# ASKING THE INCONCEIVABLE?

# PHYSICIAN-PATIENT CONFLICT REGARDING THE UTILIZATION OF ASSISTED REPRODUCTIVE TECHNOLOGIES (ARTS) BY HIV-SEROPOSITIVE COUPLES: MEDICAL, ETHICAL AND LEGAL CONSIDERATIONS

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February 2007

A thesis submitted to McGill University in partial fulfillment
of the requirements of the degree of
**Master of Science**
in Experimental Medicine (Specialization in Bioethics)

# ABSTRACT

First recognized in 1981, human immunodeficiency virus type 1 (HIV-1) continues to foster considerable medical and ethical debate among physicians with regards to treatment options in reproductive medicine. During the first decade of the HIV/AIDS epidemic, fear of viral transmission prompted many physicians to refuse to treat non-HIV-related conditions in infected individuals. In the last decade, long-term prognosis for HIV-infected individuals has risen dramatically, fuelled by the development of potent antiretroviral therapies. Given their improved state of health, an increasing number of infected individuals, many of whom are heterosexual adults of reproductive age, are requesting the use of assisted reproductive technologies (ARTs) to achieve pregnancy, either as a result of infertility factors, or as a means to diminish the risk of transmission to the uninfected partner. Although the medical community now considers HIV a chronic, manageable illness, many practitioners, citing the potential transmission of the virus to the uninfected partner and/or to the couple's offspring, as well as concerns for the psychosocial well-being of the child-to-be, continue to strongly discourage such couples from proceeding with reproductive care, even denying access in certain circumstances. However, continual advances in the treatment and prognosis of infected individuals, as well as a considerable decrease in the risk of vertical transmission, have called into question the systematic medical recommendation against the provision of ART services to HIV-affected individuals. This research examines the medical, ethical and legal aspects regarding the use of ARTs by HIV-affected couples, focusing on the professional role obligations of the providing physician. Although the risk remains that any child of such a couple could be born with or become infected with HIV, an ethical and legal analysis of this debate demonstrates that such a practice violates respect for patients' medical autonomy, specifically with regard to reproductive decision-making, and infringes upon the legal rights of the couple and the woman's rights with respect to reproductive autonomy. Moreover, the harms which may result are not sufficient to justify the categorical exclusion of individuals from ART services on the basis of HIV-seropositivity.

# RÉSUMÉ

Depuis plus de vingt-cinq ans, le virus d'immunodéficience humaine type 1 (VIH-1) provoque de nombreux débats médicaux et éthiques parmi les médecins, particulièrement en ce qui concerne les traitements potentiels de la médecine reproductive. Au cours de la première décennie de l'épidémie du VIH/SIDA, une forte inquiétude vis-à-vis la possibilité de transmission virale incita plusieurs médecins à refuser de traiter les conditions non reliées au VIH chez les personnes atteintes du virus. Au cours des dix dernières années, le pronostic à long terme pour les personnes infectées s'est amélioré de façon significative, en raison du développement de thérapies antirétrovirales puissantes. Un nombre croissant d'individus, en relativement bonne santé même s'ils sont infectés par le virus, dont un bon nombre sont des adultes hétérosexuels en âge d'avoir des enfants, demandent d'avoir accès aux techniques de reproduction assistées (TRA) pour établir une grossesse, en raison d'une incapacité de concevoir ou pour diminuer le risque de transmission au partenaire non infecté. Bien que la communauté médicale considère maintenant le VIH comme une maladie chronique et «gérable», plusieurs médecins, préoccupés par la potentielle de transmission au partenaire non infecté et/ou au fétus, ainsi que par le bien-être psychosocial de l'enfant, continuent à décourager fortement ces couples d'avoir recours aux soins reproductifs, allant jusqu'à leur en refuser catégoriquement l'accès dans certains cas. Cependant, des progrès continus dans le traitement et pronostic d'individus infectés, ainsi qu'une diminution considérable du risque de transmission verticale, mettent en question la recommandation médicale systématique de ne pas offrir les services TRA aux personnes infectées. Ce mémoire examine les aspects médicaux, éthiques et légaux liés à l'utilisation des TRA par les couples atteints du VIH, en accordant une attention particulière aux obligations professionnelles du médecin pourvoyeur. Quoique le risque demeure que n'importe quel enfant d'un de ces couples pourrait être né ou devenir infecté avec le VIH, une analyse bioéthique de la problématique fait ressortir que la pratique en question viole le respect de l'autonomie médicale des patients, particulièrement quant à la prise de décisions reproductives, et qu'elle transgresse les droits légaux du couple et de la femme quant à son autonomie reproductive. De plus, les problèmes potentiels qui

peuvent résulter ne sont pas suffisants pour justifier l'exclusion catégorique d'individus des services TRA sur la base du statut séropositif.

# ACKNOWLEDGMENTS

First and foremost, I would like to thank my advisor, Angela Campbell, for her continued guidance, wisdom and support throughout the past year and a half. I am tremendously appreciative of the time she invested in my dissertation, considering that she and I were in different cities, and had to deal with back-and-forth emails, mailings and telephone calls throughout the bulk of the work on my thesis. I would also like to acknowledge the faculty members of the Biomedical Ethics Unit: Dr. Leigh Turner, Dr. Kathleen Glass, Dr. Eugene Bereza, Dr. Carolyn Ells and Dr. Jonathan Kimmelman. Their support made completion of this dissertation possible, and provided me with opportunities throughout the year that would have otherwise been impossible.

One of my fondest memories of my time in the Master's Specialization in Bioethics is the wonderful friendships that I made with the other students in the program. A big thank you to Zoë Costa-von Aesch, Marie-Josée Dion, Ariella Binik, David McLauchlan and Carly Mutch for all of your support throughout our time together in Montreal. I wish you all the best in your future endeavours. Last, but certainly not least, I wish to thank my parents, François and Catherine, as well as my sister, Viviane, for their continued love, belief in me and sincere interest in all that I undertake. It means so much to me.

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| | |
|---|---|
| ACOG | American College of Obstetricians and Gynecologists |
| ADA | Americans with Disabilities Act |
| ADC | AIDS Dementia Complex |
| AHRA | Assisted Human Reproduction Act |
| AI | Artificial insemination |
| AIDS | Acquired immune deficiency syndrome |
| ART(s) | Assisted reproductive technology/(ies) |
| ASRM | American Society for Reproductive Medicine |
| AZT | Azido-deoxythymidine (Zidovudine) |
| CDC | Centers for Disease Control and Prevention |
| CFAS | Canadian Fertility and Andrology Society |
| CREATHE | Centres for Reproductive Assistance to HIV Couples in Europe |
| FSH | Follicle-stimulating hormone |
| GIFT | Gamete intra-fallopian transfer |
| HAART | Highly active antiretroviral therapy |
| HIV-1 | Human immunodeficiency virus (type 1) |
| ICSI | Intracytoplasmic sperm injection |
| IDU | Injection drug use |
| IUI | Intrauterine insemination |
| IVF | *In vitro* fertilization |
| IVF-ICSI | *In vitro* fertilization accompanied by intracytoplasmic sperm injection |
| MSM | Men who have sex with men |
| NNRTIs | Non-nucleoside reverse transcriptase inhibitors |
| NRTIs | Nucleoside reverse transcriptase inhibitors |
| PACTG | Pediatric AIDS Clinical Trials Group |
| PCP | *Pneumocystis carinii* pneumonia |
| PIs | Protease inhibitors |
| PID | Pelvic Inflammatory Disease |
| SOGC | Society of Obstetricians and Gynecologists of Canada |
| STIs | Sexually transmitted infections |
| ZDV | Zidovudine |
| ZIFT | Zygote intra-fallopian transfer |

# AUTHOR'S NOTE

Within this dissertation, I use the term 'HIV-affected couple' to refer to any heterosexual couple in which either partner or both partners are infected with the human immunodeficiency virus type 1 (HIV-1). In addition, the terms 'seropositive', 'serodiscordant', and 'seroconcordant' are used interchangeably with 'HIV-affected' throughout the dissertation.

Furthermore, given the variety of types of physicians who may be involved in the provision of assisted reproductive technologies, I use the term 'physician' to refer to any physician-clinician with whom a couple may interact when accessing and utilizing assisted reproductive technologies for the purpose of conceiving. This includes, but is not necessarily limited to: obstetrician-gynecologists, specialists in reproductive medicine, specialists in maternal-fetal medicine, reproductive endocrinologists, and specialists in infertility management.

# PREAMBLE

Please consider the following statement by Mark V. Sauer, Program Director of the Center for Women's Reproductive Care, affiliated with Columbia University, published in response to the commentary written about his position on providing fertility care to HIV-1-serodiscordant couples,[1] in the spring 2003 issue of the *American Journal of Bioethics*:

> I was convinced…and remain convinced today, that using assisted reproductive techniques to enhance the lives of patients with HIV-1 is appropriate. I…believe that all parties, including the children born from this technology, benefit immeasurably from our effort, despite the small risk of infection. I have found couples presenting for care are well educated to the benefits and risks involved. They are neither uninformed nor selfish in their pursuit of having biologic children. Rather, I would suggest that they are highly devoted to each other and perhaps more pair-bonded than other couples. After all, ***individuals with HIV-1 and their spouses face a potentially life-threatening infection everyday. They embrace the opportunity to have biologic children with extraordinary courage, not out of ignorance.***[2]

~ Mark V. Sauer, MD

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[1] Sauer, M.V. (2003). Providing fertility care to those with HIV: Time to re-examine health policy. *American Journal of Bioethics* 3: 33-40.
[2] Sauer, M.V. (2003). 3:1 Target article author responds to commentators. Providing reproductive care to HIV-1 serodiscordant couples: Final thoughts. *American Journal of Bioethics* 3: W10.

# INTRODUCTION

In the last 25 years, perception of the human immunodeficiency virus type 1 (HIV-1), the virus that leads to acquired immunodeficiency syndrome (AIDS), has shifted from a 'disease' thought to afflict only homosexual men to that of an illness that affects people of all ages throughout the world. Now viewed by many as a "modern plague" (Sauer, 2003), especially in the developing world, given the sheer number of individuals infected and the high mortality rate from AIDS in these countries, the virus continues to present a significant challenge to both the medical community and to general society, even in the more affluent regions of the world, which lead the way in HIV/AIDS research (Sauer, 2003). Although research findings are promising, the inherent rapid mutability of the virus has prevented the development of a vaccine or a cure to date. Nevertheless, in the 1990s, significant therapeutic advances altered the clinical course of the virus, such that HIV-infected individuals having access to pharmacological treatment and appropriate medical care can now expect to live a reasonably long and generally healthy life (Lyerly & Anderson, 2001; Williams *et al*., 2003). Today, an increasing number of those infected are heterosexual adults of reproductive age, and given their improved long-term prognosis, many of these individuals desire establishing long-term romantic relationships and starting families of their own.

Driven by the desire to approach their reproductive plans responsibly, many HIV-affected couples[3,4] wanting to conceive are now turning to reproductive specialists,

[3]Athough ARTs are utilized by several different groups of people, including those in so-called traditional male-female marriages, unmarried/single adults (primarily women), and same-sex partners (primarily lesbian couples), I have chosen to focus this dissertation on HIV-affected heterosexual couples, given the increasing number of heterosexual HIV infections, the now chronic nature of the illness, and the growing

requesting the use of assisted reproductive technologies (ARTs) to achieve their goal. ARTs are considered "all treatments or procedures[5] that include the *in vitro* [i.e., in a glass or now, more commonly, a plastic Petri dish] handling of human oocytes and sperm or embryos for the purpose of establishing a pregnancy." (International Working Group for Registers on Assisted Reproduction, 2002). ARTs are considered a 'private' form of health care, meaning that, with a few rare exceptions (e.g., partial coverage through a private income health insurance plan), the entire cost of the procedure must be paid by the patient; as such, the physician acts as the 'gatekeeper' of these technologies, determining which individuals/couples, assuming that they are able to cover the cost of treatment, will be granted access at any given time (Sauer, 2003). Nonetheless, given the reproductive complication of infertility, or sub-fertility, at the very least, that often accompanies an HIV diagnosis, ARTs are particularly appealing and well-suited to HIV-affected couples, as they provide an effective and relatively convenient means for these couples to achieve pregnancy, while minimizing the risk of transmission to the uninfected partner and/or the child-to-be (Lyerly & Anderson, 2001).

In the first years of the HIV epidemic, fear of the virus's infectiousness caused many physicians to refuse to treat HIV-infected patients for any conditions other than

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desire by many of these couples to have children, as do most heterosexual couples in the general population.

[4] HIV-infected individuals living in the developed world comprise a relatively small proportion of the world's total infected population (<10%). Greater than 90% of those infected live in developing countries, particularly those located in sub-Saharan Africa (Anderson, 1999). Of the less than 10% living in developed countries, not all will be able to afford the use of ART services, meaning that the clientele having the potential to make use of these services likely consists of no more than 5% of the world's total HIV-infected population. Nevertheless, I consider this demographic group one of importance, for the reasons listed above [See note 3].

[5] Examples of ARTs include, but are not limited to, *in vitro* fertilization and trans-cervical embryo transfer, gamete intra-fallopian transfer, zygote intra-fallopian transfer, tubal embryo transfer, gamete and embryo cryopreservation, oocyte and embryo donation, and gestational surrogacy. Artificial insemination (AI) is technically not considered a form of ART, because gametes are not manipulated *in vitro* (WHO, 2002).

those related to the virus (Zuger & Miles, 1987). When HIV-affected couples first began requesting reproductive assistance, physicians always advised against proceeding, even denying access outright in some circumstances, citing the prognosis for the infected parent(s) and the risk of transmission to the uninfected parent and/or to the child (Englert *et al*., 2001; Sauer, 2003). By the late 1980s and early 1990s, many major medical establishments in North America, particularly in the United States, including, most prominently, the US Centers for Disease Control [now the US Centers for Disease Control and Prevention] (CDC), published recommendations advising against the provision of ARTs to both HIV-serodiscordant and HIV-seroconcordant couples (CDC, 1990; Sauer, 2003). The recommendations went largely unquestioned at the time, as the virus was thought to be highly infectious and was considered inevitably fatal if contracted (Anderson, 1999). Claiming that HIV-1 posed an "unacceptable danger" to those involved at any point in the assisted reproduction process, including the uninfected partner, the fetus, the physicians themselves and any laboratory personnel, as well as the high rate of vertical transmission from infected mothers to their infants, most reproductive centres in North America began refusing to provide reproductive care to HIV-affected couples (Sauer, 2003).

Until only a little more than a decade ago, a diagnosis of HIV was essentially considered a 'death sentence', with a rapid decline in health expected for those infected, ending in death within as little as 3 to 4 years (Anderson, 1999). However, the development of effective antiretroviral therapies in the early to mid-1990s, designed to slow the progression of the virus, led to better overall health and increased life expectancy for infected individuals, such that those having access to these drug regimens

are now living relatively normal lives. The variety of treatment options available, combined with better long-term prognosis, as evidenced by the large decline in mortality due to AIDS cases in the developed world since the availability of antiretrovirals (Hogg *et al*., 1997; CDC, 2005; UN/AIDS, 2005), has brought about a change in the way HIV is viewed, with the vast majority of primary health care providers in the developed world now considering HIV a chronic, yet manageable, condition (Gallant, 2000; Sauer & Chang, 2002).

Unfourtunately, despite the remarkable therapeutic advances in HIV treatment observed in the last decade or so, HIV-affected couples continue to be marginalized by a significant segment of the medical establishment, likely a testament to the effectiveness of the lobbying undertaken by several prominent professional medical associations to limit the reproductive freedom of HIV-seropositive women (Ethics Committee of the American Fertility Society, 1994; Faden & Kass, 1996), as well as remnants of the once-omnipresent stigma associated with HIV/AIDS, rampant as recently as 15 to 20 years ago (Zuger & Miles, 1987). Lyerly and Faden (2003) maintain that HIV-seropositive individuals are regarded and treated differently by medical professionals than are other persons who wish to access ARTs. As evidence, they point to the similarities between aspects of HIV that are felt (or claimed) to be a contradiction to reproductive assistance and facets of other medical conditions—conditions, which, for the most part, compel the physician to follow a policy of informed decision-making rather than categorical exclusion (Lyerly & Faden, 2003). According to Lyerly and Faden (2003), "the stigma that remains associated with HIV, rather than HIV *per se*, is the reason that women are not granted [reproductive] assistance."

The profound reluctance on the part of many medical professionals to treat individuals infected with HIV, for reasons related to stigma or otherwise, is not a recent phenomenon. The HIV/AIDS epidemic took many physicians by surprise, propelling them into a position of needing to care for individuals having an infectious condition of which little else was known, and prompting many of them to draw premature analogies between AIDS and other great historical epidemics, such as the Black Death, the first wave of which is estimated to have killed at least 25% of the European population between 1347 C.E. and 1351 C.E. (Gottfried, 1983). In fact, any risk(s) taken by physicians when caring for victims of the bubonic plague greatly outweighed any risk that HIV may pose to a physician caring for an HIV-infected patient today, especially in light of numerous thorough evaluations of the risks over the years; risks now considered negligible in most situations requiring medical intervention (Henderson *et al*., 1986; McCray, 1986; Zuger & Miles, 1987; Bell, 1997). Nevertheless, the emergence of HIV/AIDS during a time in which infectious disease was thought to have been permanently eradicated (Barrett *et al*., 1998; Armelagos *et al*., 2005), and the lack of a professional ethic governing the care of HIV-infected individuals (Zuger & Miles, 1987), incited many physicians to question the degree of their professional obligations toward patients with HIV/AIDS (Zuger & Miles, 1987).

Today, access to ARTs for HIV-affected couples remains severely limited in North America, with less than 5% of clinics offering reproductive care to such couples (Sauer, 2003). Interestingly, HIV-affected couples in Europe seeking reproductive assistance for the purpose of conceiving have not been subject to the same exclusionary tendencies observed in North America (Bendikson *et al*., 2002; Spriggs & Charles, 2003).

For a variety of reasons, most of which are likely related to cultural and societal attitudes particular to Europe, the European medical community was quick to embrace the pioneering work of Semprini *et al*. (1987, 1992, 1993) in Milan, Italy, a team which developed a protocol for the use of ARTs by HIV-affected couples. Although the Milan centre remained the world's sole provider of reproductive assistance to HIV-affected couples from 1989 to 1995, more than 10 clinics offering such services have been established in Europe since then (Bendikson *et al*., 2002), leading to the establishment of a linked network of clinics designed to ensure the optimization of treatment and proper monitoring of outcomes (Semprini & Fiore, 2004). The network, termed CREATHE (Centres for Reproductive Assistance to HIV Couples in Europe), links clinics in Italy, Spain, the United Kingdom, Switzerland, France, Belgium and Israel, with principal centres located in Barcelona, Spain; London, England; Saint-Gallen, Switzerland; and Toulouse, France (Semprini & Fiore, 2004). The CREATHE network has extensive experience in assisting HIV-affected couples with reproduction; from 1989 to 2003, almost 3,500 cycles of assisted reproduction were carried out in CREATHE centres, resulting in just under 500 births, without a single report of maternal or congenital seroconversion[6] (Semprini & Fiore, 2004). With such favourable findings being published in many leading medical journals, it is difficult to comprehend why the same reproductive options would not be made available to HIV-affected couples in North America.

[6] Seroconversion is defined as the time at which antibodies created in response to the virus are first detected in the blood of an HIV-infected individual. It is important to note that the window between infection and seroconversion can be as long as 3 to 6 months, and although the person may test negative for HIV during this time, **he/she is still capable of transmitting the virus to others during this window** (Letvin & Walker, 2003).

In recent years, in light of considerable treatment improvements and a significant decrease in the risk of vertical transmission, many medical professionals and bioethicists have called into question the continued categorical exclusion of HIV-seropositive individuals from assisted reproductive services, calling the practice "ethically unjustifiable" (Englert *et al*., 2001; Lyerly & Anderson, 2001; Lyerly & Faden, 2003; Williams *et al*., 2003). This dissertation will consider whether, given the increase in life expectancy and overall improvement in health as a result of the introduction of effective antiretroviral therapies, physicians specializing in reproductive medicine now have an obligation to offer ART services to HIV-affected couples; or, does any level of risk of HIV transmission to either the uninfected partner and/or unborn child justify the withholding of these services on the part of the physician? The crux of this debate centres on the view held by many physicians that HIV-affected couples are not suitable candidates for parenthood. The nature of ARTs is such that, although they are essentially medical 'instruments', they also, by definition, increase the extent to which physicians are involved in patients' reproductive decision-making. A decision which was at one time very personal and private has now, by necessity in some cases, such as with HIV-affected couples, become one of intense scrutiny and moral deliberation. However, the categorical exclusion of HIV-affected couples leads to a question of critical importance, a question which sums up the debate, as articulated by Hester (2002, p.401):

> [I]t is a curious sociological and historical fact that infertility has come to be a medical problem to be solved, raising a basic question concerning why medicine has become implicated in an individual's or couple's desire to procreate to the extent that it has developed ARTs. Ethically, though, the sociohistorical implication leads to a further question: How should the position that physicians are in relative to procreative activities be characterized in moral terms? Is parenthood itself a right to be pursued, a privilege to be gained, or simply a

> biological occurrence that may or may not be possible for any particular woman or couple?

It is in answering this question that the debate surrounding the use of ARTs by HIV-affected couples may one day be finally laid to rest; at this time, however, the debate continues to rage on, much to the detriment of the many HIV-affected couples wanting to become parents.

Needless to say, an ethical analysis of an HIV-affected couple desiring a biological child is complex, considering the physical involvement and (present and future) emotional investment of three separate parties: the mother, the father, and the child-to-be (Savulescu, 2003; Williams *et al*., 2003).[7] All relevant concerns should be factored into the analysis, all the while remembering that "each couple who is affected by HIV is unique, and the ethical appropriateness must not be generalized." (Williams *et al*., 2003). However, prior to undertaking a clinical, ethical and legal analysis of the debate, a thorough understanding of the relevant medical issues unique to HIV-affected couples is essential.

## Background Medical Issues

### *Brief Epidemiology of HIV/AIDS*

Since it was first recognized in 1981, AIDS has killed more than 25 million people worldwide; currently, an estimated 40.3 million people are believed to be living with HIV/AIDS (UNAIDS/WHO, 2005). Although sex between men remains the primary mode of transmission of HIV in North America and Western Europe, the incidence of individuals becoming infected through unprotected heterosexual intercourse

[7] See note 1.

is increasing rapidly, such that heterosexuals now make up the second largest HIV exposure group in these two regions (CDC, 2005). Amongst adolescents and young adults, the extent of heterosexual transmission is even more striking: over 50% of adolescent HIV/AIDS cases are directly attributable to heterosexual contact (CDC, 2005). In North America, Western and Central Europe, an estimated 1.9 million people were living with HIV/AIDS at the end of 2004, many of whom are heterosexual adults of active reproductive age (i.e., 15-44 years old) (Ethics Committee of the American Society for Reproductive Medicine (ASRM), 2004; UNAIDS/WHO, 2005). In Canada, 58,000 people were estimated to be living with HIV/AIDS at the end of 2005, with 27% of those having contracted the virus through a heterosexual encounter (Boulos *et al*., 2006) (Figures 1 & 2).

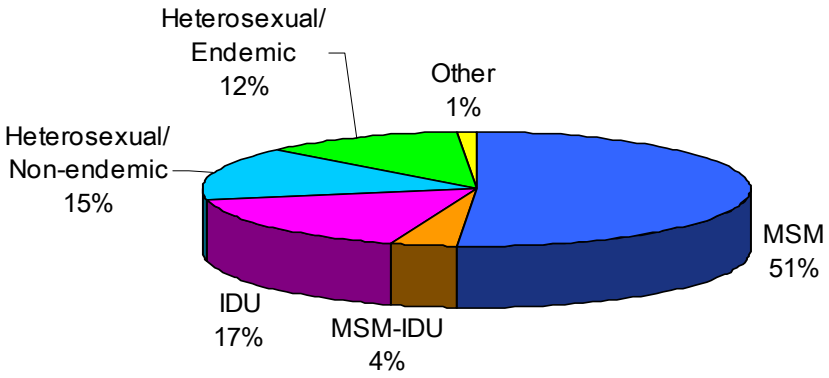
### *Clinical Manifestation of HIV*

#### *Understanding HIV/AIDS*

HIV is a retrovirus[8] which is transmitted when virus-laden body fluids from an infected person come into contact with a portal of entry of another person, usually an open wound or mucosal membrane. Several routes of transmission are possible, with blood transfusions or tissue transplants, sexual activity including vaginal or anal intercourse, perinatal transmission through childbirth or breastfeeding, sharing needles used for injections, and accidental exposures to blood or other infected body fluids in occupational settings, being the most common (Health Canada, 2004). Once

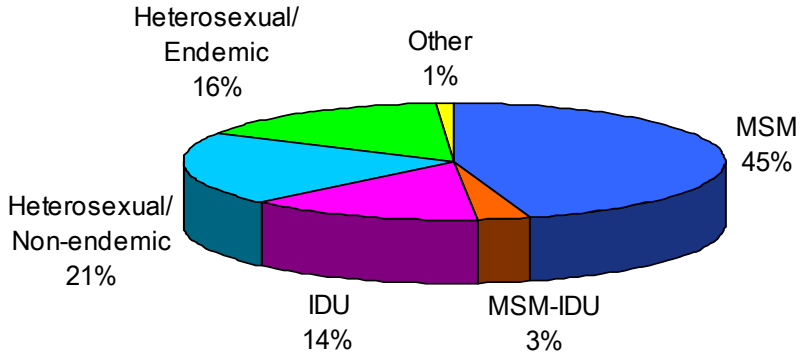
[8] A retrovirus uses single-stranded RNA, as opposed to double-stranded DNA, to encode its genome; at time of replication, double-stranded viral DNA is synthesized using genomic RNA as a template. The transcribed DNA is then able to integrate into the DNA of the host cell (Levinson, 2006).

**Figure 1**: Distribution of the estimated prevalence (existing cases) of HIV infection (including AIDS) in Canada at the end of 2005, by exposure category[†] (Public Health Agency of Canada, 2006).




[†]*Exposure Categories*: **MSM**-men who have sex with men; **IDU**-injecting drug users; **Heterosexual/Non-endemic**-individuals having heterosexual contact with a person who is either HIV-infected or at risk for HIV, or having heterosexual activity as the only identified risk for HIV; **Heterosexual/Endemic**-individuals with an origin in a country where HIV in endemic (mainly sub-Saharan Africa and the Caribbean) and is not identified as MSM or IDU; and **Other**-recipients of blood transfusion of clotting factor, perinatal and occupational transmission.

**Figure 2**: Distribution of the estimated incidence (new cases) of HIV infection in Canada in 2005, by exposure category[‡] (Public Health Agency of Canada, 2006).




[‡]Exposure categories as per Figure 1.

transmission occurs, the virus can be found in most bodily tissues, although it establishes a reservoir in the lymphatic tissue (Pope & Hasse, 2003).

During the acute phase of the infection, the virus invades host cells and causes those cells to assist in the creation and dissemination of new viral particles. Two to three weeks after infection, most individuals experience flu-like symptoms, with a transitory fever, swollen lymph glands, a rash and other mild symptoms usually present. This episode can be the only outward manifestation of HIV infection for many years, for the virus subsequently enters a phase known as the latent period, in which the virus itself is actually quite active, however clear signs and symptoms of the infection are absent (Letvin & Walker, 2003; Pope & Hasse, 2003).

*Progression of Infection*

Today, HIV-infected individuals can easily remain asymptomatic for 10 years or more, despite a stable concentration of the virus in their plasma and steady rate of destruction of CD4+ T lymphocytes (approximately 50 cells/$mm^3$ per year), resulting in a progressive decline in immune function. When the CD4+ count falls below 200 cells/$mm^3$, the diagnosing criteria of AIDS (CDC, 2005), viral concentration begins to rise exponentially, resulting in the development of non-specific signs and symptoms. In late stages of the infection, the characteristic signs of AIDS are present, notably AIDS-related opportunistic infections, such as *Pneumocystis jiroveci* (formerly *P. carinii*) pneumonia (PCP); AIDS-instigated malignancies, such as Kaposi's sarcoma; wasting; and neurological complications, such as AIDS Dementia Complex (ADC) (Lyerly &

Anderson, 2001). Interestingly, a recent study has shown that HIV-infected women exhibit a more rapid decline in CD4+ cell count, and a faster progression to AIDS and death than do men with a similar viral load. Similarly, progression to AIDS also occurs more rapidly in individuals older at time of seroconversion (Sterling *et al*., 1999).

*Treatment Advances: Antiretroviral Therapies*

To date, the inherent tendency of HIV to mutate rapidly has made the development of effective treatments tremendously difficult (Lyerly & Anderson, 2001). In an effort to increase clinical effectiveness, combination therapies, otherwise known as highly active antiretroviral therapy (HAART), consisting of two or more pharmaceutical agents from different classes, have been emphasized over single agents, which, although effective at suppressing viral load, are also more greatly prone to mutations that confer antiretroviral resistance (Lyerly & Anderson, 2001). As of the fall of 2006, HIV-infected persons in Canada have access to 19 different antiretroviral agents, or a combination thereof (Canadian AIDS Treatment Information Exchange, 2006), belonging to one of three primary antiretroviral classes: nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs), and protease inhibitors (PIs) (Lyerly & Anderson, 2001). Using a combination therapy allows for maximal suppression of viral replication, the prevention or reduction of emerging resistant variants, and encourages the quantitative and qualitative reconstitution of the patient's immune function (U.S. Department of Health and Human Services, 1998).

Prior to the introduction of HAART in the developed world in 1996, the onset of AIDS symptoms in HIV-infected individuals appeared an average of 3 years after initial

HIV infection, with death following within an average of five years (Shenfield *et al*., 2004). In HIV-infected patients with access to HAART, long-term prognosis has improved significantly, although precise estimates of life expectancy, as a result of HAART's relatively recent implementation, remain somewhat uncertain. The most recent data available suggests that HIV-infected individuals can now expect to live an average of 24.2 years from the time they begin treatment (Schackman *et al*., 2006), assuming that treatment begins when viral load is still low. Additionally, long-term prognosis is highly dependent on the patient's ability to adhere to complicated treatment regimens over a long period of time, as well as his/her body's ability to continue to respond to a particular drug regimen, given the increasing number of patients developing resistance to many antiretroviral drugs (Lyerly & Anderson, 2001; Shenfield *et al*., 2004).

### ***Modes of Transmission***

#### *Horizontal (Sexual) Transmission of HIV*

Not surprisingly, studies indicate that the likelihood of transmission of HIV during sexual intercourse involving vaginal penetration is highly variable (Royce *et al*., 1997; Peterman *et al*., 1998), depending on multiple factors, including: the infectiousness of the viral strain, the viral load, the sex of the infected partner, the existence of associated sexually transmitted infections (STIs), and the occurrence of sexual practices that induce genital and/or vaginal trauma, including inflammation and/or abrasions (Vernazza *et al*., 1999; Chakraborty *et al*., 2001). The risk of transmission of HIV varies between 1:500 and 1:1000 per unprotected sexual encounter, being lower in monogamous couples compared to individuals engaging in casual sexual encounters (Saracco *et al*., 1993; Mastro & De Vincenzi, 1996). Although studies have demonstrated a correlation

between the degree of infectiousness and the size of the viral load, regardless of the means of transmission, this does not imply that the risk of transmission disappears in the case of a low or undetectable viral concentration (Englert *et al*., 2001). In females, a strong correlation exists between the viral concentration in the blood and that in vaginal secretions, but this is not the case in males. With a much lower degree of correlation, the viral concentration in the blood does not serve as a reliable indicator of the viral load in the semen, making the determination of a male's degree of infectiousness a much more difficult task (Coombs *et al*., 1998; Hart *et al*., 1999).

*Vertical (Mother-to-Child) Transmission of HIV*

Mother-to-child transmission of HIV continues to be a significant concern within the practice of reproductive medicine. In the absence of medical intervention, a child born to an HIV-seropositive mother has an approximate 25% chance of becoming infected (St. Louis *et al*., 1993; Working Group on Mother-to-Child Transmission of HIV, 1995); vertical transmission can occur either *in utero* (Brossard *et al*., 1995), during the birthing process (Thorne & Newell, 2000), or during breastfeeding (Miotti *et al*., 1999). However, a significant breakthrough occurred with publication of the results of the Pediatric AIDS Clinical Trials Group (PACTG) 076 Study in 1994, which was terminated ahead of schedule after analysis showed a statistically significant difference in the HIV transmission rates between mothers and infants who received the antiretroviral zidovudine (ZDV/AZT) compared to those who received a placebo (Connor *et al*., 1994). Following a prophylactic treatment regimen consisting of oral administration of zidovudine to the pregnant woman during her third trimester, followed by intravenous dispensation during labour, and finally, oral administration to the newborn for the first six

weeks of life (see Appendix), the study concluded that treatment with the antiretroviral decreased the risk of vertical transmission by 66%—from 22.6% in placebo recipients to 7.6% in subjects treated with zidovudine (Connor *et al*., 1994). All women participating in the trial had a CD4+ count >200 cells/$mm^3$ and were antiretroviral naïve, but subsequent studies indicated that the PACTG 076 regimen was also effective in women with AIDS and with prior exposure to one or more antiretrovirals (Sperling *et al*., 1996). The regimen was quickly adopted as the standard of care for HIV-seropositive pregnant women by the U.S. Public Health Service, resulting in an 80% decline in new cases of perinatally acquired HIV in the United States between 1992 and 1997 (Lindegren *et al*., 1999). Most recently, studies have demonstrated that delivery by caesarean section performed prior to the onset of labour and rupture of membranes also significantly reduces the risk of perinatal transmission such that, when combined with antiretroviral therapy, the risk of vertical transmission is reduced to approximately 1-2% (The European Mode of Delivery Collaboration, 1999; International Perinatal HIV Group, 1999). In fact, the effectiveness of such regimens led to the publication of an editorial in the *New England Journal of Medicine*, in 1999, which stated that: "The success of perinatal operations leads some to consider that elimination of the infection of newborn babies by the HIV virus is an objective that could be attained in the United States." (Rogero & Shaffer, 1999). Should this goal be achieved, one of the principal justifications for the withholding of ART services from HIV-affected couples would lose all credibility.

As noted above, this dissertation will consider the issue of whether withholding ARTs from HIV-affected couples is, as much of the medical community in North

America argues, in fact ethically warranted, or whether, given the recent advances in long-term prognosis of infected individuals, as well as the dramatic decrease in the rate of vertical transmission in recent years, HIV-affected heterosexual couples should enjoy the same autonomy with respect to reproductive decision-making as do non-HIV-infected heterosexual couples. In Chapter 1, I will begin by examining the nature of the use of assisted reproductive technologies by HIV-affected couples, first outlining the desire of parenthood on the part of HIV-affected couples, followed by a discussion of matters of a purely clinical nature, including the need for ARTs by many of these couples in order to achieve pregnancy, the various ART treatment options available, and an examination of the specific issues relevant to the process of assisted reproduction in each of the three principal clinical scenarios observed in the context of the provision of reproductive care to HIV-affected couples.

In Chapter 2, I will examine the ethical considerations relevant to the provision of ARTs to HIV-affected couples, beginning with an examination of the nature of the physician-patient relationship, upon which all medical dialogue, and the ethical dilemmas that may evolve from it, is based. I will also discuss the ethical framework that forms the core of the therapeutic relationship between physician and patient. Moving into an examination of the provision of ART services to HIV-seropositive couples, I will first provide a historical account of the (attempted) use of ARTs by HIV-seropositive couples, and the debate that such a practice has evoked, followed by an examination of the fundamental ethical principles pertaining to this debate. I will then explore the physician's specific concerns with respect to this practice, and the ethical arguments put

forth by both the couple and the physician in their attempt to access ART services, and to deny access, respectively.

Chapter 3 will consist of an examination of the legal considerations relevant to the debate, including the regulation of ART services in Canada, the legal rights and responsibilities of the providing physician with respect to patient care, and legal issues and jurisprudence specific to ARTs in Canada, including accessibility and legal challenges under the *Canadian Charter of Rights and Freedoms*. To provide a more comprehensive analysis of the issues, I will also examine relevant jurisprudence from other jurisdictions, including both the United States and the European Union. The chapter will conclude with an examination of women's rights with respect to reproductive autonomy in Canada, including previous examples of judicial interference with a pregnant woman, and a discussion of potential maternal liability for prenatal conduct following the birth of the child.

Chapter 4 will offer recommendations and concluding thoughts, with a particular emphasis on matters of public policy and recommendations for clinical practice, recognizing that these are tightly linked not only within the field of reproductive medicine, but also within the entire discipline.

# CHAPTER 1:
# THE USE OF ASSISTED REPRODUCTIVE TECHNOLOGIES IN CASES OF HIV-SEROPOSITIVITY

In 1991, the *British Medical Journal* published the first peer-reviewed article on the provision of ART services to HIV-affected couples, consisting of a case report followed by an examination of the medical, ethical, and legal issues at the core of the debate (Smith *et al*., 1991). At the time, respondents demonstrated strong opposition to the provision of such treatment to these couples, a trend that continued throughout much of the 1990s, including in response to a subsequent case series and discussion on the very same topic which appeared in a 1996 issue of *Human Reproduction* (Olaitan *et al*., 1996). Respondents Rizk and Dill (1997) asserted, for example: "We feel it is premature and unethical to treat HIV infected women at this time, until there is a negligible risk of perinatal transmission and a significantly better prognosis for HIV infected mothers." Little did they know that both of their 'stipulations' would soon be fulfilled. It could perhaps be argued that the speed at which treatment advances in HIV infection were developed took many in the medical community by surprise; this achievement, however, given the ramifications it has had on life expectancy and long-term prognosis, does nothing but strengthen the clinical argument—and, by association, the ethical and legal arguments—that HIV-seropositive couples should be able to utilize ARTs in their quest to become parents.

## 1.1. Desire for Parenthood on the Part of HIV-Affected Couples

As could be expected, the increased life expectancy for HIV-infected individuals has normalized lifetime expectations, with career and family ambitions becoming a

common goal within their desire to live a satisfying, productive life (Sauer, 2003; Williams *et al*., 2003). Several studies indicate that the desire to have children is as strong for HIV-affected couples as it is for the general population (Van DeVanter *et al*., 1998; Chen *et al*., 2001; Paiva *et al*., 2003). It should come as no surprise then, that given their life-altering diagnosis, although by no means fatalistic, many infected individuals, through retrospective studies, have actually cited childrearing as a way to give purpose to life (White *et al*. 1997). Kass (1994) notes that many HIV-seropositive women report that having a child has provided tremendous benefit to their psychological and emotional well-being, suggesting that childrearing may even promote the parents' maintenance of long-term health, and fostering support for the many recent studies indicating a high degree of correlation between psychological/emotional distress and the progression of immune-based diseases, including cancer and AIDS (Evans *et al*., 1997; Leserman *et al*., 1999; Leslie *et al*., 2002; Ironson *et al*., 2005). In light of these findings, it is not surprising that in recent years, an increasing number of infected individuals, mostly heterosexual couples, have sought out the assistance of reproductive specialists in hopes of having children of their own.

### 1.2. Effect of HIV on Fertility

Although definitions of infertility vary slightly between jurisdictions, in Canada, infertility is defined as "the failure to conceive within one year of regular unprotected intercourse" (Royal Commission on New Reproductive Technologies, 1993). Traditionally, infertility has been considered to be a medical condition, the result of one or more of several medical factors. Dickens (1985) elaborates:

> Infertility includes infecundity, meaning inability to conceive or to impregnate, and pregnancy wastage, meaning failure to carry a pregnancy to term through spontaneous abortion and stillbirth. Infertility includes primary infertility, where a couple has never achieved conception, and secondary infertility, where at least one conception has occurred but the couple is currently unable to achieve pregnancy.

Recently, however, there has been an increasing tendency to regard infertility as a condition deviating from a social norm. The concept of the 'nuclear family', which assumes that the desire and need to procreate is a normal part of life, has generated strong (social) pressures on childless couples to satisfy this social norm (Mykitiuk & Wallrap, 2002). It follows, then, that HIV-seropositive couples would not be exempt from the same social pressures to reproduce, and given their improved health status, would even desire to do so. Many couples suffering from infertility are often asked why they insist on accessing ARTs to conceive, as opposed to considering surrogacy options or adoption. Most couples respond that that they have a desire for their genetic lines to be continued, such that a child can be created that embodies—biologically, psychologically, emotionally—both individuals in the couple, or at least one of the members of the couple, should the couple need to make use of gamete donation. In many couples, there is also the hope that the child will bear a strong physical resemblance to one or both parents (Purdy, 1996).

Although limited in number, studies have indicated that HIV may have an adverse effect on fertility in both symptomatic and asymptomatic women (Zaba & Gregson, 1998; Ross *et al*., 1999). Recent cohort studies indicate that HIV-seropositive women are more likely to have a history of STIs, most likely related to unsafe sexual practices, and that the risk of HIV transmission or acquisition increases threefold to fivefold in the

presence of either ulcerative or non-ulcerative STIs (Grosskurth *et al*., 2000). Furthermore, several studies have noted an increased prevalence of HIV infection in women diagnosed with pelvic inflammatory disease (PID), as well as an increase in the severity of the disease when in coexistence with HIV (Hoegsberg *et al*., 1990; Barbosa *et al*., 1997). PID is the main cause of tubal factor infertility (i.e., infertility as a result of a blockage of one or both fallopian tubes), suggesting a possible reason for decreased fertility in HIV-seropositive women; indeed, several studies have confirmed this theory (Kamenga *et al*., 1995; Barbosa *et al*., 1998; Irwin *et al*., 2000).

### 1.3. Treatment Options Using Assisted Reproductive Technologies

Since their development in the 1970s, followed by the successful birth of the first 'test-tube' baby in 1978, ARTs have revolutionized reproductive medicine, enabling individuals with little or no prior possibility of having genetically-related offspring to become pregnant relatively easily (Hester, 2002). Just as do other so-called non-traditional groups, including adults without partners, post-menopausal women, and same-sex partners, HIV-seropositive persons can also benefit from these technologies in several ways (Hester, 2002). Unprotected sexual intercourse between HIV-serodiscordant couples trying to conceive increases the risk of transmission to the uninfected partner. Likewise, ARTs can help achieve pregnancy in HIV-affected couples in which HIV-related infertility has become a problem (Lyerly & Anderson, 2001; Bendikson *et al*., 2002).

Although perhaps somewhat surprising, unprotected intercourse between HIV-serodiscordant couples for the purpose of conceiving is by no means uncommon, despite

the risks involved (Panozzo *et al*., 2003). Mandelbrot *et al*. (1997) followed 92 heterosexual serodiscordant couples (in which the male was the HIV-infected partner) who engaged in unprotected sexual intercourse for the purpose of conceiving. All patients used condoms in all instances of intercourse, except at the time of ovulation. Couples were also taught to recognize signs of ovulation to minimize the probability of viral transmission. Amongst the 92 couples, 104 natural conceptions were achieved, but only 92 pregnancies were carried to term. Of this last group, four women tested positive for HIV—two at 7 months of gestation and two postpartum.[9] The risk of seroconversion was 4/92 (4.3%), indicating that even brief periods of unprotected intercourse carry a certain element of risk (Mandelbrot *et al*., 1997). However, while it is possible that additional women may have seroconverted following publication of this study, it is also worth noting that the collection of data in this study predates the use of combination antiretroviral therapy, meaning that the infected males participating in the study would have been unlikely to have a viral load which would be deemed 'undetectable' by today's medically accepted standard (Sharma *et al*., 2003). All the same, the desire on the part of HIV-affected couples to access ARTs is understandable, as these provide a way for them to achieve pregnancy, especially if infertility factors are present, while also potentially decreasing the risk of transmission to the uninfected partner.

### 1.4. Process of Assisted Reproduction

Several reproductive technologies are available in Canada for couples seeking reproductive assistance. The reproductive technique(s) employed by a couple will

[9] Mandelbrot *et al*. (1997) reported the outcome of 104 conceptions in 92 HIV-seronegative women and their HIV-seropositive male partners. Of the 104 conceptions, there were 92 pregnancies (carried to term), four abortions, six miscarriages, and two women removed themselves from the study during their second trimester.

depend on their particular medical situation, as well as the degree of risk that they are willing to take in their attempt to have a child. Additionally, the use of assisted reproductive technologies is extremely expensive, averaging between CAD $1,500 to $5,000 per cycle in Canada and between US $3,000 to $15,000 per cycle in the United States[10] (with several cycles often being necessary before a conception occurs and/or the implanted embryo is not lost (Sauer, 2002, 2003)), resulting in the exclusion of a significant proportion of HIV-affected couples who simply cannot afford the treatment, no matter how strong their desire to have a child (CFAS/SOGC, 1999; Sauer, 2003; Thornton *et al*., 2004). Not surprisingly, studies have indicated that the majority of HIV-affected couples seeking out ARTs are university educated, steadily employed and financially secure (Klein *et al*., 2003) (Table 1). However, considering that more and more HIV-infected persons are becoming fully integrated into society, with the accompanying emotional and financial security that this usually entails, it follows that a greater number of HIV-affected couples now consider the use of ARTs an attractive and viable option.

### *Clinical Scenarios*

**Scenario 1:** *HIV-Discordant Couple (Male HIV-Seropositive)*

In couples in which the male is the HIV-seropositive partner, the risk of transmission to the female partner can be reduced if condoms are used in all instances of sexual activity. Evidently, in couples desiring to conceive, such a practice at the time of

[10] The average price of a single attempt depends on the nature of the ART treatment chosen. IUI is the least expensive treatment, while IVF-ICSI is the most expensive. The cost of treatment is also dependent upon the degree of monitoring, and whether or not fertility drugs are prescribed (Sauer, 2003). In addition, the difference in cost between the United States and Canada can be largely attributed to the presence of a market-driven health care system in the U.S.

**Table 1**: Demographics of 50 HIV-serodiscordant couples (male HIV-seropositive, female HIV-seronegative) undergoing IVF-ICSI at the Center for Women's Reproductive Care at Columbia-Presbyterian Medical Center, Columbia University College of Physicians & Surgeons, New York, New York. The data given are typical of the Center's HIV-seropositive clientele (adapted from Klein *et al*., 2003).

| | **Men** | **Women** | **Couples** |
|---|---|---|---|
| Age (years) | 38.0 ± 5.4 | 34.5 ± 5.1 | |
| Residence in Tri-State region (New York, New Jersey, Connecticut) | | | 20 (40) |
| Married | | | 44 (88) |
| Duration of relationship (years) | | | 8.9 ± 4.9 |
| Prevention of HIV transmission as reason for pursuing IVF-ICSI | | | 49 (98) |
| Length of time since HIV diagnosis (years) | 8.3 ± 5.1 | — | |
| On antiretroviral therapy | 44 (88) | — | |
| In "excellent" or "very good" health | 49 (98) | — | |
| History of opportunistic infection or AIDS-defining illness | 8 (16) | — | |
| Employment | 45 (90) | 45(90) | |
| Bachelor's or graduate degree | 41 (82) | 42 (84) | |
| Social history | | | |
| Tobacco use | 9 (18) | 5 (10) | |
| Alcohol use (>2 drinks per week) | 4 (8) | 2 (4) | |
| Illicit drug use (confined to marijuana) | 2 (4) | 0 (0) | |
| Previous intravenous drug use | 5 (10) | 0 (0) | |

Values are mean ± standard deviation or *n* (%).

ovulation would be counterproductive. However, considering that a conception can take several months to occur [the median time to conception in a couple never before having conceived is 5.2 months, assuming two or more acts of intercourse during the fertile week of the woman's menstrual cycle (Semprini & Fiore, 2004)], combined with the increased prevalence for infertility factors in these couples, often prolongs the time, and thereby the number of unprotected acts needed to achieve fertilization, increasing the risk of transmission to the uninfected partner (Semprini & Fiore, 2004). This approach has been used successfully in the past, but because several seroconversions have occurred in couples using this approach, it is not recommended nor considered safe (Semprini & Fiore, 2004).

As noted previously, the risk of HIV transmission in HIV-serodiscordant couples does not follow a linear relationship, with the potential for transmission differing between couples based on a variety of factors. A male having an undetectable concentration of the virus in his blood (i.e., <50-100 copies/mL) may still have a high viral concentration in his semen (Vernazza *et al*., 1999; Chakraborty *et al*., 2001). Therefore, Williams *et al*. (2003) conclude that it is crucial that couples in this situation do not assume that an HIV test result affirming an 'undetectable' semen viral load signifies that no HIV virus is present in the sample; albeit unlikely, transmission could still theoretically occur using sperm from such a sample. Rather, they and others note that affected couples should use ARTs in their attempt to conceive in order to decrease the risk of transmission to almost negligible rates (Marina *et al*., 1998; Al-Khan *et al*., 2003; Williams *et al*., 2003).

Although spontaneous attempts at conception are strongly discouraged for most couples in which the male is the HIV-seropositive partner, one method of assisted reproduction has shown particularly promising results for couples in this situation. The technique, known as "semen washing", is based on the premise that HIV exists primarily in the seminal fluid and not within the sperm cells themselves. Developed and pioneered by Semprini *et al*. (1987, 1992, 1993), the procedure consists of a three-step process in which sperm cells are separated from seminal fluid through several cycles of centrifugation[11]; the sperm can then be used in various assisted reproduction procedures involving intrauterine insemination (IUI) or *in vitro* fertilization (IVF) (Semprini & Fiore, 2004). Semen washing is estimated to reduce to original viral content of the sample by up to several 10-million-folds (Chrystie *et al*., 1998). Data collected by Sauer (2002), Kambin and Batzer (2004) and Semprini and Fiore (2004) show that, between the years of 1989 and 2004, 3,452 cycles of assisted reproduction using various ART procedures were carried out in reproductive centres belonging to the CREATHE network. Of these, 440 resulted in live births, and serological follow-up, albeit incomplete at the time of publication, has indicated no maternal or congenital seroconversions (Semprini & Fiore, 2004) (Table 2).

[11] Semen washing uses density gradient centrifugation, based on the principle that particles can be separated according to weight and size. The semen sample is centrifuged, which separates the spermatozoa from the ejaculatory fluid. Non-motile, low motile, poor quality and abnormal sperm and non-spermatozoa cells remain in the supernatant located in the top layers, while the sperm accumulate in a pellet at the bottom of the tube. The supernatant is discarded and the sperm pellet is re-suspended in fresh medium and allowed to incubate for 20-60 minutes, giving the sperm a chance to 'swim up' to the supernatant. The swim-up fraction should then contain only the motile sperm; the unwanted components having been removed (Semprini *et al*., 1987, 1992).

**Table 2**: Summary of available data on HIV-1-affected couples having undergone assisted reproduction in reproductive centres belonging to the CREATHE network (as of 2004) (adapted from Sauer 2002; Kambin & Batzer, 2004).

| Study (First Author) | Cycles | †No. Pts | Pregnancies | Births | Ongoing | Infections |
|---|---|---|---|---|---|---|
| **IUI** | | | | | | |
| Semprini (2001; 2000; 1999) | 1,954 | 623 | 272 | 242 | — | 0 |
| Marina (2001; 1998) | 458 | 233 | 116 | 86 | 20 | 0 |
| Tur (1999) | 155 | 67 | 32 | — | — | 0 |
| Gilling-Smith (2000) | 66 | 27 | 12 | 3 | 3 | 0 |
| Vernazza (1997) | 46 | 16 | 5 | 3 | 1 | 0 |
| Weigel (2001; 2001) | 143 | 64 | 19 | 14 | -- | 0 |
| Bujan (2001) | 62 | 28 | 14 | 2 | 11 | 0 |
| Daudin (2001) | 93 | 39 | 18 | — | — | 0 |
| Brechard (1997) | 11 | | 5 | — | — | 0 |
| **Total** | **2,988** | **1,097** | **493** | **350** | **35** | **0** |
| | | | | | | |
| **IVF** | | | | | | |
| Semprini (2001; 2000; 1999) | 70 | 62 | 20 | — | — | 0 |
| Gilling-Smith (2000) | 12 | 7 | 2 | — | — | 0 |
| Weigel (2001; 2001) | 11 | 6 | 6 | 4 | — | 0 |
| **Total** | **93** | **75** | **28** | **4** | — | **0** |
| | | | | | | |
| **IVF-ICSI** | | | | | | |
| Marina (2001; 1998) | 58 | 40 | 27 | 11 | 11 | 0 |
| Weigel (2001; 2001) | 32 | 20 | 11 | 4 | 1 | 0 |
| Jouannet (2001) | 97 | 68 | 33 | 22 | — | 0 |
| Loutradis (2001) | 2 | 2 | 2 | 2 | — | 0 |
| Sauer (2002) | 55 | 34 | 17 | 17 | — | 0 |
| Peña (2003) | 113 | 61 | 35 | 26 | 12 | 0 |
| Morshedi (2003) | 12 | 6 | 6 | 3 | 1 | 0 |
| Batzer (2004) | 2 | 1 | 2 | 1 | 0 | 0 |
| **Total** | **371** | **232** | **133** | **86** | **25** | **0** |
| | | | | | | |
| **Total all methods** | **3,452** | **1,404** | **588** | **440** | **60** | **0** |

†No. Pts = number of patients
Pregnancies = clinical pregnancy rate (including miscarriage, ectopic pregnancy, and normal pregnancy)
Ongoing = normal ongoing but undelivered pregnancies
Infections = infections with HIV-1

In HIV-discordant couples (in which the male is the infected partner) with infertility factors, IUI with the male's processed sperm, as described above, will most often not suffice to achieve pregnancy. Such couples are often ideal candidates for *in vitro* fertilization. Although this procedure carries a higher pregnancy rate per cycle than does IUI, it is considerably more invasive, requiring ovarian hyperstimulation *via* hormone injection, oocyte retrieval under sedation, and involves a 20% likelihood of multiple births, with twinning being most frequently observed (Semprini & Fiore, 2004). Alternatives to IVF include gamete intra-fallopian transfer (GIFT) or zygote intra-fallopian transfer (ZIFT), two procedures which place sperm and oocytes, or the fertilized zygote, respectively,[12] directly into the fallopian tube, increasing the probability of conception (Tournaye, 2002). In this way, conception occurs naturally, although these procedures cannot assist women with fallopian tube blockage.

Couples affected by severe infertility factors often require a more aggressive form of treatment. One procedure, termed intracytoplasmic sperm injection (ICSI), involves the direct injection of a single 'washed' sperm into the cytoplasm of a single oocyte using micromanipulation under the microscope (Sauer & Chang, 2002; Semprini & Fiore, 2004). Since the sperm and the oocyte are fused 'by hand', this procedure carries a very high rate of fertilization; however, this process of fertilization differs from the natural process in that the acrosomal membrane of the sperm is not removed. As a result, the viral particles may adhere to the external spermatozoa membrane, meaning that infection of the oocyte and/or the later-stage zygote is possible (Semprini & Fiore, 2004). As such,

[12] In the ZIFT process, the fertilized zygote is implanted into one of the female's fallopian tubes, however, conception has not yet occurred. The sperm has penetrated the membrane of the oocyte, but combining of genetic material from both parents has not yet begun (i.e., nuclei from each cell have not yet fused).

ICSI is usually used as a treatment of last-resort, most often in couples suffering from severe dyspermia or for whom repetitive standard IVF treatments have not been successful (Semprini & Fiore, 2004).

This first clinical scenario is that which is most tolerated by physicians willing to allow HIV-seropositive couples to access ARTs. This can be explained by the fact that it is the situation in which horizontal or vertical transmission is most easily avoided. Thus, physicians consider this clinical situation to be the most ethically acceptable, since the risk of HIV infection can be reduced to almost zero.

**Scenario 2:** *HIV-Discordant Couple (Female HIV-Seropositive)*

In HIV-discordant couples in which the female is the infected partner, the process of conception is usually more straightforward, although steps must still be taken throughout the pregnancy and at the time of delivery to decrease the risk of transmission to the fetus (Williams *et al*., 2003). Assuming that the female partner is on an antiretroviral regimen and is deemed to have an undetectable viral load, assisted conception, either *via* IUI or IVF can proceed (Williams *et al*., 2003). Interestingly, physicians report that couples for whom the cost of reproductive assistance is prohibitive often resort to "self-insemination", in which the woman inseminates herself with her partner's freshly ejaculated semen using a sterile plastic syringe or pipette. Fertilization using this technique is indeed possible, although this method is recommended for use only by couples in which the female is the HIV-infected partner, and presupposes that the female's viral load is undetectable (Williams *et al*., 2003; Thornton *et al*., 2004).

This clinical scenario is more problematic that the first described above. Although insemination procedures are logistically simpler in this scenario, there is a greater risk that the fetus could become infected either *in utero* or at the time of birth, given the mother's HIV-seropositivity. For this reason, physicians are especially reluctant to allow these couples to access ARTs; indeed, no clinics offering services for these couples exist in North America (Sauer, 2003). Nevertheless, the reduced risks tied to adherence to the Pediatric AIDS Clinical Trials Group regimen[13] prior to birth and avoidance of breastfeeding implies that the refusal of access to couples in this situation is unjustifiable.

**Scenario 3:** *HIV-Concordant Couple (Both Male and Female HIV-Seropositive)*

In the case of HIV-concordant couples, the process of conception can be complicated by the fact that both partners may be infected with different viral subtypes of HIV. For this reason, these couples are also encouraged to use condoms in all instances of sexual intercourse, such that one partner does not transmit a mutated version of the virus to the other [mutation being not an uncommon occurrence in individuals adhering to an antiretroviral regimen] (Williams *et al*., 2003). In couples having different viral subtypes, assisted reproduction is approached in much the same way as it is for HIV-serodiscordant couples, considering that the infection of a partner [of a different subtype] with an alternate subtype—such that co-infection, and possibly, super-infection, is

[13] The estimated costs to the couple for the medications associated with adherence to the PACTG regimen are as follows (all figures in 1996 U.S. dollars): Zidovudine: $551.25 per woman per pregnancy (antepartum), $46.11 per woman during labour and delivery, and $16.82 per newborn (see Appendix); Complete Blood Count: $21.00 per test (2 per woman and 1 per newborn); and Chemistry Profile: $35.00 per test (2 per woman), for a **grand total of $747.18** (Gorsky *et al*., 1996). Again, given the demographic of the HIV-seropositive couples considered in this dissertation, these costs are not considered prohibitive, as at least partner in the couple is assumed to have access to private income health insurance and/or the couple is deemed to be able to bear the costs of the medications (See Table 1).

present—is desired to be avoided as much as is the infection of a previously uninfected partner (Williams *et al*., 2003; Ethics Committee of the ASRM, 2004). In couples having different viral subtypes and for whom infertility factors are a barrier to conception, the process of assisted reproduction is more complex. Both partners should follow a combination antiretroviral regimen that results in undetectable levels of the virus in both partners' serum and in the male's semen, after which time IVF, with or without ICSI, can proceed (Williams *et al*., 2003; Ethics Committee of the ASRM, 2004). Once pregnant, the female should be treated with prophylactic antiretroviral therapy, as per the PACTG regimen (Connor *et al*., 1994).

Interestingly, in couples having the identical viral subtype, and for whom infertility factors are not present, the use of ARTs to achieve pregnancy is rare. Most often, these couples are simply advised to attempt conception in the same way as does most of the general population, according to a schedule of properly timed intercourse (Williams *et al*., 2003). Of course, should the female partner become pregnant, she would still need to be treated with prophylactic antiretroviral therapy to reduce the risk of perinatal transmission during the latter stages of pregnancy and during the birthing process (Connor *et al*., 1994; Semprini & Fiore, 2004).

Evidently, this scenario presents significant challenges to the physician. Care must be taken to ensure that either partner does not transmit the infection to the fetus, a risk that increases significantly if both parents are HIV-seropositive. Couples in this situation will likely encounter the greatest amount of resistance on the part of physicians and will, with all certainty, be the last to be able to access ARTs, should guidelines ever

be loosened significantly. It would seem likely, however, that as assisted reproduction techniques continue to be perfected, the medical community should become more open to requests by couples in this situation.

No matter which of the above clinical scenarios the physician should encounter, it is crucial, as in any medical intervention, that the physician employ the standard practices of risk reduction and prevention of harm. The rise in demand for reproductive assistance by HIV-affected couples has necessitated an evolution in the traditional methods of communication within the physician-patient relationship, such that reproductive specialists take on a greater informative and counselling role. The provision of ARTs to HIV-affected couples is as much an issue of communication and partnership as it is a medical issue; as such, a thorough discussion of the debate requires an examination of the physician-patient relationship in this context, an issue which leads fittingly into an examination of the ethical issues at hand, a task that I shall tackle next.

# CHAPTER 2:
# ETHICAL CONSIDERATIONS

The physician-patient relationship is, by nature, one characterized by a power imbalance (Emanuel & Emanuel, 1992; Roter, 2000). Emanuel and Emanuel (1992) assert that this power imbalance is expressed through several key elements, including: (1) who sets the agenda and goals of the visit (the physician, the physician and the patient in negotiation, or the patient); (2) the role of the patients' values (assumed by the physician to be consistent with their own, jointly explored by the patient and physician, or unexamined); and (3) the functional role assumed by the physician (guardian, advisor, or consultant) (Roter, 2000). Historically, in modern medicine, the physician dominated the physician-patient relationship, "dictating medical inquiry away from the person of the patient to the biochemical and pathophysiology of the patient." (Roter, 2000). The ascendancy of biomedicine during the twentieth century, concerned primarily with the molecularly-oriented biomedical sciences, contributed to the denigration of communication within the physician-patient relationship, resulting in the patient's perspective given little to no credence (Shorter, 1985). This ideology became so entrenched in modern medical practice that, despite recent attempts to re-integrate the focus on the patient as a person into medical dialogue, which forms the core of the current therapeutic relationship, physicians, for the most part, continue to consider the patient's complaint(s) in either a biomedical or disease context, as opposed to a broader, more inclusive, illness context, in which the patient's perspective is given significant attention (Mishler, 1984; Engel, 1988; McWhinney, 1989). As a result, many physicians are prone to paternalistic ideals (Roter, 2000), not necessarily because they themselves

subscribe to the model, but simply because they have been trained within the context of this framework. In this model, the physician dominates decision-making both with respect to information sharing and to medical services/treatment options, and determines how to proceed next. While the physician may think that he/she is acting in the patient's 'best interest', as obliged, determinations as to what constitutes the patient's best interest is usually based on the assumption that the patient's values and preferences are identical to those of the physician (Roter, 2000). Although efforts to erode the tradition of medical paternalism are finally beginning to meet with success in all fields of medicine, it remains that there exist very few, if any, clinical encounters within medical practice in which the use of this model is more apparent than in the physician-patient relationship between the providing physician and the couple in the provision of ARTs to HIV-affected couples (Englert *et al*., 2001; Pennings, 2003).

Historically, the field of reproductive medicine has bared the brunt of attempts to test the limits of paternalism and autonomy within the medical profession; the woman's right to choose to abort, or more recently, to choose to have a caesarean section, being prime examples (Dickenson, 2002). The request to access ARTs on the part of HIV-affected couples is perhaps the most complex dilemma to face the field yet (Sauer, 2003). Although the tendency on the part of the physician may be to employ a strongly paternalistic model in the context of a request to access ART services by an HIV-affected couple (Schäfer *et al*., 1996; Pennings & de Wert, 2003), it is important to note that HIV-affected couples, by their very request to access these technologies, are not playing the corresponding role of the 'passive patient', as is traditionally seen in the paternalistic model of the physician-patient relationship (Shultz, 1985). While it is certainly true that

there was a time, perhaps only 15 years ago, where HIV-affected couples would, by and large, have been reluctant to even request access to ARTs, despite a strong desire to conceive, this is no longer the case today (Sauer, 2003). Most of these couples, for reasons already discussed, consider themselves socially integrated, having the same desires and needs as non-HIV-affected couples. Thus, it is reasonable that, in any medical encounter, these couples would expect the same treatment, consideration and respect on the part of a physician that would be given to non-HIV-affected patients (Klein *et al*., 2003). The establishment of clinics and networks facilitating access to reproductive care, such as CREATHE, is evidence that respect for these couples' desire to become parents is growing, likely the result of significant lobbying on their part.

It is important to note, however, that there are undoubtedly many situations in which the physician's perspective merits thoughtful consideration on the part of the patient. In the provision of ARTs to HIV-affected couples, the couple may benefit from the physician's knowledge in reproductive medicine and possible previous experience with other couples having already navigated the ART process. Roter (2000) stresses an optimal relationship model of "relationship-centered care", essentially one of mutuality, in which there is "optimal integration and synthesis of both the biomedical and lifeworld perspectives." Ideally, the provision of ARTs to HIV-affected couples would revolve around this (type of) model, for it allows both the couple and the physician to play an equal role in shaping the relationship.

**2.1. Ethical Responsibilities of the Physician**

All physicians in Canada are expected to abide by the Canadian Medical Association's *CMA Code of Ethics*, which is based on fundamental principles and values of medical care, including compassion, beneficence, non-maleficence, respect for persons, justice and accountability (CMA, 2004). One of the fundamental responsibilities of the *CMA Code of Ethics* (Update 2004) includes a "refus[al] to participate in or support practices that violate basic human rights." In the context of responsibilities to the patient, the *CMA Code of Ethics* (Update 2004) stipulates that:

> [I]n providing a service…[the physician must] not discriminate against any patient on such grounds as age, gender, marital status, medical condition, national or ethnic origin, physical or mental disability, political affiliation, race, religion, sexual orientation, or socioeconomic status.

In addition, the physician must "provide…patients with the information they need to make informed decisions about their medical care, and answer their questions to the best of [his/her] ability." (CMA, 2004). Of most relevance to this dissertation, the physician "must respect the right of a competent patient to accept or reject any medical care recommended." (CMA, 2004), a position consistent with the Royal College of Physicians and Surgeons of Canada, which has stated that "when a physician's view of the best interest of the fetus conflicts with the view of the pregnant woman, the role of the physician is to provide counselling and persuasion, but not coercion." (Flagler *et al*., 1997; Flagler & Bioethics Education Project Committee, 2004).

With specific respect to the ethical responsibilities of the physician in the context of the provision of ARTs, the Canadian Fertility and Andrology Society (CFAS) and the Society of Obstetricians and Gynecologists of Canada (SOGC) have issued a joint policy

statement (1999) with respect to the conduct that physicians are expected to follow when providing ART services to patients. As recommendations, they state (CFAS/SOGC, 1999):

> (1) Non-medical, social factors should not impede participation in or use of any reproductive technology. This proscription applies both to the donation and to the use of sperm, oocytes or embryos. Accordingly, no group of individuals should be denied participation in, or access to, such technologies. However, individual participation or use of assisted reproduction could be denied for the welfare of the child; and
>
> (2) If a physician cannot accept inclusion of a certain group of individuals based on social factors because of personal conscience, the physicians is obligated so to inform the patient, and to refer him or her to other qualified medical professionals who will assist the patient in addressing the medical problem(s).

Although these recommendations emphasize that social factors should not factor into the physician's decision whether to allow HIV-affected couples to utilize ARTs, it would appear that those physicians continuing to resist these couples' participation deny so primarily on this basis; that is, the possibility of HIV infection in either the uninfected partner and/or child poses, in the physician's opinion, too great a potential threat to the future welfare of the child to allow the couple's participation in the ART process. As discussed previously, the problem with using such a rationalization is that there is no way to determine definitively how, if at all, the child-to-be's welfare will be compromised or even jeopardized; thus, ultimately, such a recommendation still enables the physician to 'gatekeep' access to ARTs as he or she wishes, in accordance with his or her personal values and/or ethical beliefs. It is somewhat reassuring, however, that the physician is expected, as is the case with any other procedure to which he or she objects, to refer the patient(s) to another medical professional who is willing to provide the service in question (CFAS/SOGC, 1999; CMA, 2004).

## 2.2. Historical Perspectives

Perhaps surprisingly, debate surrounding medically assisted reproduction is not a recent phenomenon. The first recorded case of assisted reproduction occurred in the 1880s in Philadelphia, when a physician used sperm, donated by a medical student, to inseminate a woman whose husband was sterile. After the child's birth, the case was published in an American medical journal, and the physician's actions provoked public outrage (Rigby, 1984). With respect to HIV, given the very limited degree to which HIV and AIDS were understood in the early to mid-1980s, it is not surprising that "historically, the medical community has considered HIV a serious barrier to reproduction." (Thornton *et al*., 2004). As early as 1985, the U.S. Centers for Disease Control encouraged all HIV-seropositive women to avoid pregnancy as a result of the poor prognosis associated with HIV infection and the high risk of perinatal transmission (CDC, 1985). In 1987, the American College of Obstetricians and Gynecologists (ACOG) followed the CDC's lead, recommending that physicians advise HIV-infected women to not become pregnant, and discuss termination options with HIV-infected women who do become pregnant (Kass, 1994).

In 1990, following the revelation that a woman had been infected with HIV during the course of several rounds of artificial insemination using sperm from her HIV-seropositive husband [a hemophiliac who had acquired the infection through a blood transfusion], the CDC issued a recommendation against artificial insemination using the semen of HIV-infected men. Furthermore, the CDC recommended that couples in which one or both partners were infected go so far as to abstain from sexual intercourse, or *consistently* use condoms, essentially erasing any possibility of pregnancy (CDC, 1990).

In 1993, the Ethics Committee of the American Fertility Society [now the Ethics Committee of the American Society for Reproductive Medicine (ASRM)] published guidelines recommending against the provision of ARTs to HIV-affected couples, encouraging physicians instead to counsel couples about the potential consequences of using infected sperm, and discuss the options of donor insemination [assuming the male is the HIV-infected partner], adoption, or not having children (Ethics Committee of the American Fertility Society, 1994). Although the guidelines did not go so far as to suggest that physicians should not provide ART services to HIV-affected couples under any circumstances, the Committee did state that the "physician has no obligation to offer services if it is believed there is a risk to patient or offspring." (Ethics Committee of the American Fertility Society, 1994). This position was later supported by the International Federation of Gynecology and Obstetrics Committee for the Study of Ethical Aspects of Human Reproduction, which, in 1997, stated that only HIV-seronegative individuals should be allowed to access physician-provided services relating to ARTs (Schemer, 1997). Interestingly, in 1993, the American College of Obstetricians and Gynecologists revised its 1987 recommendations, allowing for more flexibility on the part of its members; nevertheless, it maintained that the exclusion of HIV-seropositive patients from infertility services could be considered morally justifiable. The Committee on Ethics (1993) stated:

> If an [HIV-] infected woman desires assistance in becoming pregnant, it is appropriate that she and her physician consider both her interest in childbearing and the potential for suffering in an infected infant before making a decision about treatment. As always, physicians should consider the medical and moral appropriateness of a given treatment when determining whether to participate.

Although discrimination toward HIV-seropositive patients[14] has declined in recent years (de Bruyn, 1998), it remains standard practice to deny ART services to infected individuals, especially in North American reproductive care establishments, primarily due to the unique medical and ensuing ethical concerns surrounding reproduction in these individuals (Klein *et al*., 2003).

### 2.3. Fundamental Ethical Principles as they Pertain to the Use of ARTs

Ethical issues arising in medical practice are most often approached according to a principlist ethical framework (Beauchamp & Childress, 1979, 2001; Williams *et al*., 2003). This framework, first articulated by Beauchamp and Childress (1979), is based upon four 'moral' principles, designed to provide a comprehensive starting point for health care ethics (Beauchamp, 1994). Beauchamp (1994) stresses that these principles should be considered neither rules of thumb nor set in stone—rather, "they are *prima facie*: [that is,] always binding *unless* they conflict with obligations expressed in another moral principle, in which case a balancing of the demands of the two principles is necessary." The principles included in the framework are (Beauchamp & Childress, 1979, 2001):

1. **Autonomy**: the obligation to respect the decision-making capacities of autonomous persons;

[14] Discrimination toward HIV-seropositive individuals has been known to include, but is not limited to: refusal on the part of landlords to rent accommodation, exclusion from private income insurance plans, restrictions on travel to certain countries (e.g., USA), failure of employers to recognize the need for time off to attend medical appointments and temporary leave for reasons of illness, and refusal by health care practitioners to perform medical procedures not related to HIV/AIDS (de Bruyn, 1998).
See *Brown v. Canada (Minister of Health)* [1990], 66 D.L.R. (4th) 444; *Thwaites v. Canadian Armed Forces* [1993], 19 C.H.R.R. 259; *Québec (Commission des droits de la personne) v. Dr G*, [1995], R.J.Q. 1601; *Lawrence v. Canada (Department of National Revenue)* [1997], T.D. 2/97 (H.R.T.) for examples of cases alleging discrimination toward HIV-seropositive individuals.

2. **Beneficence**: the obligation to provide benefits and balance benefits against risks;
3. ***Primum non nocere* (non-maleficence)**: the obligation to avoid the causation of harm; and
4. **Justice**: obligations of fairness in the distribution of benefits and risks.

According to Beauchamp and Childress (2001), so-called guidelines or rules for ethical dilemmas arising in health care can be formulated by reference to the four principles, although additional interpretation and specification to other moral considerations (e.g., truth-telling, confidentiality, clinical equipoise in research, *etc*.) will undoubtedly be required. Nevertheless, Beauchamp and Childress' (1979, 2001) four-principles approach has garnered common acceptance amongst health care ethicists for two principal reasons: (1) the principles of beneficence and non-maleficence have long been considered proper goals of medicine, with dedication to these goals viewed as vital to being a physician; and (2) the principles of respect for autonomy and justice, traditionally neglected in health care ethics, are the result of a recent shift in medicine from a beneficence-based model of patient care to one based on patient rights, a process which was largely influenced by evolving social structures (Beauchamp, 1994).

The ethically challenging circumstances surrounding the provision of ARTs to HIV-affected couples, albeit unique for every couple, can be examined, at least initially, using Beauchamp and Childress' (1979, 2001) four-principles approach, given that many issues are common to all couples. In turn, each principle is considered here.

***Medical Autonomy***

Respect for autonomy is considered by many health care professionals to be the prevailing ethical principle in medical practice (Williams *et al*., 2003). In the medical context, this entails respecting the values, preferences, and ultimately, the decisions of patients with respect to treatment decisions, even if they conflict on any level with those of the providing physician (Lyerly & Anderson, 2001; Bendikson *et al*., 2002). Tied to respect for patient autonomy is the physician's obligation to guide the patient through a process of informed and rational decision-making (Sauer, 2003). In the case of HIV-affected couples requesting reproductive assistance, respect for the couple's autonomy would involve the provision of all necessary and relevant information, including the natural history of HIV infection, the biology of viral transmission, the risks associated with the ART procedure(s), as well as reproductive alternatives, such that the couple can make a decision which they consider right for themselves (Sauer, 2003). Finally, respect for the couple's autonomy would also necessitate a respect for their (informed) decision to attempt conception using ARTs, should this be the route they decide to pursue (Lyerly & Anderson, 2001).

All the same, several scholars have asked whether a physician's respect for a person's procreative choices should necessarily translate into a duty to provide the required reproductive services or, at the very least, refer the patient to a provider/place where the services in question are available (Overall, 1987; Robertson, 1994; Steinbock, 1996). Overall (1987) argues that there is no "ethical, political, or logical symmetry" between the right to have children and the right not to have children. However, many have challenged her position, stating that procreative liberty is a positive right, based on

the claim that a person's ability to reproduce is considered essential by many of those who request assistance to reproduce, because they view this ability as a crucial component of the expression of their existence as a human being (Robertson, 1994; Steinbock, 1996). Both Robertson (1994) and Steinbock (1996) extend this moral right to procreate to non-coital reproduction—with the most frequent users of ARTs, those with (natural) infertility factors, most likely in mind. Steinbock (1996) states: "The right to reproduce belongs to fertile and infertile people alike. The mere physiological fact of infertility should not deprive people of the right to reproduce, any more than the fact of blindness should deprive people of the right to read." It should follow, then, as argued by Lyerly and Anderson (2001), that limits on reproductive decision-making may be no more legitimate in HIV-affected couples requesting ART services than they are in non-HIV-infected couples without infertility factors. However, the principle of autonomy is not absolute, as are any of the ethical principles; in accordance with the need for complement with the other ethical principles, the physician's obligation to respect patient autonomy cannot cause serious harm to others or seriously limit others' liberty (Beauchamp & Childress, 2001).

***Beneficence and Non-Maleficence***

In the medical context, beneficence refers to the commitment by health care professionals to promote the health and well-being of their patients (Lyerly & Anderson, 2001; Williams *et al*., 2003). This duty, along with its negative form, non-maleficence, is viewed as self-evident, and is considered a key tenet of medical practice (Sauer, 2003). Physicians are expected to provide treatment in such a way that emphasizes both the good of the patient and the good of society as a whole (Sauer, 2003). In this regard, the

provision of ARTs to HIV-affected couples is no different than any other medical process. In this case, beneficence requires that the physician consider not only the couple's current medical status, but also how a child, should they conceive, might impact positively on their psychological health and well-being, and consequently, on their physical health, in the long-term [See section 1.1] (Kass, 1994; White *et al*., 1997; Lyerly & Anderson, 2001). Nevertheless, proponents of protocols denying reproductive care to HIV-affected couples argue that such unofficial policies are necessary in order to ensure the protection of society at large (Sauer, 2003). Concerns raised about the risk of viral contamination of tissue cultures and storage facilities in the laboratory, given that the aspiration of oocytes is not a bloodless procedure, is often officially cited as one of the reasons for the exclusion of these couples (Sauer, 2003); however, as noted by Lyerly and Anderson (2001), "we [physicians] practice in an era of universal precautions in which the exclusion of persons from hospital facilities based on infection is…unethical." As such, although great prudence should be invoked at all times in the ART clinic to minimize these theoretical risks, obligations of beneficence toward the community cannot be considered sufficient to justify the exclusion of HIV-affected couples from ART services (Lyerly & Anderson, 2001; Sauer, 2003).

Non-maleficence, unlike the principle of beneficence, is a constant duty; "first do no harm" being another key tenet of medical practice (Sauer, 2003). Physicians are ethically obliged to ensure that all technical expertise is available to them when performing a procedure or administering a treatment, and that they themselves are competent to perform the procedure (if applicable), such that the degree of risk is always minimized, in as much as is so far possible (Williams *et al*., 2003). Even so, it is

important to remember that potential harms could result to the couple, the child-to-be, any clinical staff, and society at large, and this should be taken into consideration by the couple, and the physician guiding their reproductive decision-making (Lyerly & Anderson, 2001; Williams *et al*., 2003).

***Justice***

The principle of justice is, without a doubt, the most crucial in the debate surrounding the ability of HIV-infected individuals to utilize ARTs. With regard to health care treatment and delivery, the consideration of justice requires that physicians treat all individuals fairly, and that the provision of medical services to these individuals not be discriminatory (Lyerly & Anderson, 2001). As described previously, the major concern cited by reproductive specialists is the risk that children will be born with HIV as a result of reproductive assistance provided to their HIV-affected parents (Lyerly & Anderson, 2001; Bendikson *et al*., 2002; Lyerly & Faden, 2003). Considering the prognosis for an infected newborn, this is a valid concern, but both Lyerly and Anderson (2001) and Lyerly and Faden (2003) argue that the principle of justice requires that the medical community consider whether policies designed to prevent congenital illness, whether HIV-related or otherwise, unfairly burden a particular group of individuals with a particular disease or disability.

Consider the provision of ART services to a couple in their late 30s (the typical demographic among individuals granted reproductive assistance), suffering from infertility but otherwise free of any known medical conditions (Lyerly & Faden, 2003). Pregnancies in women over the age of 35 carry an increased risk of congenital illness,

particularly genetic conditions such as trisomy 21 (Down syndrome). As in children with congenitally-acquired HIV, children with Down syndrome are at increased risk for severe medical problems, including cardiovascular and gastrointestinal anomalies, and often impose significant emotional and financial burdens on their family. Interestingly, however, the risk of a 39-year-old woman giving birth to a child affected by a chromosome abnormality *actually exceeds* that of an HIV-seropositive woman treated with antiretroviral therapy during pregnancy transmitting the virus to her child (Palomaki & Haddow, 1987; Lyerly & Anderson, 2001). Although chromosome abnormalities are detectable prenatally, and women in such a position do have the option of selective termination, those who elect not to undergo prenatal diagnosis are not categorically excluded from reproductive care (Lyerly & Faden, 2003). [In fact, many couples at high risk for having a child with a specific genetic disorder are *encouraged* to access ART services to increase, as much as possible, the likelihood of giving birth to a healthy baby, by using pre-implantation genetic diagnosis (Peterson, 2005)]. Similarly, although they may be advised against proceeding, women with (traditionally-defined) chronic conditions such as insulin-dependent diabetes or lupus are not categorically denied access to assisted reproductive treatment either. Women with insulin-dependent diabetes, for example, have pregnancies characterized by at least a fourfold increased risk of numerous severe congenital abnormalities, including caudal regression, neural tube defects, and cardiac and renal anomalies, along with such obstetrical risks as intrauterine grown restriction, pre-eclampsia, and premature birth (Lyerly & Faden, 2003).

Additionally, the circumstances described above are similar to those encountered by couples who know that they are carriers of an autosomal recessive genetic disorder,

such as Tay-Sachs disease, sickle-cell anemia, or cystic fibrosis (Ethics Committee of the ASRM, 2004). Although such couples may elect to terminate a pregnancy should a prenatal genetic test come back positive, they may also choose to risk having an affected child as opposed to adopting, using a gamete donor or forgoing parenthood altogether. It is possible that each individual in the couple could contribute their non-diseased dominant allele at the time of conception, such that the diseased allele is effectively eliminated from the immediate family's genetic pedigree (beginning with the child of the couple in question), but chance dictates that, in a given conception, the risk of transmitting an autosomal recessive genetic condition can never be reduced below 25%.[15] Given that the risk of perinatal HIV transmission can be reduced to as little as 1-2%, the Ethics Committee of the American Society for Reproductive Medicine (2004) argues that physicians "who are willing to provide reproductive assistance to couples whose offspring are irreducibly at risk for a serious genetic disease should find it [equally] ethically acceptable to treat HIV-positive individuals or couples who are willing to take reasonable steps to minimize the risks of transmission", for the chance of a negative outcome, that is, the birth of a child with a disabling condition, is, ultimately, the same in both cases. If we suppose, for a moment, that the 'negative' outcome occurs in each of the cases, it is reasonable to assume that both children's families will encounter similar medical, emotional and financial challenges throughout the course of the child's (and possibly, the child's adult) life. Ultimately, the only difference between the two is the decreased life expectancy (at the present time) for the HIV-infected child compared with

[15] If each parent is a carrier of an autosomal recessive genetic disorder, each is said to be heterozygous for the diseased trait (*Aa*). The child may inherit either one of each parent's two alleles, meaning that the child will have one of $2^2$=4 possible genotypes: *AA*, *Aa*, *aA* or *aa*. Thus, there is a 25% chance that the child will have the genotype *AA* (normal), 50% chance of genotype *Aa/aA* (carrier), and 25% chance of genotype *aa* (affected).

the child afflicted with a genetic disorder [with significant variation in life expectancy for the spectrum of known genetic disorders]. In fact, beyond parental supervision of an antiretroviral regimen and the need for increased precautions with respect to the child's bleeds, an HIV-infected child most certainly requires less 'around-the-clock' care than a child with Down syndrome, for example. In the end, no distinction can—or should—be drawn between the child of an HIV-affected couple and a couple at risk of transmitting a genetic disorder, and therefore, the couples themselves.

Given these findings, why does the medical community routinely treat HIV-affected couples in a different manner than it treats couples who have chronic diseases or couples for whom an increased risk of congenital genetic disease exists? Is a 2% risk of vertically transmitted HIV really any different from a 2% risk of an irreversible genetic disorder? As noted by Lyerly and Faden (2003), both sets of situations involve pregnancies in which there is a high risk of having a child with a disabling condition, but only HIV-affected couples are categorically excluded from assisted reproductive treatment—suggesting that rather than actual risk, it is the continuing fear and stigma associated with HIV—remnants of a period of "unacceptable danger" (Sauer, 2003)—that fosters the reluctance and refusal on the part of physicians and policymakers to consider HIV-affected couples in the same way as any other heterosexual couple wanting to conceive (Spriggs & Charles, 2003).

## 2.4. The Physician's Professional Role Obligations: Proper 'Bedside Manner' in the Fertility Clinic in the Era of ARTs and HIV

### *The Physician's Main Concerns*

The reluctance or outright refusal by physicians to provide ART services to HIV-affected couples stems primarily from a concern about the risk of HIV transmission as a direct result of the ART procedure, whether seroconversion occurs immediately or at a later time. According to Sauer (2003), three primary safety risks exist:

1. The possibility that the virus will be transmitted to the uninfected partner;
2. The risk of vertical transmission to the fetus; and
3. The danger of infecting other tissue or embryos in the laboratory.

Additionally, there are concerns about the welfare of the child (whether or not the child(ren) become(s) HIV-infected), and about the parent's/s' ability to raise the child(ren), given their potentially fatal illness and the situation's potential socioeconomic impact on the family (Sauer, 2003). Frodsham *et al*. (2004) argue that the child's welfare should be an essential consideration for any couple considering reproductive assistance, adding that it is imperative that both the couple and the reproductive specialist carefully consider the environment in which the child may be born into and raised, ensuring that it is conducive to physical, psychological and emotional growth and development (Frodsham *et al*., 2004).

### *Preconception Counselling*

*Evaluation and Disclosure of Risk Unique to the Couple*

Although each person in an HIV-affected couple has the capacity to decide whether or not to take the risk(s) that are inherent to ART procedures involving the reproductive tissue of HIV-infected individuals, the same cannot be said for the child who may be conceived as a result of one or more of these procedures. First, it is vital that the couple be aware of the risk of transmission to the uninfected partner, if applicable. Although assisted reproduction techniques are by far the most effective method of preventing transmission of infectious diseases, they remain a relatively recent innovation, and many have yet to be perfected with specific regard to the removal of infectious material (Semprini & Fiore, 2004). As such, an uninfected female must be prepared to accept the risk that she could become infected if even a minute amount of HIV remained affixed to her partner's sperm prior to insemination, or likewise, if an embryo was unknowingly infected prior to implantation.

Additionally, the couple must be aware of the potential risk of transmission to the fetus or to the child during delivery. Although they may be seeking reproductive assistance to reduce this risk, and will be successful at that, the fact remains that any ART procedure carries an element of transmission risk (at the time of the procedure or beyond) regardless, and that no method, with the exception of refraining from reproduction altogether, can ensure the birth of a non-HIV-infected child (Ethics Committee of the ASRM, 2004). Furthermore, disclosure of an infected infant's fate should be made clear to the couple. A child who contracts HIV either prenatally or perinatally usually succumbs relatively quickly to the infection. For reasons still not fully understood,

although likely related to having an immature immune system, infants who become infected with HIV in the womb or during the birthing process usually progress to AIDS within their first year of life and die shortly thereafter (Hutton, 1996). Children who do survive into childhood are generally plagued by significant health problems, becoming progressively more severe as they age, with death usually occurring in early adolescence (Hutton, 1996). Lastly, it would be important for the couple to realize that pregnancy can pose other risks to an HIV-seropositive female,[16] with opportunistic infections developed during pregnancy and certain antiretroviral medications used by long-term non-progressors both having the potential to cause severe complications, [17] including increased risks of preterm delivery, congenital malformations, and increased risk of spontaneous abortion (Brocklehurst & French, 1998; U.S. Public Health Service, 1998; Ethics Committee of the ASRM, 2004). Should the child be born HIV-infected, the couple must consider what impact, if any, this would have on their ability to support the child and raise him or her until adulthood, given the constraints of their own illness with which they must deal on a daily basis (Delvigne *et al*., 1990; Ethics Committee of the ASRM, 2004).

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[16] Interestingly, pregnancy does not appear to have contradictory effects on HIV infection itself. French and Brocklehurst (1998) conducted a meta-analysis of seven prospective cohort studies and found no statistically significant differences in the rates of death, HIV progression, progression to an AIDS-defining condition, or fall in CD4+ count below 200 cells/$mm^3$ between cases and controls. Other studies have indicated that viral load also remains relatively stable over the course of pregnancy in both HIV-infected pregnant and non-pregnant women (Burns *et al*., 1998).

[17] Certain antiretroviral agents are known teratogens. These include efavirenz (Sustiva®), a very powerful NNRTI, and hydroxyurea, a compound often used in conjunction with an antiretroviral regimen. Documented birth defects as a result of these agents include severe defects of multiple organ systems, including the genito-urinary and nervous systems, anencephaly, mitochondrial dysfunction, and cleft palate (Lyerly & Anderson, 1999; Williams *et al*., 2003).

*Psychological and Socioeconomic Impacts on the Child*

Should the child of an HIV-affected couple be born free of the infection, there remain a multitude of issues which require serious consideration by the parents. What impact will the parents' sero-affected status have on the child? While the fact remains that any child may be orphaned at any time for reasons beyond anyone's control, children with HIV-infected parents are more vulnerable to losing one or both parents prematurely. In a study by Klein *et al*. (2003), which looked specifically at the motivations, concerns, and desires of HIV-serodiscordant couples wishing to have children through assisted reproduction, all couples reported that they had discussed with each other the possibility of raising a child alone in the event of the premature death of one spouse. Most people would agree that the death of a parent is one of the most devastating traumas a child can experience, but as indicated by Shenfield *et al*. (2004), and rightly so, the life expectancy of an HIV-infected parent may be quite comparable to a parent who has cancer or a genetic disease such as cystic fibrosis. Thus, Shenfield *et al*. (2004) suggest that when reproductive assistance is provided to HIV-affected couples, there should be evidence that at least one parent is likely to be able to raise the child until adulthood. Additionally, Klein *et al*. (2003) note that few couples in the study had addressed the possible need for third-party parenting, should the demise of both parents occur. Given the transmission risks possible with ART procedures such as IVF-ICSI—notably, the possibility that viral particles will go undetected prior to insemination—consideration of this issue is definitely warranted. It is also crucial to consider the direct psychological effects on the child, if he or she were to become HIV-infected during the assisted reproduction process. Beyond the obvious psychological issues related to the diagnosis itself, which will affect

all children, even if they are too young to comprehend the severity of the condition itself, Campbell (2000) notes that children who are HIV-seropositive quickly become aware that they are 'different' from their peers. Their social interactions will be impacted, and the way in which their HIV status is perceived by others members in their community may cause them to perceive their condition as shameful and morally reprehensible (Campbell, 2000). Although this is less likely to be the case if the child is raised by parents who are themselves HIV-affected, the fact remains that children will be more sensitive to the possible stigma and rejection that they may encounter in their communities, such as an attempt to prohibit their attendance at a school, daycare, or from an extracurricular activity, than will their parents, even if HIV-affected themselves, simply because they are often not old enough to understand the basis (or lack thereof) of other people's fears.

In any event, parents must consider what ramifications their illness and/or possible early death may/will have on the financial security of the child (Sauer, 2003; Frodsham *et al*., 2004). Prior to the introduction of highly active antiretroviral therapy, concern about the socioeconomic welfare of the child was one of the primary reasons used as justification for refusing reproductive assistance to HIV-affected couples. Numerous authors (Steinbock & McClamrock, 1994; Olaitan *et al*., 1996; Rizk & Dill, 1997) have argued that the child would be disadvantaged by the reduced life expectancy of the infected parent, with Steinbock and McClamrock (1994) going so far as to say that when the "social realities" are considered, a child born to someone with HIV is less likely to have a chance at a good life. As Gilling-Smith *et al*. (2001) note: "[These concerns], until now, provided sufficient grounds for most units offering assisted reproduction to

close their doors to patients infected with HIV who ask for help or who test positive in their preliminary investigation." However, given that perception of the true nature of the virus has evolved since the introduction of HAART, should it not be fair to expect a corresponding evolution of attitudes regarding the parenting and providing abilities of HIV-affected couples?

***What Makes a 'Good' Parent?***

Although such a turnaround on the part of physicians would be most welcome, and is certainly warranted, the fact remains that the medical profession is fraught with paternalistic ideals so deeply engrained that only recently has there been a concerted effort to change physicians' attitudes toward patient care, particularly that of HIV-infected individuals. With respect to reproductive decision-making, Stone (1990) asks if the medical profession should be involved in couples' reproductive decision-making at all:

> Are doctors uniquely competent to decide who will be fit parents? Indeed, apart from the question of medical suitability for a particular treatment, we should *ask whether this is a medical decision at all* or whether it is rather a moral, social and political question. [Emphasis added]

Spriggs and Charles (2003) argue that inherent in the physician's decision to deny treatment to HIV-affected couples is the assumption, conscious or not, that HIV-infected individuals are not suitable parents—and that it is their HIV-seropositive status that makes them so. Spriggs and Charles (2003) propose that, ultimately, in the eyes of these physicians, an HIV-affected couple's request for reproductive assistance is a demonstration of their unsuitability for parenthood. Although there are no empirical studies in the literature to support Spriggs and Charles' (2003) contention, Watkins

(1995) notes that predictions about the parenting abilities of people with disabilities are especially prone to error and bias. In fact, Watkins (1995) states that "factors unrelated to disability often have a more significant impact on parental fitness than does the disability itself." While certain physicians may be uninformed with respect to this important detail, their presumptions as to the parenting abilities of these couples, unfounded as they may be, inevitably raise questions as to a disease or an illness's moral nature. In moral terms, does HIV differ significantly from another condition; that is, "is it worse for a child to be born to a parent who is HIV positive than to a parent with some other condition [medical or otherwise]?" (Spriggs & Charles, 2003). Does an individual's HIV diagnosis impact his/her ability to be a 'good' parent? Who constitutes a 'good' parent? Is the physician's reluctance to treat an HIV-affected couple compromised by assumptions as to how the patient(s) contracted the virus? If the medical community is to continue to criticize HIV-affected couples for wanting to procreate, it should take an equally deserving look at all couples in the general population who, without reservation, have children for what the medical community should consider equally invalid or 'wrong' reasons. Many reasons are cited for wanting to have children, including: having a liking for children; thinking it will save a faltering marriage; wanting to provide a brother or sister for another child; to avoid having an 'only child'; to 'replace' a child who has died; wanting 'completeness' in the family by having a child of each sex; and even for no reason at all (Pohlman, 1969). Can a couple who thinks that having a child will save their marriage really be considered any more suitable for parenthood than an HIV-affected couple? As argued by Spriggs and Charles (2003), "we have no reliable way of predicting who will or will not be a good parent and no agreed

upon measure of what makes a good parent." Of course, certain individuals exhibit characteristics which are not conducive to good parenting, such as the tendency for physical or emotional abuse; even so, with most individuals, as stated by Harris (1998), it would seem "…unreasonable to conclude that someone will not be a fit parent in advance of their being permitted to procreate." The difficulty in assessing prospective parents shows that the exclusion of HIV-affected couples from the ART process for reasons of concern about the welfare of the child is unfounded, considering that [non-HIV-infected] couples who conceive naturally do not have to justify their desire to have children nor prove their ability to parent (Spriggs & Charles, 2003). Coleman (2002) adds: "A parent's inability to care for a child would have to be truly extraordinary to justify a decision to withhold ARTs." It would seem safe to say that, given their improved long-term prognosis and better overall health, these couples could not be considered to have a "truly extraordinary" inability to parent.

McHale (2002) notes that much of the debate surrounding reproductive rights considers an individual's rights and choices: for example, the woman's right to reproduce, or a couple's right to marry and choose to begin a family. However, there is another view that has emerged in conservative circles in recent years, that of responsible parenting or controlled choice, a view suggesting that individuals might not be entitled to reproduce in all situations (Purdy, 1996; McHale, 2002). In fact, at the core of this rhetoric is the belief that there may be some situations in which individuals should not reproduce, and even situations in which they should be required not to reproduce (McHale, 2002). Determining when such a 'duty' would arise, however, requires a thorough evaluation of the harms or risks of reproduction. Most obviously, advocates of

this view argue that a duty not to reproduce be imposed in situations in which, were reproduction to take place, the resultant child would suffer an obvious form of harm after birth, and that this type of harm should be avoided, for it renders the life of the child far too difficult for him or herself and begets too significant a burden on others, including his/her caregivers (McHale, 2002). Purdy (1996) argues that it is wrong to reproduce when the child-to-be will be unlikely to have what she terms a 'minimally satisfying life'. Although Purdy (1996) acknowledges that it is extremely difficult to define what constitutes a 'minimally satisfying life', she suggests that it should entail, at the very least, an honest attempt to secure health for the child. However, it would be unreasonable to say that an HIV-affected couple's decision to proceed with ART services necessarily translates into a failure to secure health for the child. In fact, the very participation of the couple in the ART process can be taken as a clear demonstration of this attempt.

While Beauchamp and Childress' (1979, 2001) four-principles approach to health care ethics is certainly worthy of the attention which it receives, there is a growing tendency within bioethics circles to apply a favourable risk-benefit ratio approach when evaluating ethical dilemmas in health care. This approach can be thought of as a 'more modern' ethical principle, and although it was originally contextualized for determining the ethical appropriateness of clinical research (Levine, 1987; Weijer, 1999; Emanuel *et al*. 2000), the application of its philosophy is a well-established, though perhaps not yet well-documented, tradition within clinical ethics, when situations arise in which multiple options (e.g., regarding medical interventions, treatments, care, *etc*.) are available to the patient (Bereza, personal communication, 2006). Although using such an approach may seem elementary in nature, in that it is somewhat akin to devising a list of pros and cons,

it works surprisingly well because at its core is the logical notion that risks must be minimized and potential benefits enhanced (Emanuel *et al*., 2000). However, if we apply a favourable risk-benefit approach to reproductive decision-making, McHale (2002) asks if such a ratio, should it be unfavourable, lead to a moral duty not to reproduce?

Robertson (1994) argues that there are very few, if any, situations in which an unfavourable risk-benefit ratio would legitimate ethically limiting an individual's or a couple's reproductive choices. He maintains that there are few medical conditions which would render the life of a child so horrible that its interests would have been better served if it had never been born (Robertson, 1994). This view is supported by several other authors, including Powers (1996). He states: "Philosophically, proving that a child is 'harmed' by being born—even with a severe and debilitating illness such as HIV infection—is extremely difficult, requiring some demonstration that a child is worse off than never having lived at all."[18] (Powers, 1996). Evidently, given the nature of this stipulation, such a determination is impossible. Savulescu (2003) notes:

> It is clear that it is better to live without HIV than with HIV. It is not at all clear whether it is worse for a child to exist with HIV than not to exist at all. So there is no reason from the child's perspective to prevent practices that risk creating a child with HIV when the alternative is only non-existence.

Numerous authors have also raised the question as to whether it is possible for the physician to 'harm' a child by assisting with the conception process (Powers, 1996; Lyerly & Anderson, 2001; Spike, 2003; Williams *et al*., 2003; Murray, 2005). Of course, the possibility of infecting the seronegative partner is also always a concern, but he/she, being of legal age, agrees to participate in the treatment process knowing the risks to him

[18] See section 3.4 "Maternal Liability for Prenatal Conduct after the Birth of a Baby" for a discussion of wrongful life claims pursued through litigation.

or herself (Williams *et al*., 2003). A child, however, does not control under what circumstances he or she is brought into the world, meaning that he/she, likewise, does not have a say as to what risks are taken by his/her parents and/or prenatal caregivers (Murray, 2005). Indeed, despite the low risk of transmission, Lyerly and Anderson (2001) call the birth of even one child infected with HIV "tragic". Although this characterization is extreme, it remains that there may very well be situations in which physicians should consider the future welfare of children-to-be; however, should this be a routine obligation? The answer to this question depends upon the physician's characterization of the fetus. Although the physician cannot consider the fetus to be a person (with the legal rights that this entails), he/she may deem the fetus to merit consideration from an ethical perspective, leading to another question: what is the moral status of the fetus? (Murray, 2005).

***The Moral Status of the Fetus***

Although the fetus is not considered to have any legal rights under Canadian law [See section 3.4], debate re-emerges periodically as to whether there exist *moral* obligations to the not-yet-born (Murray, 2005). Historically, considerations of moral obligations to the not-yet-born have been intertwined with the degree of viability of the fetus, with the lack of consensus regarding this issue stemming much of the debate about the legality of abortion (Murray, 2005). However, such a consideration is not directly relevant to the discussion regarding the use of ARTs by HIV-affected couples because the viability of the fetus is not the primary consideration in this context; rather, it is the potential harm of the conception itself, and its possible ramifications. That is, any harms induced upon the 'fetus' are relevant, whether they occur at the moment of conception (as

an embryo), at the time of birth or even shortly after birth (as an infant). Murray (2005) argues that "an act resulting in harm to a not-yet-born person (who will eventually be a full-fledged person according to everyone's moral theory) is as great a harm as if it were done later." As evidence, he notes (Murray, 2005, p.229):

> Imagine two different cases. In the first, a man assaults a woman with the intention of inflicting grave harm on her fetus. He succeeds, causing permanent, irreparable damage to the fetus's spinal cord, resulting in paralysis. In the second case, all the circumstances are identical, except that the man attacks an infant rather than a fetus, with the same result—permanent, irreparable paralysis. Was the first act any less wrong than the second? In both cases, lifelong harm was done to humans who, whatever your beliefs about when personhood begins, would eventually cross that line and attain full moral status.

The argument for the irrelevance of the timing of infliction lends further support to the position adopted by many physicians with respect the provision of ARTs to HIV-affected couples, however, it is imperative to remember that moral obligations to any person are not all-or-none—duties to the not-yet-born are but one of many factors that must be considered in determining the moral acceptability of an act, whether undertaken by the physician or the parents-to-be (Murray, 2005).

In most cases, both the physician and the parents-to-be would agree that each party has a duty to do what is reasonable to protect the child-to-be from harm. But what risks are considered 'reasonable'? What is it that makes certain risks reasonable in the eyes of the physician, while others are considered the kind that 'responsible' parents would not take? (Murray, 2005). Murray (2005) contends: "The probability of harm and its severity should it occur are certainly relevant. Also significant are the importance of the purpose for which the risk is run and the avoidability of the risk." Obviously, every case will be unique, and of particular problem, is that the answers to such questions will

likely differ between physicians. The degree to which a physician considers whether he or she may be harming a child by participating in the assisted reproduction process, if at all, will be influenced by his or her perception of the potential threat to the child's welfare. According to Murray (2005), the fetus becomes a 'patient' when its welfare becomes the physician's concern. Although the fetus is cared for by a physician when in the womb (e.g., monitoring of heartbeat, ultrasound imaging, amniocentesis, *etc*.), does this care and attribution of patient status necessarily extend to consideration of the child's future well-being, both during the gestation period and beyond? Many authors, including Sauer (2003) and Murray (2005), reject such a suggestion, stating that even parents' duties to protect their children from harm can extend only to known and probable dangers; sacrificing all actions which could *potentially* lead to harm is completely unrealistic. As concluded by Murray (2005): "We must continue the work of clarifying our obligations toward both the fetus destined to be born and the mother who retains her full moral individuality and interests, and in whose body that developing person exists for a time." Attempts to ensure non-maleficence on the part of either the physician or the parents-to-be cannot justify public or official policies which would force the fulfillment of moral obligations by either of these parties. Duties to the not-yet-born must be considered in conjunction with other morally important factors relevant to the parent's/s' decisions; doing anything but is a gross oversimplification of the concept of duties to a fetus.

### *Screening Practices and Beliefs of ART Programs*

In recent years, several studies examining the screening practices and beliefs of fertility clinics both in the United Kingdom and the United States have been conducted

(Savas & Treece, 1998; Stern *et al*., 2001; Gurmankin *et al*., 2005). While all studies revealed that fertility clinics consider the stability of the patients' (couple's) relationship of primary importance (Savas & Treece, 1998; Stern *et al*., 2001; Gurmankin *et al*., 2005), most striking are some of the responses to questions concerning programs' likelihood of turning away candidates, based on their beliefs, in the survey conducted by Gurmankin *et al*. (2005). In a survey sent to the program directors of 369 American ART clinics in the fall of 2001 (overall response rate of 58%), Gurmankin *et al*. (2005) asked each program about its beliefs as they apply to the screening of potential candidates. While 59% of the clinics surveyed agreed that everyone has the right to have a child, only 43% of clinics agreed with the statement that they do not have the right to stop anyone from attempting to conceive, and 44% agreed that they do not have the right to decide who is fit to be a parent (Gurmankin *et al*., 2005). Gurmankin *et al*. (2005) go on to emphasize that significant variation was seen when clinics were given specific hypothetical scenarios regarding their likelihood of turning away the candidates described; thus, it would be reasonable to expect that similar variation would exist with respect to clinics' attitudes regarding the acceptability of HIV-affected couples as candidates for reproductive care in their establishment. Gurmankin *et al*. (2005) suggest that the variation observed in their survey is perhaps reflective of the fact that unlike other countries (e.g., the United Kingdom), the United States does not have professional or national guidelines for screening potential candidates for ART services; as a result, the choice to grant or refuse access is left up to individual programs. In terms of HIV-affected couples requesting access to ARTs, it would appear that the lack of guidelines

only encourages programs' policies to refuse access, as clinics do not have to justify, or routinely review, their decision to not provide reproductive care to these couples.

The degree of variation evident in clinics' policies with regard to treating HIV-affected couples is concerning, primarily because it demonstrates that clinics have vastly different views as to whom constitutes a 'suitable' client—and it is these subjectively-held views which determine whether potential clients are ultimately granted or denied access to ART services. Deacon and Boulle (2006) note that since the late 1980s, numerous studies have been undertaken to pinpoint the factors that affect HIV/AIDS-related stigma and discrimination among health care professionals. While early studies established a strong correlation between knowledge about HIV, fear of infection and stigma/discrimination (Henry *et al*., 1990; Krasnik *et al*., 1991), more recent studies have failed to establish such a link (Zuber & Werner, 1996; Najem & Ozuku, 1998), suggesting that increased knowledge of the HIV virus has tamed fears of infectivity within the medical community. Nevertheless, Deacon and Boulle (2006) note that perceived infection risk at work, albeit small, may be enough for medical professionals to show prejudicial attitudes toward people living with HIV/AIDS in certain circumstances in which more intimate contact with these patients is likely, such as is the case in the use of ARTs by HIV-infected patients. Are such prejudicial attitudes based in any way in reality? Perhaps, in the sense that there are reports of physicians having become infected with HIV *via* their HIV-infected patients, although these occupational exposures occurred in the context of needle stick injuries or surgery (Gerberding, 1999). Should such rare instances of infection propel physicians to deny ART services to HIV-infected patients? No, because doing so violates the reproductive rights of HIV-affected couples, and

precautions can be taken to manage the risk of infection at all points during the ART process.

*Consequences Relating to the Omission of Care*

An issue of perhaps even greater concern, and of particular relevance to the current trend of denying reproductive assistance to HIV-affected couples, is the potential harm created as a result of the omission of care (Sauer, 2003; Williams *et al*., 2003). As stated by Sauer (2003), "reproductive drive is incredibly strong, and patients are known to take risks—beyond what may be reasonable—in order to have a baby." Interviewed in the context of Klein *et al*.'s (2003) study, several HIV-affected couples reported that, should they be denied access to reproductive care, they would probably abandon condoms and attempt pregnancy nonetheless. Considering that the abandonment of safer-sex practices would undoubtedly lead to HIV infection in previously healthy individuals, the medical community is no more condoning of this method of achieving conception (Sauer, 2003). In addition, Nolan (1990) reports that in many couples having been refused access to assisted reproduction (for whatever reason), there is a tendency to distance themselves from the medical structures by which they feel rejected, raising concern as to whether the woman, once pregnant, would obtain appropriate prenatal care, including adhering to the Pediatric AIDS Clinical Trials Group regimen, if infected herself. It would appear therefore that although the constant obligation of non-maleficence may be driving the physician's actions with respect to the requests for reproductive assistance from HIV-affected couples, the physician may very well do more harm than good by refusing to honour such requests. As stated fittingly by Murray (2005), "some wrongs are minimally so…sometimes the effort to correct a wrong itself

creates new moral problems. The moral and other costs of enforcement may outweigh the good that might be done." When it comes to reproductive decision-making, this must always be kept in mind.

While it is obvious that the provision of ARTs to HIV-affected couples requires a thorough examination of the ethical issues pertinent to the debate, consideration of the legal issues which may be faced by either the physician or couples having been denied access is equally warranted. No matter how the physician may feel (morally) about the provision of ART services to these couples, it is crucial that he/she be aware of the legislation that governs medical practice in the jurisdiction(s) in which he/she practices, particularly that relevant to the discussion at hand, and be aware of his/her legal rights and responsibilities in the care of HIV-seropositive persons, as well as the legal rights of HIV-seropositive patients themselves. An examination of these issues forms the focus of the next chapter.

# CHAPTER 3:
# LEGAL CONSIDERATIONS

The Law Reform Commission of Canada (1992) has noted that "[m]edically assisted procreation is perhaps one of the best examples of the challenges posed by the development of medical science and the tensions to which they give rise for the law." Unlike most other forms of medical practice, in which consequences of the medical intervention(s) are most often confined to the patient and/or to his/her physician (Royal Commission on New Reproductive Technologies, 1993), the use of ARTs unequivocally generates broader societal implications (Mykitiuk & Wallrap, 2002), most of an ethical or a legal nature. Thus, the continued development of ARTs inevitably raised concern with regards to the legal implications for all involved parties when using such technologies to conceive a child. After a series of failed attempts to draft and enact comprehensive legislation addressing the legal issues raised by ARTs, dating back as early as 1989 (to the appointment of a Royal Commission on New Reproductive Technologies), Canada's *Assisted Human Reproduction Act*[19] (AHRA) was finally enacted on March 29, 2004, with the purpose of regulating assisted human reproduction and related research in Canada. Ultimately, the Act was enacted to preserve and protect human individuality and diversity, and the integrity of the human genome.[20]

It is important to note, however, that although the AHRA regulates the use of new reproductive and genetic technologies by listing prohibited practices and describing the circumstances under which controlled activities may be carried out, the majority of the

[19] *Assisted Human Reproduction Act*, 2004, c.2 [not in force].
[20] *Ibid*, at s.2.

regulations have been drafted with control over a broad range of activities in mind; that is, the nature of ARTs, notably the continued emergence of new reproductive technologies, or modifications to technologies already in use, is such that no piece of legislation can take into account all possible end results of their use, and the accompanying implications. This contention stands at the very core of Dworkin's (1996) view on the limits of law in bioethical decision-making. He contends that, because advances in biomedicine are evolving at such a rapid rate, the legal system can make no positive contribution to the field, and thus should play no role, or at most a very limited role, in its regulation (Dworkin, 1996). Although such views are most likely not front-and-centre in the minds of legislators, there can be little doubt that the need for constant re-evaluation of issues in the field of reproductive medicine, as new technologies become available, has contributed to the relative lack of, and speed at which, legislation has come into effect. As an example, all provinces and territories have legislation regulating the use and exchange of human tissues, presumably for purposes of organ transplantation, but the definition of "tissue" appears to differ between provinces (Mykitiuk & Wallrap, 2004), with some provinces and territories (i.e., Quebec, Northwest Territories, Nunavut) having no [explicit] definition whatsoever. In these jurisdictions, the question as to whether human tissue includes gametes, for example, is at the court's discretion. Given this "legislative uncertainty", as it is labelled by Mykitiuk and Wallrap (2002), the provinces of Ontario, Manitoba and Prince Edward Island have amended their human tissue legislation to expressly exclude gametes and embryos. Aside from human tissue legislation, no province, as of yet, has enacted legislation relating specifically to the provision and use of ARTs (including issues relating to standardization and uniformity

for the definitions of infertility, access criteria, or possibility of funding in certain medical circumstances); at this time, the regulation of reproductive technologies remains under complete federal jurisdiction (Mykitiuk & Wallrap, 2002).

### 3.1. The Physician's Professional Role Obligations: Knowing the Law

In many ways, assisted reproductive technologies are unlike other forms of medical intervention. Quite simply, the almost exponential proliferation of the technologies involved in assisted reproduction make them distinct from other, more traditional medical interventions (Mykitiuk & Wallrap, 2002). ARTs are unique in what they accomplish: human reproduction outside of sexual intercourse. In addition, ARTs can produce or isolate human reproductive material outside the human body. This raises a myriad of questions: to whom does the reproductive material belong? How should reproductive entities such as sperm, ova, zygotes and embryos be regarded and treated? Who has control over them? (Mykitiuk & Wallrap, 2002). Beyond simple logistics, ARTs have the potential to create novel social arrangements, which present society is, in many ways, unequipped to deal with. Recent uses of ARTs include post-menopausal pregnancy, embryos conceived at one time and inseminated at later/different times, and post-mortem insemination, to name a few (Lippman, 1995; Mykitiuk & Wallrap, 2002). Thus, it follows that ramifications of bioethical decision-making with regards to ARTs affect not only the patient but, in fact, have a far greater impact on all members of society (Royal Commission on New Reproductive Technologies, 1993). This is especially true in Canada, where the existence of a publicly funded health care system generates almost constant rehashing as to which medical interventions should be covered under provincial health care insurance plans.

***The Use and Regulation of ARTs in Canada***

Regulating the use of ARTs in Canada is complex, the result of its many facets falling under federal jurisdiction, but being used in provincial contexts which regulate their own health care systems. Jackman (2000) has argued that the government's creation of the Royal Commission is strong enough evidence that it considers the use of ARTs a "national concern", which should be under federal jurisdiction only. Indeed, through the AHRA, Parliament now regulates many aspects of ARTs also falling under other federal jurisdictions, including criminal law (e.g., *via* criminal prohibitions on cloning), and trade and commerce (e.g., *via* prohibitions on importing and exporting reproductive material to and from other countries, such as the United States (Cheney, 1998), and receiving payment for sperm or oocyte donation (Rivard & Hunter, 2005)). Nevertheless, it could be argued that the patient's *use* of ARTs falls under provincial jurisdiction because the ultimate use of these technologies occurs within the context of physician-patient relationship, often in private clinics that are either stand-alone facilities or located within/associated with a hospital (Rivard & Hunter, 2005).

The rights and freedoms of all Canadians, including those pertaining to health care, are guaranteed under the *Canadian Charter of Rights and Freedoms*[21] ("*Charter*") (Mykitiuk & Wallrap, 2002; Washenfelder, 2003). Of most relevance to rights relating to health care, including ARTs, are potential challenges to section 7 (the right to life, liberty and security of the person) and section 15(1) (equality). A limit on the s.7 right to life, liberty and security of the person requires justification by the state only if the limitation is inconsistent with the principles of fundamental justice. Further, for all *Charter*

[21] *Part I, The Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c.11.

guarantees, the Government may justify a derogation from a constitutional freedom or right if it can be shown that this limit is reasonable and demonstrably justified in a free and democratic society.[22] Interestingly, perhaps already anticipating challenges to the *Charter* in the context of the "reproductive revolution" (Robertson, 1994), the Law Reform Commission of Canada stated, in 1992: "It seems likely that either liberty or security of the person, or both, will be found in a future case to include the right to procreate." (Law Reform Commission of Canada, 1992). The *Charter* does not explicitly include a right to procreate, but Mykitiuk and Wallrap (2002) suggest that should such a right exist, it would most likely exist within the s.7 right to liberty or the right to security of the person.[23]

In instances in which individuals believe that their *Charter* rights have been infringed upon in their being denied access to ART services, the lack of legislation regulating assisted reproduction, specifically the use of ARTs within the context of the physician-patient relationship (Mykitiuk & Wallrap, 2002; Rivard & Hunter, 2005), suggests that most individuals and/or couples will likely seek to invoke various pieces of human rights legislation upon being denied access (Mykitiuk & Wallrap, 2002). Human rights legislation is unique in that, unlike the *Charter*, which applies only to government action or inaction, it applies to activities undertaken in both the public and private sectors,

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[22] *Ibid*., at s.1.

[23] Reproductive freedom has been considered in the U.S. context. In *Skinner v. Oklahoma*, the Court ruled that the sterilization law at issue was unconstitutional, appearing to recognize a positive right to reproduce. Stating that "marriage and procreation are fundamental to the very existence and survival of the [human] race", and characterizing the right to reproduce as "one of the basic civil rights of man [sic]", Douglas J. held that the forced sterilization of repeat criminal offenders violated the Equal Protection Clause of the Fourteenth Amendment. See *Skinner v. Oklahoma*, 316 U.S. 535 [1942] at 541. In later cases dealing with the right to access contraception and abortion, the Court confirmed a right not to reproduce. See *Griswold v. Connecticut*, 381 U.S. 479 [1965]; *Roe v. Wade*, 410 U.S. 113 [1973]; and *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833 [1992].

including acts by individuals or corporations (Mykitiuk & Wallrap, 2002). On an international scale, the General Assembly of the United Nations' *Universal Declaration of Human Rights*[24] includes the right to establish a family. Article 16 states: "Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and found a family. …The family is the natural and fundamental group unit of society and is entitled to protection by society and the State."[25] However, it is important to note that the scope of application of international declarations, such as the *Universal Declaration of Human Rights*, varies depending on the extent to which they are recognized by a country and integrated into its domestic law. Thus, a declaration deemed to give individuals one or more rights in one jurisdiction may not be considered to do so in another.

In Canada, most provincial human rights codes recognize that individuals shall not be discriminated against on the basis of "race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, disability and conviction for which a pardon has been granted." (Mykitiuk & Wallrap, 2002). Of most relevance to the discussion at hand, the *Canadian Human Rights Act* states: "Where the ground of discrimination is pregnancy or child-birth, the discrimination shall be deemed to be on the ground of sex."[26] Somewhat problematically, the various provincial human rights codes contain nuances in their language, meaning that the interpretation of legislation could potentially result in vastly different outcomes in cases alleging

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[24] *Universal Declaration of Human Rights*, GA Res. 217 (III), UN GAOR, 3rd Sess., Supp. No.13. UN Doc A/810 (1948) 71 (UDHR).
[25] *Ibid.*
[26] *Canadian Human Rights Act*, R.S.C. 1985, c.H-6, s.3.

infringement of *Charter* rights (Mykitiuk & Wallrap, 2002). Very broadly, the *Quebec Charter of Human Rights and Freedoms* ("Quebec *Charter*") states:

> Every person has a right to full and equal recognition and exercise of his [sic] human rights and freedoms, without distinction, exclusion or preference based on race, colour, sex, pregnancy, sexual orientation, civil status, age except as provided by law, religion, political convictions, language, ethnic or national origin, social condition, a handicap or the use of any means to palliate a handicap.[27]

More specifically, noting the right of equal treatment in the context of goods, services and facilities, the Ontario *Human Rights Code* states:

> Every person has a right to equal treatment with respect to services, goods and facilities, without discrimination because of race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, age, marital status, same-sex partnership status, family status or disability.[28]

Thus, while it is important that physicians have a thorough knowledge of the rights of their patients in the jurisdiction in which they practice, they should also be aware that, given the discrepancies between provincial statutes concerning human rights, the nature of medical procedures/treatments such as ARTs are likely to engender various forms of legal action, which may or may not be justified in a society such as ours, in which health care needs must be balanced against available resources. In addition, given that we have most likely only seen the beginning of the "reproductive revolution" (Robertson, 1994), it seems safe to say that cases alleging discrimination at the hands of physicians practicing in the field of reproductive medicine will only increase in the years to come.

### *Legal Issues and Jurisprudence Specific to ARTs in Canada*

First and foremost, it is important to note that the crux of this dissertation rests on the assumption that all couples, including HIV-affected couples, are able to access

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[27] *Quebec Charter of Human Rights and Freedoms*, R.S.Q. 1977, c.C-12.
[28] Ontario *Human Rights Code*, R.S.O. 1990, c.H-19, s.1.

assisted reproductive technologies should they so wish. Realistically, however, the Canadian public's ability to 'access' ARTs is a matter of ongoing debate. Access to ARTs is, in fact, limited by a number of factors, including, most prominently, screening procedures employed by the physician, and the high cost of treatment (Mykitiuk & Wallrap, 2002). Unlike the situation in the United States, where access is (usually) principally determined by an individual's or a couple's ability to cover the entire cost of the ART procedure(s) (with selection criteria playing a smaller, albeit still important role), the existence of a publicly funded health care system in Canada complicates matters significantly (Shanner & Nisker, 2001). Under this type of system, decisions regarding whether to cover specific health care interventions are guided by a need to "ensur[e] access to medically necessary and appropriate treatment while avoiding inappropriate use at both micro (individual patient) and macro (health policy) levels." (Shanner & Nisker, 2001). When deciding whether to cover an individual treatment, numerous factors are considered, including: continual evidence-based assessments of the intervention's safety and effectiveness, the full costs of the intervention to the health care system (e.g., total costs per successful outcome and the costs of complications) and the availability and comparative results of other options, should they exist (Neumann *et al*., 1994; Shanner & Nisker, 2001). Ultimately, in the interest of balancing competing health care priorities and the right of fair access to the best interventions across all types of health care needs, Canadian provinces have chosen not to insure ART services under their provincial health care insurance plans, with one notable exception,[29] (Shanner &

[29] The *Ontario Health Insurance Plan* ("OHIP") provides funding for up to three complete cycles of *in vitro* fertilization for women who show "complete bilateral anatomical fallopian tube blockage". See *General Regulation* under the Ontario *Health Insurance Act*, R.R.O. 1990, Reg. 552, s.24.

Nisker, 2001; Washenfelder, 2003), a decision which, as I discuss below, has not gone unchallenged.

When an individual or couple wishes to access ARTs, he or she/they usually approach a physician working in a private fertility clinic or one associated with a public hospital. Assuming that the individual or couple is able to cover the cost of the ART procedure(s), the couple is subject to various selection criteria, most of which centre on the potential benefits and risks to the health and safety of both participants based on their medical histories, and the effect that these factors may have on the woman's ability to carry a pregnancy to term (Shanner & Nisker, 2001). The selection criteria employed may be determined by the fertility clinic itself, set out in professional guidelines which physicians are expected to follow, or specified by the legislature in a particular jurisdiction (Shanner & Nisker, 2001). In a survey of Canadian fertility clinics within the Royal Commission on New Reproductive Technologies (1993), selection criteria reported in effect included: health status of the participant(s), age, race and ethnicity, physical disability, marital status, the presence of a partner, sexual orientation, psychological maturity, intellectual capacity, financial status, place of residence, and the presence of other children in the home (Mykitiuk & Wallrap, 2002). In a comparable survey of fertility clinics in the United States, undertaken by Gurmankin *et al*. (2005), other criteria (in addition to those mentioned above) considered by the clinics included: history of illicit drug use, HIV status, mental health status, reasons for wanting a child, religion, and criminal history. Not surprisingly, these criteria raise a multitude of ethical issues. Do fertility clinics have the right to collect this type of information? Perhaps more importantly, are clinics acting within their [legal] rights by refusing to provide

reproductive care to particular individuals, depending on their answer(s) to particular questions? Should clinics have the right to discriminate based on certain criteria but not others? The various legal challenges that have been brought forward in many jurisdictions would suggest that there appears to be no clear answer to these questions, at least under the law, a further support to Dworkin's (1996) claim that law can make no—or only a very limited—positive contribution to bioethical decision-making.

### 3.2. Legal Challenges Brought Forth in Canada

The importance which Canadians attribute to health care, and by association, the (perceived) right to access health care, has stressed the health care system, particularly its administration, in many ways, not the least of which are the ongoing discussions and debates as to which medical interventions and/or treatments should be insured in a health care system which is primarily publicly funded. In this "reproductive revolution" (Robertson, 1994), in which new reproductive technologies are continually emerging, each one more sophisticated and costly than the previous, the question must be asked: does there exist a right to procreate within the constitutionally guaranteed right to liberty? And if so, does this right include a right to access any and all medical services necessary to procreate? (Robertson, 1994; Eriksson, 2000; Mykitiuk & Wallrap, 2002; Washenfelder, 2003).

In recent years, several cases have come before the Supreme Court of Canada, instigated by individuals and/or couples claiming that their *Charter* rights have been infringed upon by various regulatory frameworks that have limited, either directly or indirectly, their access to ARTs. In the context of denial of access to ARTs, the *Charter*

may be invoked by any individual who wishes to challenge statutory provisions and regulations that limit access either directly on the basis of medical factors (limitation of access which will usually have been accorded by a physician) or, conversely, indirectly on the basis of services listed under provincial health insurance plans (Mykitiuk & Wallrap, 2002). According to Mykitiuk and Wallrap (2002), three types of constitutional arguments could be invoked in order to gain access to ARTs. First, it could be argued that a positive right to procreate may be constructed on the basis of the s.7 right to liberty. Section 7 of the *Charter* provides: "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice."[30] Alternatively, it could be argued that the s.7 right to liberty includes a positive right to health care and that access to ARTs is an intrinsic component of that right.[31] Finally, access to ARTs could be sought using s.15(1). Section 15(1) of the *Charter* provides:

> Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.[32]

Such a challenge could be successful if it could be shown that government legislation or action provides some individuals access to ARTs, while access is denied to other individuals who are members of a class of persons enumerated under s.15(1) or of an

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[30] See Canadian *Charter*, *supra* note 21 at s.7.

[31] In *Chaoulli v. Quebec (Attorney General)*, appellants George Zeliotis and Jacques Chaoulli, argued that provincial legislation prohibiting Quebec residents from taking out insurance to obtain health care services in the private sector already available under Quebec's public health care plan deprived them of access to health care services as a result of the waiting times faced in the public system; as such, the waiting times violated their rights to life and security. The majority of the Supreme Court ruled that although the *Charter* does not confer a freestanding constitutional right to health care, "where the public system fails to deliver adequate care…in the face of delays in treatment that cause psychological and physical suffering, the prohibition on private insurance jeopardizes the right to life, liberty and security of the person of Canadians in an arbitrary manner." See *Chaoulli v. Quebec (Attorney General)* [2005], S.C.J. No. 33.

[32] See Canadian *Charter*, *supra* note 21 at s.15(1).

analogous class, making it possible to claim discrimination. At this point, it is important to note, as do Mykitiuk and Wallrap (2002), that:

> A *Charter* challenge places the onus on the parties seeking access to [A]RTs to show that a right or freedom has been infringed in legislative purpose or effect. [Thus], a person seeking access under s.7 of the Charter has the onus to demonstrate that the deprivation of life, liberty or security of the person is not in accordance with the principles of fundamental justice.

Likewise, a person seeking access to ARTs under s.15(1) would have the onus to demonstrate that he/she has been the subject of discrimination before and under the law.

***Cases Involving Questions about Reproductive Choice as a Human Right***

In the last two decades, several cases have examined the nature and scope of reproductive autonomy. In this connection, *E. (Mrs.) v. Eve*[33] and *Korn v. Potter*,[34] are noteworthy. The case of *E. (Mrs.) v. Eve*, examined whether a court had the power, based on *parens patriae*[35] jurisdiction, to authorize the contraceptive sterilization of a mentally disabled woman, and whether such a sterilization could be considered to be in the woman's best interests. Citing "the grave intrusion on a person's rights and the certain physical damage that ensues",[36] the Court ruled that courts' *parens patriae* jurisdiction does not permit them to authorize a non-consensual sterilization for non-therapeutic purposes. Although the question as to whether there is a *constitutionally* protected right to procreate had yet to come before the Supreme Court (Mykitiuk & Wallrap, 2002), La Forest J. did suggest that there was "a growing legal recognition of

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[33] *E. (Mrs.) v. Eve* [1986], 2 S.C.R. 388.
[34] *Korn v. Potter* [1996], 134 D.L.R. (4th) 437 (B.C.S.C.).
[35] *Parens patriae* (*L.* "father of the people") refers to the public policy power of the state, in common law, to override the rights of the natural parent, legal guardian or informal caregiver, and to act as the parent of any child or individual who is in need of protection, such as a child whose parents are unable or unwilling to care for him or her, or an incapacitated or dependent individual, even without statute law to allow them to do so (Scott, 1986).
[36] *Eve*, *supra* note 33 at 431.

the fundamental character of the right to procreate."[37] Furthermore, "the great privilege of giving birth", and "[t]he importance of maintaining the physical integrity of a human being…particularly as it affects the privilege of giving life", led La Forest J. to characterize the proposed sterilization as an "irreversible and serious intrusion on the basic rights of the individual."[38] However, although the *Eve* decision may imply the existence of a fundamental right to procreate, Mykitiuk and Wallrap (2002) suggest that even if the courts were to find a right to procreate protected by s.7 of the *Charter*, it would most likely be viewed as a negative right;[39,40] that is, the right to procreate without interference from the state, and not a positive right to the use of ARTs, even if these technologies be necessary for a couple to conceive.

The case of *Korn v. Potter*, also focusing on questions of human rights in connection with access to ART services, stemmed from a request for artificial insemination from a lesbian couple, Tracy Potter and Sandra Benson. The couple approached the defendant physician, Dr. Korn, a Vancouver physician and surgeon specializing in the treatment of infertility through artificial insemination by donor, who refused to grant them access, stating that his practice had suffered financial loss after he had been involved as a witness in litigation proceedings between a recently separated

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[37] *Eve*, *supra* note 33 at 59.
[38] *Eve*, *supra* note 33 at 85.
[39] Other cases pertaining to health care or medical treatment have suggested that the right to health care is a negative right, and that for the courts to be involved in determining access to health care (in Canada, a matter within the authority of the State), deprivation of one or more of a person's legal rights must be demonstrated. In *Rodriguez v. British Columbia (Attorney General)*, Sue Rodriguez, a woman suffering from amyotrophic lateral sclerosis (Lou Gehrig's disease), sought an order to allow a qualified medical practitioner to set up the technological means to allow her to end her own life (by her own hand) at a time of her choosing. In *Rodriguez*, the majority of the Supreme Court of Canada upheld the decision of the British Columbia Supreme Court, agreeing that s.7 of the *Charter* could not be interpreted so as to include a constitutionally guaranteed right to take one's own life as an exercise in freedom of choice. See *Rodriguez v. British Columbia (Attorney General)* [1993], 3 S.C.R. 519.
[40] See *Chaoulli*, *supra* note 31.

lesbian couple to whom he had provided services. As a result of significant media attention surrounding the proceedings, Dr. Korn stated that he had received numerous anonymous telephone complaints about his practice of providing artificial insemination services to lesbian couples, and thus decided soon after that he would stop doing so. Although Dr. Korn admitted that he refused Ms. Potter and Ms. Benson's request for reproductive assistance, he noted that he provided them with the names of two physicians whom he believed would assist them. Nevertheless, Ms. Potter and Ms. Benson filed a complaint with the College of Physicians and Surgeons of British Columbia, alleging that Dr. Korn's refusal to provide lesbians with artificial insemination was discriminatory. The College dismissed the complaint, stating that, barring the need for urgent or emergency medical services, a physician has the right to refuse services to a patient. Ms. Potter and Ms. Benson then filed a complaint with the British Columbia Council of Human Rights, alleging that Dr. Korn had denied them a service which he customarily provided on the grounds of their sexual orientation, an act in violation of section 3(b) of the British Columbia *Human Rights Act*.[41] The Council found the complaint valid, after which time, Dr. Korn appealed to the British Columbia Supreme Court, which subsequently dismissed the petition.

In denying Dr. Korn's petition, the Supreme Court found that the Council of Human Rights did not err in finding that Dr. Korn discriminated against Ms. Potter and Ms. Benson on the basis of their sexual orientation. The Court asserted that the fact that other providers of the service existed, and that Dr. Korn provided their names to Ms. Potter and Ms. Benson, could not sanction the discrimination prohibited under the *Human*

[41] British Columbia *Human Rights Act*, S.B.C. 1984, c.22.

*Rights Act* by any one provider (here, being Dr. Korn). In addition, the Court found that the Council's finding that Dr. Korn did not have a reasonable justification for refusing to accept Ms. Potter and Ms. Benson as patients was not unreasonable. The Court noted that the Council had carefully considered the impact that being a witness involved in litigation had had upon Dr. Korn, and had concluded that there had been no significant financial loss to his practice as a result. Additionally, the Court agreed with the Council's conclusion that that the preferences of clients, whatever they may be, cannot be a defense to a complaint of discrimination. Thus, although some members of the general public may have objected to Dr. Korn's custom to provide artificial insemination to lesbian couples, this fact could not justify Dr. Korn's subsequent exclusion of certain groups of patients from his practice.

*Section 7 Charter Claims Associated with Reproductive Autonomy*

Within the reproductive context, two cases raising the question of s.7 rights have come before the Supreme Court of Canada. The first, the landmark case of *R. v. Morgentaler*,[42] considered the (then) criminal provisions limiting access to abortion in Canada. The majority of the Supreme Court found that such criminal prohibitions violated the pregnant woman's s.7 rights to liberty and security of the person by interfering with bodily integrity and subjecting the woman to serious psychological stress. Noting that the right to liberty described in s.7 of the *Charter* "guarantees to every individual a degree of personal autonomy over important decisions intimately affecting their private lives", Wilson J. added:

[42] *R. v. Morgentaler* [1988], 1 S.C.R. 30.

> This decision [whether to terminate a pregnancy] is one that will have profound psychological, economic and social consequences for the pregnant woman. …It is a decision that deeply reflects the way the woman thinks about herself and her relationship to others and to society at large. It is not just a medical decision; it is a profound social and ethical one as well. Her response to it will be the response of the whole person.[43]

In articulating the conception of liberty protected by the *Charter*, Wilson J. relied on several American cases, notably *Skinner v. Oklahoma*[44] and *Eisenstadt v. Baird*,[45] both of which have held that the right to liberty includes the right to privacy, and consequently, the right to procreate. Ultimately, being a decision that fundamentally affects both the physical and psychological well-being of the woman, Wilson J. acknowledged that the choice to terminate a pregnancy falls within the realm of decisions that are protected from governmental interference by the right to liberty. Interestingly, Washenfelder (2003) notes that although *Morgentaler* is (ultimately) a criminal case, it is important for all reproductive rights cases in that it recognized that decisions relating to reproduction (e.g., the ability to conceive, or conversely, lack thereof) are linked to psychological stresses. Thus, it may be that a woman's desire to terminate a pregnancy may elicit a psychological response as intense as that of a woman not being able to conceive. Do both women have an equal right to procreate? Perhaps, although it is not clear if this right, should it exist, includes a right to access any and all medical services necessary in order to do so, should it be necessary.

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[43] *Ibid*., at 171.
[44] *Skinner v. Oklahoma*, 316 U.S. 535 [1942], at 541.
[45] *Eisenstadt v. Baird*, 405 U.S. 438 [1972], at 453. Brennan J. for the majority recognized that the right to privacy includes "the right of the individual, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision to bear or beget a child."

***Health-Related Challenges Pursued under Section 15(1) Charter: Equality***

As mentioned previously, it is also possible that, upon refusal by a physician, individuals could challenge their denial of access to ARTs under s.15(1) of the *Charter*. A claim of discrimination could be justified under s.15(1) if it could be shown, for example, that non-HIV infected couples can access ARTs with relative ease (again, assuming that the couple is prepared to cover the cost of the services)—that is, that physicians are drawing an unfair distinction between HIV-infected couples and non-HIV-infected couples by denying access on the basis of a medical condition. The Royal Commission on New Reproductive Technologies (1993), for example, argued that if access criteria is based solely on the presence of [a definition of] medical infertility, discrimination would be unlikely to occur. Although the aim of drawing such a distinction was to prevent discrimination based on social prejudices, many physicians argue that the condition underlying the couple's diagnosis of medical infertility (i.e., HIV infection) cannot be ignored—for without the presence of HIV infection, the infertility factors (present as they are in the couple) would not exist. Nevertheless, as I show below, at least one Canadian court has ruled that a medical diagnosis of infertility can constitute a disability, thus opening the door for couples to pursue claims under *Charter* s.15(1) in instances where they are denied access or coverage to a medical treatment, essentially deeming irrelevant the reason(s) underlying the couple's infertility factors.

The principle of fair access has been upheld by the Supreme Court under the equality provisions of s.15(1) of the *Charter*. In *Eldridge v. British Columbia*,[46] the Court found that the province's failure to provide interpreters for deaf patients denied

[46] *Eldridge v. British Columbia (Attorney General)* [1997], 151 D.L.R. (4th) 577 (S.C.C.).

those patients access to essential services, stating that all patient groups must be able to access a comparable set of services, medical or otherwise. However, there have been instances in which the Court has refused claims for access to particular services on the premise of s. 15(1) of the *Charter*. In *Auton (Guardian ad litem of) v. British Columbia (Attorney General)*,[47] the Court overturned lower court rulings,[48] which had initially determined that autistic children's rights to medically necessary treatments were violated by the province's failure to insure early intensive treatment for the disorder, even though other treatments for autism, used at a later age, were insured. The Supreme Court found no violation of equality in the province's choice about funding treatment for autism, noting that the *Canada Health Act*[49] and British Columbia's *Medicare Protection Act*[50] do not promise that any Canadian will receive funding for all medically required treatment; core funding is only provided for services delivered by medical practitioners, with partial funding for non-core services being at the province's discretion.

Of most relevance to this dissertation, being cases directly dealing with reproductive rights, are the cases of *Cameron v. Nova Scotia (Attorney General)*[51] and *Susan Doe v. Canada (Attorney General)*.[52] The case of *Cameron v. Nova Scotia (Attorney General)* involved a s.15(1) challenge to the funding criteria applied under the Nova Scotia *Health Services and Insurance Act*[53] in relation to the provision of IVF and ICSI to infertile couples. The claimants, an infertile couple, Alexander Cameron and

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[47] *Auton (Guardian ad litem of) v. British Columbia (Attorney General)* [2004], 3 S.C.R. 657.
[48] *Auton (Guardian ad litem of) v. British Columbia (Attorney General)* [2002], B.C.J. No. 2258 (C.A.); affg [2000], B.C.J. No. 1547 (S.C.); leave to appeal to S.C.C. granted [2002], S.C.C.A. No. 510 (QL).
[49] *Canada Health Act*, R.S.C. 1985, c.C-6.
[50] *Medicare Protection Act*, R.S.B.C. 1996, c.286.
[51] *Cameron v. Nova Scotia (Attorney General)* [1999], 177 D.L.R. (4th) 611 (N.S.C.A.); affg [1999] 172 N.S.R. (2d) 227 (S.C.); leave to appeal dismissed (without reasons) [1999], S.C.C.A. No. 531.
[52] *Susan Doe v. Canada (Attorney General*) [2006], 79 O.R. (3d) 586.
[53] Nova Scotia *Health Insurance Act*, R.S.N.S. 1989, c.197.

Cheryl Smith, sought benefits under the *Health Services and Insurance Act* for the costs associated with the use of these ARTs. After their request for coverage was denied, the couple appealed to the Nova Scotia Court of Appeal, arguing that IVF and ICSI were, for them, like other infertile couples, medically necessary procedures, and the province's failure to fund IVF and ICSI under the *Health Services and Insurance Act* constituted discrimination (against infertile persons) on the grounds of disability under s.15(1) of the *Charter*. Mr. Cameron and Ms. Smith provided the court with evidence that IVF treatments were clinically indicated and medically required to treat their infertility factors, and showed that IVF treatments were within the scope of infertility treatments then insured in Nova Scotia (Washenfelder, 2003). Associate Justices Chipman and Pugsley of the Court of Appeal found that the province's policy of not insuring IVF and ICSI drew a distinction between the fertile and the infertile, as only the infertile need ARTs to conceive. Recognizing the social, cultural and political context of infertility, Chipman and Pugsley JJ.A. concluded that "infertile people can be classified as disabled",[54] and that the failure to insure IVF denied equal benefit of the law to the appellants and that the denial of treatment was on grounds of a physical disability (i.e., infertility) (Washenfelder, 2003), amounting to "adverse effect discrimination" (Mykitiuk & Wallrap, 2002) under s.15(1) of the *Charter*. The Court noted:

> The government has failed to ameliorate the position of the infertile compared with fertile people. They are unequally treated because they are denied a medically recommended treatment appropriate for them. The fertile on the other hand have no restrictions on access to Medicare for pre-natal treatments and treatments relating to childbirth. Every aspect is covered.[55]

[54] See *Cameron*, *supra* note 51 at 655 (D.L.R.).
[55] See *Cameron*, *supra* note 51 at 654-55 (D.L.R.).

Interestingly, however, although the Court found that IVF could be considered a medically necessary treatment, it determined that the exclusion of IVF and ICSI from the provincial public health insurance plan was justified under s.1 of the *Charter* on the grounds of resource allocation within the public health care system. The government's current policy of universal public health insurance coverage necessitates that, in order to provide the best possible health care coverage for all Canadians, given limited financial resources, some services must be excluded in order to control health care costs; currently, such uninsured services include ARTs—a decision that is justifiable under s.1 of the *Charter*, because their exclusion is connected to the aim of the legislation (i.e., "guarantees the rights and freedoms set out in [the legislation] only to such limits prescribed by law as can be demonstrably justified in a free and democratic society"[56]) (Mykitiuk & Wallrap, 2002). Moreover, Chipman and Pugsley JJ.A. found that the applicants' *Charter* rights to equality were only minimally impaired by the exclusion of these services. Although this decision does effect a hardship (primarily financial) on couples (Washenfelder, 2003), the fact that other procedures aimed at infertility treatment, albeit on a smaller-scale and less costly, are covered, led the Court to find that the effect of the exclusion on these rights was proportional to the objective of the Nova Scotia *Health Services and Insurance Act*. The decision was appealed to the Supreme Court of Canada, but leave was denied. Nevertheless, even though the infringement was deemed justifiable given the government's need to control health care costs, the *Cameron* decision is important as it marks the first time that unequal access to ARTs as a treatment for infertility factors was recognized to amount to an infringement of *Charter* rights (Mykitiuk & Wallrap, 2002; Washenfelder, 2003).

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[56] See *Part I*, *The Constitution Act, supra* note 21.

Most recently, a case involving assisted reproduction alleging infringement of both s.7 and s.15(1) rights, that of *Susan Doe v. Canada (Attorney General)*, came before the Ontario Superior Court of Justice. The case involved a woman, Susan Doe, who argued that the definition of "assisted conception" in the federal regulations governing artificial insemination violates the constitutional rights of lesbians. Using the definition of assisted conception as "a reproductive technique performed on a woman for the purpose of conception using semen from a donor who is not her spouse or sexual partner",[57] the Regulations prohibit the processing and distribution of semen from donors who come from within an excluded group, with persons with indications of high risk for HIV falling within this group.[58] (Other persons falling in the group include persons over the age of 40, persons with indications of high risk for the Hepatitis B and C virus or human T-cell lymphotropic virus, and men who have had sex with a man, even once, since 1977). A woman may apply for "special access authorization" if she seeks to be inseminated using the semen of an excluded group, as long as the semen tests negative for HIV and Hepatitis B and C. Ms. Doe argued that the Regulations infringed on the liberty and security of lesbian women seeking artificial insemination, as well as upon the equality rights of this group by imposing restrictions on them which are not imposed upon women seeking insemination with the semen of their spouse or sexual partner.

Susan Doe (or "S") was a 39-year-old lesbian who, with her long-time partner "J", having already had a child using the sperm of a semen donor "D", desired to have a second child whom would be a full biological sibling to their first. "D" was prepared to

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[57] See *Processing and Distribution of Semen for Assisted Conception Regulations*, S.O.R. 196-254 under the *Food and Drugs Act*, R.S.C. 1985, c.F-27.
[58] *Ibid*.

provide semen samples again, but for reasons unknown, agreed only to provide a maximum of six samples to "S". Realizing that it often takes more than one attempt to conceive successfully, "S" wanted to use assisted conception to maximize her chances of conceiving given the limited number of samples available. However, since "D" was a gay man and over the age of 40, he was refused participation in the process. Ultimately, the Ontario Superior Court of Justice dismissed the application, stating that the definition of assisted conception did not deprive Ms. Doe of her right to liberty because it deprived her of, or significantly burdened, her right to make a choice as to who would father her child. Furthermore, the Court noted that the applicant's frustration at the Regulations could not be characterized as a deprivation of the right to security of the person. Of particular importance, the Court ruled that in these circumstances, sexual orientation was not the basis for the differential treatment, and thus, Ms. Doe's s.15(1) rights had not been infringed upon.

Although the case is based primarily on s.15(1) equality rights, alleging discrimination on the grounds of sexual orientation (and not on the basis of a medical condition or infection), the *Susan Doe* case is still relevant to the discussion at hand. In its decision, the Court noted that the Regulations mandating the exclusion of certain groups of donors "is to protect the health of women undergoing assisted conception, to reduce the risk to women and their partners of acquiring transmissible infectious diseases and to reduce the risk to their unborn children of acquired transmissible infections and suffering birth defects."[59] Thus, the difference between lesbians seeking artificial insemination with the donor of their choice and women seeking insemination with the

[59] See *Susan Doe*, *supra* note 52 at 77.

semen of their spouse or sexual partner is the (appropriate) presumption that the latter implicitly accept all risks to themselves and to any children that they may bear in their decision to engage in sexual intercourse with their spouse or partner. The Court further noted:

> Women proposing to use semen from donors who are their spouses or sexual partners are excluded from the definition of assisted conception because there is no point in imposing the Regulations on women who have already been exposed to any risk that exists. The justification for the exemption of spouses and sexual partners cannot be a recognition that women are entitled knowingly and voluntarily to accept the risks to themselves and to their unborn children associated with conceiving a child with the donor of their choice [even if the donor be HIV-seropositive].[60]

In a case of a lesbian couple, given that neither partner is engaged in an ongoing sexual relationship with the semen donor (who acts here only as a contributor of genetic material), the Court felt that there was not a sufficient relationship between both parties for both women in the couple to be able to voluntarily accept the risks to the child, given that neither partner in the couple exposes herself to these same risks on a regular basis. Thus, application of this reasoning to HIV-affected couples requesting the use of ARTs to conceive suggests that these couples, despite being HIV-affected, would not fall under the umbrella of an excluded group. Building upon the *Susan Doe* reasoning, although the couple would be using semen from an HIV-infected partner (if the male is the HIV-infected partner), they would necessarily qualify for assisted reproduction based on the fact that they are each other's sexual partners, not even requiring special access authorization. HIV-affected couples would be exempt because, as is the case with women proposing to use the semen of their spouse or sexual partner for assisted conception, the uninfected partner in the HIV-affected couple would already have been

[60] See *Susan Doe*, *supra* note 52 at 78.

exposed to any risk that exists. Although such reasoning seems apparent, it would be interesting to see if it would be equally endorsed by a Court if the applicants were an HIV-affected couple alleging infringement of s.15(1) rights on the basis of discrimination due to HIV status.

### 3.3. Legal Challenges Brought Forth in Other Jurisdictions

Recently, the European Court of Human Rights handed down a decision also relevant to the discussion at hand, that of *Dickson v. The United Kingdom*.[61] This case involved a couple, Kirk and Lorraine Dickson, wanting to conceive using artificial insemination (AI). Mr. Dickson was convicted of murder in 1994, and was sentenced to life in prison without possibility of parole for 15 years. In 1999, while serving his sentence in a UK prison, Mr. Dickson, then 27 years of age, met his wife, Lorraine, then 41 years of age, who was also imprisoned, through a prison pen pal network. In 2001, the couple married. At the time of their marriage, Mr. Dickson had no children; Mrs. Dickson had three children from previous relationships. Soon after, they decided they wanted to conceive; however, Mr. Dickson was not permitted conjugal visits. In October, 2001, Mr. Dickson applied to the prison administration for the right to use facilities for AI. In December, 2002, following her release, Mrs. Dickson added her name to the request. Their lawyers presented their request to the Secretary of State, stating that, given Mr. Dickson's earliest release date (set for 2009) and Mrs. Dickson's age, it was highly unlikely that the couple would be able to have a child together without the use of AI facilities. In May, 2003, the Secretary of State denied their application, citing state policy.

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[61] *Dickson v. The United Kingdom* – 44362/04 [2006] ECHR 430.

In refusing to grant the couple permission to access AI facilities, the Secretary of State gave the following reasons. First, having been initiated while both were imprisoned, the couple's relationship has not been tested in the normal environment of daily life, suggesting that the long-term strength of their union was unknown. Secondly, the Secretary felt that there were insufficient provisions in place to provide for the material welfare of any child which might be born. Thirdly, there appeared to be little in the way of an immediate support network for Mrs. Dickson and any child that would be born to her. In addition, there was concern that the child would be without his or her father for an important part of his/her childhood years. Lastly, and of most concern, the Secretary felt, in light of the violent nature of Mr. Dickson's crime, that there would be legitimate public concern that the punitive and deterrent elements of Mr. Dickson's sentence were being circumvented if he were allowed to father a child by AI while imprisoned for murder. At this point, it is important to note that Mr. and Mrs. Dickson were prepared to absorb all costs related to the artificial insemination procedure(s).

Mr. and Mrs. Dickson applied for a judicial review of the Secretary of State's decision. Their request was denied by the High Court, followed by the Court of Appeal, and after exhausting domestic remedies, the couple applied to the European Court of Human Rights in November, 2004. In the application, the couple argued that, in refusing to allow them to access AI facilities, the State had failed to fulfill a positive obligation to secure respect for private or family life, and the right to found a family, violations of articles 8 and 12 , respectively, of the *Convention for the Protection Human Rights and*

*Fundamental Freedoms*.[62] In addition, the applicants noted that, should Mr. Dickson be permitted conjugal visits, the need for AI facilities would not exist, and as such, the Secretary of State was effectively denying Mr. and Mrs. Dickson's right to found a family. In April, 2006, the Court found that it had not been shown that the decision to refuse AI facilities in the present case was arbitrary or unreasonable. Speaking for the majority, Bonello J. noted:

> I am hardly convinced that procreating a child through artificial insemination by a life prisoner is embraced in the right secured by Article 12. *The concept of 'family'* enshrined in Articles 8 and 12, *in my view, requires more than the mere forwarding of sperm from a distance in circumstances which preclude the donor from participating meaningfully in any significant function related to parenthood.* 'Family' necessarily implies at least the possibility of emotional and physical proximity, bonding, the assumption of parental responsibilities, together with a vestige of communal life. This, of course, only applies to the husband. In his case, the very nature of life imprisonment makes sure to pre-empt a priori all, or most, of these requisites.[63] [Emphasis added]

The majority further noted that two principles underlie the State's policy to deny requests for AI facilities by prisoners: first, the desire of maintenance of public confidence in the penal system, and second, concern for the welfare of any child conceived as a result of ARTs, and therefore, the general interests of society as a whole. In being asked to permit prisoners to access AI facilities, the majority ruled that the State is put in a position to become an active accomplice and participant in a future conception. Again speaking for the majority, Bonello J. noted that there is an expectation that the State hold itself to standards higher than those beyond its control in the free procreation market, and concluded that the state has a positive obligation to ensure the effective protection and the moral and material welfare of children. It is interesting that the European Court of

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[62] *Convention for the Protection Human Rights and Fundamental Freedoms*, as amended by Protocol No. 11; Rome, 4.XI.1950. The *Convention* is also known as the *European Convention on Human Rights* (ECHR).
[63] See *Dickson*, *supra* note 61.

Human Rights likens the involvement of the State in the request by prisoners for AI facilities to that of an "active accomplice". This is much like the characterization of physicians (of whom requests for ARTs are made) imposed by Pennings (2003), who depicts the physician as an "accessory". However, Pennings (2003) views the physician's accessory status as contributing *positively* to the procreative plans of HIV-affected couples requesting access to ARTs. He believes that physicians have a major role to play in these circumstances; most importantly, as providers of assistance whose actions will promote risk reduction. As such, Pennings (2003) argues that the physician, in fact, has a duty to assist HIV-affected couples.

Interestingly, the United States, without going so far as to actually address many of its citizens' need for some form of universal health care coverage, has formally recognized the challenges that many of its citizens face when trying to access medical or social services. In 1990, in response to evidence that increasing numbers of individuals with disabilities were experiencing discrimination in attempting to secure medical care, the United States enacted the *Americans with Disabilities Act*[64] (ADA) (Lyerly & Anderson, 2001). Specifying that "no individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation", with "public accommodation" defined as including "the professional office of a healthcare provider", the Act offers protection for individuals having a condition consistent with the statute's definition of a disability. Under the ADA, a disability is defined as: (1) a physical or mental impairment that substantially limits one or more of a person's major

[64] *Americans with Disabilities Act*, 118 S Ct 2196 [1990].

life activities; (2) a record of such impairment; and (3) being regarded as having such an impairment.

When the ADA was enacted in 1990, only AIDS, not HIV, was explicitly classified as a disability under the statute; the Act offered no protection for individuals with asymptomatic HIV infection (Lyerly & Anderson, 2001). However, in 1998, the United States Supreme Court decision on *Bragdon v. Abbott*,[65] a case brought on by a woman who was refused dental services in a particular setting as a result of her HIV-seropositivity, established that asymptomatic HIV infection qualifies as a disability under the ADA. The woman, Sidney Abbott, disclosed her HIV status to her dentist, Dr. Randon Bragdon, upon a visit to his Bangor, Maine clinic in 1994. Upon finding a cavity, Dr. Bragdon offered to fill the cavity, but only in a hospital setting, revealing that he had a policy against filling cavities of HIV-infected patients in his office. In addition, he informed Ms. Abbott that she would be responsible for the additional fees that would be incurred by the in-patient procedure. After declining his offer, Ms. Abbott brought suit against Dr. Bragdon, alleging unlawful discrimination under the ADA on the basis of her HIV infection, what she argued was her disability. However, considering that asymptomatic HIV was not established as a disability under the law at the time, Ms. Abbott was required to make the case that asymptomatic HIV infection did, in fact, constitute a disability as defined under the ADA. She did so successfully, arguing that asymptomatic HIV infection constitutes a disability because it interferes with a person's ability to reproduce normally. Citing that her HIV status relegated her to being unable to reproduce naturally without the risk of transmission to her partner or to a child, and thus

[65] *Bragdon v. Abbott*, 524 U.S. 624 [1998].

"controlled her decision not to have a child", Ms. Abbott argued that, for her, the ability to reproduce constituted a "major life activity",[66] as noted in the ADA, and so to the degree that asymptomatic HIV limited the major life activity in her life it constituted a disability (Lyerly & Anderson, 2001). The Supreme Court ruled in Ms. Abbott's favour, finding that asymptomatic HIV did indeed qualify as a disability under the ADA.

The Court's decision rested primarily on a key clarification as to what constitutes a "major life activity" under the ADA. The Court concluded that, just as do aspects of a person's life that have to do with working and learning, "reproduction and the sexual dynamics surrounding it are central to the life process itself", and thus also encompass "major life activities". The Court then stated that HIV "substantially limits" the major life activity of reproduction because the risk of sexual or vertical transmission can cause the person to decide not to have a child naturally, ultimately limiting the person's reproductive choices. As such, being a physical impairment which limits the particular life activity of reproduction, the Court ruled that HIV does qualify as a disability under the ADA. According to Lyerly and Anderson (2001), the *Bragdon* decision is considered a precedent-setting decision for three principal reasons. First, it establishes HIV infection as a disability under the law [in the United States]. Second, it mandates objective risk assessment by health care providers who consider exclusion of HIV-infected individuals from their standard clinical practice (Annas, 1998; Gostin, 1999). Lastly, it establishes that a condition that precludes an individual from reproducing normally constitutes a disability (Wolf, 1998). Thus, the Court's ruling also effectively established that infertility should be considered a disability under the ADA, for it constitutes a condition

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[66] *Ibid*., at 1.

that precludes an individual from reproducing normally (Wolf, 1998). Ultimately, it was expected that this decision would have a significant impact on the provision of ART services to HIV-infected patients (Bendikson *et al*., 2002); although this has not been the case as of yet in the United States, it is possible that given similar cases in other jurisdictions, such as *Cameron*, it is only a matter of time before this jurisprudence is successfully used to bring about an official change in policy regarding the use of ARTs by HIV-affected couples in North America.

In the end, what specifically does the *Bragdon* decision mean for HIV-affected couples requesting the use of ARTs to achieve pregnancy? Beyond that it established that a physical impairment that interferes with the ability to reproduce normally qualifies as a disability under the ADA, thereby implying better funding and insurance coverage, it implies that if infertility is considered a disability under the law [in the United States], then ART services used to overcome infertility factors cannot either be discriminatory (Lyerly & Anderson, 2001). Ultimately, it would be unlawful to discriminate against HIV-affected couples, particularly if the service in question is reproductive assistance. Although there is no Canadian statute equivalent to the ADA, a comparable determination of infertility as a disability was made by the majority in *Cameron*. Thus, theoretically, both non-HIV-infected couples, such as the appellants in *Cameron*, and HIV-affected couples alike should be able to obtain the use of ART services to achieve pregnancy, for both requests for reproductive assistance would be based on the presence of infertility factors. However, unlike in the United States, where the ADA can be used to obtain state, federal, and/or private funding for health care services, which can (theoretically) include ART services, the determination of infertility as a disability under

s. 15(1) of the *Charter* in *Cameron* was not sufficient to justify full coverage of ARTs under a provincial public health insurance system, even in the case of a medical diagnosis of infertility. Thus, at this time, it is unlikely that rulings such as that of *Cameron* would have any greater or more specific meaning for HIV-infected persons, either in terms of general medical care or reproductive assistance, than they do for non-HIV-infected persons.

### 3.4. Women's Rights with Respect to Reproductive Autonomy

As noted by Mykitiuk and Wallrap (2002), "women's reproductive lives and abilities have long been the subject of state scrutiny and interference." The advent of ARTs forced a re-examination of many of the traditional ways in which women's reproductive autonomy is (or has been) regulated by our legal system. Although women enjoy more rights to control their own reproductive capacity than ever before, some state interference with the reproductive autonomy of women persists today (Mykitiuk & Wallrap, 2002). The forms of interference[67] most relevant to the use of ARTs by HIV-affected couples—judicial interference with pregnant women in the alleged interest of the fetus, and maternal liability for prenatal conduct after the birth of a baby—will each be examined in turn here.

Although Canadian law does not recognize fetal rights, there is a growing inclination on the part of many physicians to consider fetal interests when caring for a pregnant woman; this stems principally from the monumental strides which have been

[67] An alternate form of judicial interference in the reproductive autonomy of women pertains to the way in which surrogacy contracts are dealt with under Canadian law. See the *Assisted Human Reproduction Act* (s.6), and two provincial examples: the *Civil Code of Québec* (art.541) and the Alberta *Family Law Act* (S.A. 2003, c.F-4.5, s.12).

made in prenatal and perinatal technology, such as the development of detailed ultrasound imaging and the successful undertaking of some forms of *in utero* fetal surgery, making it difficult for the physician not to consider the fetus as a patient, albeit a patient in the mother's body (Harrison *et al*., 1984; Steinbock & McClamrock, 1994). Although most pregnant women are deeply concerned about the well-being of the child they are carrying, some pregnant women (and their partners) engage in behaviours and make choices which are potentially (some of which have been proven) hazardous to the fetus. For example, Flagler *et al*. (1997) note that malnutrition, alcohol and substance abuse, excessive caffeine and nicotine use, spousal abuse, a chaotic lifestyle, and lack of medical care during pregnancy also have a significant impact on the health and well-being of the fetus, yet these are often overlooked by physicians and social services agencies, whom, unfourtunately, seem to believe that these situations are so out of control that any outreach on their part can be of no help to the pregnant woman. In the last two decades, several Canadian cases have centered on women's rights with respect to reproductive autonomy. Many of these arose in the years immediately following the *Morgentaler* decision, and although these cases centered on paternal challenges to women intent on having an abortion,[68] they did set precedents for future cases involving other expressions of women's rights with respect to reproductive autonomy.

***Judicial Interference with Pregnant Women in the Alleged Interest of the Fetus***

In recent years, numerous cases alleging maternal liability for prenatal conduct/injury after the birth of a baby, as well as claims of wrongful birth and wrongful life, have come before Canadian courts. As I discuss below, to date, the courts have

[68] *Diamond v. Hirsch* [1989], M.J. No. 377 (QL) (Q.B.).; *Murphy v. Dodd* [1989], 63 D.L.R. (4th) 515 (Ont. H.C.J.).; *Tremblay v. Daigle* [1989], 62 D.L.R. (4th) 634 (S.C.C.).

failed to find that there is a sufficient relationship between a woman and the child she is carrying to give rise to a duty to care on her part during the pregnancy, confirming the limited nature of fetal rights under the law. It would appear, therefore, that even if an HIV-affected couple were granted access to ARTs, and conceived as a result, it would be unlikely that any child born with HIV as a result of any part of the ART process (or the resulting birth) would be able to claim successfully against his/her mother for pre- or perinatal transmission of the infection, or against his/her parents for wrongful life.

In a notable case of judicial interference with a pregnant woman in the alleged interest of the fetus, that of *Tremblay v. Daigle*,[69] Jean-Guy Tremblay sought to prevent his former girlfriend, Chantal Daigle, from undergoing an abortion. Arguing that the fetus is entitled to protection under the Quebec *Charter* and the *Civil Code of Lower Canada*[70] [now the *Civil Code of Quebec*] ("*Civil Code*"), Mr. Tremblay applied for and was granted a provisional injunction under article 752 of the Quebec *Code of Civil Procedure*[71] on July 7th, 1989, which prevented Ms. Daigle from proceeding with her plans to terminate the pregnancy. Ten days later, Mr. Tremblay was granted an interlocutory injunction, which was upheld by the Quebec Court of Appeal on July 20th. In granting Mr. Tremblay the interlocutory injunction, the Superior Court judge found that a fetus is a "human being" under the Quebec *Charter* and thus enjoys a right to life under s.1. In addition, the judge concluded that this determination was consistent with the *Civil Code*'s recognition of the fetus as a juridical person. After considering the appellant rights under s.7 of the Canadian *Charter* and s.1 of the Quebec *Charter*, the

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[69] *Tremblay v. Daigle* [1989], 62 D.L.R. (4th) 634 (S.C.C.).
[70] *Civil Code of Lower Canada*, articles 338, 345, 608, 771, 838 and 945.
[71] *Code of Civil Procedure*, R.S.Q., c. C-25, article 752.

judge ruled that the fetus's right to life should prevail in this case. Ms. Daigle immediately applied for leave to appeal this order to the Supreme Court of Canada; the appeal was heard before the entire Court on August 8th. At this time, Ms. Daigle was approximately 22 weeks pregnant. Immediately after the lunch recess, Ms. Daigle's lawyer informed the Court that he had just received word that Ms. Daigle had secured an abortion. Nevertheless, the hearing proceeded, and the Court delivered a unanimous decision striking down the injunction.

In its ruling, the Court noted that "the injunction must be set aside because the substantive rights which are alleged to support it—the rights accorded to a foetus or potential father—do not exist."[72] The Court found that the term "human being" in the Quebec *Charter* did not specifically include the fetus; therefore, the fetus is not entitled to the right to life conferred by s.1. The Court remarked that the Quebec *Charter* is written in very general terms, and makes no reference to the fetus or to fetal rights. The Court then considered the status of the fetus under the *Civil Code*; likewise, the Court ruled that the term "human being", as used in article 18 of the *Civil Code*, in that "every human being possesses juridical personality", cannot be taken to include the fetus. Additionally, the *Civil Code*'s provisions, while granting patrimonial interests to an unborn child, are subject to substantive condition that the fetus be born alive and viable. Although not directly applicable to the Quebec *Charter*, the status of the fetus at common law (i.e., Anglo-Canadian law) was also considered by the Court. The Court noted that in common law, the fetus must be born alive and viable to enjoy rights. Ultimately, the Court ruled that "in light of the treatment of foetal rights in civil law and, in addition, the

[72] See *Tremblay*, *supra* note 69.

consistency to be found in the common law jurisdictions, it would be wrong to interpret the vague provisions of the Quebec *Charter* as conferring legal personhood upon the foetus."[73] Thus, Mr. Tremblay and Ms. Daigle's unborn child was not entitled to legal protection under neither the Quebec *Charter* nor the *Civil Code*, and despite being the potential father, Mr. Tremblay was not entitled to participate in decisions concerning Ms. Daigle's pregnancy. Ultimately, as noted by Rodgers (2002), the Court's decision in *Tremblay* settled the question as to whether the fetus was entitled to protection prior to birth, an issue which had not been settled by the Supreme Court in the *Morgentaler* decision, and put an end to injunction applications in this context.

Another case, that of *Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.).*,[74] involved a 22-year-old woman from a Manitoba aboriginal community, "G", who was pregnant with her fourth child and was addicted to sniffing solvents (Ms. G had previously lost custody of her three children to social welfare services; all were born with major birth defects resulting from substance abuse on her part during each of the pregnancies). When Ms. G. was 22 weeks pregnant, Winnipeg Child and Family Services asked the Manitoba Court of Queen's Bench to confine her to a treatment facility for the remainder of her pregnancy, and to enjoin her from using "intoxicating substances" until after her child's birth. Schulman J., sitting on the Court of Queen's Bench, described the case as:

> A classic dilemma…An expectant mother sniffs solvent to the probable detriment of her unborn child. If nothing is done, the child when born will surely suffer.

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[73] *Ibid*.

[74] *Winnipeg Child and Family Services v. G. (D.F.).* [1996], 138 D.L.R. (4th) 238 (Man. Q.B.); revd [1996], 138 D.L.R. (4th) 254 (C.A.); affd [1997], 3 S.C.R. 925

> Yet, anything which can be done necessarily involves restricting the mother's freedom of choice and, if she persists in the habit, her liberty.[75]

Nevertheless, Schulman J. ordered that Ms. G. be placed in the custody of the Director of Winnipeg Child and Family Services at Winnipeg's Health Sciences Centre until she gave birth, with the power to have her forcibly treated. Justice Schulman's order was based on provisions in the Manitoba *Mental Health Act*,[76] noting that several medical expert witnesses considered Ms. G. to be mentally incompetent. However, when the case went to the Manitoba Court of Appeal, the Court found that that the lower court's findings were not based on credible evidence, including that offered by the medical expert testimony. In addition, the Court found that the social service agency's action was taken because of worries about her fetus, and not because of concern about the health and safety of Ms. G. herself. Thus, the Court of Appeal overturned the original ruling, stating that there was no legal authority to order a competent pregnant woman to undergo a medical intervention which she does not want. Winnipeg Child and Family Services took the issue to the Supreme Court of Canada, which, in October, 1997, upheld the Manitoba Court of Appeal's ruling, asserting that no person has a legal right to interfere with a pregnant woman whose behaviour threatens her fetus. The Court confirmed that should a woman, assuming she is competent, refuse medical advice or treatment during the course of her pregnancy, her decision must be respected even if the physician believes that her fetus will suffer or become endangered as a result.

As was the case in *Tremblay*, central to the Court's ruling was the limited nature of fetal rights in both Canadian common law and Quebec civil law (Capen, 1997).

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[75] *Ibid*.
[76] *Mental Health Act*, R.S.M. 1987, c. M-110.

McLachlin J., as she then was, writing for the majority, noted that the fetus is not a person under the *Civil Code of Quebec*, the Quebec *Charter*, or under the *Criminal Code*[77] of Canada. McLachlin J. further stated that because the fetus has no legal rights until it is born, no person can stop a mother from taking a course of action, even if it is potentially harmful to the fetus; however, action may be taken when the child is born, should the mother's behaviour continue to be potentially harmful to the child. The Court also considered whether the doctrine of *parens patriae* could support Winnipeg Child and Family Services' request for involuntary detention and treatment, which would recognize a right to protection on behalf of the fetus. McLachlin J. found that such a request would require an extension of common law tort principles or of the doctrine of *parens patriae*, and would require, among other steps, overturning the rule that legal rights accrue only at birth. Stating that such judicial activism should be confined to incremental change only, McLachlin J. refused to grant such an extension. Ultimately, McLachlin J. upheld the Court of Appeal's ruling, agreeing that the courts have no power to force a competent pregnant person to undergo a medical intervention that she does not want, and doing so would infringe upon the woman's fundamental liberty, even if, as in this case, Ms. G.'s actions may be harmful to her fetus.

***Maternal Liability for Prenatal Conduct after the Birth of a Baby***

In 1999, the Supreme Court of Canada ruled on *Dobson (Litigation Guardian of) v. Dobson*,[78] a case which further clarified the legal regulation of women's reproductive autonomy in Canada (Mykitiuk & Wallrap, 2002). As discussed above, previous cases before the Court had related to the right of pregnant women to terminate their

[77] *Criminal Code*, R.S., 1985, c.C-46; see *R. v. Sullivan* [1991], 1 S.C.R. 489.
[78] *Dobson (Litigation Guardian of) v. Dobson* [1999], 2 S.C.R. 753; [1999], S.C.J. No. 41 (QL).

pregnancies and the right to resist imposed medical treatment during pregnancy. In *Dobson*, the Court was asked to consider whether a subsequently born child could sue his or her mother for maternal conduct during pregnancy. The defendant in *Dobson*, Cynthia Dobson, was driving on a snowy road in Moncton, New Brunswick, when her car collided with another vehicle. At the time of the accident, Ms. Dobson was 27 weeks pregnant; later that day, her son, Ryan, was born by caesarean section. Ryan was born with mental and physical impairments, all of which were believed to have resulted from the impact of the collision. Ryan, acting through a litigation guardian, sued his mother, alleging that her negligent driving had resulted in permanent injuries to his body. As stated by Mykitiuk and Wallrap (2002), "at issue was the legal entitlement of a fetus born alive and viable to bring a tort action in negligence against his biological mother for injuries allegedly incurred *in utero*." Speaking for the majority, Cory J. built on the reasoning in *Winnipeg Child and Family Services* and applied the test of tort liability, previously set out by the Court in *City of Kamloops v. Nielsen*[79]; chiefly, was there a sufficient relationship between the pregnant woman and her fetus to give rise to a duty to care on her part, such that should a court determine that she did not fulfill her duty, she could be sued by her child for damages occurred *in utero*? Ruling that such a relationship did exist would impose a duty of care on pregnant women with regard to the fetus, thereby interfering with the privacy and autonomy rights of pregnant women. Furthermore, such a ruling would involve the Court in having to determine a judicial standard of care for pregnant women[80] (necessitating judicial scrutiny of maternal behaviour), a task which the Court considered seemingly impossible. The majority

[79] *City of Kamloops v. Nielsen* [1984], 2 S.C.R. 2.
[80] See *Winnipeg Child and Family Services*, *supra* note 74 at 768.

characterized the relationship between the woman and her fetus as unique, but branded the imposition of a duty to care as "a severe intrusion into the lives of pregnant women, with attendant and potentially damaging effects on the family unit."[81] Notably, the Court asserted no analogy could be made between the pregnant woman's potential liability and that of a negligent third party. Imposing liability upon a third party could occur without interfering with the third party's right to control his or her life, but the same could not be said for the woman, should liability be imposed upon her for her conduct during pregnancy (Mykitiuk and Wallrap, 2002). Justice Cory also concluded that the creation of tort liability for conduct during pregnancy could have detrimental consequences for the relationship between the mother and her child, and between the child and his or her family upon birth.[82] Ultimately, the Court refused to allow tort liability to become entitlement to reproductive autonomy (Mykitiuk & Wallrap, 2002). As noted by Mykitiuk and Wallrap (2002):

> Had the Court held otherwise, the decisions of the Supreme Court of Canada in *Morgentaler*, *Tremblay v. Daigle* and *Winnipeg [Child and Family Services (Northwest Area)] v. G.[D.F.]* would have been seriously compromised. Decisions and actions taken during pregnancy would have been protected during gestation only, and liability would have arisen upon viable birth.

Building upon its previous ruling denying the state the freedom to interfere with women's reproductive capacity,[83] the Court recognized women's rights with respect to reproductive autonomy to be protected against tort liability (Mykitiuk & Wallrap, 2002). In 2005, the province of Alberta enacted the *Maternal Tort Liability Act*,[84] which reverses the ruling in *Dobson* to some extent in that jurisdiction. This legislation provides a

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[81] See *Winnipeg Child and Family Services*, *supra* note 74 at 775.
[82] See *Winnipeg Child and Family Services*, *supra* note 74 at 782.
[83] See *R. v. Morgentaler*; *Tremblay v. Daigle*; *Winnipeg Child and Family Services (Northwest Area) v. G.(D.F.)*.
[84] *Maternal Tort Liability Act*, S.A. 2005, c. M-7.5.

measure of compensation for a child who sustains prenatal injuries as the result of negligent driving of his or her mother. The *Maternal Tort Liability Act* applies only to motor vehicle accidents and provides financial compensation to benefit the injured child, also providing protection for mothers by prohibiting claims against them beyond the limits of their insurance policies. Thus, although the debate may continue as to the moral status of a fetus, the Supreme Court of Canada has upheld women's right to life, liberty and security of the person and has confirmed the limited nature of fetal rights under the law.

Although the fetus may enjoy only limited legal rights at this time, wrongful birth[85] and wrongful life[86] actions are well documented in Canadian jurisprudence. The concept of wrongful life is often associated with medical outcomes of new genetic technologies and, of particular relevance here, assisted reproductive technologies. A claim of wrongful life, a concept of tort law, is brought on by a child born with severe impairments, usually when he or she is of age to initiate the proceedings. The essence of the (child's) claim is the allegation that but for the provider's negligent failure, he or she would not have been born at all, and that his or her life with a [resulting] disability has caused and will continue to cause pain and suffering, as well as financial loss (Coleman, 2002). At the core of the claim of wrongful life is the child's claim that had the physician

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[85] Wrongful birth actions are brought by the parents; the essence of the claim is for increased costs and emotional distress associated for caring for a child with disabilities. Although these claims were initially met with reluctance on the part of Canadian judges, they are now fairly well established in the Canadian courts system. See *Doiron v. Orr* [1978], 86 D.L.R. (3d) 719 (Ont. H.C.); *Colp v. Ringrose* [1979], 3 Med. L.Q. 72 (Alta. T.D.); *Arndt v. Smith* [1994], 21 C.C.L.T. (2d) 66 (B.C.S.C.); *Arndt v. Smith* [1997], 148 (D.L.R.) (4th) (S.C.C.).

[86] Wrongful life actions are brought by the child and/or thorough a litigation guardian. Such a claim has been advanced in relatively few cases compared to wrongful birth actions; all have been dismissed by the courts, citing public policy. See *Bartok v. Shokeir* [1998], S.J. No. 645 (C.A.); *Jones v. Rostvig* [1999], 44 C.C.L.T. (2d) 313 (B.C.S.C.); *Patmore (Guardian ad litem of) v. Weatherston* [1999], B.C.J. No. 650 (B.C.S.C.) (QL).

provided proper prenatal care that would have detected the impairments in time, the mother could have aborted the fetus (Coleman, 2002). Coleman (2002) reports that few jurisdictions have recognized the tort of wrongful life, principally because these courts have concluded that the legal system cannot rationally determine whether the burdens of a particular existence outweigh the benefits of life itself [See Section 2.4]. In discussing problems with the wrongful life analogy in the context of ARTs, Coleman (2002) notes that it is effectively impossible to apply the wrongful life standard to decisions regarding the provisions of ARTs because it "assumes the very question at issue—the birth of the child." In other words, the very fact of the child's existence outweighs even the worst of disadvantages. It is not possible to determine if any child, once born, would prefer to have his or her existence taken away (Coleman, 2002). Peters (1989) explains: "The instinct of self-preservation, along with other related feelings like hope and faith, may explain the conclusion that a miserable life is worth continuing, but not worth receiving."

Interestingly, the *Dobson* and *Winnipeg Child and Family Services* cases leave open the question of whether a child born with an injury as the result of prenatal conduct on the part of the mother could bring a legal claim against a health care provider. In the provision of ART services to an HIV-affected couple, could a child born HIV-infected bring a legal claim against the physician who provided fertility services to the parents, knowing that either one or both of them was HIV-seropositive? Could a child born with HIV sue his/her father for infecting the child, either *via* the mother or directly to him/her *via* the *in vitro* process? Although jurisprudence has indicated that maternal liability is limited, to date, the courts have not ruled whether paternal liability might be considered analogous to that of a third-party, whom can be sued for prenatal injuries that he/she has

caused by negligent acts. Although the grounds on which future rulings are based cannot be predicted, I would argue that claims alleging physician negligence in the provision of ART services to an HIV-affected couple (by providing the fertility services to a couple *knowingly* affected by HIV) would not be recognized by a court of law. The debate surrounding this issue assumes the *provision of information* by the physician, usually with a significant elaboration of all risks involved in an HIV-seropositive pregnancy, an act that he or she feels will convince the couple *not* to proceed with reproductive care using ARTs. Assuming this is the case, the physician could not be found to have been negligent, but in fact, quite the contrary. It is not surprising, therefore, that, to date, no Canadian court has recognized a wrongful life claim (Mykitiuk and Wallrap, 2002; Rivard & Hunter, 2005).

Although a certain degree of state interference in women's reproductive autonomy is probably necessary for the good of society, such as a child being able to benefit financially upon injury in a motor vehicle accident where insurance coverage is available, cases regarding judicial interference in the alleged interests of the fetus in the last two decades have ruled in favour of the pregnant woman, recognizing her right make decisions with respect to her body, noting that she is in the best position to do so. To date, it would appear that all cases pertaining to fetal rights before the Supreme Court of Canada have shown that, ultimately, no person can stop a mother from taking a course of action that may be harmful or detrimental to her fetus. In the case of HIV-affected couples wanting to conceive using ARTs, it is not at all certain that the ART process will render the child infected with HIV. Even if harm were likely (and it is by no means the case), decisions such as that of *Tremblay* and *Winnipeg Child and Family Services*

suggest that a woman (and here, her husband/spouse/male partner, if she so chooses) could not be denied access to technologies by which a child may be conceived on the basis of any potential harm to the fetus.

# CHAPTER 4:
# RECOMMENDATIONS AND CONCLUSIONS

It is without question that HIV has transformed the way in which medicine is practiced, and in no field has this been felt as strongly as in reproductive medicine. While still a relatively new addition to medical practice, ARTs have provided HIV-seropositive couples, who previously had few, if any, options with regard to parenthood, the ability to conceive and give birth. However, as emphasized by Lyerly and Anderson (2001), this expansion of options came at the cost of a loss of privacy with regard to reproductive decision-making, traditionally a very personal and private matter for couples. Within the context of the physician-patient relationship, physicians were faced with the responsibility of providing reproductive care to individuals whose medical autonomy was to be respected, while also needing to fulfill a duty of non-maleficence. Increasing numbers of requests for access to ARTs by HIV-seropositive couples, however, meant that striking this delicate balance shifted to integrating many of the physicians' personal moral considerations into medical practice in this context, restricting the choices of HIV-seropositive couples in the process, a practice which, unfourtunately, appears to continue (Lyerly & Anderson, 2001). What has become clear in recent years is that discriminatory policies against HIV-seropositive couples are no longer medically, ethically or legally defensible, and that just as the profession of medicine evolves every day with the discovery of new diseases and treatments, so must the viewpoints of the physicians involved.

## 4.1. Societal Considerations

### *Disability as a Social Construction*

It is worthwhile to note that this research has unequivocally presupposed that *any and all* HIV-affected couples, whether serodiscordant or seroconcordant, would want to raise a child who him/herself is not HIV-infected, and would be very distressed, if not devastated, if their child contracted the virus at some point during the ART process. But is this a reasonable assumption? The principle goal of bioethics, in practical terms, is to maximize the degree of 'good' and minimize the degree of 'harm' in each given situation requiring the making of a decision or the taking of a course of action, based upon a thorough analysis of the relevant and available information (Bereza, personal communication, 2006). Such a 'decision' is often not a decision at all in the commonly accepted sense of the word; medical professionals and bioethicists commonly encounter ethical dilemmas in medical practice in which the medical team's determination of the 'right' or 'best' course of action or decision with regard to a particular treatment, based on commonly accepted ethical principles, is (or at the very least, seems) contrary to the patient's desired course of action with respect to the treatment. Indeed, such a situation has been documented with respect to reproductive decision-making within the Deaf community.

According to Mundy (2002) and Lane (2005), an extensive deaf community, known as the Deaf-World, exists throughout the world, whose primary language is American Sign Language (ASL). Its exact population size is unknown, but estimates range from 500,000 to 1 million members (Schein, 1989). Members of this group call themselves capital-D *Deaf*, compared to small-D *deaf*, and consider their deafness not as

a medical affliction which should be corrected, but rather, as a cultural identity (Mundy, 2002). Traditionally, the terms *deaf* and *hearing impaired*, encompassing the so-called small-D *deaf*, have referred to a much larger and more heterogeneous group than those identifying themselves as members of the Deaf-World (Padden & Humphries, 1988; Lane, 1995). According to Lane (2005), this larger group, estimated to comprise 20 million Americans (Binnie, 1994) and 2.8 million Canadians (Canadian Association of the Deaf, 2002), is made up almost exclusively of individuals who, ultimately, consider themselves as hearing people with a disability. As stated by Lane (2005), they distinguish themselves from the members of the Deaf-World in that they:

> [H]ad conventional schooling and became deaf after acculturation to hearing society; they communicate primarily in English or one of the spoken minority languages; they generally do not have Deaf spouses; they do not identify themselves as part of the Deaf-World or use its language, participate in its organizations, profess its values, or behave in accord with its mores.

In the vast majority of cases, these individuals' identification of their limited hearing or inability to hear as a disability is based on the values of the community in which they were raised (Lane, 2005). Most of these individuals are the children of hearing parents who, recognizing the difficulties that the deaf encounter on a daily basis, encouraged their children to embrace as many opportunities as were available to them in the hearing world (e.g., oral education, hearing aids, cochlear implant surgery). Although a discussion regarding the ethical appropriateness of these actions is beyond the scope of this section, it would seem safe to say that most parents in this situation would do the same, in an effort to give their child(ren) every opportunity to succeed in the inherently competitive world in which we live. Interestingly, however, the Deaf-World does not see it this way. Its members want to have Deaf spouses, welcome Deaf children, and interact

with other culturally Deaf people—intellectually, socially, politically, and the list goes on. In a March, 1990, edition of the television news magazine, *Sixty Minutes*, I. King Jordan, President of Gallaudet University, the world's only liberal arts university for the deaf, located in Washington, D.C., was asked if he would like to be hearing. He replied: "That's almost like asking a black person if he [sic] would rather be white. …I don't think of myself as missing something or as incomplete. …It's a common fallacy if you don't know Deaf people or Deaf issues. You think it's a limitation." (Fine & Fine, 1990). As asserted by Lane (2005), "in short, they [members of the Deaf-World] see being Deaf as an inherent good."

It should not be surprising, therefore, that the importance to which the Deaf-World bestows upon its cultural identity would similarly extend to reproductive decision-making. There is evidence that many Deaf-World couples deliberately attempt to 'create' deaf children by using ARTs, such that the likelihood of the birth of a deaf child can be maximized (Mundy, 2002; Scully, 2004). A March, 2002, article in the *Washington Post Magazine* (Mundy, 2002) profiled a Washington, D.C., lesbian couple, Sharon Duchesneau and Candace McCullough, both of whom are deaf, who sought out a male donor to father a child for them (they would eventually have a second child using the same donor). The donor was chosen because he came from a family having five generations of deafness. Once pregnant, pedigree analysis by a genetic counsellor predicted, based on the family histories, that there was a 50-50 chance that the child would be deaf. Both of the couple's children were in fact born deaf: their firstborn, a daughter, is profoundly deaf; their son has profound hearing loss in one ear and severe hearing loss in the other. The couple, however, take issue with critics who suggest that

they 'tried' to have a deaf baby. Interviewed prior to their son's birth, they insisted: "A hearing baby would be a blessing. A deaf baby would be a special blessing." (Mundy, 2002). Nevertheless, the critical response to this couple's story, and the many others like it, is predictable. To most individuals, *wanting* a deaf baby is utterly incomprehensible. Mundy (2002) notes:

> It may seem a shocking undertaking: two parents trying to screen in a quality, deafness, at a time when many parents are using genetic testing to screen out as many disorders as science will permit. Down syndrome, cystic fibrosis, early-onset Alzheimer's—every day, it seems, there's news of yet another disorder that can be detected before birth and eliminated by abortion, manipulation of the embryo or, in the case of *in vitro* fertilization, destruction of an embryo. Though most deafness cannot be identified or treated in this way, it seems safe to say that when or if it can, many parents would seek to eliminate a disability that affects one out of every 1,000 Americans.

Interviewed in the context of the article, R. Alta Charo, Professor of law and bioethics at the University of Wisconsin, agrees: "I think all of us recognize that deaf children can have perfectly wonderful lives. The question is whether the parents have violated the sacred duty of parenthood, which is to maximize to some reasonable degree the advantages available to their children." (Mundy, 2002). Although I am by no means suggesting that a disability such as deafness can be equated with HIV, an infection for which there remains no cure, stories such as that of Sharon Duchesneau and Candace McCullough are a reminder that individuals afflicted with what greater society labels a 'disability' may not, in fact, consider such a label to apply to themselves. As such, these individuals may desire and seek to live their lives as would any other individual, with the expectation that the same rights and privileges with respect to lifestyle choices, such as parenthood, and the responsibilities that these entail, apply equally to them as well.

***Disclosure of HIV Status***

It is also important to note that this dissertation has assumed that an HIV-affected couple wanting to access ARTs for the purpose of conceiving have disclosed their HIV status to the physician. But what if they themselves are unaware of their seropositivity? At the end of 2005, an estimated 58,000 people were living with HIV or AIDS in Canada, of whom more than 25% have not been diagnosed with the infection (Boulos *et al*., 2006). In the United States, the estimated number of people living with undiagnosed HIV (or AIDS) is proportionally higher, numbering over 200,000 (CDC, 2005). Clearly, given these individuals' increased risk of transmission, these numbers are frightening. Statistics such as these foster the ongoing debate as to whether physicians should require HIV testing in all couples seeking reproductive assistance (ASRM, 2004). Currently, in Canada, pregnant women are offered HIV testing at the time the pregnancy is first confirmed; however, they have the right to refuse to be tested (Flagler *et al*., 1997). This is based on respect for the woman's autonomy, and testing cannot occur under any circumstances without her explicit consent. Moreover, even if the pregnant woman agrees to HIV testing, and is subsequently found to be HIV-seropositive, she has the right to refuse to undergo treatment, even if such treatment is potentially beneficial to her fetus (Flagler *et al*., 1997). In the case of pregnant women, physicians must respect both a refusal to be tested for HIV, and a refusal of treatment for HIV (should a woman test positive for HIV). The situation extends to women wanting to become pregnant using ARTs. The Ethics Committee of the American Society for Reproductive Medicine (2004) recommends that practitioners encourage all individuals and couples wanting to conceive to undergo HIV testing, not simply those requesting access to ARTs. They

further recommend that all gamete donors and recipients be tested for HIV and other STIs, and that the offer of testing be extended to recipients' partners (Ethics Committee of the ASRM, 2004). Ultimately, although the physician cannot require that a patient be tested for HIV, whether or not in the context of requesting access to ARTs, knowing the HIV status of a individual and/or couple before the establishment of a pregnancy enables the physician and the health care team to assist the patient better and help him/her/them make safer reproductive choices (Ethics Committee of the ASRM, 2004).

### 4.2. Recommendations for Clinical Practice: *A Model of Contextualized Counselling*

As in any problem-solving exercise, the ultimate goal of an ethical analysis is to derive a solution to an ethical dilemma using the individual expertise of members of a multi-professional team working in the context of a collaborative model (Freeman *et al*., 2000). The process for the formulation of the recommendations for the question at hand is no different. Lyerly and Anderson (2001), Lyerly and Faden (2003), and Williams *et al*. (2003) all advocate the use of a multidisciplinary approach using a model of "contextualized counselling", which calls for reasoned and reflective decisions regarding childbearing. Using this model, physicians lead an:

> [I]nformative discussion of the implications of undergoing or foregoing assisted reproduction, including the potential meaning of pregnancy and childbearing for the patient, her [/(their)] family, and the child who might be born…focus[ing] on each particular patient's life circumstances and also on how the context of the HIV infection will impact childbearing.
>
> (Lyerly & Faden, 2003)

Within this model, prospective patients are counselled through referrals to infectious disease, maternal-fetal medicine, reproductive endocrinology, and social work and/or clinical psychology and/or psychiatry, to ensure a thorough informed consent process

(Williams *et al*., 2003). Assuming that the HIV-affected couple is comprised of partners who are suitable medical candidates for participation,[87] a model of contextualized counselling enables the couple to critically examine their options, taking into consideration their unique situation. Lyerly and Anderson (2001) note:

> With contextualized counselling, some couples might examine their values and still decide that even a minimal risk of transmission to a partner or a child is unacceptable, and may opt out of reproductive assistance. However, others may decide—after careful consideration of the risks and benefits, reflection on their personal values, commitments, and life circumstances, and with an understanding of the potentially profound implications of childbearing in the setting of HIV infection—that engaging in assisted reproduction is what they want to do. Contextualized counselling makes such a deliberate decision possible.

***Contextualized Counselling in Action:***
***The Center for Women's Reproductive Care,***
***Columbia-Presbyterian Medical Center, New York***

In 1997, the Ethics Committee at the Center for Women's Reproductive Care at Columbia-Presbyterian Medical Center, in New York City, considered a request to allow an HIV-serodiscordant couple to access ARTs at the establishment (Sauer, 2003). The request was approved (with restrictions), and subsequently, a protocol designed to meet the needs of couples in this situation was developed and implemented. The medical center's institutional review board (IRB) simultaneously approved a study to examine the efficacy of treating HIV-serodiscordant couples (in which the male was the seropositive partner), using IVF and/or ICSI of eggs retrieved from the female partner. In approving both the protocol and the study, respectively, the Ethics Committee and the IRB elected not to allow the participation of couples in which the female was the seropositive partner

[87] Although there exist no standard medical acceptance criteria, Williams *et al*. (2003) suggest that the couple should be highly motivated; have well-controlled HIV with a stable CD4+ count, undetectable virus in the serum and the semen (<50-100 copies/mL); and antiretroviral medication adherence of >90%.

(primarily because vertical transmission is still known to occur), a practice which continues at the Center to this day.

The program at the Center for Women's Reproductive Care subscribes to a model of contextualized counselling, much like that described above. Prospective HIV-seropositive patients are screened carefully and must satisfy several medical criteria for entry into the program (Sauer, 2003) (Table 3). In addition to meeting medical criteria, prospective patients are also asked to consider a series of inquiries relating specifically to the psychosocial aspects of reproductive care (Table 4) (Klein *et al*., 2003; Sauer, 2003). Klein *et al*. (2003) stress that the questionnaire is not designed to eliminate a given couple based on one or more answers that they give (i.e., there is no 'right' or 'wrong' answer to any given question); rather, it is principally a tool to help the couple make informed decisions as to their reproductive care, and ultimately, to encourage them to think about the broader consequences of the treatment option(s) they are considering. Given that couples are always highly motivated, Klein *et al*. (2003) and Sauer (2003) report that these couples do not enter into such care flippantly.

The program's director, Dr. Mark V. Sauer, is one of the North American medical community's strongest advocates for the use ARTs by HIV-seropositive couples wishing to conceive, and was instrumental in the design and implementation of the Center's protocol. As of early 2003, the Center for Women's Reproductive Care had performed more than 100 cycles of IVF-ICSI on HIV-serodiscordant couples, without a single seroconversion in either the treated patients or the children later born to them (Sauer,

**Table 3**: Entry criteria for prospective HIV-1-serodiscordant couples (male HIV-seropositive, female HIV-seronegative) interested in undergoing IVF-ICSI at the Center for Women's Reproductive Care at Columbia-Presbyterian Medical Center, Columbia University College of Physicians & Surgeons, New York, New York (adapted from Klein *et al*., 2003; Sauer, 2003).

| |
|---|
| • HIV-1-seropositive male, HIV-1-seronegative female |
| • CD4+ count > 200 cells/$mm^3$ (male partner) |
| • Viral load < 20,000 copies/mL (male partner) |
| • Absence of active AIDS-defining illness |
| • Documented visit with an infectious disease specialist within preceding 3 months |
| • Normal physical examination (male and female partner) |
| • Age < 45 years (female partner) |
| • Basal (cycle day 3) †FSH < 15 mIU/mL and estradiol < 65 pg/mL |
| • Absence of active or acute sexually transmitted infection (male and female partners) |

†FSH: follicle-stimulating hormone

**Table 4**: List of reproductive inquiries included in entry questionnaire issued to prospective HIV-serodiscordant couples (male HIV-seropositive, female HIV-seronegative) wishing to undergo IVF-ICSI at the Center for Women's Reproductive Care at Columbia-Presbyterian Medical Center, Columbia University College of Physicians & Surgeons, New York, New York (adapted from Klein *et al*., 2003; Sauer, 2003).

| |
|---|
| • How many children do you have with your current partner? |
| • Any history of known infertility or difficult achieving pregnancy in the past? |
| • Have you previously had unprotected sex to achieve pregnancy? HIV status known at the time? |
| • Would you have unprotected sex in the future if no alternative for conception available? |
| • Would you consider artificial insemination with donor sperm to prevent viral transmission? |
| • Would you consider posthumous reproduction with frozen-banked sperm? |
| • Have you discussed with your partner the potential risk of viral transmission to the uninfected partner? To the child? |
| • Have you discussed with your partner the consequences of early death to the surviving spouse and child? |
| • Have you discussed with your partner third-party parenting in the event of the early death of one or more parents? |
| • Would you tell a child of parental HIV status? |
| • If IVF-ICSI is successful (healthy child and no viral transmission), would you undergo another cycle to have more children? |
| • Would you be willing to share your experience with other HIV-serodiscordant couples? |

2003). Sauer (2003) reports that the program has thrived largely as a result of self-referrals,[88] noting that, not surprisingly, a vast network of health information is shared among individuals in the HIV-seropositive community. Although the Center currently only offers services to HIV-serodiscordant couples (in which the male is the seropositive partner), Dr. Sauer has again and again proposed the establishment of an open policy at the institution, and although it has yet to be endorsed by the Center's Ethics Committee, he is committed to seeing that the Center will offer reproductive care to all HIV-affected couples in the not too distant future (Sauer, 2003).

### 4.3 Final Thoughts

Although no published statistics are currently available as to the socioeconomic class and other classifiers of individuals who seek reproductive assistance in Canada, or those who have requested and been subsequently denied access to ARTs, due to the traditionally confidential nature of such data (CFAS/SOGC, 1999), physicians providing reproductive care to HIV-affected couples (Sauer & Chang, 2002; Klein *et al*., 2003; Peña *et al*., 2003; Sauer, 2003) report that discrimination against HIV-seropositive couples seeking access to ARTs is commonplace, especially when the North American *milieu* is examined as a whole. Given the overall improvement in the health status of HIV-infected individuals, including the increase in life expectancy, as well as the significant reduction observed in perinatal transmission of HIV, it can no longer be considered clinically, ethically, or legally justifiable to exclude HIV-affected couples from reproductive care involving ARTs on the basis of HIV status alone. It is time for

[88] Self-referrals being HIV-affected couples who have contacted and subsequently undergone reproductive care at the Center for Women's Reproductive Care, on the advice and/or encouragement of other HIV-affected couples who themselves had previously accessed ART services at the Center.

the North American medical community to acknowledge the advances that have been made in the realm of HIV treatment; HIV-infected individuals must be viewed as persons whose infection is no longer the sole determinant of their health. As such, physicians must recognize that HIV-infected individuals are entitled to the same rights and privileges as non-HIV-infected individuals in the context of access to ARTs, at least with respect to medical care, and should encourage their patients to live their lives to the fullest. For many HIV-affected couples, this means experiencing the joys of parenthood.

As mentioned previously, I have deliberately chosen to focus this dissertation on HIV-affected heterosexual couples. I do this not meaning to downplay the importance of the situations that other individuals and couples, notably individuals wanting to raise one or more children as single parents or same-sex couples, may find themselves in attempting to access ARTs; it is clear that many such individuals and couples have requested reproductive care in recent years, with mixed results, and will continue to want to do so in the coming years. What is not clear is how individuals (wanting to raise children on their own) or same-sex couples would fare if HIV-seropositive or HIV-affected, respectively. Given the many challenges that HIV-affected heterosexual couples currently experience when attempting to access ARTs, it seems safe to say that it would be extremely difficult, if not impossible, for single parents and same-sex couples to access ARTs at this time. Nevertheless, future studies using HIV-seropositive individuals (wanting to raise children as single parents) and HIV-affected same-sex couples as case illustrations may encourage their access to ARTs.

Ultimately, it is imperative that physicians consider the ramifications of their actions should they deny an HIV-affected couple access to ARTs. The couple may decide attempt conception on their own (and, in doing so, abandon the barrier methods they normally use), an act which puts the uninfected partner and/or unborn child at greater risk. Thus, providing a means for HIV-affected couples to achieve pregnancy, one which tailors reproductive care by a physician to the couple's unique medical circumstances, is actually likely to do much more good than harm. As stated by Lyerly and Faden (2003):

> Whether, with whom, and when to have children are among the most precious and private decisions in a person's life. HIV-seropositive women and the partners of HIV-seropositive men should be able to consider childbearing in the context of their own lives and, if they choose, have access to technologies that enable them to become pregnant in the safest way possible.

In doing so, these couples necessarily foster their future role as caregiver, educator, protector, and enculturator (Hester, 2002). In these situations, Hester (2002) argues that the use of ARTs constitutes an expression of meaningful parenting; the ARTs themselves are but "instruments" in the couple's quest to become parents. Advocating for the "artful" use of ARTs, Hester (2002) contends that:

> The meanings of fertility and infertility are not singular. Likewise, the meanings of parenthood that patients who seek the aid of ARTs carry with them are unique meanings, novel to their own socially situated, narrative selves.
>
> […]
>
> Instead of concern to overcome procreative obstacles, a focus on the *artful* use of ARTs in developing the deeper meaning of parenting…recommits the medical encounter to a significant connection between its means and ends—between the decisions made in order to become parents and the kinds of parents they will become.

As such, I argue that in the challenging setting of HIV infection, couples who wish to take on the role of parents should be respected and admired, both by the physicians caring for them and society alike. I believe that their children will be forever recognizant.

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# APPENDIX:

**Three-part zidovudine (ZDV/AZT) regimen for prevention of perinatal transmission of HIV-1** (Connor *et al*., 1994)

| | |
|---|---|
| **Antepartum** | Oral administration of 100 mg ZDV 5 times daily (or 300 mg twice daily), initiated at 14-34 weeks gestation and continued throughout the pregnancy |
| **Intrapartum** | During labor, intravenous administration of ZDV in a 1-hour loading dose of 2 mg per kg of body weight, followed by a continuous infusion of 1 mg per kg of body weight per hour until delivery. |
| **Postpartum** | Oral administration of ZDV to the newborn (ZDV syrup at 2 mg per kg body weight per dose every 6 hours) for the first 6 weeks of life, beginning at 8-12 hours after birth (Note: intravenous dosage for infants who cannot tolerate oral intake is 1.5 mg per kg body weight intravenously every 6 hours). |