account for individual differences in reproductive decision-making. Below Karen described what ultimately concerned all the study participants living with HIV with respect to their vulnerability and longevity:

I can't control it [HIV], what's gonna happen, you know getting sick. I can to a certain extent if I take care of myself, but there's that other part, the actual day I'm gonna die. I can't control it. And I've had that question in my mind a lot. Like when I was first diagnosed, I was feeling sorry for myself. Putting myself down. Not taking care of myself. Like what the hell, I'm gonna die anyway. I don't know when but I know I'm gonna die. Could be tomorrow. Could be a year. Could be years from now and that question is still in my mind. How far along the road do I have to live? I'll

never know. But I want to be here for my kids. So I take my medications and just make the best of my life.

The women's experiences of vulnerability and longevity to a greater or lesser extent depended on what was happening in their everyday lives. These experiences involved several critical elements that are part of the process of struggling while striving. Together, the interacting elements influenced each unconscious or conscious decision about taking risks in sexual relations and childbearing. Based on the women's stories, these combined elements explain how their conflicts between shameful or guilty feelings and a longing to be loved and love others are ignored, mitigated, or even resolved. Lisa, a First Nation woman of 40 years living with HIV since 1997, described such contradictory feelings, desires, and needs:

I think of it [having a baby] often myself. How come? I don't know. I just wanna make everything right, like another chance for a new life in giving life. It would give me a reason to live. Like I wish I could have a baby but I can't do it 'cause of my alcohol abuse and the HIV. But it's nice to dream. You know, I don't wanna hurt nobody. Like he's not [HIV] positive. So we don't have sex.

As the women struggled and strived while living with their disease, they were motivated, sustained, or constrained by the elements of this process. For them, these elements involved a strong desire to stay alive, managing fears of the disease, discovering spirituality, and belonging in the world. Over time, the women interpreted these elements in different ways, and these meanings affected their diverse perceptions about living as a woman with HIV. Ultimately, it was their overall sense of vulnerability and of longevity that determined whether they would risk deadly connections.

In the next section, each element will be described to explain the way in which the core process manifested and is played out in the lives of the women in the study.

### Wanting to Live

'Wanting to live' is a human response to a diagnosis of HIV in which one fights against the odds for survival. "Why me?" or conversely, "why not me?" for the many study participants who knowingly engaged in HIV high risk behaviors were critical questions asked by each study participant living with HIV. With no known cure, the common response to these questions was voiced by Cindy:

I wanted to die, because I thought well, I was gonna die anyway. I was still ignorant [about] the facts of being HIV positive. I didn't know anything about it. I was scared. I felt so alone.

Suicide may be contemplated, or even attempted, in response to the realization of a poisoned fate. However, much to the surprise of study participants a sense of 'wanting to live' emerged within themselves that prevented suicide. This desire was partly due to a fear of dying and a realization that once dead, they would be greatly missed by family, friends, or pets, as in the case of Brenda, a 35-year old First Nation single mother who uses crack and was diagnosed with HIV in 1993:

... the only thing that stopped me [from killing myself] was my eighteen month [old] son. He was on the other side of the door bangin' on it. Crying for me. That's the only thing that saved me. I had the rig [needle] in my hand, my arm all ready and I had some of it [heroin] in there [the vein]. I was ready to go down and the only thing that stopped me from doin' all, the whole thing, was my son. Without him I wouldn't be here. I know it. I woulda killed myself right that day.

All of the 32 study participants living with HIV claimed that the stronger the bond shared in relationships, the more intense was their desire to live. Below, Susan expressed an alternative point of view about wanting to live:

Everyone knows they're gonna die. But probably one of the worst things anybody in the health care field can do, is to put a timeline about how long do I have. [Be]cause it's suddenly putting death in your face, like hanging the cloud of death around you. What is needed is to remember you live and you die. When you die that's part of life. And so it's taking death to be part of life rather than death taking away life.

The desire to live was further strengthened by a positive, pragmatic attitude and appreciation of the fragility of life, by emphasizing the “here and now.” This is described by DJ, a 35 year old widow with a nine year old daughter who was diagnosed with HIV in 1992:

I think everything happens for a reason. I don't think my life's ruined from HIV, may be it's better. Life is what you make [of] it. You know, I don't think they'll ever find a cure for HIV but they will find a control. And I hope and no one can take that away from me. I just look at the positive instead of the negative side of things. Like if I'm not gonna be here long then I might as well be happy. I always say if I'm gonna be here till I'm forty, I'm gonna do more living than a lot of people do in eighty years. It's quality versus quantity. Maybe I'm the blessed one, [be]cause I know that death can happen at anytime.

In wanting to live, all the women in the study claimed that they did the best they could and did not fear death. This condition results in movement towards striving for longevity and greater motivation in struggling with vulnerability. Thus, a woman is likely to be more optimistic about her mothering capacity and, if a mother, experiences minimal mothering anxiety because she is feeling less vulnerable, staying healthy, and achieving her life aspirations.

For study participants with a history of injection drug use, a diagnosis of HIV was considered a “wake-up call” that kindled a sense of wanting to live. In this instance, survival is about turning away from drug addiction, and realizing that no drug or frequency of drug use is powerful enough to make the raw, tormenting pain of HIV disappear. Exhausted and tormented by chaotic lives, the woman makes a decision about whether or not to die or live, as in the case of Heather, a 29-year-old woman who was recovering from an eight-year heroin and cocaine addiction after being diagnosed with HIV in 1997:

[when using cocaine and heroin] I figured that I was gonna die out there. Whether I kill myself or somebody else kills me. And I didn't wanna die anymore. I was dying everyday out there. I wanted to live. [So] I think this HIV thing is a good thing for me [because] I now care about myself. I take care of myself, health wise [too].

According to the 27 study participants with a history of substance abuse, a diagnosis of HIV triggered only a small percentage of drug addicts to change their lifestyle. The majority considered this diagnosis to be a “death-call,” as shared by Howl, the common-law spouse of Heather who was also a recovering drug addict,

a lot of HIV positive people on the street they don't care . . . if they're alive. Before like, they were careful when they do their crime. They're careful if they get caught. You know, they plan things. Now they just go and do it. They don't care if they get shot. They're not careful anymore [be]cause they're dying anyway, that's what they're saying.

All of the 32 study participants living with HIV claimed that they had a strong desire to live, but at times they despaired about their predicament, became depressed, and wanted to die. Such moments of giving up on life or losing hope about the future were fueled by increasing signs and symptoms of HIV-related conditions, increased suffering as a result of these conditions, and more anxiety about being or becoming a burden on others as a result of declining health. Resignation to dying and death results in movement away from striving for longevity and greater difficulty in struggling with vulnerability. A woman becomes less optimistic about her mothering capacity and, if a mother, experiences greater mothering anxiety that reduces her desire to have children.

All the study participants living with HIV claimed that their passion for living was driven by hope for a cure and belief in their dreams. For them, wanting to live was a primal aspect of the process of struggling and striving. It changed over time and was subject to their varying everyday circumstances. They were also compelled by their desire for living to identify their own priorities. All of these 32 study participants ended up focusing on “the journey” rather than the duration of or time remaining in their poisoned fate. Bill was diagnosed with HIV in 1997 at the same time as his spouse, Samantha. He is a First Nation 30-year-old man and occasional crack user who described his perspective about living that was shared by the majority (30/38) of study participants:

I make plans you know, but I don't really go for those goals. Because I live one day at a time. Tomorrow may never come. Yesterday's already



gone. Today's the only day you can live for. Take and enjoy each moment as if it's your last. So that's my outlook on life.

### Managing Fears of HIV

Sometimes it's not always possible to be positive. Like if you got rejected by a friend [be]cause of your diagnosis or you're not feeling good or you've had some bad news about your blood status or your liver enzymes or something. At that point instead of thinking bad, [I] try to do something about it. And I think as long as I try to do everything I can then I know it's okay [be]cause I've done everything I could.

- DJ

In wanting to live, all the women in the study like DJ spoke about the need to manage their fears of the disease and fears of an uncertain life, the two major elements of vulnerability. They spoke about managing their disease fears by doing things to protect themselves from harm and avoiding any "negativity in their lives" (i.e., focus on positive thinking and socializing with strong, optimistic, happy individuals). In so doing, they were able to preserve their health. 'Managing fears of HIV' is defined in the context of the study as handling and limiting fears to contain the physical, psychological, and emotional harm caused by HIV. 'Handling fears of HIV' is about acting to protect against harm. 'Limiting fears of HIV' is about applying intellect and emotions in ways to prevent and remove threat of harm. The individual learned about the disease and its available treatments, made decisions about treatment and care, and reframed thinking that contributed to being optimistic about life. In the end, managing disease fears enabled the women in the study to transform wanting to live into staying alive. For them, when fears were contained their health was preserved. They experienced less vulnerability, and greater striving for longevity was possible as a result of their immune systems defending well against HIV.

The major element of handling fears of HIV is controlling symptoms of HIV disease by monitoring levels of circulating virus to assess the condition of the immune system, and intervening with the best treatments and care to decrease or prevent ill-health. Management of HIV is complex and, as observed by Michael, is like "skating on thin ice."

Being healthy or free from HIV-related symptoms can change at any time due to failure of antiretroviral treatments from drugs not being tolerated, not being taken properly, or HIV becoming drug-resistant. A deteriorated immune system made women living with HIV physically vulnerable to HIV-related conditions (e.g., cytomegalovirus or varicella zoster). When unhealthy, a woman was more likely to have greater difficulty in struggling with vulnerability and placed less importance on striving for longevity. T-Bone, a 34-year-old divorced mother of two adolescent sons was diagnosed with HIV in 1992:

I used to get excited about new treatments and stuff. But now I don't anymore. Like I've lost my enthusiasm. [Be]cause may be it's gonna help someone, may be it's not. My last experience I was feeling very sickly. I was really worried, "Am I gonna get AIDS now?" Like I couldn't tolerate this particular medication. I was nauseated everyday and that's a very unhappy feeling. You feel like throwing up all day and I wasn't lookin' forward to doing anything. Now I'm off everything and I feel pretty good. But I'm afraid 'cause what if new medication doesn't work? What if I get bad side effects again? Then what? So it's like a lot [of the] time I'm in between a rock and a hard place, that [kind of] feeling.

The major element of limiting fears of HIV is protecting self psychologically and emotionally by: (1) denying the reality of their HIV; (2) synchronizing treatments with everyday life; and (3) knowing reasons for staying alive. In this way, the women in the study were able to minimize or contain psychological, physical, and emotional harm from HIV and to maximize health. Like all the women in the study, Nancy mentioned that any success in limiting fears of HIV changed constantly and over time:

I'd say it's a day-to-day thing. Some days it's really good. Some days are really bad. Uhm, up and down. You know, there's times when I'm having sex and all that I can think about is HIV. And then there are other times when it's the furthest thing from my mind. But there's the reminders. Definitely.

When two women in the study did not experience symptoms of HIV (i.e., persistent yeast infections, cervical dysplasia, or changes in their menstrual cycle), they pretended for about six months that their life was no different than prior to their diagnosis. They delayed finding out what was needed to maintain their health to escape facing the

reality of living with HIV. Sexuality and heterosexual intercourse remained as natural expressions of human need. Their disease was a kept secret and condom use was inconsistent because it reminded them of their disease. If condoms were used, they told their sex partners that protection was needed against pregnancy as opposed to preventing HIV transmission. In this way, unprotected heterosexual intercourse allowed these women to feel normal and be like other women. The use of drugs and alcohol further inhibited condom use and momentarily allowed these women to forget about being infected with a deadly virus. In denying HIV existed in them, these two particular women contained their fears of HIV, did not doubt their mother capacity, nor did they fret over mothering anxiety. As far as they were concerned, in the first six months after being diagnosed with HIV, struggling with vulnerability while striving for longevity was not part of their reproductive lives.

When taking antiretroviral medication, 12 women experienced minimal or no side effects and were able to stay healthy and maintain their lifestyle. By synchronizing their treatments, with everyday life they considered that HIV was like any other chronic, life-threatening condition (e.g., insulin-dependent diabetes). Five other women perceived their disease in the same way, using vitamins and herbs (e.g., Vitamins C, E, multivitamins, ginseng, and royal jelly) rather than antiretroviral therapy. They believed that anti-HIV medications were toxic and would only worsen their "poisoned bodies." By identifying HIV as another socially accepted disease, these women in the study were also able to compartmentalize their fears of HIV. Like all of the other women in the study, Heather emphasized that living in the present moment helped to minimize fears of HIV:

I don't even think about suffering before dying or being a burden on loved ones. I think when the time comes. That's when I [will] deal with it. [Be]cause I could sit here and worry myself to death. And I know that bad thoughts will make me sick. Sick thoughts will make me sick and I can't afford that. Not today.

However, these women confessed that it was impossible to eliminate fears of sex after accepting HIV as a part of their lives that needed care and attention. Another seven women in the study who monitored their HIV health status and were not taking antiretroviral medications shared similar fears of sex. These fears ranged from dread and trepidation, to fright and terror because of the potential to give HIV through sexual intimacy.

To feel good about sexuality while living with HIV, the women in the study spoke about ways of handling and limiting or managing fears of sex. 'Handling fears of sex' included abstinence of sexual intercourse, mutual masturbation, and consistent condom use. These behaviors enabled the women to fulfill their sexual needs and desires while protecting others from HIV. 'Limiting fears of sex' included gathering information about heterosexual transmission of HIV, deciding about condom use, denying HIV serostatus to sex partners, determining whether it was possible to enjoy sex again, and if so, exploring sexual pleasure that was safe and comfortable for themselves and their partners. The loving support of their sex partners enhanced handling and limiting fears of sex for these women. However, this support may be short lived because it depends on the sex partner's capacity to handle and limit his own fears of HIV. Laura, a 35-year-old Caucasian single woman who was diagnosed with HIV in 1996, described the complexity of managing fears of sex:

I said to her [a friend recently diagnosed with multiple sclerosis]. I said, as similar as it is, you know our decision making factors, when you sleep with someone they think, oh what a beautiful woman! I'm really turned on by her. All these things. When I sleep with somebody, these guys have all these thoughts going through their heads. Oh my God, am I gonna die because of this one thing? You know, what is she giving me 'cause the condom slipped a bit. Have I got this [HIV] now? And oh my God, I found a cut in my mouth and we were kissing last night or we had oral sex. Do I have AIDS now? All these crazy thoughts that go through their heads that I can't control. I'm not there so I can't talk them down from it. I can give them information or point them in the right direction but it's pretty scary [for them]. So it's a lot different than just being with someone and going, oh, guess we should use a condom, honey.

When managing fears of sex effectively and staying healthy, like the 22 women in the study who synchronized treatments (including vitamin and herbal therapy) with everyday life, struggling with vulnerability was manageable and striving for longevity achievable. As a result of being healthy, a woman in the study could be optimistic about her mothering capacity and, if a mother, she likely experienced minimal mothering anxiety.

When antiretroviral medications failed for three women in the study, drug-resistant HIV developed and horrible side effects from HIV-related medications (e.g., peripheral neuropathy or constant nausea and vomiting) occurred which increased vulnerability and decreased longevity. In light of deteriorating health, they asked questions about quality of life and reasons for staying alive, as Lori, a 35-year-old Caucasian mother who was diagnosed with HIV in 1991, admitted:

some of the days I've been so sick I wish I wasn't here. It would have been easier on me if I had died. But I wanted to live, [be]cause of my son, and now my husband. Someone has to take care of him, them.

Like the other 23 mothers in the study, Lori's responsibility as the primary caregiver provided a purpose and meaning for managing fears of HIV. Tolerating ill-health and fighting against the odds for survival was reported to be worth every bit of comfort and security obtained from being a mother.

Knowing reasons for staying alive enabled these three women to adapt to changes in their health. Their vulnerability increased yet motivated them to better manage their fears of HIV. Struggling with vulnerability often consumed their limited energy. Striving for longevity was constrained because it depended on the successful handling and limiting fears of HIV. Fears of sex were reduced by sexual abstinence due to diminished or absent libido and/or the realization that in a relationship "hugging, holding, and having someone" were as important as sex. In having greater difficulty struggling with vulnerability and less energy to strive for longevity, a woman became less optimistic about her mothering capacity, and if a mother, she experienced greater mothering anxiety, as shared by Cindy:

And like D. [my spouse] has been wantin' to have another baby and I want another baby but it's like then I say, why? Why should we even try, like I don't wanna go through the same thing I did with J. wondering if the baby's gonna be HIV and stuff. And like now that my counts so low I'm afraid that it's too risky.

Managing their fears of HIV emerged as an important aspect of the women's experience of 'struggling with vulnerability while striving for longevity.' By controlling their fears, all the women in the study reported they learned to live with HIV and to cope with the triple burden of the disease. In simplifying and re-evaluating their goals, priorities, and beliefs in life, they succeeded in dealing with the practical and pragmatic aspects of living with HIV. However, managing fears of HIV failed to resolve any fears or anxiety about their future in terms of dying and death. To reduce the stress of "death anxiety," and to gain varying degrees of inner peace, all but one women in the study began exploring their spirituality.

#### Awakening Personal Spirituality

All the study participants knew that society considers death a taboo subject. They were aware that talking about death and dying is considered by others to be rude, bad luck, or both. Without a cure for HIV and with many friends dying from AIDS, this aspect of life could not be ignored by the 32 HIV-seropositive study participants. As noted by Spring, "to face death it's like wakening up all the parts of you that you don't have to deal with when you're healthy." However, knowing death can come at anytime was not easy to accept. Joe, who was not HIV seropositive and was Crystal's primary support person for more than three years, expressed this:

Me and Crystal have to live every day knowing Crystal is going to die. She's 25 and we actually do pretty good 'cause the virus is undetectable and Crystal doesn't take any medications. But it's hard to accept. Like do I even have 10 years [with her]? And it was hard to begin with, like when we first had the baby. It was hard. I can remember Crystal waking up and crying. And there was nothing I could do. There was nothing. I felt kind of helpless. I felt like I couldn't do anything. And [since then] somebody told me that I had probably did the best thing and that was just be there. I never ever at the time left her alone.

In this study 'awakening personal spirituality' is defined as discovering or renewing their spirituality. When individuals denied this aspect of life, they often doubted their personal capacity to struggle and enjoy life. As a result, these individuals had a pessimistic outlook and were bitter about their unfortunate circumstances. When awakening their spirituality, study participants discovered that their 'true self' represented an eternal spirit, and that this part of self was connected in some way to "an almighty but not punishing force." Mark, the primary support person of Cindy for six years, shared a view of this higher force that was shared by all but four study participants: "a God [who] will give me what I need, but maybe not what I want." Fears of dying and death were minimized while struggling with vulnerability was manageable and greater striving for longevity was possible, as a result of having faith in the unknown and trusting themselves as spiritual beings.

In the study two women reported denying their spiritual selves. Elmo shared her experience:

I'm not into religion and [be]cause I'm just getting comfortable believin' in myself, how can I believe in somebody when I don't believe in myself. I'm just coming to terms with believing in myself. Like the things I can do and things that can't be done. You know, then putting all my energy in believing in something, someone I've never seen. And if there is a spirit part of self, then it's a shock. It's a part of me I don't know about [be]cause I'm still discoverin' who I am, you know.

Diana claimed to have a philosophy of life that was not too religious or Christian but more about common sense and being a decent person. Most of the women spoke about experiencing varying degrees of personal transcendence and transformation from awakening their spirituality. In this way, they were able to discover, re-claim, or strengthen their spiritual, religious, or philosophical belief system. For example, DJ, CJ, Cupcake, and Susan cherished even more their beliefs in God. Heather, Christina, Crystal, Recovery, and Spring found comfort in Christianity that they had not thought about since childhood. The other 18 women carefully examined what they believed in and

then drew on traditional sources like mysticism, Buddhism and the First Nation medicine wheel to create an eclectic philosophy of life.

Death-related events, such as surviving drug overdoses, car accidents, physical or sexual assaults, and having their babies or own mothers die, heightened their awareness of everyday life in terms of where they are coming from, where they are going, and who they are. The death of a child, stillbirth, or miscarriage was particularly traumatic for five mothers in the study. In losing a life, or potential life, these women reported wondering about the purpose of life and subsequently questioned their beliefs in God or the Creator, and their relationship with this higher force. Below are Spring's experiences of witnessing her grandmother dying of old age and her two-and-half-year-old daughter dying of a HIV-related condition:

She wasn't afraid. She was like my grandma when she died. My grandma died at 94 and she always believed in God and she was happy to go [because] she knew she would be taken care of just like my S. [daughter]. My grandma closed her circle [when she died]. The circle was just smaller for S. I'm sure when she was suffering [for two months] and everything she went through are all the same things that we go through in life. But she did it in a very short time. That's what comfort[s] me when I think about it. Her life was complete. I'm sure about that.

The majority (27/29) of the women in the study recognized the spirit of true self and spoke about gaining inner strength in feeling that they were an important part of the universe. Some of them even suggested that there was a plan for the universe, as reported by LK, who recognized an unplanned pregnancy in 1993 as a turning point in her reproductive life:

We don't know why these things happened but this is a gift from God. And you don't need to ask why. Those were the only words [spoken by my elders] that made sense to me at that time. And may be those were words that I wanted to hear. I don't know the answer. But I knew in my heart and in my soul and [by] my strong intuitiveness that this [pregnancy] was right for me. That I could deal with this [situation].

This knowledge that all human beings are related through one spiritual source decreased loneliness or social isolation experienced from living with HIV. Fear of dying was



diminished by knowing that self is more than just a body or ego, and includes the existence of the spirit of true self. Crystal offered her own explanation for recognizing her spirit of true self:

I believe there's a God. I pray, but at the same time I won't be too disappointed if after I die, there is nothing because I won't have a chance to be disappointed. Do you know what I mean? It's kinda like I'm trying to cover all my bases. You know. What if there is God? And that heaven and hell do exist? Are you will[ing] to take that chance? Like if you die and there is nothing, it doesn't really matter. But if there is, I hope to be on the right side of it [heaven].

All but two women in the study talked about endeavouring to make peace in themselves by resurrecting and reconciling their past with their present life. In this way they could face the future, enjoy any goodness in their lives, help others enjoy their lives, and, if mothers, teach their children how to be loving persons who respect others while making a better world. To sustain their faith in the unknown and to worship the sacredness of God or the Créator, these women talked about, in varying degrees, praying to communicate their fears, anxieties, and joys with their spirit self or God. If First Nation in ethnicity, the women spoke about smudging which is a traditional ritual of burning fragrant sage. This ritual involved brushing the smoke all over the body to purify it and to renew connection with the Creator. Three others spoke about going to church, meditating on a regular basis, and walking in the woods or on beaches to quiet the mind and body and attune to the spirit self in silence. By awakening personal spirituality, 27 women in the study reported being able to resolve or mitigate the psychological and emotional suffering that occurred when facing a turning point in their reproductive lives. In response to pregnancy, 13 women in the study spoke about appealing to a beneficent, personal higher force for guidance and acceptance in their reproductive decisions to gain confidence in their mothering capacity. The 13 women who chose to carry on with pregnancy found inner strength from their spiritual or religious faith and from trust in "a Higher Force that gives them only what they can handle." To sustain their faith during pregnancy and to reduce

mothering anxiety, these women spoke about praying and asking God to spare their babies from being HIV infected. Two women spoke about bargaining with God. Recovery, who was addicted to heroin and cocaine, made such a bargain in 1993 when she learned simultaneously that she was pregnant and HIV seropositive:

Let me see how I worded this [my prayer]. Okay, Lord, uhm. I ask you to give me another child. Like I've always wanted a baby and I wasn't doing a second abortion. I wasn't ready for it. So please give me a child. If you have to give me AIDS in order to have this child, then I'll have it. But let me have the child first. So I traded my life for hers. That's basically what I did to get her from God. But I worried all the way through pregnancy. I was so scared that I was gonna give my child AIDS. Like the nurses told me, they'll only live to five if they are born with it and that they get sick all [be]cause of my HIV.

The six women who chose to terminate pregnancy also found inner strength from their spiritual or religious faith because they believed that God or the Creator would forgive them for this action. They were able to reconcile much of the suffering that arose from the conflict experienced in their hearts from not wanting to have an abortion and in their minds from worrying about dying and abandoning their children at a young age or giving HIV to their future babies. To ease guilt from having an abortion, LK found spiritual strength in a different way:

The buffer zone was, "okay, I'm sorry that I had to do this [terminate pregnancy]. You know, I apologize." Like at some level this little person was there briefly for a moment and I'm sorry I couldn't be your parent. And for whatever reason you've become part of my journey and there's that part of it that in a way, I did kill this person. But it wasn't this, "Oh my God, I'm terrible. I've had an abortion kinda thing." It was like, this is just part of the journey and I'm very blessed. I'm very blessed to have had this opportunity to feel like a normal woman. That sort of normalcy, that millions of other women have felt, that same feeling regardless of their HIV status, their physical health or well-being or whatever.

The majority (27/29) of the women in the study claimed that awakening personal spirituality was an important aspect of their process of struggling and striving while living with HIV. They experienced inner strength from connecting with a beneficent higher force, a force that diminished their struggle with vulnerability and helped them to strive for

longevity. They felt an enhanced personal capacity to face life and death which contributed to more confidence in their 'mothering capacity' and more courage to manage 'mothering anxiety;' this condition might contribute to having a baby in the near future. All but two women were able to renew, restore, or discover "their faith in life" and their ability to make reproductive decisions about conceiving, terminating or continuing with pregnancy that let them, as Susan said, "have peace with God and sleep at night."

### Yearning for Connection

In being able to thrive while living with HIV, all the women in the study reported that they agonized in varying degrees whether to involve others with their poisoned fate. 'Yearning for connection' is defined in the context of the study as longing for connection with other persons like family members and friends or pets. The term 'connection' refers to an interdependent relation that included a commitment in responding to the needs of those involved and of the relationship. Two major aspects of connection are 'caring' and 'attachment.' Based on the view of all the study participants, 'caring' is defined as feelings of kindness, love, support, and involvement with others. 'Attachment' is the bond that occurs when loving a person, child, or pet. The nature of this caring and attachment is a reciprocal relationship. Howl, who was the common-law partner of Heather for more than one year, offered this view about the complexity of a connection:

It's love. It's a relationship. It's the whole process. Everything. It's not just one part of the relationship. And it's made stronger when it comes from all directions. Just to care and being whole. It's not because I like the sex or it's because she's closer to my mind, my personality. It's not like that at all. Like we're total[ly] different individuals. We have totally different beliefs and we like different things. It's not that we have similar taste or anything. It's not from what we have or what's in the surface. It's not coming from there. It's just a mystery that comes from the heart. I cannot explain and if I could explain it wouldn't be love.

When women in the study experienced mutual respect in their social relations, they indicated that their capacity to love and be loved was nurtured from connecting with others. They experienced no longer being alone, making struggling with their own vulnerability

much easier. In knowing others cared about them, they reported gaining inner confidence, not wanting to give up on life, and striving even more for longevity. Courage enabled these women to overcome any fear of rejection that suppressed or decreased their yearning for connection. Laura believed a person who is not living with HIV would have to be exceptional to accept her disease. As a result, she wondered whether it was realistic to long for connections:

One day I sat and started to cry [be]cause I thought, well if I had just started dating somebody and after a month we were talkin about intimacy and he told me he was [HIV] positive and would I stay? I don't know that I would. You know. I don't know if I could accept it. So how can I expect somebody else to accept me this way. I don't know if I would say, oh well, that doesn't matter. I mean I realize that you can kill me with this thing. That I'm fine with it sorta thing.

The experience of a poisoned fate taught all the women in the study about the benefits of having connections. Specifically, all of them had suffered privately, and to decrease or resolve this suffering, they searched for love and discovered it within themselves. In discovering the importance of self-love before loving others, all the women reported having an even greater appreciation of a person wanting to connect with them or loving them without reason. This love, "giving unconditionally one's heart," is described by Heather in relation to Howl, her common-law spouse of more than a year,

If I didn't have my partner, I don't know where I would be. I don't know if I would be on this earth. You know. And it's [be]cause of the love there. Like I was always searching for love. Love from the drug or love from a John [a man who paid for sex] or you know like I'd find a John and try to make them someone else. I didn't get it from my family and now I have it from a person that loves me very much. He was there for me even when I was using heroin and working the streets.

The more time and energy, both physical and emotional, devoted to keeping a connection meant less opportunity to dwell on fears of HIV. From having connections, the women in the study had a sense of belonging in the world, being loved, and loving others; this helped further reduce the struggle with their own vulnerability and enhance striving for longevity. Another outcome reported by all the women in the study was personal

happiness from the on-going comfort and security of a connection. For example, Laura knew that her close friends were still angry and blamed her boyfriend of five years for infecting her with HIV. Still, Laura chose to secretly spend time with him because of their connection:

It's meeting my need to be loved. Being accepted and just having somebody look at you [and] still be desirable. Instead of looking at like, ugh, walking, talking virus spreader. Like I know I will never be able to marry him or anything like that but for now it [the connection] makes me feel accepted. It makes me feel loved. It makes me feel sexual. It makes me feel like a whole woman. And that's the only person I've been with the last five years that made me feel that way. The other ones tried as hard as they could but they were both [HIV] negative but I really never felt like I was enough. I just felt that there was just something lacking.

Sadness or loss of happiness also occurred when connecting with others. All the women reported experiencing varying degrees of distress from knowing that when they died their cherished friends, family members, and/or pets would be abandoned. The women dreaded dying and having their loved ones left alone with memories and grief. The greater degree of intimacy or depth of feeling contributed to greater personal happiness or sadness in their lives. In the case of Lisa, connection was the reason for staying alive:

If he [my boyfriend] hadn't been around, I probably would have committed suicide that day. I coulda killed myself this last year. But I didn't. He was there for me. He was there for me when I wanted him. All the time. It made a huge difference. Like he tells me every day that he loves me and that it doesn't matter me being [HIV] positive.

A paradoxical danger of having connections with others was the potential to be vulnerable. The longer a connection existed, the greater the vulnerability, especially when loss of a connection is predictable, for example when two mothers in the study cared for their dying HIV-seropositive children. Women were also at risk when private fears of living with HIV were exploited by others, as in the case of Spring, who was treated badly by the father of her children:

[He was] mentally abusive, abusive in his words, making me feel that I was lucky to have him. I wouldn't get any better and with that fuckin' disease I

wouldn't get nobody and, you know, he used that a lot. He's the best I can get anyways, so I better hang on to him.

Sometimes, vulnerability occurred when strong attachments resulted in co-dependency, as observed by Bill:

Now, after being together for more than four years, it's progressed where there's a dominating factor. I don't explain the reason as to why we're going out or what we're gonna do. It's just you know, get ready, we're going out. And remember the last time I was hospitalized? S. was lonely and lost without me. She'd come by to the hospital and was drinkin' and doing drugs 'cause I'm not home.

Michael expressed a different view of vulnerability, one that emerged from being with Diana ever since she was diagnosed in 1993, and was echoed by the other primary support persons who shared their partner's poisoned fate:

As I head off to work at about quarter to eight, I'll say did you take your pills? And I mean so much when I say that. I mean I want you to stay alive. I mean I need you in my life. And the little things like the housekeeping chores I do before I leave is my way of saying have a good day. It's important for me to do these things but I do not verbalize enough. And may be again as a typical male, I do not touch in non-sexual ways nearly enough. When I touch her face and kiss her gently, she melts. Not sexually, but in a way that just makes us feel so much closer . . . There's the fact that our relationship is [also] limited in time. That in all likelihood I'm going to face the world without her in the next two or three years. I'm terrified that she's gonna start getting sick in two or three years. And I'm gonna be on my own (crying).

Women are likely to experience less vulnerability when a connection is brief or involves little intimacy. In preventing any deep intimacy in a connection, a woman may ensure happiness simply as a result of not being alone or socially isolated. For example, at a non-profit organization called Big Sisters, Laura volunteered as an older sister for a girl who could benefit from consistent, loving, supportive companionship. In this way, Laura reported satisfying her yearning for connection and having a purpose in her life from helping others, without risking real loss.

Sometimes women faced greater struggles with vulnerability and focused little on longevity because they made only short, superficial connections, promiscuous sexual

encounters devoid of any caring and attachment. For 12 women in the study who were experienced sex trade workers, these particular connections were physically intimate but were just an aspect of prostitution or "turning tricks." CJ, a 34-year-old Caucasian woman recovering from heroin and cocaine addiction and living with HIV for more than 11 years, longed for connections with others, but was unable to act on this need because of a spoiled sense of sexuality resulting from sex trade work and the stigma of HIV:

Intimacy is being close to someone and being able to tell them everything. You know just having a real tight bond. But it's been so many years. You know, I live like a double life. It's like I'm two people [be]cause I work the streets [prostitution]. Doing blowjobs and stuff. So it's hard to get intimate when you've been workin' the streets. And a lot of people just don't understand the disease. Like this gentleman I really, really cared for well I knew his thoughts on HIV, that he was so scared. So there was no way I could ever be intimate with him [be]cause I couldn't tell him I'm HIV.

Yearning for connection emerged as the social aspect of the larger process of struggling and striving while living with HIV. All the study participants acknowledged that the benefits of having connections outweighed the potential danger of physical harm and anxiety of HIV-related stigma. Each connection was mutually beneficial and satisfied a need for caring and attachment. As a result, they struggled less with vulnerability, had greater social support and could strive for longevity, knowing that others depended on them.

The longing for loving relationships affected women in several ways. When a HIV-seropositive woman suppressed her need for connection, she experienced less confidence in her mothering capacity. She would also suffer greater mothering anxiety if she isolated herself from other HIV-seropositive mothers who could share practical and pragmatic aspects of motherhood. In contrast, a woman's yearning for connection might motivate her to become a mother for the first time, or to have another child in order to increase connections with others. On the other hand, if a woman living with HIV doubted her mothering capacity and experienced mothering anxiety from social isolation, she might

avoid having a baby, and might satisfy her need for caring and attachment through mutually beneficial relations, as Diana who, like three other women in the study, did with her pet:

You can get it from a dog. That's truly special. Dog and cats. Look at this. That's my cat. I love her. She's my child. You know. I don't feel bad about taking her for my needs. (laughs) You know what I mean. She depends on me and I depend on her. How pathetic, but it's true. And if you're fulfilled that way. You know love and to be loved are being met. You're less likely to have those other urges like have a child to get those needs met.

Laura chose not to become a mother and remarked that her tropical fish and many plants that thrived as a result of her care and attention fulfilled her yearning for connection.

In summary, the overarching process of affirming life despite a poisoned fate encompassed the very complex realities faced by women living with HIV as they made reproductive decisions. This process forced women to deal with the competing issues of struggling with their own vulnerability while, at the same time, striving for longevity. As they did so, they experienced emotional, psychological, behavioral, spiritual, and social challenges, such as wanting to live, managing their fears, awakening personal spirituality, and yearning for connection.

These experiences set up conditions which shift as the woman's life with HIV unfolds and her life context changes. Where the woman finds herself in terms of struggling and striving will determine to a significant extent whether she will, through sexual activity or having a baby, risk a deadly connection. For example, if a woman is feeling strong, healthy, and optimistic about living a long time, she may risk a deadly connection since she is not afraid or intimidated at the prospect of possibly transmitting the virus. Others may feel more ambivalent, and still take the risk, such as when a woman is relatively healthy but feels afraid and quite vulnerable: her emotional need for connection may override her knowledge of the risk. Others may be so physically and emotionally vulnerable that they simply deny their situation; in this case, they may be unable to decide to protect others, and in the end, will take the risk.



### Risking Deadly Connections

I remember sitting in the Positive Women's Network [dining area] and uhm another woman saying, "you know I have to lie to my doctor about my husband and I having unsafe sex. Like I'm in a monogamous married relationship and I have to lie to my doctor about having unsafe sex." Like there's something seriously wrong here. For her to lie about what she chooses for her body. You know, there's this fear it's not gonna be okay with somebody, with my doctor, with whoever. And I just thought, you're the only woman in the entire time that I have had this [HIV] that I've heard say that. And I can totally relate to that. I can totally relate to that.

- LK

'Risking deadly connections' essentially was the act of unprotected intercourse which might lead to the infection of the partner, or conception and infection of the fetus. Whether or not women took this risk depended in large part on what motivated her to make this connection (i.e., vulnerability or longevity) and the woman's sense of 'how risky is risky?' That is, women risked or avoided deadly connections based on their own sense of relative risk. How women calculated this risk changed over time and in relation to their life context. The following section describes how women assessed the relative risk of 'risking deadly connections,' how doing so led to heartbreaking decisions, and how individual differences accounted for different outcomes in the overarching process of affirming life despite a poisoned fate.

### Determining Relative Risk of Risking Deadly Connections

Women determined relative risk associated with unprotected intercourse and pregnancy in four main ways: (1) practicing common sense; (2) romanticizing sex; (3) sensing HIV risk; and (4) moralizing potential harm. All the study participants emphasized that knowledge is not enough to change behavior, especially when it comes to having sex, and that it was the meaning of risk that ultimately determined their behavior. They spoke about using consistency and care regarding risking deadly connections. In this case, the term 'care' had a dual meaning: (1) paying attention to proper condom use and (2) censoring their sexual behavior. In the latter, this meaning was based on the social norms

about sexual responsibility (i.e., safer sex involved particular behaviors to reduce sexual transmission of HIV).

This process of determining relative risk of risking deadly connections was highly subjective in that it allowed each woman to justify, consciously or unconsciously, how they behaved (i.e., whether they were consistent or inconsistent, careless or careful about using condoms) at each turning point in their reproductive lives. When having sex, all the women reported that to some extent they had to reconcile the psychological needs and powerful emotions in being loving, sexual persons with the intense fear of giving HIV to their sex partners. In being careful or careless about risking deadly connections when having sex, women faced decisions about contraception that protected both against pregnancy and against the spread of HIV, as noted by Louie:

When I use a condoms it's to keep the other person healthy. Like if I was to have sex with anybody else but this person, I would be using a condom not to protect against pregnancy but to protect [against giving] HIV. And then it's a bonus to realize, hey, I don't have to worry about pregnancy so much.

Practicing common sense. The women spoke about ignoring or using contraception in terms of 'practicing common sense.' Failure to use contraception was considered by all study participants to be "stupid," "not very smart," or "inexcusable" because pregnancy could result. Yet only one study participant reported using contraception consistently to protect against conception and heterosexual transmission of HIV. Even prior to becoming infected with HIV, most women in this study had inconsistently used contraception.

'Practicing common sense' was reported by five women as their reason for having a tubal sterilization. These women were mothers who believed that they were too old to risk childbearing or that they could not endure the psychological and emotional trauma of either giving HIV perinatally or terminating pregnancy. A tubal sterilization provided the means for handling and limiting fears of HIV transmission perinatally as shared by Crystal:

My perception is that they [HIV-seropositive children] don't live long. I think they only live to be like seven and even if they do live to ten or longer that's not very long as far as I'm concerned. And it's an awful way to have to die. You know, to be born just to be sick and unhealthy and have to take drugs to be healthy. And then to have your brothers and sisters watch you die and suffer. That's pretty awful for everybody, I think. You know for A., M., and J. [her children]. I think that's what bothers me the most is the thought of being the one who's made the child suffer. That I had a way by having my tubes tied and practice being safe when having sex. Then I know there's one less person that has to go through it.

For three mothers, they claimed they were practicing common sense when they refused to have a tubal sterilization. Their concerns about the impact of a tubal sterilization on mothering capacity and future pregnancy choices is voiced by LK:

If there's a cure and I'm around when it happens I'm gonna have more kids. Like that's on everybody's mind. It's just part of like you don't want that hope taken away from you. You don't want somebody come and burst your bubble. You don't want somebody else's fear. Well, this is what's in store for you kinda thing. You know the statistics, the numbers. The indefinite, the definite you're gonna die kinda thing. Like everyone's quick to tell you that. And it's like okay I can hear that. And it's like I never got my tubes tied because I knew there's a possibility. And if I take away that possibility by cutting a piece of my body out then I'm never gonna know what's gonna happen. And for me it comes down to this is the consequence of not doing that. Now I have a child. And I think about the next ten years and the ten years after that. You know what I do today will have an effect on the future in one way or another.

In contrast, two primary support persons indicated that having a vasectomy or a tubal sterilization would increase risking deadly connections. Simps, Jane's spouse for more than seven years, had witnessed his nine-month-old daughter die of an HIV-related condition four years ago:

I think she respects my opinion about the fact I definitely don't want to have any more kids. Like any risk [of perinatal HIV transmission] is too high. Unfortunately I haven't gone under the knife to have that fixed [a vasectomy]. But I think that kinda keeps us in check as far as safe sex [using condoms]. I think if there was no chance of getting pregnant, then chances are safe sex would fall by the wayside uhm not on a regular basis, but semi-regular basis.

The majority (19/29) of women reported using condoms or condoms in combination with another birth control method as contraception to prevent a deadly

connection. For all the study participants, the meaning of condom use was affected by their life context that contributed to risk taking as described by Destiny,

It's kinda two fold thing for the use of condoms. One is the birth control issue and the two the disease control issue. I think early in our relationship it probably was more birth control as opposed to disease control. I mean they've always been fairly equal, but I think it was a little more biased toward the birth control. Like except very early in the relationship, after we got married we tended to use condoms more frequently. Then later as we got more attuned to having children and becoming more accepting of that we had more unprotected sex [used no condoms].

Prior to being diagnosed with HIV, birth control pills were most often reported as the recommended contraceptive by physicians because this method was assumed to be 100 percent safe against pregnancy. For the majority (16/29) of the women in the study, this method was not effective because of poor compliance from hating to take pills, forgetting to take the pills, or deliberately avoiding them because of bothersome side effects such as headaches, feeling bloated, and weight gain. Although these same women knew that they could get pregnant when having sexual relations if they did not take their birth control pills properly, they did not use additional contraception. Three women, after being diagnosed with HIV, refused to take birth control pills because they believed that their bodies were contaminated enough by HIV and toxic antiretroviral medications.

Women often ignored common sense when they had a serious drug addiction or had amenorrhea as a result of their drug addiction; or when they were in their early teens because they did not want others to know that they were sexually active. Cindy ignored the possibility of pregnancy (as did 16 other women) through careless reproductive behavior: "As long as I was getting away with it [not getting pregnant], I didn't bother about birth control." "Believing they were sterile" was another explanation for ignoring common sense as described by LK and five other women:

until my daughter's birth, I didn't believe I could get pregnant. Physically get pregnant. Because during my teenage years I never got pregnant. Up until 21 [years of age] we used condoms sometimes but not all the time. And I don't get pregnant so I don't have to think about it.

Thus, contraceptive use represented the 'practical' determinant of relative risk. All the study participants agreed that proper contraceptive use decreased the chance of a deadly connection and simplified reproductive decision-making. The more women reported fearing pregnancy, the more care they took with contraceptive use as a way to avoid a heartbreaking decision about continuing or terminating a pregnancy.

Romanticizing sex. When the women distinguished between lust as physical desire and love as emotional feeling in a sexual relationship, this process was referred to as 'romanticizing sex.' Lust referred to passion that was primarily motivated by the psychophysiological arousal brought on by another person. Love referred primarily to intimacy and feelings of caring, support, and involvement toward another person. All the women in the study reported being motivated in using condoms. However, their good intentions could be thwarted by romance, that is, being swept away by lust, by love, or both, as in the case of Louie:

I've said to him many times you're the only person I love and yet, you're the only person I'll put at risk. Like that doesn't make sense. Right? Like if I was acting in a loving way towards you, I would make you use condoms.

In contrast, these same emotions and physical sensations could motivate women to be more careful and abstain from sexual intercourse or insist on proper condom usage.

In light of love or lust as an aspect of sexual intimacy, all the study participants complained that condom use made having sex mechanical. As Michael noted, "you have to stop and perform some technical functions before proceeding with the act [sexual intercourse]." For the eight women in the study who talked freely about experiencing lust as "raging hormones" and "feeling horny," the strong desire to act on sexual urges compelled them to be careless about condom use. Only Jane remarked that when she had a craving for actual sexual intercourse she was more careful about using condoms to protect against an unintended pregnancy.

All the women in the study emphasized that when love motivated and sustained a heterosexual relationship, condom use was often inconsistent or nil, which paradoxically resulted in a higher risk of a deadly connection. For them and their primary support persons in the study, being in love meant being in a committed, monogamous relationship, where, according to LK,

you find someone who's willing to struggle with you, accepts you as you are and despite your flaws and problems to be there [for you]. You respect and trust each other and do not worry about being judged.

Love created a greater desire for the majority (24/29) of the women in the study to perceive sex as "making love" that feels more intimate, emotionally and physically, and more natural when not using condoms. Four women in the study spoke about experiencing love and lust simultaneously; this contributed to "living in the moment" and achieving a "profound connection" with their sex partners from not using condoms. When intense emotions and physical urges brought forth either love or 'loving passion,' the women reported that thoughts about the consequences of risking deadly connections was momentarily extinguished. Love and loving passion compelled all but five women in the study to be careless about condom use, increasing deadly connections. Another five women spoke about love for their boyfriends, husbands, or spouses as the reason for being more careful about avoiding risking deadly connections (i.e., protecting against giving the partner HIV through sexual contact). Only DJ was cautious about love and lust that contributed to avoiding or being careful about risking deadly connections as a means of protecting her vulnerability:

I am concerned about me. And my feeling is as a female, we're the receivers. It's fairly hard for HIV to be given to a man from sex. But I feel that as females we're gonna be receiving other infections and that's my worry. And you know, I got it [HIV] from loving someone and I don't wanna be hurt like that again.

For all the study participants the use of a barrier contraceptive method like male condoms was a reminder of the dangers of sexual intimacy. The six primary support

persons who were HIV seronegative talked about not using condoms occasionally to reassure their loved one that they were neither afraid of HIV nor did they fear getting it. The other two primary support persons believed unprotected vaginal intercourse was risk-free because they shared the same diseases and were committed to a monogamous relationship. Inconsistent condom use or its absence was done based on the belief that there was little danger in the woman giving HIV to her sex partner or on a romantic notion regarding the peril of a deadly connection, as confessed by Heather:

I wanted to see what his reaction was. Which was very selfish and stupid of me to do. [Be]cause I coulda got a condom but I didn't. I wanted to see if he would still have sex with me without a condom. In my mind without telling him this. You know testing whether he really loved me, truly accepted me. And he did. He would risk his life to be with me.

Of all the study participants, only one couple talked about trying female condoms to prevent deadly connections. They claimed that female condoms were less convenient than male condoms and destroyed any romance in having sex, as reported by Michael,

[Female condoms] they're harder to insert [be]cause you insert it into a woman's vagina. The advantage of course is that D. [his wife] can do this ahead of time so that in the heat of passion things would all be ready to go. But the thing sticks out two or three inches. So the esthetics are not attractive and then you've got to find the ring and make sure you've got the right hole and so on. (slight laugh). The very first time D. and I tried it, I missed. I didn't get it in the ring and it ended up being unsafe, unprotected sex with D. It actually was a little riskier (laughs) at that time.

Thus, the emotional aspects of sex could be seen as the 'romantic' determinant of relative risk. Romance either excused risking a deadly connection or justified avoiding such risk.

Sensing risk of HIV. All the women in the study considered themselves to be nurturers and lifegivers, not "murderers." To mitigate the risk of transmitting HIV psychologically and intellectually through sexual intimacy and childbearing, all the study participants deferred to either intuition, deliberation, or both. In this study, 'sensing risk of HIV' referred to women's sense of intuitive or calculated risk that minimized or resolved the unknown in risking deadly connections.

Three women in the study spoke about 'intuitive risk of HIV' when making decisions about pregnancy. Each woman found that medical information about the risk of giving HIV perinatally was not helpful in diminishing contradictory thoughts and strong feelings about giving life and having a child/family. These women ended up listening to an inner voice that they claimed was intuition. This inner voice informed each of them to not fear childbearing and to believe that they would have a healthy baby free of HIV. Susan described intuition and its role in her reproductive decision-making:

Part of it [intuition] is within you and some of it is given wisdom for the moment. You know for that particular situation. So I think part of it is common sense, wisdom for the moment, and a gut feeling. What does it say in the deep, deepest part of self. I remember asking this old Jamaican woman about how to make a huge decision and she said that if you can make the decision and you can sleep, that's the decision to go with. If you're feeling tumultuous and wakin' up and you're always wondering, she says, that's not the right decision to make. So if it's chokin' the fear outta ya, it's not the right decision.

All the primary support persons and four women in the study spoke about the "calculated risk of HIV" when having sex. By intellectualizing feelings such as "I have nothing to be afraid of because we're taking controlled risks," they were able to practice "risky sex" and not use condoms. Based on medical information, risky sex involved sexual behaviors that decreased the chance of a conception or infection and that allowed these study participants to feel normal and be like other intimate, heterosexual couples. For example, the six primary support persons who were not living with HIV knew that they could get HIV from a woman through sexual contact. However, they regarded the chance of transmission as unlikely or even non-existent when the woman's viral load was zero. Michael elaborated more fully on the notion of risky sex:

[Be]cause HIV concentrations are far greater in blood than in vaginal secretions, reasonable precautions means using a condom most of the time. We've always been comfortable with ah fellatio [be]cause we talked to some doctors in Vancouver and were told there was absolutely no record of somebody getting it [HIV] from fellatio with an uninfected. And just recently we have started to become comfortable with cunnilingus [be]cause I am not aware of any actual recorded cases [of HIV] that is from cunnilingus either. . . . You know, when she [his wife] starts having like a 300,000 viral



load we're probably gonna have to change some of our practices.  
[Be]cause I'm not deliberately trying to kill myself.

Denial is another aspect of how women and their partners calculated risk. Once the possibility of infecting those they loved was accepted, the majority (27/29) of women in the study experienced immense fears and anxiety about having sex and childbearing.

Sometimes the risk of giving HIV was ignored or denied. Happy and Mouse knew unprotected sexual intercourse was risky but reported that their boyfriends of more than five years had refused to use condoms. However, they claimed that their boyfriends' subsequent HIV infection resulted from sharing dirty crack pipes with friends as opposed to monogamous, risky sex with them. Denying risk of HIV when having sex allowed the majority (34/39) of study participants to ignore common sense and use contraception inconsistently thus increasing the risk of deadly connections.

Women also calculated the relative risk of a deadly connection resulting from pregnancy. Study participants calculated the risk of perinatal transmission based on knowledge that the chances of the mother giving HIV to the child ranged from 10 to 50 percent. For all the study participants, this information contributed to fears about creating a deadly connection and anxiety about childbearing as noted by LK:

If I flip a coin, you're thinking 50-50. It's heads or tails. It's like playing Russian roulette with you know one bullet in the gun kinda thing. It just has this dread attached to it. It's like well 50-50, you know, you either are or you aren't. There's no in-between. At least with 25-75, there's a bit more of a gray area. There's room to move. It's like okay, well I could deal with that. There's like one in four chances. It just gives you a bit of hope. If it was 50-50, it would be like shit. Do I wanna do that? Do I wanna take a chance? That's too heavy duty of a responsibility.

Even when they believed there was a 10 percent chance of HIV perinatal transmission, six women in the study experienced horrific pregnancies from worrying that their baby would end up being the one out of ten babies born from HIV-seropositive mothers infected with HIV. Howl emphasized that for himself and his common-law spouse, Heather, the calculated risk of HIV was irrelevant when continuing pregnancy:

Even if we didn't do anything and it [HIV perinatal transmission rate] was 25 percent, we're not gonna change anything. We gonna do the best we can. We are not acting because of odds. And even if it was 99 percent chance baby is healthy. If we made a mistake in deciding to go with it [the pregnancy] and found out, one percent chance [baby will be HIV seropositive] we're still gonna do the best we can to keep the baby healthy.

LK was the only woman in the study who spoke about using both intuition and deliberation when faced with an unintended pregnancy. Her mental process is described below:

HIV and pregnancy has a lasting perception. A lot of it is very factual. The fact that there is transmission and complications that can come from having a baby if you're HIV positive and possibly losing your child. Then there's the uncertainty. Confusion. Excitement and fear. You just feel vulnerable. I think any woman feels that way when she's pregnant. And when you're dealing with the possibility of a life-threatening illness or something happening to your child uhm you feel guilty. You feel afraid about what's gonna happen. And I'm responsible if something happens. I'm the one that did this. Like I don't know what will happen. But I knew in my heart and in my soul and from my strong intuitiveness that this [having the baby] was right for me. That I could deal with this. I just had to trust my own judgment and believe in myself. And knowing my family's there to support me that made a huge difference. We would get through it one way or the other.

Thus, sensing risk of HIV can be viewed as the 'intellectual' determinant of relative risk. None of the women in the study wanted to infect others with HIV and pass on the suffering of a poisoned fate. Still these women were no different from other human beings in wanting to be loved and loving others. For them, sexual intercourse was a means to receive and express love; yet paradoxically it threatened love itself by taking life when HIV was transmitted through sexual intimacy. For 13 women in the study, pregnancy decisions were influenced by the known HIV perinatal transmission rate. Sensing risk of HIV thus enabled the majority (32/39) of the study participants to rationalize risky behavior and to cope psychologically with the unknown consequences of risking deadly connections at turning points in their reproductive lives.

Moralizing potential harm. Like all the study participants, Michael emphasized that "what you know on a rational level and what you feel emotionally is different" with respect

to risking deadly connections. In this study, 'moralizing potential harm' referred to how women minimized or resolved conflicting emotions, values, and beliefs about the moral dilemma in potentially giving HIV through sexual intimacy and childbearing. All the study participants claimed to be "good people" who did not wish to have or give HIV. Yet when having sex without contraception, particularly without a condom, every woman faced the prospect of conceiving and infecting her sex partner, future baby, or both. In being the possible cause or source of HIV infection, all the women in the study experienced varying degrees of paranoia from their potential to kill those they loved. They reported valuing life and feeling responsible for taking care of others by protecting them and preventing the harm and suffering from a poisoned fate, as voiced by Crystal (a former sex trade worker):

I'd say well we have to get a condom [be]cause I don't know if you're okay or not. Couldn't really tell them that I was HIV, it was me. I'd say it was them. And I was always careful about condoms [be]cause a lot of them have families and I don't wanna be responsible for them. You know, killing him, his wife and God knows she could get pregnant and his kid.

Crystal emphasized to her spouse that condom use was acting morally in preventing HIV transmission and diminishing harm to others: "I've said to him, you know, Mom's gonna need you, and I need you to be healthy and strong for the kids [be]cause they're gonna need him, too." However, Crystal's concerns were often ignored by her spouse. Like the majority (25/29) of the women, Crystal admitted having sex without condoms for reasons previously discussed or when refusing to use condoms may lead to violence. In risking deadly connections, the majority (24/29) of the women tried to relieve their guilt by reminding themselves that their power to protect against HIV sexual transmission was limited:

When I had some asshole that said no way I'm gonna use a condom, I thought, well, fuck you buddy. Go ahead. Fuck me. And actually that's quite common. Other women said the same thing and not necessarily working the streets but with any guy who insists not to use a condom. They thought well they're adults and responsible for their actions. I can't be responsible for him and if he wants to do that, that's his problem.

- Heather

However, some exerted considerable control; to avoid conflict with their sex partners and to resolve the moral dilemma of exposing others to a life-threatening, infectious disease, four women in the study abstained from sexual intercourse.

'Honoring life in the womb' emerged as an aspect of moralizing potential harm when pregnant. Having a baby may be chosen as a way to create a new life where the woman was in a loving relationship and was striving for longevity. Alternatively, terminating pregnancy may be chosen to spare a future life (i.e., the death of a HIV-infected baby or orphaning a healthy baby from the mother's poisoned fate).

All the women in the study agreed that it was wrong to deny the childbearing rights of women living with HIV. However, there were varying opinions about whether it was fair to exert these rights in light of living with a stigmatized, incurable disease that can be transmitted perinatally. Crystal elaborated the ethical concerns raised by the majority (24/29) of the women in the study who did not support HIV-seropositive women choosing to have more than one child:

[In childbearing] you're playing russian roulette with an innocent child no matter how good the medications are now. There's still the chance that you're giving your own flesh and blood, pain and suffering just for your own selfish needs. That's what I think it is. If you already have children why bring another into the world? I can understand when women have a baby for the first time and are [HIV] positive. Like there's no good reason to go out and purposely get pregnant when you're HIV positive if you already have children.

Different kinds of love particular to having a baby influenced the way in which a woman could honor life in her womb. 'Romantic love' referred to personal fantasies that a child would bring a couple closer together or was the product of their love for each other. 'Baby love' referred to women's reports of the "hole in my heart" and a yearning to cradle her own baby. 'Maternal love' referred to a natural longing to be a mother. 'Self love' referred to esteeming self and knowing true love begins and ends with self. When motivated by these feelings, childbearing symbolized an act of love that filled an emptiness or loneliness in a woman's heart, overcame a void in a couple's life, and celebrated life.

These same feelings may influence a woman to honor a life in the womb by terminating pregnancy. The responsibility of being a mother may prevent a woman from taking a chance in creating a deadly connection. Self love may compel a woman to preserve life because the burden of mothering would increase her vulnerability.

Thus, moralizing potential harm was the 'ethical' determinant of relative risk. When having sex, all the women in the study concluded that their moral responsibility to protect others from getting HIV was absolved when their sex partners knew about their HIV serostatus and refused to use condoms. When pregnant, all the women in the study acknowledged the moral anguish from conflicting desires to fulfill their dreams to have children and become a mother and to protect their unborn children from pain and suffering. In moralizing potential harm about terminating or continuing pregnancy, women were clear that there was no right or wrong decision. All the study participants indicated that the decision to abort or to carry the baby to term was a caring and compassionate one. Louie elaborated how she resolved her moral dilemma when facing an unintended pregnancy as a significant turning point in her reproductive life:

When I thought about having an abortion, well [it was] not necessarily am I killing a healthy baby, [be]cause I may not be. I may be taking a lot of suffering away from a child. Or it might be the vice versa. I might be taking the life of a healthy child.... Like, you don't know it's a chance either way. The thing with me is, if you have the abortion, then you never will know. Well, I was given support, that's the one best thing [the doctor] gave me, support to have the kid. He made me believe it was quite possible [my baby] would be negative. And so many other positive things happened at the same time with the family...all the support I got, and everything was so positive. So for me, how can it be a big mistake when there were so many positive things? So that that's where I went with [my pregnancy]. But, well, you know if they'd a sent me to the other doctor [who said six months ago I should be sterilized] I would not of had the child, because I wouldn't of believed there was a chance the baby would be okay...I wouldn't have believed I was killing a baby. I would have believed I was like taking away sickness. Like [being pregnant and HIV positive] is something bad, morally wrong.

In summary, women interpreted HIV risk associated with unprotected intercourse and pregnancy by considering the practical, romantic, intellectual, and ethical determinants of relative risk. The process of determining relative danger minimized women's fears and

anxiety about giving HIV when “having sex and babies.” These determinants were used by every woman in the study to justify their decisions about risking or avoiding deadly connections. The following section presents the way in which risking deadly connections sometimes led to heartbreaking decisions in the overall process of affirming life despite a poisoned fate.

### Heartbreaking Decisions

All the women in the study talked about the process of deciding to risk or avoid deadly connections as being heartbreaking emotionally. The 25 women who continued to have sexual relations were torn in their hearts and minds between wanting sexual intimacy and wanting to protect others from getting HIV, as poignantly described by Louie:

It broke my heart the first time he didn't use a condom. What that told me was that it's not good enough with a condom. If it was good enough with a condom he wouldn't be trying to not use one. So then we went back and forth, back and forth for about three months. I'm the one who's crying and upset. Then I just gave up on it. Like I can't be responsible for this. He had to be responsible for himself. I can't be responsible for both of us. Then it was I can't not use condoms [be]cause it would make me cry [be]cause I couldn't use them. Then I decided well fuck it, who cares. Like I'm 18. He's 35 and I'm the one who's upset.

They spoke about feelings of hurt, pain, sorrow, or even grief in response to the multiple losses of a poisoned fate. The types of losses felt most deeply by these women depended on their sense of their mothering capacity and mothering anxiety. These losses included: loss of carrying on the family lineage, if they were too afraid to risk childbearing; loss of control from living with a life-threatening, infectious, stigmatized disease; loss of pregnancy experience from avoiding childbearing; loss of emotional experience from not bonding physically and emotionally with a child of their own; loss of dreams from choosing not to have a child/family; and loss of parenting from not becoming a mother.

Risking or avoiding deadly connections required women to make heartbreaking decisions, even with support from sex partners, friends, family, and health professionals

like doctors, nurses, or social workers. The emotional impact of these decisions depended on multiple factors and conditions at turning points in these women's reproductive lives:

Where I'm at in my life [is that] I'm choosing to not [get pregnant] and I have that choice. You know, it's a conscious decision that no, I don't want children at the moment. And I don't know what would happen if I accidentally got pregnant. I don't know how these thoughts [like] fears of passing HIV to my child and coping with the responsibility of infecting my child would change or what I'd do. [Because my partner and I] we're at the point [in our lives] where we're saying let's be able to take care of ourselves first. And then there's days we don't have food. There are days when you know that it's a struggle to get by.

- Nancy

The majority of the women (23 of 29) reported experiencing regret or even guilt from the possibility of killing those they cherished when they chose consciously or unconsciously to be careless and increase risking deadly connection. In contrast, every time they chose consciously or unconsciously to be careful and avoid risking deadly connections, they reported regret and grief from depriving themselves of feeling normal and being like other loving, heterosexual women.

For example, when having sex, the majority (25/29) of the women mentioned at times "feeling poisoned and being poison" despite the love and affection of their sex partners, as observed by Michael:

My point is that I don't treat Diana like she's toxic. And yet the more open I get with her in our sexual relationship, in some ways, the more inhibited she gets. And that's her problem. She worries about me and that, that lobotomizes her excitement and pleasure because [HIV] it's an infectious disease.

When pregnant, 15 women in the study spoke about their conflicting hearts and minds where "choice is chance" as emphasized by Lori:

You have to choose on whether you wanna take a chance. That's basically it. Because no matter, what it's not a hundred percent safe. And no one else can make that choice. It's the person that's gonna have the baby and hers alone.

Being pregnant with twins and having a primary support person or future father living with HIV, T-Bone revealed the complexity of her heartbreaking decision:

I had a lota fear. And the father, he ended up in jail and couldn't come out here. So I just told him I couldn't go through with it. I didn't wanna take the chance of the babies being born sick or you know, what if one was sick and one wasn't. That's not fair. It's just not fair all the way around. And also what if I got sick or he got sick and we couldn't look after them. Whether they were sick or not, what if we got sick. But the main reason [to have the abortion] was the babies. Didn't want them to come into this world with AIDS or HIV.

At this point in her reproductive life, she was in recovery for drug addiction; she was struggling with vulnerability while striving to prolong her own life. She had two sons aged seven and 11 who lived with their respective fathers. In making the heartbreaking decision to avoid pregnancy and not risk giving HIV to her future babies, T-bone was able to feel grateful that she was already a mother with two healthy children. In so doing, she was able to preserve her life and strive to stay healthy, and to build close relationships with her sons. T-bone concurred that in choosing to terminate pregnancy, she was affirming life despite a poisoned fate.

### Summary of Study Findings

All the women in the study claimed that the process of affirming life despite a poisoned fate captured their experience of reproductive decision-making. The competing elements of struggling with vulnerability and striving for longevity inherent in living as a woman of childbearing age meant dealing with fears of HIV, reflecting on spirituality, and suppressing or yearning for connection. Whether or not a woman eventually took a chance in possibly infecting others with HIV depended on her sense of her own vulnerability and longevity. Women used practical, romantic, intellectual, and ethical determinants to calculate the relative risk of deadly connections and accounted for the diverse and often contradictory feelings and thoughts they experienced when making such a decision. This personal calculation and meaning of HIV risk ultimately influenced every reproductive



decision. Just as every decision marked a turning point in their reproductive lives, each turning point exposed the tension in the reproductive decision-making process. The decision to risk or avoid deadly connections was repeated over and over again as the conditions in a woman's life shifted.

These findings revealed a strong awareness that reproductive decision-making while living with HIV is a complex process that does not lend itself to a simple explanation. Women in the study were constantly reminded that adaptation to their disease is a never-ending process. In particular, women's experiences of affirming life despite a poisoned fate and risking deadly connections demonstrate the traumatic effects of HIV diagnosis with regards to mortality, infectivity, and social stigma. These terms reminded the women that learning to live with their disease is a highly emotional process. The terms used in this theory reflect this reality. Yet for one study participant and others (i.e., health professionals who reviewed the theory), these terms provoked feelings of repulsion.

Interestingly enough, the emotional content of these theoretical terms was valued by the rest of the women in the study. They agreed wholeheartedly that the various components and overall process of affirming life despite a poisoned fate resonated with their life experiences. In speaking honestly about their feelings and reproductive behavior, they broke the silence and isolation of their personal suffering. Further, they hoped in voicing the impact of HIV on their reproductive decision-making, they would no longer be treated as victims, but would be respected as individuals who faced heartbreaking decisions in wanting to protect others while satisfying their needs for a normal woman's life.

In remaining grounded in the women's experiences this theory imparts some understanding about what it is like "under their skin." We learn that their diverse lives accounted for individual differences in their decision-making. We learn that living with HIV affects their reproductive decision-making in four distinct ways: (1) sex becomes more dangerous because of the possibility of transmitting a deadly disease; (2) pregnancy decisions are complicated by both the powerful social norms of motherhood and the

devastating potential to transmit HIV perinatally; (3) the social stigma of HIV and gaps in knowledge about treatment and HIV pathogenesis in women contribute to confusion and ambivalence when facing decisions about risking deadly connections; and (4) reproductive decision-making is about sexual decision-making that fulfills powerful human needs while simultaneously dealing with issues of disease, abandonment, or death.

This theoretical framework has implications for women living with HIV and their primary support persons as well as for health professionals who provide counseling for HIV-seropositive women. The following chapter will discuss these implications and make recommendations based on the study findings.

## CHAPTER VI

### DISCUSSION

This final chapter begins by comparing relevant literature with study findings to examine the contribution of this project with regard to existing knowledge about reproductive decision-making of HIV-seropositive women. A discussion of the limitations of the study is included, followed by implications for counseling women living with HIV who face decisions about sexuality and pregnancy, and finally, recommendations for future research and policy.

#### Literature Relevant to Study Findings

The final step in developing a grounded theory is to determine its relevance (Wilson, 1989). The significance of this substantive theory is elucidated in part by discovering similarities and discrepancies with other work. Literature that addresses the same key issues as this theory (i.e., sexuality, reproduction, and perception of HIV risk for women living with HIV) has been considered and literature previously reviewed in Chapters II and IV is reinterpreted in light of this study's findings.

#### Reproductive Decision-Making Literature

##### Biomedical Perspective

In the reproductive decision-making literature, the biomedical perspective is used to focus on reproductive behavior, such as contraceptive use, pregnancy, and abortion. Published research tends to focus on specific population groups based on age (i.e., adolescent girls, primiparae older than 35); ethnicity (i.e., Hispanic, Black African, or First Nation women); disease (i.e., breast cancer, cystic fibrosis, multiple sclerosis, a hereditary condition like Down Syndrome or Tays-Sachs disease); disability; or specific pregnancy issues (i.e., the use of technology like in-vitro fertilization). In this way the multiple

factors influencing contraception and/or pregnancy outcomes are identified for assisting women who face reproductive decisions.

### Cost-Benefit Model

Much of the existing literature about contraceptive use is based on a cost-benefit model derived from economic theory (Currie, 1988). A cost-benefit analysis suggests that individuals perceive the benefits and burdens of becoming pregnant and having a child in relation to not becoming pregnant. These factors are weighted differently in relation to a woman's stage of life (Furstenberg, 1980). For example, cognitive ability increases with age (Gordon, 1996) and the meaning of motherhood changes with increased options in life, such as getting an education or developing a career (Gerson, 1985; O'Donnell, 1985). Benefits in pregnancy and motherhood as reported are primarily those satisfying psychological needs [i.e., self-esteem and self-worth among adolescent females (Dickerson, 1995; Kaplan, 1997; Musick, 1993; Polakow, 1993)]. In contrast, costs of an unintended pregnancy are in terms of individual, social, and monetary losses with higher costs increasing motivation to use effective contraception (Currie, 1988).

In using this cost-benefit approach, the individual is assumed to be responsible for making reproductive decisions according to a rational process. Reproductive behavior thus becomes the focus of research and intervention rather than the situations that lead to those behaviors. For example, Luker (1975) used the grounded theory method to explore the role of therapeutic abortion for 500 women who attended an urban abortion clinic in Northern California. A decision-making model of risk-taking emerged in which contraceptive risk was based on the immediate costs of contraception and the anticipated benefits of pregnancy. Abortion represented an option for reversing the consequences of contraceptive risk-taking. Along these lines, Miller (1986) argued that a woman's contraceptive vigilance and her actual use of contraception for every sexual encounter depended on balancing the positive and negative feelings about becoming pregnant and

using an effective birth control method. Zabin (1994) referred to this process as the personal "calculus of choice" (p. 95).

The limitations in using a "trade-off" approach to make reproductive decisions is evident in research on pregnancy outcomes among women or couples who are at risk of transmitting a disease. These individuals often choose to continue pregnancies or plan to have children after being informed about high genetic risk and the severity and treatability of a disease [i.e., families informed of a perinatal lethal condition (Hassed et al., 1993); couples identified at risk for producing children with sickle cell anemia (Neal-Cooper & Scott, 1988); parents at risk of conceiving another child affected by cystic fibrosis (CF) (McCrae, Cull, Burton, & Dodge, 1973; Boue, Muller, Simon-Bouy, Faure, & Boue, 1991); and couples at risk of transmitting a genetic condition (Frets et al., 1990) like Down Syndrome (Oetting & Steele, 1982)]. Other studies about the reproductive outcome of genetic counseling reviewed by Kessler (1989) showed that reproductive intention is influenced by perceived risk as opposed to known risks. Accordingly, reproductive decisions are based on the personal meaning of risk information and the life context. A strong desire to have children particularly influenced women and couples to minimize or ignore high genetic risk (Frets et al., 1990; Mennie, Axworthy, Liston, & Brock, 1997). Reproductive decision-making is thus a complex process, and contrary to some widely-accepted assumptions, there is little evidence for a causal relationship between known risk factors and an individual's intention to reproduce.

This study highlights, as other reports do, the powerful importance of the woman's life context in making reproductive decisions. In a follow-up study with 164 couples two to three years after genetic counseling, Frets et al. (1990) determined that high genetic risk and relatives' disapproval of having children had an emotional impact on their reproductive decision-making process. This emotional impact was similar to that which was reported by women in this current study. As long as women perceived a high HIV risk of mother-to-child transmission and had little or no social support when becoming pregnant, they

experienced high levels of mothering anxiety and doubted their mothering capacity. In such a situation, a woman living with HIV is likely to terminate a pregnancy. Again this decision shows that the reproductive decision-making process is not just about calculating risks, but rather is a contextualized, emotionally-laden process based in part on a woman's perceived and idiosyncratic meanings of pregnancy, abortion, and motherhood.

Women who had been treated for breast cancer voiced similar concerns as the women in this study regarding pregnancy decisions (Dow, 1994; Siegel, Gorey, & Gluhoski, 1997). However, the generalizability of these concerns is limited because of qualitative research design and use of retrospective in-depth interviews. Dow (1994) interviewed 16 women from Boston who had children after breast cancer and Siegel et al. (1997) interviewed 50 women from New York who contemplated having children after breast cancer. The 66 breast cancer survivors, like the women in this study, shared similar perceived benefits in having children. These included fulfilling a life goal, appearing to be like other women who are mothers, and reconnecting with friends in the community. Any cherished desire to have a child was not diminished by their breast cancer. As observed by Siegel et al. (1977), some women chose not to act on this desire due to concerns for their health and their future children's health. These women worried about their cancer re-occurring and, if they died, abandoning their children. They feared that their future children could get birth defects or cancer as side effects from previous chemotherapy and radiation treatments. To minimize this risk, most women postponed pregnancy so that their bodies were free of these toxins. However, like some women in this study who were 30 to 40 years old, they were afraid of delaying conception because of their "biological clock" and age-related pregnancy risks.

For many women, having a child after breast cancer was perceived as a means to affirm life. It was an effective "motivator to stay alive and be healthy" (Siegel et al., 1997, p. 37). In this current study, 'affirming life' referred to the dynamic, overall process of reproductive decision-making as a means to assert again and again the power of life

through reproduction. A broader view of affirming life distinguished the greater magnitude of risk transmission and the central importance of motherhood and childbearing perceived by women in this study.

Similarly, women living with other life-threatening conditions [e.g., multiple sclerosis (Smeltzer, 1994)] worry about their uncertain future, the health of their future children, or both (Dow, 1994; Siegel et al., 1997). Despite fears and anxiety, these women have children to create hope in their lives and to be like other childbearing women. The tremendous emotional meaning of having children shows the power of motherhood in defining a woman's perception of self. Mothering and having babies is a common source of pride and identity, a reason to go on living, and a way to feel normal. Having children enhances the quality of life. Nevertheless, making their pregnancy decisions is a stressful process based on individual circumstances with special attention to disease progression (Dow, 1994; Dow, Harris, & Roy, 1994; Siegel et al., 1997).

HIV-seropositive women have both a life-threatening and transmissible disease contributing to great uncertainty when facing reproductive decisions. These differences in disease condition need to be considered when examining the process of reproductive decision-making for women living with HIV. The following section will explore how these differences are addressed in the literature.

### Reproductive Decision-Making of Women living with HIV Literature

#### Biomedical Perspective

A biomedical perspective is reflected in the majority of research reports on reproductive decision-making of women living with HIV, in that the potential infectivity of women living with HIV is examined with women viewed as vessels of infection for men and vectors of pediatric AIDS (Amaro, 1993; Carovano, 1991; Rodriguez, 1997). Their bodies are regarded as hosts for killer cells and sources of disease (Goldstein, 1997; Gorna, 1996). Over time, this literature has accumulated scientific data on the nature of the

epidemic for women, the different factors associated with transmitting HIV heterosexually and perinatally, the medical consequences of pregnancy on HIV disease progression, the impact of HIV on pregnancy, the probable risk of mother-to-child transmission, and the impact of HIV on a newborn.

Pregnancy outcome studies show that women living with HIV are no different from other women who face a life-threatening or transmissible disease. They want to become pregnant (De Vincenzi et al., 1997; Heyward et al., 1993) and have children (Cabral, 1998; Henrion, Mandelbrot, Firtion, Cremieux, & Henrion-Geant, 1993; McCarthy et al., 1993; Rudin et al., 1998; Stratton, Mofenson, & Willoughby, 1992). In Rwanda, as in other African countries, there is a cultural norm of large family sizes to ensure family survival (Orubuloye et al., 1998). Allen et al. (1993) reports that women with fewer than four children are likely to become pregnant again. Like women in this study, other women will take necessary medical measures, even with potential risks to their own health, to ensure that their child is HIV-free [e.g., increasing trend for the use of cesarean section and perinatal antiretroviral therapy (Deveikis et al., 1998; Firlag-Burlacka et al., 1998; Kind et al., 1998; Lyall et al., 1998; Lutz-Friedrich et al., 1998; Mandelbrot et al., 1998; Read, 1998)].

From a biomedical perspective, sexuality and sexual behaviors are viewed as biological behaviors and risk of HIV transmission is considered in relation to these behaviors. For example, anal and vaginal intercourse are examined as potential routes of transmission. The presence of sexually transmitted diseases (STDs) (Cameron et al., 1989; Plummer et al., 1991), circumcision (Seed et al., 1995), and menstruation (European Study Group on Heterosexual Transmission of HIV (ESG), 1992) are examined as co-factors of transmission. It is of some importance to note that many of the participants in this study did not find this information helpful when faced with the reality of a sexual encounter. They wanted to know their options for different situations such as the relative risks of sex practices other than vaginal and anal intercourse (i.e., fellatio and cunnilingus



or oral sex and use of sex toys). Thus, more research is needed about the efficacy of transmission routes and the factors that may reduce or eliminate the risk of infection (Gorna, 1996).

In the early 1990s, the escalating heterosexual spread of HIV among women created a greater need to develop better HIV prevention programs (Sherr, 1996). Research shifted to separating sexual behavior from contraceptive behavior in order to focus on women's attitudes about condom use (Worth, 1989). Based on assumptions that attitudes represented normative values, the purpose of this type of research was to identify attitudes that could predict safer sex behavior, particularly condom use among women most vulnerable to acquiring HIV through sex (e.g., female injection drug users, sex trade workers and women of ethnic minorities disproportionately affected by HIV) (Exner, Seal, & Ehrhardt, 1997). Unfortunately, HIV-seropositive women were either excluded from these studies, or they represented a small portion of these studies (Kline et al., 1992; Pivnik, 1993; Sobo, 1995; Worth, 1989). As a result, findings in regards to attitudes about risk-taking among infected women were absent, or were conflated with those derived from reports of seronegative women.

### Health Belief Model

The health belief model is one of the most common explanatory models used to study factors for predicting sexual behavior in spreading HIV (Kendall, 1996; Long, 1996; Williams, 1991). The health belief model extends the previously discussed cost-benefit approach to focus on the impact of knowledge, attitudes, and beliefs of HIV as predictors of sexual behavior (Rostenstock, Strecher, and Becker, 1990). By perceiving a severe health threat, believing this threat is real, and believing in the efficacy of recommended behaviors, it was assumed that an individual's knowledge about HIV risk would motivate safer sex or the avoidance of risky sex behaviors (Rostenstock et al., 1990). Safer sex in this case refers to risk-reduction behavior for preventing sexual transmission of HIV through safe practices (i.e., massage, licking and kissing each other, mutual masturbation),

possibly risky practices (i.e., oral sex, sharing sex toys), to risky sex (i.e., unprotected vaginal or anal intercourse or any practice that may traumatize genital tissue and cause bleeding) (Berer & Ray, 1993). Because male condoms, when used consistently and properly during sexual intercourse, effectively prevent HIV transmission (Pinkerton & Abramson, 1997), they are recognized as the best barrier contraceptive method for safer sex (Berer & Ray, 1993; Exner et al., 1997).

In some cases, knowledge and beliefs about HIV risk clearly motivate behavior. In this study, knowledge about HIV serostatus prompted three women to have tubal sterilization because they did not want to make anymore difficult decisions about pregnancy. This same reason may have compelled seropositive women to have had tubal sterilization more often than seronegative women in two recent studies (Bedimo, Bessinger, & Kissinger, 1998; Lindsay et al., 1995). Other reports have noted better use of contraception following HIV diagnosis (Hankins, Gendron, Tran, Lamping, & Lapointe, 1997). But for many women, like some in this study, neither knowledge of HIV transmission, nor fears of infecting others, are sufficient to motivate behavior which protect against pregnancy or prevent HIV sexual transmission. While De Vincenzi (1997) reported that women were less sexually active following HIV diagnosis, thus contributing to lower incidences of pregnancy and live-births among women living with HIV in France, among the 329 women who remained sexually active, 20 percent did not use contraception. Lindsay et al. (1995) and Bedimo et al. (1998) observed high abortion rates for HIV-seropositive women compared to their uninfected counterparts, indicating unplanned or repeat pregnancies due to unreliable contraception. Further, even when contraceptive use was reported, women may have failed to protect against sexual transmission of HIV (Diaz, Schable, & Chu, 1995; Hankins et al., 1997).

The development of other safer sex models [e.g., the AIDS Risk Reduction Model (Catania, Kegeles, Coates, 1990), and those based on the concept of self-efficacy (Bandura, 1989), the theory of reasoned action (Jemmott & Jemmott, 1991), and social

cognitive theory (St. Lawrence et al., 1998)], extended the basic elements of the health belief model to explain risk-taking behavior. Prevention strategies based on these models have had limited effects on behavioral change, since heterosexual contact remains most often identified as source of HIV infection for women in Canada (Health Canada, 1997). The inefficacy of these models may in large part be due to the limitations of the reductionist biomedical approach that focuses on the infectious aspects of HIV, compartmentalizes risk-taking as a consequence of knowledge, discrete attitudes, or isolated behavior, and ignores the social context of sexual behavior (Goldstein, 1997; Gorna, 1996; Long, 1996; Squire, 1993; Williams et al., 1996).

A strictly biological view of HIV transmission results in the use of safer sex models and interventions focusing on reproduction and the use of condoms or protected sexual intercourse. However, for participants of this study, this narrow interpretation of sexual relations fails to address the concept that "having sex" is more than procreation. Sex is about gratification, fulfilling fantasies, pleasure, enjoying the present moment, and not thinking about the long term, unless conception is desired (Gorna, 1996). Each sexual encounter may involve intercourse of varying duration and varying frequency, as well as oral sex and the use of sex toys that affect HIV transmission. As suggested by Gorna (1996), Squire (1993), and Goldstein (1997), mechanisms of HIV transmission involve both physiological conditions and the contexts in which sexual behavior occurs.

Thus, social determinants of HIV transmission must be considered. Murphy, Lynch, Desmond, & Mulcahy (1993), reporting on a study in Ireland, suggested that poor contraceptive use may result in contexts where large families are the norm, and where social welfare payments and housing provision are based on the number of children in a family. The status of the couple relationship is likely to be a powerful determinant, as was found in this study. Condom use was higher among casual partners (66 percent) than among steady partners (58 percent) in a study of 392 HIV-infected Canadian women (Hankins et al., 1997). In a convenience sample of 83 predominantly single women living

with HIV, Clark, Kissinger, Bedimo, Dunn, and Albertin (1997) noted that such women were more likely to use condoms with their steady sex partner, and of the 11 women who never used condoms, only two indicated that it was the partner's decision.

### Gender Perspective

A gender perspective addresses the cultural norms of gender identity and roles as well as the power differences in sexual relationships (Exner et al., 1997; Goldstein, 1997; Gorna, 1996, Long, 1996). A sexual relationship is conceptualized as a dynamic process involving both personal and interpersonal experiences (Holland et al., 1992; Browne & Minichiello, 1994). During each sexual encounter, two individuals interact and bring their own beliefs about what is normal for having sex (Browne & Minichiello, 1994). As reported by many of the study participants, risky sex occurred when male dominance characterized masculinity, female compliance represented femininity, and condom use was viewed negatively.

For example, Pivnik (1993) interviewed 126 female methadone users from the Bronx in New York city; 16 were HIV-seropositive and 78 were Latino. Open-ended questions were asked to learn about meanings associated with contraception, HIV infection, and childbearing. Pivnik (1993) claimed that the study participants distinguished between a gender and cultural view of their childbearing roles. From a gender view, femininity involves female submission and masculinity is about sexual prowess. From a Hispanic cultural perspective, women are modest, naive and responsible for giving birth to children, men possess male machismo and are expected to father children, and unequal power relations exist between spouses (Pivnik, 1993; Mays & Cochrane, 1988). Any suggestion that a Hispanic man should use condoms is tantamount to rejecting both his ability to procreate and his sex partner's ability to bear children (Pivnik, 1993). Similar to the experiences of the women in this study, these findings suggest that negotiating safer

sex is a complex process that involves the symbolism of condoms, the impact of condom use on a particular relationship, and cultural gender norms of heterosexual behavior.

Condom use may also be affected by unexamined assumptions. For example, a heterosexual couple may engage in unprotected anal intercourse because they consider it to be "good pleasurable sex" (Browne & Minichiello, 1994, p. 247). A woman who does not really enjoy anal sex may comply to satisfy her male partner's needs based on the norms of heterosexual behavior. Because condoms are associated with homosexuality, promiscuity, and disease, the couple ignores the need to use them (Browne & Minichiello, 1994; Peart, Rosenthal, & Moore, 1996).

The emphasis on male condom use for preventing sexual transmission of HIV is, in itself, a gender-based risk reduction strategy. (Although in recent years female condoms have been available, condoms in this study refer exclusively to male condoms). Women need the co-operation of their sex partners to use condoms. When they felt powerless in their sexual decision-making and sexual relationships, women in this study were unable to assert their need to protect themselves through condom use. Sobo (1995) explored the psychosocial barriers to safer sex for 38 urban, African-American women and learned that "condomless sex" paradoxically enabled them to ignore HIV risk (p. 455). "HIV/AIDS risk denial" was a psychosocial strategy of using biased optimism for negating HIV risk in sexual relationships (Sobo, 1995, p. 463). This denial was based on cultural ideals of romance and monogamy, and was supported by "the wisdom narrative" where women believed that they had the ability to judge who was a "clean" and "good" man (Sobo, 1995, p. 468). When a woman believed that a man could be trusted as someone suitable for a committed relationship, unsafe sex then symbolized love and devotion. The "monogamy narrative" referred to an idealized, faithful, romantic relation that is similar to the "American dream of fidelity" (Sobo, 1995, p. 469). Together these narratives serve and justify the women's decisions not to use condoms.

The finding in this study of the romantic determinant of relative risk extends Sobo's (1995) notion of HIV/AIDS risk denial. A broader view of romance exists where both love and lust (i.e., physical attraction and emotional feelings) are present in an ideal monogamous relationship. Sexual intimacy is an expression of romance that involves both love and carnal pleasure. In reference to romanticizing sex to determine the relative danger of risking deadly connections, many participants claimed that sex without condoms was a way of removing barriers emotionally and physically during sexual intercourse.

"Condomless sex" was also perceived as being symbolic of commitment for the study participants. There were six HIV-seronegative primary support persons who, on occasion, knowingly ignored the risk of becoming HIV infected and refused to use condoms. In this instance, unsafe sex verged on a romantic, self-sacrificing act. This behavior reflects the potential of HIV/AIDS risk denial to reduce an individual's sense of personal susceptibility and to forget in the short term the impending death of a beloved spouse.

However, based on the experiences of some women in this study, the "wisdom and monogamous narratives" could also be adapted to fit their sexual context, in that condom use symbolized a true loving relationship rather than a necessary protection against cheating partners. This fits Sobo's (1995) claim that condom use could mean "beneficent prophylaxis" as a form of HIV-related altruism in preventing the transmission of HIV (p.175). Some women in the current study tried to explain condom use in this way by emphasizing that, if their sex partners really cared about the relationship, they wouldn't question the use of condoms. However their sex partners often resisted and the women ended up practicing unsafe sex because they felt powerless and wanted sexual intimacy to nurture themselves and the relationship.

For example, Dave, the spouse of Melissa for more than seven years and who was diagnosed with HIV five years ago, explained his attitudes about "condomless sex:" "I have never used condoms in the past, not now, and certainly not in the future. . . [When condoms are used] well, it's like taking a bath with saran wrap on. Now who would enjoy

that?" Melissa recognized the risks of not using condoms but she was not prepared to change for the same reason as the majority of women in the study who did not use condoms consistently. She stated, "well, we never used them after all these years. Besides [sex] it just isn't the same when it's not skin-to-skin." Similar social and emotional benefits of sex without condoms are reported by other men and women that account for the deeply ingrained, negative attitudes about male condoms (Galligan & Terry, 1993; Pivnik, 1993; Ray et al., 1995; Sobo, 1993; Sobo, 1995). These attitudes are closely linked to cultural values and sexual norms and result in immense barriers to the negotiation of safer sex.

From a gender perspective on sexual behavior, the economic and social conditions which contribute to violence against women, women's inability to protect themselves from harm, and increased risk of HIV-seropositive women to infect others can be understood. (Holland, Ramazanoglu, Scott, Sharpe, & Thomson, 1992; Worth 1989). A woman's ability to practice safer sex is limited if she feels powerless. The consequences can be seen in research about women living with HIV who experience threats of violence or violence in their lives. Fears of physical abuse, emotional abuse, and abandonment resulting from disclosure of HIV serostatus were reported by a few women in this study. Similar fears have reportedly been voiced by other women: 45 percent of 136 health care providers surveyed from Maryland indicated that at least one of their clients feared being physically hurt if her partner knew that she was infected (Rothenberg, Paskey, Reuland, Zimmerman, & North, 1995).

Once victimized through sexual assault or abuse, some women may experience lack of self-esteem and difficulty establishing intimate relationships and perceive they have limited or no control over sexual HIV risk (Sterkl, Cordeiro, Springer, & Elifson, 1998). This was true for some women in the present study, as fears of repeated violent victimization often prevented them from asserting needs and demands for safety. Other women have reported that partner violence and threat of violence constrain negotiating safer

sex (Morrill & Robbin, 1997). Substance abuse is sometimes a consequence of victimization, particularly child sexual abuse, and is used to escape psychological pain and shame (Cook, 1997; Deamant et al., 1996; Morrill & Robbin, 1997). As was the case of a few women in this study, drug addiction and exchange of sex for drugs, money, or shelter put women at even greater risk for sexual and physical violence (Cook, 1997; Deamant et al., 1996; Vlahov et al., 1996).

To date, there is no empirical research linking HIV and violence in women's lives (Zierler, 1997), but it is noteworthy that in a survey of 110 women living with HIV in British Columbia, 74 percent of them reported having been sexually assaulted or abused (Kirkham & Lobb, 1998). The high proportion of HIV-seropositive women experiencing violence in their lives raises questions about the psychological effects of physical, sexual, and emotional abuse as well as the effects of these experiences on sexual relationships.

Of the 17 women in this study who survived child sexual abuse, escaped from domestic violence, or recovered from drug addiction; the majority reported having had to first learn about self-respect, self-love, and self-worth before they even wanted to try to make a better life for themselves. A few women, who as sex trade workers were raped, beaten, brutalized and left for dead keep these dark secrets deeply hidden in their memories. They prefer to forget these horrible experiences and to focus on staying healthy and being free of illegal drugs. Following reform in their lives, they were less promiscuous and more conscious of their potential to infect others with HIV through sex. All these women also emphasized that, despite the negative or even horrendous past sexual incidents, they learned by communicating their fears and needs with their patient, loving sex partners that "sex was a good thing involving much pleasure and little pressure." Individual differences in sexual risk-taking and condom use were partly based on both perceived gender differences in sexual behavior and perceived danger of transmitting their disease through sexual activity.



In the context of HIV/AIDS, the gender perspective also highlights the economic and sociocultural constraints affecting women's roles as girlfriends, wives, or mothers (Gupta, Weiss, & Mane, 1996). Of the few qualitative studies about sexual decision-making that use a gender perspective, most include seronegative women or sometimes only a small proportion of seropositive women (Holland et al., 1992; Kline et al., 1992; Pivnick, 1993; Worth, 1989). Kline et al. (1992) suggested the gender-based assumptions about economic and structural barriers may not necessarily restrict women in asserting themselves in sexual relationships. Disadvantaged Black and Hispanic women from New York claimed that they exerted power in sexual decision-making with their male sex partners by reasoning or by withholding sex (Kline et al., 1992). Barriers to practicing safer sex were related to perceptions of risk to a relationship such as the benefit or cost in using condoms rather than gendered norms of sexual behavior. These findings suggest that conclusions about HIV risk-taking behavior based on gender analysis may not account for the actual experiences of women and men. When using a gender model, women's roles in socially structured unequal relationships are considered and women's subjective experiences of HIV risk-taking, particularly those of HIV-seropositive women, are ignored. Thus, questions remain unanswered about the unique and different ways in which seronegative and seropositive women respond in preventing the sexual spread of HIV.

A few qualitative studies have described the psychological, social, and cultural influences on reproductive decisions of women living with HIV (Hutchison & Kurth, 1991; Sowell & Misener, 1997; Pivnik et al., 1991; Pivnik, 1994). Hutchison and Kurth (1991) suggested that when a HIV seropositive woman becomes pregnant, there is a "the psychoreproductive response" (p. 17). This cognitive reaction involves two psychological processes: (1) articulating the pregnancy decision by using an internal locus of control, drawing on personal morality, or recognizing a desire for children and motherhood, and (2) coping with the pregnancy decision by having faith, thinking positively, accessing the

medical system, and managing HIV self-care. Other contextual factors like culture and socioeconomic status greatly shaped both a woman's self-perception and pregnancy options. The sample of 11 HIV-seropositive women included eight African Americans, one Latina, and two Caucasians from New Haven and Brooklyn. Similar findings were reported by Sowell and Misener (1997) from focus groups with 18 African American and four Caucasian, HIV-seropositive women from rural communities in Georgia and South Carolina. Support from families and sex partners was an additional factor influencing reproductive decision-making identified by this cohort. Pivnick et al. (1991) and Pivnick (1994) stress the importance of mother-child co-residence as a critical factor in making pregnancy decisions for 50 HIV-seropositive, drug using women from the Bronx in New York city. All of the women who had been separated from their children because of uncontrolled drug use chose to continue with a pregnancy, whereas those who had lived with a child for the child's entire life terminated pregnancy. As these studies and others show, there are multiple factors affecting women's pregnancy decisions (Henrion et al., 1991; Holman et al., 1989; Johnstone et al., 1990; Kline et al., 1995; Selwyn, Carter et al., 1989; Sunderland et al., 1992). Since many of these factors were determined either through retrospective interviews or qualitative analysis, the relative importance of the factors and how they relate with each other remains unclear (Selwyn & Antonello, 1993).

Similar factors when making pregnancy decisions were identified by women in this study; however, they represented only part of the overall reproductive decision-making process. The findings of this study indicate that reproductive decision-making involves choices about both sexuality and childbearing. When women in this study made these related but separate reproductive decisions, the risk of transmitting HIV was a critical concern. These decisions were not simply rational or irrational, but were emotionally laden and contextually dependent, and unfortunately, not always well-informed regarding the most effective treatments and best HIV prevention practices. Decisions were sometimes freely made, and at other times were coerced, often in response to threat of violence by sex

partners. For the women in the study, the cost-benefit analysis of risk-taking expanded to include their life context and the personal reality of having a disease that would probably kill them and potentially kill others with whom they shared their lives.

### Extending Existing Theoretical Perspectives

The theory generated in this study addresses some limitations of extant knowledge by recognizing the importance of contextual factors, the effects of the disease on the woman's sense of herself and her life, and the inequalities of sexual relations. Other models proposed to date on the potential infectivity of HIV-seropositive women view risk either as a causative factor for changing behavior or simply as another risk among many that women face within the context of social inequity. The model proposed here suggests a different understanding of HIV risk by considering both the transmissibility and the fatal aspects of the disease as factors that contribute to the uncertainty and complexity of women's reproductive decision-making.

In this proposed theory, risk is conceptualized as being relative in an appraisal process where knowledge about risk of HIV transmission is neither passively received nor accepted at face value. Through experience, each person creates meaning of how he or she sees things and labels them in terms of relative risk. With regards to information about HIV transmission, women personalized HIV risk by reflecting on its relevance and fit in their lives, and then acted based on their own interpretation of HIV risk.

In this study, women's personal meaning of HIV transmission changed over time and varied in relation to on-going changes of the day-to-day living with HIV. The HIV risk was further interpreted in light of practical, romantic, intellectual, and ethical considerations women used as determinants of relative risk. These determinants addressed the interaction between the diverse and sometimes contradictory emotions, and thoughts, present when making sexual or reproductive decisions. For every sexual encounter and

pregnancy decision, women's perception of HIV risk influenced whether they took any chance of exposing others to their disease.

A focus on HIV-seropositive women's experiences permits an understanding about the effects of HIV on a social, spiritual, and sexual person having to constrain decisions about "having sex and babies." Social isolation was reported as a cruel and undesirable consequence of their disease. This outcome is especially harmful for women who require connection with other people, regarded as a deep need rooted in one's identity defined as "self-in-relation" (Surrey, 1991, p. 52). This concept recognizes the centrality of connection in a woman's sense of self and awareness that interpersonal connections and intimacy from close relationships nurture a woman's survival and well-being (Surrey, 1991).

Internalized stigmatization and discrimination related to HIV may restrain a woman from accessing valuable sources of emotional support or may trigger a woman to sever ties with others. This detrimental reaction occurs from perceiving the dual danger of infecting someone with HIV and facing potential rejection or abandonment when disclosing their infection. Fears of additional discrimination may further alienate women, as was true for some in this study, to feel that they no longer belong in the world. As shown in this study's findings, a woman living with HIV experiences much vulnerability and may ignore the long term consequences in risking deadly connections as she desperately seeks connection with others through sex or having a baby and becoming a mother.

The theory generated in this study can be used to inform clinical practice, research, and policy. However, there are some study limitations that should be considered.

### Study Limitations

This study has several limitations in relation to the sample which will affect generalizability of findings. For example, the majority of participants heard about the project from other study participants or by reading notices advertised at local community-

based HIV/AIDS organizations and in a provincial newsletter for persons living with HIV/AIDS. Women who were comfortable enough to discuss private concerns with a stranger and able to articulate their thoughts, feelings, and beliefs about the phenomenon under study were interviewed. Other potential participants who may have felt threatened about participating in this project were members of visible minority groups. Despite the promise of confidentiality and anonymity, they may have feared that participation in this project would lead to their diagnosis being disclosed and as a result, they (and possibly their family and friends) would be ostracized in small, close-knit, ethnic communities. Low participation of minority women and those not using HIV/AIDS community resources (e.g., those newly diagnosed) may have contributed to a gap in the depth and detail of information gathered and thus limited theory development.

Women and primary support persons who volunteered to participate were initially reticent about discussing their sexual lives, especially with an "academic stranger." They often stated, "you know what I mean" rather than expressing fully their feelings and thoughts about sex or describing in detail specific sexual practices. I would defuse their discomfort by using humor, by changing to a less threatening topic, or by sharing comments from other participants to let them know that they were not alone regarding their fears, concerns, and anxieties about sexuality and reproduction. In reassuring them, I may have at times inadvertently introduced some premature closure in discussion. Conversely, study participants might have agreed with me or appeared supportive about suggested interpretations to avoid embarrassment or exposure of private matters. As trust and rapport developed, a few women and one primary support person admitted during follow-up interviews that they had lied about their use of condoms or other aspects of their sexual practices.

Following the second interview, I observed there was often less need to 'please' the researcher as most of the study participants spoke candidly about sexual intimacy and described their contradictory and unpredictable behavior with regards to contraceptive use

and pregnancy decisions. The accuracy of reported sexual behavior may have been compromised by the retrospective nature of the data. Selective memories may have exaggerated claims about practicing or avoiding risky sexual behavior, and inconsistency or absence of preventive measures may have been reported. However, detailed descriptions of reproductive decision-making situations and life experiences suggest questions were being answered honestly. Locally produced meanings of sexuality and childbearing were also expressed by study participants contributing to the grounded theory's Western sociocultural bias.

Another limitation of the study relates to the generalizability of theory proposed. More variation in subjects and greater range of interview data can result in a wider applicability of a grounded theory (Carpenter, 1995; Chenitz & Swanson, 1986; Glaser & Strauss, 1967). In this study, attempts were made to test the categories, the links between categories, and developing interpretations by recruiting women with different life experiences. Unfortunately, it was not possible to access additional women living with HIV who did not, for example, have a history of substance abuse, who were from a visible minority group other than First Nation or aboriginal peoples, and who had incomes greater than \$20,000 per year. Thus, the concept of 'managing fears of HIV' may be applicable to any woman living with HIV but the actual experience specific to this concept will be different for a female injection drug user living in a rural community where few women are known to be infected than for a woman from a visible minority group who lives in a densely populated community where AIDS mortality is high.

A second issue of generalizability concerns the fact that the majority of women in the study had a history of substance abuse and history of violence in their lives. Extensive or active drug use has been suggested to interfere with judgment and impair sexual decision-making resulting in more risky behavior (Kline et al., 1992; Worth, 1989). The use of crack-cocaine is particularly associated with high risk behaviors, including multiple sex partners and unprotected vaginal, anal, and oral sex from sex trade work to support

drug addiction (Communicable Disease Control and Health Prevention Centers, 1991; Garfain et al., 1996; McCoy & Inciardi, 1993). Violent victimization damages a woman's self-image and self-esteem that impairs her ability to protect herself from harm or to establish intimate relationships (Sterkl et al., 1998). These characteristics of the women were examined as important sources of data for conceptualizing the reproductive decision-making process, in discriminating the prominent concerns of the study participants. As suggested by Mouse, a former polydrug user: "all women are made the same. It doesn't matter what nationality, color, race, or creed you are. Having babies is something guys can't do. That's what's so important."

According to Glaser and Strauss (1967), a credible grounded theory should "fit" the applicable substantive area, be easily understood by laymen, and work for a variety of situations by explaining, interpreting, and predicting the phenomenon of interest. Two health professionals were asked to evaluate the accuracy of the generated theory. One had worked for more than four years at a drop-in clinic as a counselor for street youths and young adults who were: at risk for testing HIV seropositive, infected themselves, or affected by someone living with HIV/AIDS. She concurred that the grounded theory fit with her experiences as a witness of HIV-seropositive women's unfolding lives. The other, a program director at a Women's Health Center, agreed that the substantive theory fit her experiences of reproductive counseling for women living with HIV.

Two couples were asked to evaluate whether the theoretical framework made sense and resonated with their own reproductive decision-making experiences. The first couple, Dave and Melissa, were diagnosed with HIV when their son was sickly and tested HIV-seropositive in 1993. Due to their polydrug addiction and inability to provide a stable home, they chose to have their HIV-infected son adopted by another family. Melissa reported being sexually assaulted when she was a child and doing sex trade work to support her past polydrug addiction. In 1996, when faced with another unplanned pregnancy, Melissa and Dave decided that they wanted to raise their future baby themselves

so they went “cold turkey” and experienced total drug withdrawal on their own. Melissa took ZDV to reduce the chance of giving HIV to her baby who is currently two years old and not infected. Dave had a vasectomy shortly after their daughter was born.

The second couple, Buzzed and Cupcake, did not have a history of substance abuse or violence in their lives. They had already had a one year old son when Cupcake was diagnosed with HIV during the fifth month of pregnancy. Her religious beliefs prevented her from having an abortion. Like Melissa, she took ZDV to reduce perinatal HIV transmission. During this pregnancy, Cupcake decided that she would have a tubal sterilization after her child was born so that she would not have to face another horrific pregnancy. The daughter of Buzzed and Cupcake is presently four years old and HIV-free. Both Buzzed and Cupcake acknowledged not using condoms. Buzzed stated that once Cupcake’s health deteriorated he would use condoms, mainly because he would need to stay seronegative so that he would be able to raise their children. He also remarked that they had “little sex” due to varying work shifts and the need for Cupcake to get her rest on her days off from full-time work. With few opportunities of being exposed sexually to HIV, and transmission less efficient from woman-to-man, he assumed that there was little chance of becoming infected.

Both couples indicated that the theoretical framework accurately portrayed their reproductive decision-making process. They were simultaneously intrigued and satisfied that the details of the substantive theory managed to capture the salient issues they faced when making decisions about sexuality and reproduction. They emphasized that due to HIV-related stigma, HIV serostatus was a well-kept secret. Social isolation resulting from the stigma contributed to both Melissa’s and Cupcake’s ignorance of other women living with HIV. These women especially appreciated hearing that they were not alone in practicing risky sex or using condoms inconsistently. Like other women in this study, they monitored their health and were frightened of infecting others, particularly when trying to meet both their partners’ and their own sexual needs and desires.



Despite study limitations, the positive feedback from two clinical experts and these two couples suggest that the proposed grounded theory is a credible explanation of the reproductive decision-making process of women living with HIV.

### Implications for Clinical Practice

The study findings offer important insights about the reproductive decision-making of women living with HIV. A unique characteristic of women living with HIV is the triple burden of a life-threatening disease that is infectious and stigmatized which powerfully affects decisions about "having sex and babies." Thus, this substantive theory suggests specific implications to the care of women living with HIV, their primary support persons or sex partners, and health professionals who work with them. These implications will be discussed in terms of HIV stigma and the decision-making process.

### HIV Stigma

Of most importance is the impact of stigmatization and how it exacerbated the suffering in living with HIV and threatened quality of care for women living with HIV. The shame and blame associated with HIV stigma may contribute to a fear of more discrimination, thus making HIV-seropositive women reluctant to access health and social services. In contrast, fear of contagion (Meisenhelder & LaCharite, 1989), death-related anxiety or a greater awareness of personal mortality (Sherman, 1996), and lack of basic HIV knowledge (Plant & Foster, 1993) may contribute to an avoidance or reluctance to work with HIV-seropositive people on the part of nurses. Other health professionals including doctors, psychologists, social workers as well as peer counsellors and outreach workers have reported experiencing profound discomfort when learning that an HIV-infected woman wants children, gets pregnant, or does not use condoms (Denenberg, 1996).

The prevalence of HIV stigma warrants careful attention by health professionals as their own values and beliefs might seriously interfere with care (Meisenhelder & La Charite, 1989; Whipple, 1992). Personal biases about pregnancy decision-making must be addressed in light of ethical issues related to human rights and abortion (Kurth, 1993; Meisenhelder & La Charite, 1989). An increased sensitivity to issues of spirituality, sexuality, and the meaning of death would enhance a health professional's ability to appreciate the trauma of being HIV seropositive, and to assist women as they adjust to their diagnosis and experience changes in themselves as sexual, spiritual, and social persons. Based on the study findings, health professionals also require current knowledge about HIV specific to women and human sexuality as well as a comfort level when talking about sexual intimacy, drug abuse, and partner violence. In this way, accurate up-to-date information can be offered and women's reproductive rights respected.

The social isolation resulting from HIV stigma should be recognized as a critical factor affecting both reproductive decision-making and the psychological well-being of HIV-seropositive women. To access health care, HIV-seropositive women must admit their serostatus, which makes them vulnerable to potential verbal abuse and maltreatment by service providers (Kochen et al., 1991; Ong, Clarke, Dunbar, & Mandel, 1993; Seals et al., 1995). Even more damaging to them is the prevailing view among health professionals that HIV-infected women should not have children (Bayer, 1990; Kass & Faden, 1996a). Many health professionals share their beliefs with HIV-seropositive women while emphasizing that women should make their own childbearing decisions (Nolan, 1989; Kass & Faden, 1996a; Kurth, 1993). While health professionals and other workers may be clear about their personal opinions and may not intend to be coercive, women living with HIV may feel scared and lonely and may feel compelled to forgo childbearing as a means of gaining approval or acceptance. An understanding of their 'poisoned fate' as the specific context in which HIV-seropositive women make reproductive decisions would assist health professionals to recognize the importance of setting aside personal values and

showing respect and maintaining confidentiality so that trusting relationships can be established with HIV-seropositive women.

### The Decision-Making Process

Based on these study findings, health professionals must realize that only the woman herself can identify what she needs because every woman's reproductive decision-making experience is different. Sometimes women cannot express their problems because they are ambivalent and confused about sexuality or reproduction. Another barrier to communication is that most women (and men) do not know how to talk about sexuality or sex (Klein-Alonso, 1996). By listening to stories about their experiences, the health professional can individualize care and foster a supportive and reflective process for women. When telling their stories, HIV-seropositive women think about their experiences and learn what is important for them (Klein-Alonso, 1996). In hearing their stories, both the women and health professionals gain insights about the profound effects of HIV.

Talking about the competing elements of the theory, 'struggling with vulnerability' and 'striving for longevity' may assist women and the primary support person or sex partner to make sense of the varying experiences of living with HIV. Sensitivity to the woman's level of vulnerability and longevity may help primary support persons to better assist HIV-seropositive women in both staying healthy and facing uncertainty about life expectancy. For example, HIV-infected women should know about the viable options for optimizing health (i.e., antiretroviral therapy, proper nutrition, adequate rest, and stress management). Alternative medicine including vitamin therapy, herbs, homeopathy, acupuncture, therapeutic touch, and massage therapy may be effective for managing toxic side effects of antiretroviral therapy, reducing stress, or restoring the immune system (Diaz, 1996; Glover, 1996; The Burton Goldberg Group, 1994). Before using any of these therapies, a woman should have access to and as much available information as possible about a specific HIV treatment so that an informed decision can be made.

An understanding of HIV risk based on the on-going changes of living with HIV and the different relative risks as viewed by the women in the grounded theory may assist HIV-seropositive women in the following ways. They may gain insights about the confusion and contradiction present in reproductive decision-making to provide clarity about what they want to do. By acknowledging their potential to risk deadly connections, HIV-seropositive women may recognize a need for options available to protect against pregnancy and STDs and to prevent others from getting their disease. For example, a low concentration of HIV is generally present in vaginal fluids (Gorna, 1996). Hormonal changes resulting from pregnancy, the use of the oral contraceptive pill, and menopause as well as infections and damage to the genital tract increase the prevalence of white blood cells, contributing to greater infectivity of vaginal fluids (Clemetson et al., 1993). Barrier contraceptive methods (i.e., male or female condoms, diaphragm, and cervical cap) can be used to decrease infectivity through sexual relations. HIV-seropositive women should know about the importance of lubrication to facilitate proper use of condoms and to prevent friction that causes physical damage during sexual intercourse (Gorna, 1996; Reid, 1996). They should also know about greater risk of transmission from vaginal sex during menstruation and when vaginal candidiasis is present (ESG, 1992). Such information may assist women in creating strategies to reduce harm and limit risk during sex.

The most salient issue in a HIV-seropositive woman's reproductive decision-making concerns the conflict between risks of HIV and her need to satisfy normal human desires. For many women there has always existed a tension between the danger and pleasure of sex (Vance, 1984). On one hand, women want sexual intimacy and bonding, and on the other, they fear the consequences of sex such as STDs and pregnancy. This tension is heightened in light of a HIV-seropositive woman's potential infectivity and the social isolation resulting from HIV stigma, and is further complicated by powerful forces of sexual gratification and pleasure, and desires to have children. It is also important for both women living with HIV and those working with them to know that following

diagnosis, sexual dysfunction is a normal response to what may be perceived as overwhelming sexual danger. Accompanying grief and loss must be acknowledged when assisting HIV-seropositive women as they work through issues related to safety and sexuality. Some women may grieve in anticipation of their own death and may need to resolve this grief before being able to adjust to changes in their sex life.

The importance of motherhood for women living with HIV greatly influences reproductive decision-making of HIV-seropositive women. The emotional meaning of motherhood for women living with HIV may be intensified as a result of their diagnosis, and thus, women who have a deep desire to have children should be helped to plan a safe conception. During ovulation, a woman could inseminate herself with her partner's sperm to prevent infecting him (Saffron, 1994). If the partner is infected, "sperm-washing" techniques which effectively remove HIV cells from the infected semen, may be available in the future (Semprini et al., 1992, p. 317).

HIV-infected women facing a decision about an unplanned pregnancy may need to reconcile the dilemma of possibly giving their disease to their future infant and a desire for motherhood. Knowing the determinants of relative risk may assist women in clarifying the danger of having children. Medical advice about vertical HIV transmission and the use of perinatal antiretroviral therapy may further assist in interpreting this danger. An understanding of their perceived 'mothering anxiety' and 'mothering capacity' may also help them cope with the uncertainty about their own health and life expectancy as well as any ambivalence about continuing with pregnancy. Health professionals could provide support by listening to the women and encouraging them to talk about the meaning of motherhood and children, thereby clarifying what matters the most to them in this situation. Health professionals should respect each woman's pregnancy decision, and should be prepared to offer more counseling as the HIV-infected woman face the consequences of that decision (Butler & Maelfa, 1996).

To assist HIV-seropositive women in achieving healthy female sexuality, health professionals must understand that the meaning of sex changes throughout a woman's life. It may be helpful to shift representations of women's sexuality from an identity orientation (i.e., being a heterosexual, bisexual, or lesbian woman) to a focus on the pleasures of sexual intimacy. This expanded view of sexuality and sexual behavior could be used by health professionals to assist HIV-seropositive women in exploring new ways of experiencing affection and sexuality safely. The social conditions and cultural context in which each woman experiences her sexuality must be taken into account, by HIV-seropositive women themselves and by those who work with them, especially in regard to the occurrence of coercion or violence during sex.

Efforts must be made to involve the sex partners of women living with HIV and to assist the couple in talking about sexuality and communicating individual needs and preferences. In counseling the couple, professional assistance could be helpful in reconciling conflicts and opinions that prevent a mutually satisfying sexual relationship. Health professionals could also provide accurate information to help demystify sexuality and to support and strengthen the use of strategies which offer the most or best protection for the HIV-seropositive woman and her sex partner. It is important to consider the realities of condom use to assist a couple in overcoming any reluctance in having protected sex. For example, according to Richters (1994), a man may lose his erection when putting on a condom or occasionally lose it during intercourse. Based on men's reports, it may be easier to apply a condom on the penis when it is not fully rigid. However, this technique can only be used if one is aware of it.

Health professionals need to recognize the importance of integrating support and increasing accessibility in order to care for women living with HIV and their sex partners. Any concerns about HIV stigma in relation to visiting a STD treatment center, or the limited scope of a family planning center could be removed by providing care at sexual health clinics like those established in the United Kingdom (Berer, personal communication;

December 8, 1998). A person-centered approach for both women and men irrespective of HIV serostatus could be used to address sexual and reproductive health concerns (Ang & Fleras, 1998; Ankrah, Schwartz, & Miller, 1996; Berer, personal communication, December 8, 1998; Cash, 1996; Fox, Williamson, Cates, & Dallabeta, 1995; Parker & Patterson, 1996). Another advantage of integrating services is that health professionals would receive adequate training and skills for working with HIV-infected women and men regarding issues about their disease and for different stages of the life cycle.

### Recommendations for Future Research and Policy

Several possible avenues for future research based on the theory proposed here suggest themselves. The next logical step would be to evaluate the study findings with more diverse groups of HIV-seropositive women. For example, the reproductive decision-making experiences of young women (i.e., aged 15 to 19) and older women (i.e., aged 35 to 45), who differ in potential to conceive and in developmental level, could be examined to explore any variation in light of the various aspects of the grounded theory. This kind of research could extend the boundaries of the substantive theory and strengthen its specificity and clinical relevance.

Prospective research is needed to determine the relevance of concepts and processes used to explain reproductive decision-making longitudinally. A better understanding could be gained about the influence of the time-related aspects of this substantive theory, including the stage of reproductive life cycle and stage of HIV on the reproductive decision-making process. More knowledge could also be developed about experiences of living with HIV over time in relation to levels of vulnerability and longevity, the perception of HIV risk, the meaning of motherhood, children, and sexuality. Specific experiences could be examined to further develop the notion of turning points in the HIV-seropositive women's reproductive decision-making process. For example, do particular experiences lead to more or less risking of deadly connections? Such research would address the

present gap in understanding the impact of HIV-related conditions on women's sexuality with regards to its expression and decisions about sex and reproduction.

Since the personal meaning of HIV risk was identified as a critical factor in reproductive decision-making of women with HIV, research could further clarify women's appraisals of the relative risk of HIV and its possible effects on both sexual and pregnancy decisions. By separating the two types of decisions, the potential relationships between the practical, romantic, intellectual, and ethical determinants of the relative danger of risking deadly connections could be explored. Whether certain determinants are considered in relation to the danger of sexual activity rather than in relation to having a baby could also be studied to suggest which ones are used for a particular situation.

Another valuable area of research would be to consider the applicability of the grounded theory for HIV-seropositive men's reproductive decision-making experiences. I am curious about gender differences which may exist in relation to reproductive decision-making experiences by HIV-seropositive men. It would be interesting to determine whether HIV-infected men differ from HIV-infected women in struggling with vulnerability and striving for longevity, in using the determinants to perceive personal HIV risk, and in risking deadly connections. Based on similar concerns identified by breast cancer survivors, I am also curious about whether this substantive theory is relevant for the reproductive decision-making of women who have other life-threatening or transmissible diseases.

Based on the study findings, policy-makers should be sensitive to the damaging effects of HIV stigma on HIV-seropositive women's reproductive decision-making. Cultural norms about femininity and masculinity greatly interfere with the ability of HIV-seropositive women to assert their needs for safety and pleasure in their sexual relationships. To help change entrenched behavior, gender-sensitive policies could be developed to address long-term societal change by influencing the different kinds of thinking regarding male and female sexuality. These policies could provide incentives for



the creative use of the mass media to alter male attitudes (e.g., shift the emphasis of being a “macho man” to the importance of being the provider or protector of the family) and female attitudes [e.g., question the tradition of the ‘obedient woman’ and re-affirm a woman’s capacity for connectedness (Jordan et al., 1991)]. By consciousness raising, there could be a shift from male domination and female subordination to interdependence in sexual relationships. In addition, modified attitudes would lead to changes in sexual behavior. However these changes could take a long time.

In the interim, women’s subordination and lack of power in society could be addressed through policies which empower women by promoting improvements in social and economic conditions for women in communities, creating employment and education opportunities for women, ensuring the accessibility of appropriate resources for HIV-seropositive women (e.g., peer-led education programs and support groups), and through research that focuses on pressing concerns of HIV-seropositive women. For example, research is urgently needed to address gaps in treatment and to develop more female-controlled HIV prevention technologies such as microbicides and non-contraceptive microbicides and the use of the diaphragm, cervical cap, or contraceptive sponge. Through the provision of comprehensive health and social services, women living with HIV could gain knowledge and support for making informed decisions about protecting others from their disease while satisfying their own needs and desires as sexual persons.

### Concluding Remarks

Conventional ways of describing and explaining the reproductive decision-making of women living with HIV have not been particularly effective for all the reasons discovered in the present study. By focusing on the experiences of women living with HIV, insights have been gained about the complex realities in which their reproductive decision-making is embedded. Staying close to the women’s shared experiences has revealed, an understanding about what it is like “under their skin.” The women in the

study were no different than other women in wanting to feel loved and lovable, and in wanting the support of others in their lives. But once diagnosed, they were silenced and isolated by the stigma of their disease. The women were especially troubled by powerful sociocultural norms about motherhood as a measure of a woman's life achievements, and by ignorance about the best ways of expressing themselves intimately and safely through sex. This perceived social pressure and recognition of sexual needs and desires confounded the immense conflict already present in the singular acts of having sex, preventing conception, terminating pregnancy, and giving birth. Every decision was heartwrenching as each one reminded the women about their poisoned fate.

In hearing these stories, reproductive decision-making must be understood in the context of HIV-seropositive women's lives. It has to be an understanding of living "in their skin," not how we think it is for them based on personal values and beliefs, but how it really is for them based on their experiences and the meaning of these experiences. For too long the voices of women living with HIV have been ignored. We finally have to listen to them; to respond to them with respect and compassion.

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## Appendix A

## TELEPHONE CONTACT FORM

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Hello, [name of prospective participant]. I was given your name from [name of contact person]. I am, Amandah Lea, a registered nurse and doctoral nursing student from the University of British Columbia who is the researcher for "Reproductive Decision-Making of Women Living with HIV." Thank you for being interested in the study. Whatever we talk about today is confidential. I am the only person who has access to this conversation. Would you like me to explain this study to you?

[If no, I will proceed in making arrangements for the interview]

[If yes] The purpose of this study is to investigate reproductive decision-making and the significance of childbearing for women living with HIV. Results will help nurses and other health professionals to provide better care for women living with HIV.

If you participate in the study, I will interview you 2-3 times. Each interview will last 1-2 hours and will be done in a place of your choice. During the first interview, I will ask you to respond to one short questionnaire that includes background information about yourself and your partner or primary support person who is most involved in your reproductive decisions. I will also ask you open-ended questions about your experience in making reproductive decisions. For example, I will ask you, "Tell me about how you decided whether or not to have a child." The second interview will give you an opportunity to share any further thoughts with me. I will summarize what you told me during the interviews to check that I understood you correctly. We may decide to meet a third time to conduct an interview with your primary support person who is most involved in your reproductive decisions.

Following the completion of each interview, you will be given a \$15 honorarium for participating in this study.

Does this sound like a study you would like to participate in?

[If no] Thank you for your time.

[If yes, I will proceed in making arrangements for the interview].

**Contact Information**

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1. Phone number: (home) \_\_\_\_\_  
(work) \_\_\_\_\_

2. Best time to call: \_\_\_\_\_

3. Is it all right to leave a message on your answering machine?

\_\_\_\_\_  
Yes

\_\_\_\_\_  
No

If yes, is there anything you would not like me to say on the machine such as my name, that I am calling about the "Reproductive Decision-making of Women Living with HIV Study," etc.?

\_\_\_\_\_  
\_\_\_\_\_

4. When and where would you like to meet to do the first interview?

Date: \_\_\_\_\_

Chosen place for interview:

Address: \_\_\_\_\_

\_\_\_\_\_

Directions to place for interview: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Appendix D

Recruitment Advertisement

Sullivan, A. (1998, March 15). HIV-positive women risk motherhood. The

Vancouver Courier, p. 10.

Researcher says need to give life overrides social outrage

# HIV-positive women risk motherhood

By Ann Sullivan  
Contributing writer

DECIDING WHETHER TO HAVE A BABY is one of the biggest decisions any woman can make, but when the woman is HIV-positive, the decision is even more complicated.

But with more women contracting the human immunodeficiency virus, and longer life expectancies for victims, more HIV-positive women are opting for motherhood, planned or not.

There's no research on how women living with the incurable illness make decisions about having children. Amandah Lea, a long-time community health nurse and a UBC doctoral nursing candidate, hopes to change that with her study on the reproductive decision-making processes of HIV-positive women.

"It is a highly controversial subject, but [HIV-positive] women will have children, so it's important we have services in place to help them," she said.

Lea interviewed 20 women who chose to have babies despite the odds of passing on the infection to their unborn children. (With anti-retroviral drugs like AZT, the risk of infecting the baby has been reduced to about eight per cent.)

The women, she said, ask themselves the same questions every woman asks when she learns she is pregnant: "Do I want this baby? Can I do this? Do I

HIV-positive women face the possibility of infecting the baby, or the chance they could die before their child can take care of itself.

have the financial and social support to care for a baby?"

But HIV-positive women face other considerations, like the stigma of living with AIDS, the possibility of infecting the baby, or the chance they could die before their child can take care of itself.

Although some are outraged by the idea of an HIV-positive woman becoming a mother—"We all focus on 'How dare they have this baby?'" Lea said—women have their own reasons for carrying a child to term.

"They may not be reasons that we support or agree with," she said, "but in some ways I don't think they're different from the reasons other mothers use when they're deciding.

"When they find out they're pregnant, [women] want to give life and care for a baby, or they want to save a child from a troubled life. Both decisions are

coming from the same place of being a good mother."

Some women, faced with the news they are HIV-positive and pregnant, view their pregnancy as evidence of a higher power, and a reason to live.

"[Women] are discovering they're spiritual beings on a human journey," Lea said. "There's a lot of that aspect coming into their decision-making."

Lea, who has close to 20 years of nursing experience, chose her research topic based on her experience of meeting people living with HIV and AIDS professionally and socially. When she told friends of her research topic, she said, they were excited and hopeful that their experiences would be more closely examined and understood.

"All of the [study participants] have appreciated the opportunity to talk without being judged," Lea said.

As a researcher, Lea said her preliminary work has already given her insight into the complex and difficult decisions HIV-positive women and their partners face.

"In the eyes of the general population, it's all wrong," she said, "but maybe it teaches us an appreciation of life and love, and the fragility of life."

Lea needs more women to take part in the study. She is seeking women who have no history of substance abuse, with incomes of more than \$20,000 who have become pregnant in the past three



## Appendix G

Table G1

Demographic Characteristics of Women with HIV (N = 29)

	n
Age (M = 31 years)	
20 - 25	5
26 - 30	8
31 - 35	12
36 - 40	4
Ethnicity	
White	
13	
Aboriginal Peoples	
Native Indian	13
Metis	2
Spanish Sicilian	1
Education (highest level)	
Elementary school	1
Some high school	15
High school diploma	4
Trade or technical school	1
Some college (1-2 years)	6
Baccalaureate degree	2
Marital Status	
Single	8
Separated/divorced	6
Married	4
Common-law/cohabiting	10
Widow	1
Employment	
None reported	19
Volunteer work	4
Part-time work	4
Full-time work	2
Gross annual income	
\$ 0 - \$ 9,999	15
\$10,000 - \$19,999	10
\$20,000 - \$29,999	2
\$30,000 - \$39,999	2

Table G2

HIV Status at Time of First Interview (N = 29)

	n
Length of time HIV status known (M = 4.25)	
0 - 2 years	10
3 - 5 years	11
6 - 10 years	7
11 - 15 years	1
Viral load (measured as HIV RNA copies/ml)	
Unknown	9
Undetectable (<500)	4
501 - 10,000	7
10,001 - 100,000	5
100,001 - 150,000	2
150,001 - 750,000	2
CD4 count (measured as cells/mm <sup>3</sup> )	
Unknown	9
0 - 200	4
201 - 350	2
351 - 500	6
501 - 1000	7
1001 - 1500	1
Antiretroviral therapy	
None	17
Dual combination	9
Triple combination	3
Duration of antiretroviral therapy (n = 12)	
Unknown	3
0 - 6 months	3
7 - 24 months	2
25 - 60 months	3
61 - 120 months	1

Table G3

HIV Risk History (N = 29)

	n
Shared dirty needles	7
Unprotected heterosexual contact	6
Shared dirty needles & unprotected heterosexual contact	14
Occupational needlestick injury	2
Alcohol and other substance abuse	
None	7
1 - 5 years	2
6 - 10 years	10
11 - 15 years	3
16 - 20 years	4
21 - 30 years	3
Sex trade work to support drug addiction	
None reported	17
Sex trade work reported	12
History of violence in their lives	
None reported	8
Violence reported	21
Sexually assaulted	
as a child	2
as an adult	7
as an adult and child	3
Other sexual offences	
as a child	10
as an adult	1
Non-sexual assault	
as a child	1
as an adult	8
as an adult and child	9

Table G4

Descriptive Information About Reproduction Prior to  
HIV Diagnosis (N = 29)

	n
Choice of contraception prior to HIV diagnosis	
None reported	6
Intrauterine device	1
Birth control pills	14
Depo-Provera shots	1
Condoms	4
Condoms & birth control pills	3
Number of pregnancies	
0	9
1	1
2	6
3	4
4	5
5	2
6	1
8	1
Number of intended pregnancies	7
Number unintended pregnancies from inconsistent contraceptive use	62
Number of abortions (n = 20)	
1	3
2	7
3	1
Miscarriages	5
Stillbirths	1
Number of live births (1 twin birth; n = 44)	
1	5
2	8
3	2
4	3
5	1

Table G5

Descriptive Information About ReproductionAfter HIV Diagnosis (N = 29)

	n
Choice of contraception	
Abstain from heterosexual intercourse	4
Depo-Provera shots	1
Hysterectomy	2
Tubal ligation	3
Condoms	10
Condoms & rhythm method	1
Condoms & Depo-Provera shots	1
Condoms & birth control pills	4
Condoms & tubal ligation or vasectomy	3
Number of pregnancies while living with HIV	
0	12
1	13
2	2
3	1
4	1
HIV status known prior to pregnancy	9
HIV status first known during pregnancy	7
HIV status unknown during pregnancy	8
Number of intended pregnancies	2
Number of unintended pregnancies from inconsistent contraceptive use	22
Number of abortions reported	
1	4
2	2
Number of births	
1	10
2	3

(table continues)

Table G5

(continued)

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Perinatal use of ZDV	
None reported	5
Not available	2
Refused	1
Use reported	8
Pregnancy outcomes	
Stillbirth	1
HIV seronegative	8
HIV seropositive	7
Living	4
Dead	3
Primary support person when making their reproductive decisions	
None reported	9
Father of the future child	16
General practitioner	1
Mother	2
Grandmother	1

---

Table G6

Demographic Characteristics of Primary Support Persons (N = 9)

	n
Age (M = 34 years)	
20 - 25	1
26 - 30	2
31 - 35	2
36 - 40	3
41 - 45	1
Ethnicity	
Caucasian	6
Aboriginal Peoples	
Native Indian	1
Metis	1
Turkish	1
Education (highest level)	
Some high school	3
High school diploma	2
Some college	1
Baccalaureate degree	2
Graduate degree	1
Duration of relationship (M = 5 years)	
0 - 1 year	1
2 - 5 years	5
6 - 10 years	3
Employment	
None reported	4
Part-time	1
Full-time work	4
Gross annual income	
\$ 0 - \$ 9,999	1
\$10,000 - \$19,999	5
\$20,000 - \$29,999	2
\$30,000 - \$39,999	0
\$40,000 - \$49,999	1

(table continues)

Table G6

(continued)

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HIV status of support person at time of first interview	
HIV seronegative	6
HIV seropositive	3
Length of time HIV status known	
0 - 2 years	1
3 - 5 years	2
Viral load (measured as HIV RNA copies/ml)	
Undetectable	1
Unknown	2
CD4 count (measured as cells/mm <sup>3</sup> )	
201 - 500	1
Unknown	2
Antiretroviral therapy	
None	3
HIV Risk History	
Shared dirty needles	2
Shared dirty needles and unprotected heterosexual contact	1
Alcohol and other substance abuse	
None	4
0 - 10 years	1
11 - 20 years	3
21 - 30 years	1
Sex trade work to support drug addiction	
None reported	8
Sex trade work reported	1
History of violence in their lives	
None reported	6
Violence reported	3
Physical abuse	3

---



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7. I understand that my decision to participate is entirely my own and will in no way affect my care. I also understand that I am free to withdraw from the study at any time, may refuse to answer any questions, may ask any audiotaped information to be erased in my presence, or may ask for any sensitive information not to be divulged.

8. I have received a copy of the information letter and this consent form to keep for future reference.

I, \_\_\_\_\_, consent to participate in this study.

Signed \_\_\_\_\_ Date \_\_\_\_\_

I would like to receive the summary report of the findings. Please mail it to me at the following address:

\_\_\_\_\_ (street)

\_\_\_\_\_ (city) \_\_\_\_\_ (postal code)

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7. I understand that my decision to participate is entirely my own and will in no way affect my care. I also understand that I am free to withdraw from the study at any time, may refuse to answer any questions, may ask any audiotaped information to be erased in my presence, or may ask for any sensitive information not to be divulged.

8. I have received a copy of the information letter and this consent form to keep for future reference.

I, \_\_\_\_\_, consent to participate in this study.

Signed \_\_\_\_\_ Date \_\_\_\_\_

I would like to receive the summary report of the findings. Please mail it to me at the following address:

\_\_\_\_\_(street)  
\_\_\_\_\_(city) \_\_\_\_\_(postal code)

5. Do you have a history of substance abuse?

\_\_\_\_\_ Yes. \_\_\_\_\_  
name of drugs and/or alcohol \_\_\_\_\_  
date \_\_\_\_\_ any rehabilitation \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_ No

6. Have you ever been pregnant?

\_\_\_\_\_ Yes. \_\_\_\_\_  
year \_\_\_\_\_  
\_\_\_\_\_ No

7. Have you ever had an abortion?

\_\_\_\_\_ Yes. \_\_\_\_\_  
year \_\_\_\_\_  
\_\_\_\_\_ Yes, spontaneous abortion \_\_\_\_\_  
year \_\_\_\_\_  
\_\_\_\_\_ No

8. Have you ever given birth?

\_\_\_\_\_ Yes. \_\_\_\_\_  
year \_\_\_\_\_  
\_\_\_\_\_ Yes, stillbirth \_\_\_\_\_  
year \_\_\_\_\_  
\_\_\_\_\_ No

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9. If your child(ren) are living with you, what is the(ir) HIV status?

\_\_\_\_\_ Positive diagnosis \_\_\_\_\_  
year & current age of child(ren)

\_\_\_\_\_ Negative diagnosis \_\_\_\_\_  
year & current age of child(ren)

\_\_\_\_\_ Unknown, being tested \_\_\_\_\_  
current age of child(ren)

\_\_\_\_\_ Unknown, not being tested \_\_\_\_\_  
current age of child(ren)

10. Have any child(ren) died of AIDS or an AIDS-related condition?

\_\_\_\_\_ Yes \_\_\_\_\_  
year & age of child(ren)

11. Are you currently employed?

\_\_\_\_\_ Yes, part time

\_\_\_\_\_ Yes, full time

\_\_\_\_\_ No

12. What was your 1996 yearly income before taxes?

\_\_\_\_\_ Less than \$10,000

\_\_\_\_\_ \$10,000 to \$20,000

\_\_\_\_\_ \$20,000 to \$30,000

\_\_\_\_\_ \$30,000 to \$40,000

\_\_\_\_\_ \$40,000 to \$50,000

\_\_\_\_\_ More than \$50,000

## 13. What is the highest level of education you completed?

1. Elementary school
2. High school
3. High school diploma
4. Trade or technical school
5. Some college
6. Baccalaureate degree
7. Graduate school

## 14. Ethnicity

1. Caucasian
2. Asian-Chinese
3. Asian-Indian
4. African
5. First Nation
6. Other \_\_\_\_\_

## 15. Are you affiliated with a church?

\_\_\_\_ Yes, \_\_\_\_\_  
name of church

\_\_\_\_ No

## 16. What is your marital status?

1. Single
2. Divorce
3. Married
4. Common-law/Cohabiting
5. Widow

## 17. Who is your primary support person in making your reproductive decisions?

[Primary support person is defined as the individual who you consider most involved in making your reproductive decisions]

\_\_\_\_\_  
identify person (i.e., partner, sister, girlfriend, general practitioner, etc).

18. Is your primary support person living with HIV infection?

            
Yes

            
No

19. If your partner or primary support person is living with HIV infection, when was he/she diagnosed?

            
Month

            
Year

20. How long have you known your primary support person?

            
Years

            
Months

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5. Are you currently employed?

☐ Yes, part time☐ Yes, full time☐ No

6. What was your 1996 yearly income before taxes?

☐ Less than \$10,000☐ \$10,000 to \$20,000☐ \$20,000 to \$30,000☐ \$30,000 to \$40,000☐ \$40,000 to \$50,000☐ More than \$50,000

7. What is the highest level of education you completed?

1. Elementary school
2. High school
3. High school diploma
4. Trade or technical school
5. Some college
6. Baccalaureate degree
7. Graduate school

8. Ethnicity

1. Caucasian
2. Asian-Chinese
3. Asian-Indian
4. African
5. First Nation
6. Other \_\_\_\_\_

9. Are you affiliated with a church?

☐ Yes, name of church \_\_\_\_\_☐ No

## Appendix N

A List of Non-Fictional Literature and Popular Press Articles Analyzed  
for the Research Study

Colterjohn, K. (1997). Positively sexual woman: A resource for women living with HIV & AIDS, (p. 14). Toronto, Canada: Canadian AIDS Society.

Cooper, R. (1998). I'm on a mission. Women Organized to Respond to Life-Threatening Diseases (WORLD), 82, 1-2.

DeJesus, J. (1998). Where would I be if I had not been diagnosed HIV+? WORLD, 85, 2-3.

Denison, R. (1995). The hardest decision I ever made. WORLD, 55, 1-6.

Diaz, M. (1998). North American positive women: We are not alone. The International Community of Women Living with HIV/AIDS (ICW) News, 5, 3.

Dina - Switzerland. (1992). In A. Rudd, & D. Taylor (Eds.), Positive women: Voices of women living with AIDS (pp. 81-88). Toronto, Canada : Second Story Press.

Federick, L. 1998. Baby love: boy or girl. Brown or blue eyes. HIV positive or negative? POZ Magazine, April, 52-53.

Hanna, D. (1991, April 17). Mother with HIV ignored warnings. The Vancouver Sun, B1, B6.

Heavey, L. (1998). My life with (& beyond) HIV in Nebraska. WORLD, 82, 4-5.

Isabel - Zimbabwe. (1992). In A. Rudd, & D. Taylor (Eds.), Positive women: Voices of women living with AIDS (pp. 127-134). Toronto, Canada: Second Story Press.

Kegan. (1998). We are testing positive. WORLD, 85, 6.

Landau, E. (1990). We have AIDS (pp. 97-103). New York, NY: Franklin Watts,

Lucey, M. (1993). One woman's story. Women Alive, February, 7.

M. - Switzerland. (1992). In A. Rudd, & D. Taylor (Eds.), Positive women: Voices of women living with AIDS (pp. 89-100). Toronto, Canada: Second Story Press.

Mitchell, A. (1994). The HIV birthright—or wrong? PlusVoice, January/February, 44-45.



61. Morrison, B. (1998). Faith, hope, and Monica. POZ Magazine, April, 56, 58-59.
- Morrison, M. (1991). Positively pregnant. Talkabout, September/October, 8-14.
- Penny. (1988). To have or not have. In I. Rieder, & P. Ruppelt, (Eds.), AIDS: The women (pp. 88-90). San Francisco, CA: Cleis Press.
- People with AIDS/HIV talk about pregnancy. (1995, July/August). Newsline, 8-18.
- Remien, R. H. (1996). Intimacy in HIV negative/positive mixed couples: Bringing forth some basic concerns. Positively, 10(5), 1, 7-8.
- Roseanne - Canada. (1992). In A. Rudd, & D. Taylor (Eds.), Positive women: Voices of women living with AIDS (pp. 132-139). Toronto, Canada: Second Story Press.
- Rosemary - Zambia. (1992). In A. Rudd, & D. Taylor (Eds.), Positive women: Voices of women living with AIDS (pp. 26-30). Toronto, Canada: Second Story Press.
- Silbiger, D. (1997). She's having a baby. Positively Aware, November/December, 34-39.
- Silversides, A. (1998). Face it: Nice girls do get AIDS. Elm Street, Summer, 95-104.
- The Women of Gupo Pela Vidda - Brazil. (1992). In A. Rudd, & D. Taylor (Eds.), Positive women: Voices of women living with AIDS (pp. 31-44). Toronto, Canada: Second Story Press.
- Trotter, B. (1996). Positive/negative relationships: A personal perspective. Positively, 10(5), p. 2.

## Appendix O

Reproductive Decision-Making of Women Living With HIV:  
A Grounded Theory

