TESTING WOMEN AS MOTHERS

The Policy and Practice of Prenatal HIV Testing

Lynne Leonard
School of Social Work
McGill University
Montréal, Québec

October 2003

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of Doctor of Philosophy.

Your file Votre référence
ISBN: 0-612-98301-3
Our file Notre référence
ISBN: 0-612-98301-3

TABLE OF CONTENTS

LIST OF TABLES vi

LIST OF FIGURES viii

ACKNOWLEDGEMENTS ix

ABSTRACTS xii

CHAPTER ONE: INTRODUCTION: THE ISSUE AND THE INVESTIGATION 1

The Issue 1

The Detection of the Potential for Perinatal HIV Transmission as a Prevention Priority 1

The Investigation 5

Policy Framework 8

Established Canadian Principles of HIV Counselling and Testing 12

Evidence of Deviation from Established Canadian Principles of HIV Counselling and Testing 14

The Ontario Context 16

Ontario's Prenatal HIV Testing Policy 17

Interpretive Framework 20

Prenatal HIV Counselling and Testing Framework 21

Organisation of the Thesis 23

CHAPTER TWO: THE CONTEXT: LITERATURE REVIEW 26

Perinatal Transmission of HIV 26

Perinatal HIV Transmission 27

Perinatal HIV Transmission Rates 27

Perinatal AIDS in Canada 29

Perinatal Positive HIV Test Reports in Canada 29

Perinatal AIDS in Ontario 33

Perinatal Positive HIV Test Reports in Ontario 33

Limitations in Perinatal AIDS and HIV Surveillance Data 37

Implications for the Study of HIV Counselling and Testing among Pregnant Women in Ontario 38

Canadian Women and HIV Infection 39
AIDS among Women in Canada 40
HIV Infection among Women in Canada 42
AIDS among Women in Ontario 45
HIV Infection among Women in Ontario 49
Limitations in AIDS and HIV Surveillance Data 56
Implications for the Study of HIV Counselling and Testing among Pregnant Women in Ontario 56
Women at Higher Risk of HIV Infection 57
Women and HIV Risk 58
Women who Inject Drugs and HIV 59
Aboriginal Women and HIV 66
Women from Endemic Countries and HIV 73
Factors Associated with Prenatal HIV Test Uptake 76
Methodological and Conceptual Implications for Further Research 85
Prenatal HIV Counselling and Testing Policies 87
A Targeted or Selective Policy 89
A Universal Voluntary Policy: The 'Opt-in' Approach 92
A Mandatory Policy 95
A Routine Policy: The 'Opt-out' Approach 102

CHAPTER THREE: METHODOLOGY 115
Study Design 115
The Researcher as Instrument 117
Study Methods 117
Sampling Strategy 118
Personal Characteristics of the Pregnant Women 119
Regional Composition 121
Sample Size 123
Recruitment Strategy 124

Data Collection: The Process of the Interview 127
Data Management and Interpretation 132
Ethical Approval 134
Ethical Considerations 135

CHAPTER FOUR: RESULTS 143

Profile of the Pregnant Women 145
Social and Cultural Characteristics 145
Experiences of Pregnancy 150

The Offer of the Prenatal HIV Test 160
Offered Prenatal HIV Test 160
Requested Prenatal HIV Test 162
Absence of Offer of Prenatal HIV Test 163
Unsure if Offered Prenatal HIV Test 166

Responding to the Offer of the HIV Test 167
Decision-Making 168
Accepting the Offer 169
Intending to Accept the Offer 175
Declining the Offer 175

Waiting for the Results 179

Principles of HIV Counselling and Testing 181
Voluntary Nature of the HIV Test 181
Informed Consent 184
Pre-test Counselling 185
Equal Benefits for Mother and Child 189
Post-test Counselling 190

Indicators of Best Practices 193

WHEN Should HIV Counselling and Testing be Presented to Women?... 193

Not in Pregnancy 193

Discussion of HIV Test Should Take Place over Several Early Prenatal Visits 195

Discussion of HIV Test Should Not Be Integrated with Discussion of Other Prenatal Tests 197

WHO Should Present HIV Counselling and Testing to Women? 198

HOW Should HIV Counselling and Testing be Presented to Women? 201

Approaches to Prenatal HIV Counselling and Testing 201

WHAT Should the Experience of Prenatal HIV Counselling and Testing Comprise? 205

Components of the Pre-test Session 205

Support While Waiting for Results 208

Universality and Importance of Prenatal HIV Counselling and Testing Must be Emphasised 208

Health Care Providers Need to Reassure Pregnant Women that Standard of Care Will Remain the Same Whether or Not They are Tested 209

CHAPTER FIVE: SUMMARY & DISCUSSION OF MAJOR FINDINGS . 211

Study Limitations 211

Enhancement Strategies 213

Triangulation of Data Sources 213

Methods Triangulation 214

Transferability 215

Methodologic Conclusions 216

Empirical Conclusions 216

Policy Implications 220

Timing of the Offer to Test for HIV 220

Presentation of the Offer to Test for HIV 221

Maintaining the Established Canadian Principles of HIV Counselling and Testing in the Prenatal Context 222

REFERENCES 228

APPENDICES 267

Appendix 1 Ottawa Project Community Advisory Board Members 267

Appendix 2 Toronto Project Community Advisory Board Members ... 268

Appendix 3 Community Agencies and Individuals Assisting with Recruitment 269

Appendix 4 Information Letter for Front-line Workers 271

Appendix 5 Promotional Brochure for Women Participants 274

Appendix 6 Participant Information Sheet and Consent Form 277

Appendix 7 Interview Guide 280

Appendix 8 Ethics Approval Letters: Ottawa Hospital Research Ethics Board 289

Appendix 9 Ethics Approval Letter: Ottawa-Carleton Health Department 295

Appendix 10 Pregnant Women Participating in the Study 297

Appendix 11 Descriptive Profile of the Pregnant Women 301

Appendix 12 Recommendations for Content and Distribution of Information for Women 307

Appendix 13 Recommendations for Health Care Provider's HIV Counselling and Testing Checklist 318

LIST OF TABLES

Table 1 Cumulative Number of Canadian Perinatally HIV-exposed Infants by Geographic Region and HIV Infection Status, 1984 – 2001 31

Table 2 Number of Canadian Perinatally HIV-exposed Infants by Maternal Exposure Category, 1984 – 2001 32

Table 3 Status in 2000 of Children Born Between 1984 and 2000 to Ontario Women Living with HIV or AIDS 34

Table 4 Number of Perinatally HIV-infected Infants in Ontario by Period of Birth and Exposure Category of Mother, 1984 – 2000 35

Table 5 Location of Health Institution Reporting Perinatally HIV-infected Infants, 1984 – 2000 37

Table 6 AIDS Cases among Canadian Women ≥ 15 years by Exposure Category and Year of Diagnosis, 1997 - 2002 (June) 41

Table 7 Positive HIV Test Reports among Canadian Women ≥ 15 years by Exposure Category and Year of Test, 1985 - 2002 (June) 44

Table 8 AIDS Cases among Canadians of All Ages by Province/Territory and Gender to June 30, 2002 46

Table 9 Location, by Public Health Unit, of AIDS Cases among Females in Ontario, 1981 – 2001 47

Table 10 AIDS Cases among Females in Ontario by Exposure Category, 1981 – 2001 49

Table 11 Positive HIV Test Reports among Canadians of All Ages by Province/Territory and Gender, 1985 - 2002 (June) 50

Table 12 First-time HIV-positive Diagnoses among Females in Ontario by Age Group at Diagnosis, 1985 – 2001 52

Table 13 Location, by Public Health Unit, of First-time HIV-positive Diagnoses among Females in Ontario, 1985 – 2001 53

Table 14 First-time HIV-positive Diagnoses among Females in Ontario by Exposure Category, 1985 – 2001 54

Table 15 Risk Factors Associated with HIV Prevalence among Women in Ottawa who Inject Drugs (N=254), 1996 – 2003 63

Table 16 Number and Percentage of First-time HIV-positive Diagnoses among Women Born in an HIV-endemic Country by Exposure Category and Health Region of Residence, 1985 – 1998 75

Table 17 First-time HIV-positive Diagnoses among Females in Ontario by Exposure Category, 1985 – 1999 120

Table 18 Synthesis of Data Relating to Percentage Determination of Location of Interviews with the Pregnant Women 122

Table 19 HIV-related Risk Behaviours and HIV-related Risk Conditions Associated with the Pregnant Women 149

Table 20 Pregnant Women's Experiences of the Offer of the Prenatal HIV Test 160

Table 21 Pregnant Women's Responses to the Offer of the Prenatal HIV Test 169

LIST OF FIGURES

Figure 1 Reported Number of Canadian Perinatally HIV-exposed Infants by Year of Birth and Current Status, <1990 – 2001 32

Figure 2 Temporal Trends in Exposure Category Associated with AIDS Cases among Females in Ontario, 1985 – 2001 48

Figure 3 Number of First-time HIV-positive Diagnoses among Females in Ontario by Year of Diagnosis, 1985 – 2001 52

Figure 4 Temporal Trends in Exposure Category Associated with First-time HIV-positive Test Reports among Females in Ontario, 1985 – 2001 55

ACKNOWLEDGEMENTS

Firstly, I need to gratefully acknowledge the sources of funding without which this study would not have been possible and which collectively enabled the depth and scope of this research. The (then) Prevention and Community Action Programmes (PCAP) of the HIV/AIDS Policy, Coordination and Programme Division of Health Canada had the wisdom to include an examination of pregnant women's experiences of and perspectives on prenatal HIV counselling and testing in their funding of an array of initiatives to inform a federal approach to the formulation of prenatal HIV counselling and testing policies to drive the development of prenatal HIV counselling and testing programmes. PCAP initially commissioned and funded a small pilot study of which I was Principal Investigator. The results of this pilot were well received by the Federal/Provincial/Territorial Working Group on HIV and Pregnancy and PCAP subsequently provided further funding for a national study to be undertaken with myself as Principal Investigator of which this investigation in Ontario is one component. Additional funding was later provided to expand the scope and reach of the study in Ontario by the AIDS Bureau of the Ontario Ministry of Health and Long Term Care as an initiative of the Ontario Prenatal HIV Testing Evaluation Working Group of the Ontario Advisory Committee on HIV/AIDS. In addition, I received career support through a National Health Ph.D. Fellowship initially awarded through the National Health Research and Development Programme (NHRDP) of Health Canada and subsequently administered as a Doctoral Research Award through the Canadian Institutes of Health Research (CIHR).

I also need to most strongly acknowledge the support that I received from community members across Ontario in developing the community framework in which to undertake this research. Many people took time out of their busy schedules to assist with engaging women with this research. These people generously undertook the myriad of tasks involved in enabling the pregnant women and myself to work together.

To all the people who helped in this way based on their commitment to include the voices of pregnant women in policy formulation and programme development, my most sincere thanks: Lorraine Barnaby, Queen West Community Health Centre, Toronto; Donna Bowers, Somerset West Community Health Centre, Ottawa; Lucie Carriérre, John Howard Society, Ottawa-Carleton Detention Centre, Ottawa; June Carroll, Mount Sinai Hospital, Toronto; Hannah Cowan, Oasis, Ottawa; Kathy Crowe, City of Ottawa Health Department, Ottawa; Leanne Cusitar, HIV Prevention Programme, Toronto Public Health, Toronto; Mary Grondin, St Michael's Hospital, Toronto; Dale Guenter, North Hamilton Community Health Centre, Hamilton; Shaun Hopkins, The Works, Toronto; Jackie Joynt, Ottawa; Susan King, Hospital for Sick Children, Toronto; Lora Kucenty, Shout Clinic, Toronto; Margaret Leslie, Breaking the Cycle, Toronto; Leanne McDonald, Wabano Centre for Aboriginal Health, Ottawa; Michelle McNeil, (then) City of Ottawa Health Department, Ottawa; LaVerne Monette, Ontario Aboriginal AIDS Strategy, Toronto; Wendy Muckle, (then) Sandy Hill Community Health Centre, Ottawa; Suzanne Newmark, Hamilton Public Health Department, Hamilton; Pat and Emily, The Well, Ottawa; Linda Pelude, City of Ottawa Health Department, Ottawa; Rita Peschka, Oasis, Ottawa; Carol Roberts, Queen's University, Kingston; Janet Rowe, (then) AIDS Committee of Toronto, Toronto; Ron Shore, Street Health Centre, Kingston; Bev Soulier, Wabano Centre for Aboriginal Health, Ottawa; Esther Tharao, Women's Health in Women's Hands, Toronto; Janis Tripp, AIDS Bureau, Ontario Ministry of Health and Long Term Care, Toronto; Zhaida Uddin, (then) AIDS Committee of Ottawa, Ottawa; Shelley Van Keffle, St Mary's Home, Ottawa.

To my fellow members of the Ontario Prenatal HIV Testing Evaluation Working Group a special thanks for sharing their professional expertise and differing perspectives on prenatal HIV counselling and testing. To Lizz Edgecombe, Janet Meldrum, Janet Nichol, Mary Strome, and Mary Whelan, much appreciation for accurate and efficient interview transcription. To Alma Estable and Mechthild Meyer of Gentium Consulting, a special thanks for analysis support.

A special feature of qualitative research endeavors is that report writing is integral to and concurrent with the overall research process. However, in re-formulating this report I came to appreciate the unique and specific support that I received to "put pen to paper." The words used by a dear friend to introduce the acknowledgement pages of his book had particular resonance:

> *The solitary task of writing is also social and collective. Family, friends and colleagues keep you going with support of every kind – emotional, conceptual, technical, editorial and strategic.* [1]

Peter Leonard provided limitless intellectual challenge and nurtured me in practical and emotional ways while doggedly protecting my writing time from distractions big and small. Protection of writing time was also made possible by the Chair of my Department at the University of Ottawa George Wells, and my colleagues Christine Navarro and Linda Pelude who kept the research ship afloat with only the necessity for me to touch the rudder from time to time and who provided efficient technical support. My many friends and colleagues in the Ottawa HIV/AIDS field were thrilled that I was finally getting to this challenge and were generous in absorbing the consequences of my reduced availability while I worked on my "book report". Linda Davies generously provided directions for the path through the wilderness of way too much information. Bill Rowe's continued faith in my writing ability and shared commitment to the important purpose of this research kept me going through the difficult moments. Abby Lippman was a source of huge support. As compassionate mentor, dedicated committee member and source of tough love, she somehow was able to dissuade me from writing about everything to writing about the things that really mattered. Such support was a driving force.

And finally, to the pregnant women who took the time and trouble to meet with me to share their thoughts and feelings about a new measure of medical investigation in an already busy and often stressful period of their lives must go the biggest thanks. Listening to and learning from these women was a pleasure and a privilege.

ABSTRACT

The convergence of compelling evidence that transmission of HIV from a pregnant woman living with HIV to her foetus can be significantly interrupted due to advances in antiretroviral and obstetrical interventions, and worrisome epidemiologic data documenting a rise in HIV infection among Canadian women, spurred the development in Canada and world wide of policies and programmes aimed at increasing the number of pregnant women who are tested for HIV. Responding to innovative therapy reducing perinatal HIV transmission risk by increasing the number of pregnant women who agree to test for HIV is clearly an important prevention objective. However, the process must be accomplished in a way that is of most benefit to the pregnant woman herself and in a way that does not compromise a pregnant woman's rights to the established Canadian principles of HIV counselling and testing.

Working with pregnant women in Ontario, the province with the highest level of HIV infection among Canadian women, this thesis articulates and interprets their experiences of prenatal HIV counselling and testing and details their perspectives on best practices. The pregnant women's evidence-based recommendations for the re-design of prenatal HIV testing programmes are provided. These unique data have important utility for federal and provincial policy makers as HIV counselling and testing policies and programmes that encompass and are grounded in pregnant womens' experiences and perspectives are likely to be maximally acceptable and thereby increase the number of pregnant women who can be apprised of prophylactic treatment to take care of their own health needs as well as those of their unborn children.

In order for pregnant women to increase control over their own health and that of their unborn children, there is clear value in all pregnant women being afforded the opportunity to know their HIV status. However, the voices of the women in this study suggest that the autonomy rights of pregnant women may well be at risk in a programme in which the current emphasis is on potential HIV infection of the foetus rather than on potential or actual infection of the pregnant woman.

RÉSUMÉ

La convergence de preuves péremptoires selon lesquelles la transmission du VIH de la mère à son fœtus peut être interrompue grâce à des percées dans le domaine des interventions antirétrovirales et obstétriques, et des données épidémiologiques inquiétantes documentant une hausse du nombre de cas d'infection au VIH chez les Canadiennes, ont favorisé l'élaboration au Canada et dans le monde entier de politiques et de programmes visant à accroître le nombre de femmes enceintes soumises à un test de dépistage du VIH. Le recours à des thérapies innovatrices en vue de réduire la transmission périnatale du VIH en augmentant le nombre de femmes enceintes qui consentent à passer un test de dépistage du VIH constitue un important objectif de prévention. La démarche doit toutefois être entreprise de façon à bénéficier à la femme enceinte et à ne pas enfreindre ses droits protégés par les principes canadiens établis en matière de counseling et de dépistage du VIH.

Chez les femmes enceintes interrogées vivant en Ontario, la province qui compte le taux le plus élevé de femmes infectées au VIH, cette thèse exprime et interprète leurs expériences en matière de counseling et de dépistage du VIH en phase prénatale et fait connaître leurs opinions sur les pratiques exemplaires. On y trouve les recommandations factuelles des femmes enceintes à propos de la restructuration des programmes de dépistage prénatal du VIH. Ces données uniques revêtent une grande importance pour les décideurs fédéraux et provinciaux puisque les politiques et les programmes en matière de counseling et de dépistage du VIH fondés sur les expériences et les points de vue des femmes enceintes et qui les intègrent sont susceptibles d'être mieux acceptés et, par le fait même, d'accroître le nombre de femmes enceintes qu'on peut sensibiliser au traitement prophylactique pour répondre à leurs besoins en matière de santé et à ceux de leur enfant à naître.

Il est indéniable qu'il faut donner aux femmes enceintes la possibilité de subir un test de dépistage du VIH pour leur permettre de mieux prendre en main leur propre santé et celle de leur enfant à naître. Les femmes interrogées indiquent toutefois que les droits à l'autonomie des femmes enceintes pourraient être menacés dans un programme qui met l'accent sur l'infection potentielle du fœtus au VIH plutôt que sur l'infection possible ou réelle de la femme enceinte.

CHAPTER ONE: INTRODUCTION

THE ISSUE AND THE INVESTIGATION

THE ISSUE

The Detection of the Potential for Perinatal HIV Transmission as a Prevention Priority

Perinatal transmission[i] of HIV refers to the transmission of the human immunodeficiency virus (HIV) from a woman living with HIV or acquired immunodeficiency syndrome (AIDS) to her foetus or infant. It is the primary mode by which Canadian children under 15 years of age become infected with HIV, accounting for 68% of cumulative paediatric positive HIV test reports and 83% of cumulative paediatric AIDS cases in Canada.[2] The anticipated rate of perinatal HIV transmission in the absence of preventive measures is estimated to be in the range 22–29 %.[3-6] However, due to recent advances in both antiretroviral[3,7] and obstetrical interventions,[8-10] this risk can now be reduced to less than 2% among those pregnant women living with HIV and AIDS who are aware of their positive status, who are in a position to be able to choose to access the range of antiretroviral treatments and medical interventions now available, and who do not breastfeed.[11-14]

Compelling evidence that transmission of HIV from a pregnant woman living with HIV or AIDS can be significantly interrupted through prophylactic treatment or medical interventions has particular significance in the worrisome context of increasing numbers of Canadian women acquiring AIDS and HIV infection. In Canada, despite an overall significant decline in rates of AIDS incidence in recent years, the number of reported AIDS cases among women (adolescent and adult women aged 15 years and over), and the proportion of all adult reported AIDS cases comprised by women has been increasing.

---

[i] The term 'perinatal transmission' is used in this thesis to reflect the fact that this is the term used in HIV/AIDS surveillance and reporting in Canada. The term 'vertical transmission' is now less commonly employed, with the Joint United Nations Programme on HIV/AIDS (UNAIDS) terminology of 'mother-to-child transmission' (MTCT) in more common use worldwide.

Prior to 1993, adult and adolescent women comprised 6% of the total number of annual reported AIDS cases among adults in which gender and age are known. This proportion increased to 8.5% in 1995 and in 2000, reached a level not previously seen since the monitoring of the epidemic began, with adult and adolescent women accounting for 15% of annual adult AIDS diagnoses. This proportion has further increased to 17% in the first 6 months of 2002. This differential proportional increase on gender lines is most evident in the number of reported adult AIDS cases among those 15-29 years of age. In this group, the proportion of women among reported AIDS cases rose from 10% before 1993 to 47% in 2001. This proportion was 43% between January and June 2002.[2] HIV surveillance data also suggest increasing levels of HIV infection among Canadian women. Nationally, before 1996, adult and adolescent women comprised just 11% of cumulative positive HIV test reports with known age and gender among adults in Canada. This proportion increased sharply in 1998 to 22% and increased again to 25% in 2001. In the first half of 2002, this proportion has increased slightly to 26% of all positive HIV test reports with age and gender classification.[2,15] The proportion of women among all adult positive HIV test reports varies considerably with age and has consistently been highest among adolescents and young adults aged 15 to 29 years.[2,15]

The convergence of the recent success of innovative measures in virtually eliminating the possibility of perinatal HIV transmission, and the situation of an increase in Canada and worldwide in incident and prevalent cases of AIDS and HIV among women of childbearing age, made the early detection of the potential for perinatal HIV transmission a prevention priority. The early detection of HIV among pregnant women in order to reduce perinatal transmission of the virus became an evidence-based public health imperative. The situation demanded a reconceptualisation of earlier public health policy positions on prenatal HIV counselling and testing established in the pre-prophylactic era. Effective policies were now required to operationalise and maximise the science of perinatal HIV transmission prevention to guide the development of programmes, protocols and

guidelines aimed at increasing the number of pregnant women who are tested for HIV:

> *Because of the clear benefits to this treatment, every effort should be made to detect mothers of previously unknown HIV-1 status so that they can be allowed to make informed decisions that will influence the health of the newborn infant.* [16]

In order to detect these HIV-infected but unaware pregnant women described above, and in response to dissemination of the results from successful prevention interventions in the perinatal HIV transmission domain, a plethora of studies were undertaken in the mid to late 1990s. These studies sought to identify predictors of prenatal HIV test acceptance with the objective of demonstrating on which factors policy strategies and associated health promotion, health education and programme interventions should concentrate in order to increase the uptake of prenatal HIV testing among women.[17] The studies have been further rationalised on the premise that health policy experts, public health officials, clinicians, and health care professional bodies who understand the range and determinants of voluntary HIV test acceptance in the prenatal context can more critically operationalise and evaluate prenatal HIV testing policy.[18] As Sorin and colleagues explain,[19]

> *An understanding of factors that lead childbearing women to accept HIV testing is essential to the success of voluntary testing programmes. Yet, very little is known about factors that influence pregnant and postpartum women to accept or reject HIV C&T [HIV counselling and testing].*

With few exceptions, these early studies examining women's acceptance of screening for HIV in pregnancy use quantitative methods of enquiry. As described in the next chapter, these studies report statistically significant correlates of prenatal HIV testing uptake or delineate factors which significantly and independently predict pregnant women's decisions to undergo prenatal HIV testing. The majority of these studies examine individual elements of the HIV counselling and testing process such as demographic and behavioural characteristics of the pregnant women (e.g., age, racial/ethnic identification, education, marital status, income, HIV testing history[17,20-37]); attitudinal attributes of the pregnant women (e.g., self-perceived risk of HIV infection, knowledge and attitudes towards HIV infection, perceived benefit

of accepting HIV testing;[17,22,24-26,28,29,32,34,35,38]) provider factors (e.g., strength of endorsement of prenatal HIV testing, perceived competence, sociodemographic characteristics[23,26,29,31,33,39,40]); and structural or health system variables such as the organisational context of prenatal care provision, ease and accessibility of testing, and characteristics of pre-test counselling.[23,32-34,36,41,42]

However, despite this vast array of quantitative studies, no clear picture emerges of the discrete variables associated with a pregnant woman's decision or intention to accept or decline HIV counselling and testing in the prenatal period. Study findings are inconsistent and often contradictory and fail to develop a coherent framework across studies. For example, inconsistency in results exists among those studies examining the relationship between specific demographic characteristics and prenatal HIV test acceptance. The contradictory nature of some findings is evidenced in the fact that a pregnant woman's perception of her own HIV risk has been found to independently predict test acceptance in some studies[17,22,29,32,34,35] and not in others.[24,25,28] Evidence of the relationship between attitudinal variables and test acceptance is at best inconclusive as the attitudinal factors found to significantly predict acceptance vary across studies.

This absence of consistent findings across studies suggests that important contextual factors are being missed. For example, if several studies report that the pre-test counselling experience significantly predicts test uptake[32,33,41] and other studies report that this experience does not significantly modify test-acceptance behaviour or intentions[23,29], important contextual factors that influence the pregnant women's responses to these situations may be behind the inconsistency, contextual factors that have been missed due to the constraints inherent in the purely quantitative methods used.

Clearly, a focus on pure determinants, without a fuller appreciation of the nature and impact of those determinants, can lead to inconclusive and contradictory findings. Moreover, the search for relationships between determinants and testing outcomes

frequently offers little insight into *why* a particular determinant affects testing rates. For example, studies demonstrating an association between a positive attitude towards prenatal HIV testing and test acceptance fail to identify *how* women form positive attitudes towards testing.

THE INVESTIGATION

The investigation presented in this thesis:

- aims to build on and develop the body of knowledge that presently exists in the prenatal HIV counselling and testing domain;
- rejects the underlying tenet of earlier investigations that simply modifying the factors identified through quantitative methods alone as significant correlates of pregnant women's decisions to test will increase prenatal HIV test uptake; and
- adopts a different paradigm of scientific enquiry in using qualitative methods to interpret the emic of pregnant women.

The study is predicated on the firm belief that failure to attend to pregnant women's experiences of the HIV counselling and testing process, and to the cultural context that informs this experience, will result in programmes that fail to increase prenatal HIV testing uptake and thus further fail to provide pregnant women with the resources they require to make the best decisions not only for their children, but also for themselves.

The overall objective of this study, therefore, is to provide experientially derived information to inform the evaluation and re-formulation of prenatal HIV counselling and testing (PHCT) policy and associated guidelines. Rather than identifying and cataloguing differences between pregnant women who do and do not accept prenatal HIV testing, my investigation aims to contribute new knowledge by describing the process through which pregnant women's understandings and decisions regarding HIV counselling and testing are shaped. It explores the meaning that pregnant

women associate with pre-natal HIV testing and gives consideration to the cultural context within which information is synthesised and decisions are made.

Congruent with the study's overall objective and with the intent of providing new and original knowledge, my study also explicitly elicits characteristics of best practices in prenatal HIV counselling and testing from the perspectives of the pregnant women themselves. HIV counselling and testing policies and associated programmes that encompass and are grounded in pregnant women's perspectives on prenatal HIV testing best practice are more likely to be maximally acceptable to pregnant women and thereby increase the number of pregnant women who can be apprised of prophylactic treatment to take care of their own health needs and those of their unborn children.

The case for involving the perspectives of pregnant women in the conceptual development of a programme addressing their needs for HIV testing in pregnancy is a strong one. Emerging research from other medical domains addressing women's perceptions and fears surrounding their health and treatment options underscores the urgent need to study women's perceptions regarding HIV testing in pregnancy prior to recommending or implementing policies and programmes to address this issue.[43] As Cohen asserts[44],

> *If we do not understand how our patients perceive and respond to our recommendations, our health promotion and screening programmes will be hampered.*

Thus, research based on pregnant women's experiences and perceptions of PHCT will provide a more thorough understanding of how pregnant women may interpret and respond to HIV testing policies. The consequences of negating the relevance and validity of their perspectives are likely to be profound. Research that is carried out and interpreted without reference to the social, economic and political context of women's lives often distorts women's perceptions and behaviours and fails to provide accurate insights.[44]

However, integration of the perspectives of pregnant women as consumers of PHCT policies is a conceptual approach that has largely been omitted in the development and implementation of prenatal HIV testing programmes to date. In discussing early British governmental guidelines regarding prenatal HIV testing policy in a paper examining why antenatal[ii] attenders decide to have an HIV test, Meadows and Catalan[28] comment that,

> *... during the formulation of these guidelines and in other similar discussions, the rationale for offering testing and the methods employed often seem to derive from the opinions of the medical staff and other professionals on what is in the best interest of mother and child.*

The primacy of the views of health professionals and the exclusion of the views of pregnant women as consumers of the service perceived by Meadows and Catalan is far more explicit in other studies. The foregrounding of the views of medical experts in formulating policy responses is evident in several British studies outlining descriptions of the implementation process of PHCT policy. In a study from the mid 1990s Mercey and colleagues[27] describe the consultations that took place prior to implementation of a policy of universal PHCT,

> *A universal voluntary antenatal HIV testing policy was introduced at this central London teaching hospital in June 1993 following local consultation with obstetricians, virologists, genitourinary physicians, health advisors and midwives.*

A few years later in 1998, in a letter to the editor of the Lancet describing their policy change from offering prenatal HIV testing only when HIV-related risk factors are disclosed to a policy offering universal counselling and HIV testing as a response to the dissemination of the results of innovative therapy with perinatal transmission interruption properties, professionals from the Rotunda Hospital in Dublin, Ireland describe the same process of consulting only with health professionals,

> *This linked HIV-1 testing was introduced after widespread consultation within the hospital with medical, nursing, and medical-social work department personnel.*[16]

[ii] 'Antenatal' is the UK term for prenatal, and is used in this thesis in the context of describing or reproducing data from UK studies.

The foregrounding of the views of medical professionals and the marginalising of the views of pregnant women in designing and implementing policies that will have a profound effect on them continues. In a study published just last year (2002) by Keane and colleagues,[42] medical personnel dominated the working group responsible for the process whereby routine antenatal HIV screening was introduced in Cornwall, a rural county with low HIV incidence in the southwest of England,

> *A working group, with representation from genitourinary medicine, Truro Public Health Laboratory, midwifery, obstetrics, paediatric, public health, infection control (Royal Cornwall Hospital), and the heath authority was convened. The group decided to commence routine antenatal HBV/HIV screening together on 1 April 2000 in Cornwall.*

Thus, distinct among policy studies in the prenatal HIV counselling and testing domain, this study promotes and gives voice to the perspectives and grounded recommendations of the expert consumers, the pregnant women themselves. With these data, and in contrast to the practices of PHCT policy implementation previously described, Federal and provincial policy makers will have an opportunity to involve the grounded expertise of pregnant women in the evaluation and re-formulation of a policy designed to meet their needs. Integrating pregnant women's perspectives on best practices in PHCT in policy revisions will maximise the capacity of such policies to increase prenatal HIV test uptake, resulting in substantial and significant gains for women. Increasing the number of women who access prenatal HIV counselling and testing will ensure that as many Canadian women as possible are afforded the opportunity to gain increased information and thereby control over their own health as well as that of their children.

Policy Framework

In addition to constructing evidence-based expert policy and programme recommendations, this study also responded to important ethical concerns that have been raised relating to the application of established Canadian HIV counselling and testing policy in the prenatal context. It was important to examine pregnant women's experiences of HIV counselling and testing in the prenatal context from the

perspective of the application of the established Canadian principles of HIV counselling and testing for two interconnected reasons. One emanated from my review of the literature on HIV counselling and testing, and the other, evidence-based, was driven by previous research I had undertaken in this domain.

In a comprehensive review of the legal and ethical underpinnings of Canadian HIV testing policy[45], the concern evolved that pregnant women may experience undue pressure to undergo HIV testing in an era of prophylactic treatment for perinatal HIV transmission. As Jürgens and Palles state in this review which was prepared for the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society,

> *Now that a possible preventive treatment has been found, the pressure to test pregnant women is great. In the rush to respond to this innovative therapy, there is a serious risk that the basic rights of the mother will be swept aside.*

A consideration of the discourse outlining the objectives of prenatal HIV counselling and testing in the pre-and post-prophylactic HIV perinatal transmission era supports this concern. As described below, the emphasis in offering HIV counselling and testing in the prenatal context changed dramatically from an approach in which overall concern for the pregnant woman was central to the process, to an approach, made attractive with the advent of perinatal HIV prevention possibilities, in which concerns for the potential infection of the unborn child appear to override concerns for the actual or potential HIV infection of the pregnant woman.

Prior to 1994, before the advent of available and effective prophylactic treatment to reduce perinatal HIV transmission, offering HIV testing in the prenatal context was generally constructed as women-centred. It was variously characterised as an opportunity for a pregnant woman to gain knowledge about her health status in order to guide personal and clinical decisions[46,47] and to adopt HIV-preventive practices to prevent further transmissions[47]; as an opportunity to consider termination of the pregnancy to avoid the risk of giving birth to a child infected with HIV or a child that would be orphaned[47,48]; as an opportunity for health care providers to encourage behaviour change and adoption of HIV-protective practices among pregnant women

at higher risk of HIV infection[20,49]; and as an opportunity for assurance for a pregnant woman that she had not contracted the virus or, if positive, the ability to benefit from medical care and early treatment.[20,47,49] Further emphasising the lack of connection between testing pregnant women for HIV and reducing perinatal HIV transmission, HIV testing among pregnant women was also offered "*for the purpose of epidemiological surveillance*"[22] as levels of HIV infection among pregnant women have been characterised as important markers of HIV prevalence and incidence among the wider population of heterosexual women.[2] In fact, in terms of the relationship between offering prenatal HIV testing and reducing perinatal transmission of HIV infection in this period, the general consensus was that testing pregnant women for HIV in the absence of effective preventive treatment would not significantly further any public health policy objective to prevent the spread of HIV. As Field[50] starkly argued at this point,

> *once a woman is pregnant, the test can help contain HIV only if it leads to abortion.*

Since this period however, for federal and provincial/territorial policy makers, health care professionals and pregnant women in Canada and worldwide, the success of innovative therapy and medical interventions in virtually eliminating the possibility of perinatal HIV transmission significantly changed the prenatal HIV counselling and testing landscape. The impetus for this change occurred in 1994 with the landmark clinical data originating from the US Pediatric AIDS Clinical Trial Group Protocol 076 (PACT076) placebo-controlled clinical trial which demonstrated the efficacy of monotherapy with AZT (zidovudine) in achieving a two-thirds reduction in perinatal transmission.[3] The world-wide dissemination of these data was swiftly followed by international studies of AZT in pregnancy confirming these early PACT076 results or achieving even lower rates of perinatal HIV transmission.[13,14,51-55] These early significant clinical findings, together with recent advanced developments in antiretroviral[3,7] and obstetrical interventions[10,56] reducing these rates even further, demanded a recalibration of the benefit-burden ratio of a pregnant woman knowing her HIV status. Efforts to increase HIV counselling and testing among women in prenatal care in order to identify those women who could benefit

from such preventive interventions now had obvious appeal from the standpoint of perinatal HIV risk reduction. It was this outcome that came to be the catalyst driving the development of prenatal HIV counselling and testing programmes.

In contrast, therefore, to the stated objectives of earlier prenatal HIV tests in the pre-prophylactic era, less well emphasised now is that increasing HIV testing among pregnant women provides an opportunity for seemingly healthy pregnant women unaware of their HIV-positive status to benefit from early diagnosis and thus be in a position to decide on the range of treatment options for *themselves* as well as the range of prophylactic interventions available to them to reduce transmission to their child. As Cafferkey and colleagues[16] clearly delineate, the balance of the objectives of HIV counselling and testing in the prenatal context had now clearly swung away from the mother's health to an emphasis on the pregnant woman knowing her status so that she could make decisions in the interest of her child's health. The earlier focus on the pregnant woman accessing testing in order to make informed decisions about her own health has dissipated:

> *Because of the clear benefits to this treatment, every effort should be made to detect mothers of previously unknown HIV-1 status so that they can be allowed to make informed decisions that will influence the health of the newborn infant.*

Even the language changes as reduction of HIV perinatal transmission becomes paramount. The pregnant woman has become de-personalised, emphasising her marginality to the process:

> *This discovery [PACT076] highlighted the importance of identifying HIV-infected* ***parturients*** *to minimize the number of HIV-infected infants.*[24] (Emphasis added.)

Does this shift in policy discourse play out in the practice of prenatal HIV counselling and testing? In the pressure to test women as mothers, is the expressed concern confirmed that the rights of pregnant women to the established Canadian principles of HIV counselling and testing are being swept aside? These principles of HIV counselling and testing, developed from a consensus of position statements of key Canadian organisations, are described below.

Established Canadian Principles of HIV Counselling and Testing

Following the identification of HIV as the etiologic agent of AIDS in 1984 and the subsequent development and availability of a diagnostic test for HIV infection in 1985, HIV testing[iii] has been the subject of extensive scrutiny regarding its legal and ethical use. Issues of a political and ethical nature, and issues of privacy, community and public health, social economic discrimination, coercion and liberty surfaced early on.[57] In the late 1980s a concerted effort was made by several Canadian organisations such as the Canadian Bar Association-Ontario, the Royal Society of Canada and the Federal/Provincial/ Territorial Advisory Committee on AIDS to respond to these issues in a way that would both respect the human rights of individuals and, at the same time, promote the goals of protecting public health.

Perhaps the most significant among the subsequent plethora of issued reports and formulated policy statements and recommendations from these organisations regarding HIV testing in Canada was the 1988 report of the National Advisory Committee on AIDS (NAC-AIDS).[58] NAC-AIDS established a *"general principle governing HIV antibody testing in Canada."* This principle established voluntary testing as the preferred approach for HIV testing in Canada. A voluntary approach was considered to facilitate HIV testing; to avoid harms while seeking the greatest benefits from HIV testing; and to minimise the likelihood of coercion.

This principle has come to embody what has been described as "a broad social, legal and medical consensus"[45] of the Canadian approach to HIV testing. This consensus derived from the recommendations of those Canadian organisations

[iii] The most commonly applied test detects the presence of antibodies to the virus rather than the presence of the virus itself. It is therefore more accurate to refer to the test as an HIV-antibody test. Polymerase chain reaction testing (PCR) does detect the presence of the virus itself but is much less commonly utilised. However, in order to be consistent with most texts on the subject, in this thesis the term HIV testing will be used.

detailed above that studied the issues raised by HIV testing soon after the development of the test and also from organisations that issued later reports and position statements. These organisations included the Parliamentary Ad Hoc Committee on AIDS[59], The Ontario Law Reform Commission[60], the Canadian Public Health Association[61] and the Canadian Medical Association.[62] All of these groups concluded that HIV testing should generally only be undertaken with the informed and specific consent of the person being tested.

Thus, based on the principle established by NAC-AIDS and widely endorsed by significant Canadian organisations, the consensus that has emerged in Canada is that, except in a few well-defined circumstances[iv], people should be tested for HIV only:

- with their informed, voluntary and specific consent;
- when counselling and education before and following testing are available and offered; and
- when confidentiality of results or anonymity of testing can be guaranteed.

Clarification of the legal and ethical principles of HIV testing in Canada and the operationalisation of the required conditions of informed consent, pre-and post-test counselling and confidentiality are contained in the *Counselling Guidelines for HIV Testing* prepared by the Expert Working Group on HIV Testing: Counselling Guidelines and published by the Canadian Medical Association (CMA).[62] Prior to publication, these Guidelines[v] were reviewed by a national advisory group composed of representatives from the Canadian AIDS Society, the Canadian Association of Nurses in AIDS Care, the Canadian Haemophilia Society, the Canadian Paediatric Society, the Canadian Public Health Association, the College of Family Physicians

---

[iv] These circumstances are generally, but not exclusively, limited to the testing of blood, organ, tissue, ovum and sperm donors and donors of body parts in medical research, treatment or transplantation.[45]

[v] Although frequently referred to as the CMA Guidelines, in this thesis this text is referred to simply as the Guidelines, acknowledging, as described above, that the content was developed by the Expert Working Group on HIV Testing: Counselling Guidelines, rather than the CMA.

of Canada and the Society of Obstetricians and Gynaecologists of Canada and further circulated to a broader range of physicians and other health care professionals. The objectives of these Guidelines, the most current recommendations for Canadian health care providers, are

> *[t]o provide physicians and other health care professionals with concise, easy-to-read counselling guidelines related to serologic testing for human immunodeficiency virus (HIV).*

As explained in the introductory text, the Guidelines are *"not intended to be construed or to serve as a standard of medical care."* However, in reviewing the legal parameters of the PHCT debate, Stoltz's contention is that practising physicians do regard them as a standard of care and as a result would most likely be treated as such by any court called upon to consider the matter.[63] As these Guidelines thereby embody the established principles of HIV counselling and testing, the Guidelines are used in this study as the policy framework in which to interpret and analyse the HIV counselling and testing experiences of the pregnant women.

Evidence of Deviation from Established Canadian Principles of HIV Counselling and Testing

The second and related reason for using this framework to interpret and analyse the experiences of the pregnant women was to confirm, and if substantiated, to develop the policy and practice implications of early findings from the pilot to this study.[64,65] This pilot phase involved in-depth exploratory interviews or guided conversations with ten pregnant women from Montréal and Ottawa recruited through strategies aimed at accessing pregnant women from a range of life situations considered likely to impact on their experience of the prenatal HIV counselling and testing process. Emerging findings from this study suggested that HIV counselling and testing in pregnancy was not always carried out in accordance with the established principles and protocols for HIV counselling and testing previously described, that for some women HIV counselling and testing in pregnancy was a deviation from the established protocols. In particular, for some

pregnant women, the experience fell far short of an informed, voluntary process in which they had choice, as two women explain:

> *I don't remember there being that much explanation about the tests themselves. It's more like, "This is what you have to be tested for."*
>
> *I probably could have said, "No, I don't really want to." But I kind of felt that it was part of the whole package and I didn't think that I had a choice … I didn't feel it was an offer.*

Interestingly, two of the women who thought that HIV testing was not "part of the whole package" but at the discretion of the pregnant woman, shared their perceptions of their health care provider's influence on their decision making. Although the first woman was able to resist the influence and assert her wish not to be tested, the second woman felt that she had little choice in the matter, that is, she did feel under undue pressure to accept HIV testing in her pregnancy:

> *I felt that she [the doctor] did definitely want me to have it done. But she obviously realised that I was adamant that we felt that we didn't need that. But I did feel that she did want us to have it done … I would think that there are other people who would find it difficult to refuse that. I'm fairly strong minded and I'm very sure about my views, so therefore it wasn't, especially on that matter, something that I could be pushed into. But I think definitely that there was a pressure there, that they wanted to have it done.*
>
> *My doctor told me she wanted me to have it. She wasn't leaving me much of a choice … So I did.*

In addition to experiencing the process as less than voluntary, some pregnant women were very clear that they had not given their consent to being tested:

> *It wasn't a consent really. It was more like, this is the way it's going to be.*
>
> *No [my consent was not asked for]. Not at all. I felt that it was, as I said before, part of the test and I just went along with it.*
>
> *No [I didn't get a sense I could have agreed or not agreed to have the test]. I thought it was mandatory, so I didn't question it. I didn't have much of a problem with it. If I would've, I probably would have expressed some negative thoughts. But I didn't have a problem with it. It was more like, "This is what you are getting tested for today."*

Thus, the voices of the pregnant women in the pilot do indeed suggest the potential for the risk suggested by Jürgens and Palles. The risk that their rights to the established principles of HIV counselling and testing could well be comprised in the special circumstances of a programme substantially initiated and driven by the objective of reducing perinatal HIV transmission and perhaps only secondarily to address the issue of HIV infection among women. Such findings needed further elaboration and clarification. If substantiated among a wider and diverse group of women these findings had clear implications for the construction of best practices in the policy and practice of HIV counselling and testing in the prenatal context.

Finally, there were compelling reasons for undertaking this research in Ontario both from an epidemiologic perspective and from a policy perspective.

The Ontario Context

From an epidemiologic perspective, as discussed in detail in Chapter One, engaging pregnant women in a process with proven HIV prevention capabilities and a process providing early access to treatment for women whose HIV status was not previously known, had particular importance in Ontario. The number of reported AIDS cases among women in Ontario is the second highest reported in Canada. The number of positive HIV test reports among Ontario women is the highest in Canada and shows a recent increase. These data arguably reflect the relative size of the population in Ontario compared with other provinces. However, they do underscore the rationale of a research focus on a province in which rates of HIV prevalence and incidence among women are very high and thus the potential for perinatal HIV transmission correspondingly a major issue. Such considerations underpin the current policy debates in Ontario. Further emphasising the urgent importance of developing effective PHCT programmes in Ontario is the fact that among Canadian infants known to be exposed perinatally to HIV, Ontario reported the highest proportion of HIV-exposed infants with a confirmed HIV positive diagnosis.

From a policy perspective, examining the prenatal HIV counselling and testing process from the perspective of pregnant women in Ontario has particular resonance as there is considerable pressure for the province to change its PHCT policy. As discussed below, Ontario's PHCT policy had previously undergone a conceptual shift in response to the results of the PACT076 trial and there is now renewed pressure for a significant policy change and consequent revised implementation of the province's prenatal HIV testing programme.

Ontario's Prenatal HIV Testing Policy

In 1995, with the early detection of HIV among pregnant women firmly established as a priority in the reduction of perinatal HIV transmission, Dr. Schabas, Ontario's (then) Chief Medical Officer of Health recommended that

> *HIV antibody testing* ***be discussed with all pregnant women*** *and women considering pregnancy. HIV antibody testing should be made available to any woman who requests it.*[66] (Emphasis added.)

However, this recommendation of a universal discussion of testing appears to be somewhat modified by Dr. Schabas' further assertion that

> *[t]he success of this approach to the prevention of maternal-foetal HIV transmission depends on the ability of health care providers* ***to identify women at increased risk.***[66] (Emphasis added.)

As Jürgens points out, the overall message being put forward suggests that the primary focus was to be placed on the identification of pregnant women's risk factors and not on the voluntary testing of all pregnant women and women considering pregnancy.[67]

Despite this recommendation of a universal discussion of HIV testing in the prenatal context, the findings of a study commissioned by the AIDS Bureau of the then Ministry of Health, and completed by Remis in 1997 revealed that only a limited number of HIV-infected pregnant women had in fact been identified and treated in Ontario since the release of the results of the PACTG 076 trial. The results of the Remis study estimated that between July 1994 and December 1995 only 18-19% of HIV-infected pregnant women had been identified and treated and that perinatal

HIV transmission was a growing problem.[68] On this basis, the Ontario Ministry of Health decided that the recommendation for prenatal HIV testing should be reviewed and the Working Group on Prenatal HIV Testing was reconvened as part of the Ontario Advisory Committee on HIV/AIDS.

Consequently, on World AIDS Day December 1st 1998, three years after the introduction of a policy of a **discussion** of HIV antibody testing with pregnant women, Ontario's (then) Health Minister, Elizabeth Witmer, presented a revised policy whereby HIV testing would **be offered** to all pregnant women and women planning a pregnancy:

> *[t]he Ministry of Health, in conjunction with physicians and midwives in Ontario, will make voluntary HIV antibody testing available for all pregnant women and women planning a pregnancy, either as part of routine prenatal screening or through the current HIV testing programme. Women should be counselled about the benefits and risks of HIV antibody testing and must give their informed consent before their physician or midwife orders the test.*

Dr. D'Cunha, Ontario's Chief Medical Officer of Health and Director of the Public Health Branch, outlined the revised policy, described as a "universal HIV prenatal screening programme", in a letter to all physicians in Ontario. The rationale for the change in policy direction was explained by Dr. D'Cunha on the basis of ensuring that as many women as possible have access to the benefits of early diagnosis and treatment for themselves as well as reducing the number of infants in Ontario born with HIV infection. Specifically, the goals of the new policy, as described in Dr. D'Cunha's letter to physicians, are:

- To protect the health of women in Ontario by diagnosing HIV infection as early as possible so they may seek appropriate care and treatment;
- To provide better care for women with HIV;
- To prevent transmission from mother to baby;
- To reduce the number of infants born with HIV infection; and
- To reduce the costs associated with caring for women and children with HIV.

Although Minister Witmer announced the proposed changes on December 1st 1998, the letter detailing the new policy to the 75,000 physicians in Ontario was not mailed until the end of January 1999. Thus, effective the beginning of February 1999, the Ministry of Health and Long Term Care Prenatal Testing Programme now includes the option of HIV testing, as recommended by the Ontario Advisory Committee on HIV/AIDS and the College of Physicians and Surgeons of Ontario. The revised Prenatal Screening Requisition Form for blood tests includes, as before, the choice of hepatitis B surface antigen, rubella and syphilis testing, but now also has the option of selecting HIV testing. Specimens collected using this new form are retained for four to six weeks following receipt, thus allowing time for a pregnant woman to decide on HIV testing following the prenatal visit.

The Ontario Ministry of Health and Long Term Care published a framework to guide health care providers in undertaking HIV testing. The *HIV Test: Counselling Checklist for Health Providers* was developed as a specific component of the Ministry's Prenatal HIV Testing Programme and the guidelines and counselling concepts it embodies are specific to this programme. The Ontario Counselling Checklist was widely distributed as part of the health care provider's package announcing the programme.

As described, Ontario has implemented a policy generally characterised as an 'opt-in' approach whereby pregnant women are routinely counselled about HIV testing and are universally offered an HIV test to which they need to explicitly give their consent to have completed. However, a routine 'opt-out' policy whereby the HIV test is routinely administered unless the pregnant woman actively declines is being canvassed by eminent health care professionals in Ontario.[69,70] In a recent editorial in the *Canadian Family Physician,* Remis and colleagues[71] recommend that in order to ensure as many HIV-infected pregnant women as possible know their HIV status and to reduce mother-infant transmission in Canada,

All provinces should adopt routine HIV testing for pregnant women and take an opt-out rather than an opt-in approach.

It is of particular concern for policy development in Ontario that all the authors of this editorial are members of the Ontario Ministry of Health and Long-Term Care Prenatal Evaluation Committee of which I am also a member. If Ontario is not to repeat the experience of history of foregrounding health care professionals' views on the optimal practice of prenatal HIV counselling and testing to the exclusion of pregnant women's views, it is essential that the grounded perspectives of pregnant women are heard in this debate.

Interpretive Framework

I have undertaken this research from a feminist standpoint perspective, conceptualised as taking women's views and experience as the core privileged concern. Thus, research undertaken from this perspective stresses a particular view stemming from concern and respect for women's lived experience and a view that builds on and from women's experiences.[72] Debates continue to proliferate in the literature promoting feminism in research as to whether there is a distinct feminist research method; or if feminism is a perspective on a given method rather than a method itself; and if a feminist approach can be considered a research methodology.[72-88]

In their discussions of the application of feminist theory in nursing research, McCormick and Bunting[89] list the criteria generally considered to identify and define a feminist research approach as the following: the principal investigator was a woman; feminist methodology was used; the study had the potential to help the subjects as well as the researcher; the research focused on the experience of the woman; the investigator's purpose was to study women within their role as women; the word "feminist" or "feminism" was used in the report; bibliographic references to the feminist literature were made; and non-sexist language was used. Through their own review of the literature promoting feminism(s) in research they identified

several characteristics of a feminist research perspective which included: women and issues of gender are the central concern; research questions and answers are for the benefit of some women rather than simply about women; and there is emphasis on subjectivity and women's context of experience. In this thesis, the principles of feminism, in particular valuing women and attaching validity to their experiences and a desire to bring about change through social action[75] and the characteristics of feminist research identified by McCormick and Bunting described above, guided the process and formed the interpretive framework for my research.

Prenatal HIV Counselling and Testing Framework

Five themes informed my perspective on prenatal HIV counselling and testing (PHCT):

- HIV counselling and testing in pregnancy does not, in and of itself, reduce perinatal HIV transmission.

  Reduction of perinatal HIV transmission can only be achieved through the body of the pregnant woman. For PHCT to result in reduced HIV perinatal transmission, the pregnant woman needs to make one or more informed treatment decisions. PHCT is not therefore the sole panacea for perinatal HIV risk reduction; rather it represents a stage in the perinatal HIV risk reduction process. It is a stage in which pregnant women found to be HIV-positive can be informed about the range of interventions available to them to reduce transmission to their baby with the objective of supporting women's informed decision-making to reduce that risk.

- Testing for HIV in pregnancy is substantively different from other screening performed in the context of regular prenatal care.

  The maternal serum screening test (MSS) for example, gives information about a pregnant woman's risk of having a baby with certain conditions such as Down syndrome or neural tube defects (e.g., spina bifida). It is a

screening test that requires further diagnostic tests to confirm the risk. As is the case with most other prenatal screening tests, no information on the health status of the mother is gained or revealed by MSS screening. No other prenatal screening test reveals the presence in an asymptomatic pregnant woman of a chronic disease for which there is no cure.

In contrast, PHCT is a process which first and foremost may offer a seemingly healthy pregnant woman a diagnosis of an incurable disease. In addition there are serious personal, social and legal consequences of testing positive for HIV. The well documented stigma and discrimination that persists for people living with HIV and AIDS further contributes to the diminished future quality of life for newly diagnosed people.

- HIV counselling and testing in pregnancy provides an important and unique treatment opportunity for asymptomatic HIV-positive women.

  For many women, consultations for prenatal care may be their only occasions of access to medical care. This is likely to be the case among the most marginalised women who comprise those women at increased risk of HIV infection. As such, effective and sensitive PHCT presents not only an important but also unique opportunity for women for early diagnosis and to learn of and consider the benefits of early treatment.

- HIV counselling and testing in pregnancy provides an important and unique prevention opportunity for HIV-negative women.

  The comprehensive process of HIV counselling and testing in pregnancy offers the opportunity to raise awareness of HIV risk and prevention strategies among women testing HIV-negative who may have been previously unaware. It represents an important and unique opportunity to provide pregnant women who have tested HIV-negative with the information they may need to remain HIV-negative.

- Ensuring as many women as possible have the opportunity to accept HIV testing through an informed HIV counselling and testing process is an important public health prevention objective with unquestionable added value and importance for pregnant women and women considering pregnancy.

Organisation of the Thesis

Through a review of the literature in the PHCT and associated domains, **Chapter Two**, in its totality, descriptively constructs the epidemiologic, social, cultural, methodologic and policy context for the examination of the policy and practice of HIV counselling and testing in pregnancy.

There are five sections to the chapter. The first three discuss the literature addressing HIV infection among women and children in Canada, thus establishing not only epidemiologic and cultural context but the primacy of the need for this investigation. The fourth section considers the approach and results of other studies in the literature in the PHCT domain thereby contextualising the distinctiveness and establishing the utility of the parameters of the current study to prenatal HIV counselling and testing policy and programme development in Canada. The final section adds further context by critically discussing, through a review of international literature, the development and theoretical underpinnings of PHCT policy approaches. Establishing this policy context provides a framework within which the policy and practice implications of the current study can be understood.

Chapter Three describes how I undertook this research. It describes the construction of the investigation starting with the design, and situates myself, as the researcher, within the context of that design. The specific methods of the investigation are then described in terms of how I addressed the requirements of appropriateness and adequacy through the framework of the sampling strategy and the sample size. The collaborative work I undertook in engaging with

pregnant women; the process of the interview; and the methods I used to interpret the women's narratives are then subsequently detailed. The chapter concludes with information on the ethical approval process and a discussion of my responses to ethical concerns related to interviewing women in general and specifically in the HIV prevention domain.

Chapter Four opens with a descriptive profile of the pregnant women participants who worked with me on this study. The detailed description of the women's experiences of their pregnancies lays out the context within which they made decisions around prenatal HIV testing and the context in which they would experience the results of HIV testing. The chapter is then divided into three further sections each related to the women's experiences of the interconnected components of the HIV testing experience. The second section of this chapter describes the application of Ontario's prenatal HIV testing policy in terms of the women's experiences of the offer of the HIV test and details the nature of the women's decision making in response to that offer. For those women who did undergo testing, their experiences of waiting for the test results are described. This section is followed by an analysis of the women's experiences in terms of the established Canadian principles of HIV counselling and testing. The issues examined are the voluntary nature of the offer of the HIV test; informed consent and pre-test counselling; and post-test counselling. The chapter concludes with a description of the pregnant women's perspectives on best practices in prenatal HIV counselling and testing. Specifically, an interpretation of the pregnant women's recommendations in terms of when HIV counselling and testing should be offered; by whom; the way in which it should be offered; and what the experience of prenatal HIV counselling and testing (PHCT) should comprise.

The final chapter, **Chapter Five**, discusses the main findings of the study and the resulting implications for PHCT policy re-evaluation and redevelopment. The chapter begins with an assessment of the study limitations within which the findings can be considered. The strategies of triangulation and transferability

applied to enhance the validity and credibility of the findings are described. Methodologic and empirical conclusions are discussed. The final section of this chapter speaks to the fundamental objective in carrying out this research, namely that advancements in prenatal HIV testing policy are enabled through the integration of the perspectives and recommendations of the experts in prenatal HIV counselling and testing, the pregnant women themselves. This section therefore focuses on specific recommendations for policy and programme development derived directly from the analysis of the experiences of the pregnant women and their own perspectives on best practices in HIV counselling and testing in the prenatal context. In this way, this research can claim to be for women instead of simply research about women.

CHAPTER TWO
THE CONTEXT: LITERATURE REVIEW

Through a review of the literature in the prenatal HIV counselling and testing (PHCT) and associated domains, this chapter, in its totality, descriptively constructs the epidemiologic, social, cultural, methodologic and policy context for the examination of the policy and practice of HIV counselling and testing in pregnancy.

There are five sections to this chapter. The first three discuss the literature addressing HIV infection among women and children in Canada thus establishing not only epidemiologic and cultural context but also the primacy of the need for this investigation. The fourth section considers the approach and results of other PHCT studies in the literature thereby contextualising the distinctiveness and establishing the utility of the parameters of the current study to prenatal HIV counselling and testing policy and programme development in Canada. The final section adds further context by critically discussing, through a review of international literature, the development and theoretical underpinnings of PHCT policy approaches. Establishing this policy context provides a framework within which the policy and practice implications of the current study can be understood. A more detailed description introduces each section.

PERINATAL TRANSMISSION OF HIV

This section characterises perinatal HIV transmission and perinatal HIV transmission rates, and establishes the extent of perinatal HIV transmission in Canada and in Ontario in particular. The reported HIV-related behaviours, practices and risk conditions among the mothers of perinatally HIV-exposed and perinatally HIV-infected Canadian children in general and Ontario children in particular are described. Limitations in the epidemiological data resulting in likely underestimates of the extent of perinatal AIDS and the level of perinatal HIV infection in Canada are described and implications for the present study discussed.

Perinatal HIV Transmission

Perinatal transmission of HIV can occur in the uterus prior to birth (intrauterine),[90-92] during birth at the time of labour and delivery when the foetus makes contact with maternal blood and mucosa in the birth canal (intrapartum),[93] and following birth through breastfeeding (postpartum).[94] In the absence of breastfeeding, it is estimated that intrauterine transmission accounts for 25-40% of infection and 60-75% of transmission occurs during labour and delivery.[95] Among women who breastfeed, approximately 20-25% of perinatal infections are believed to be associated with intrauterine transmission, 60-70% with intrapartum transmission or very early breastfeeding and 10-15% with breastfeeding.[96] As a result of successful prevention interventions directed at late prenatal and intrapartum transmission, it is likely that among women who breastfeed, most notably in developing countries, there may well be a trend towards an increasing proportion of transmission related to breastfeeding. In fact, in a recent randomised clinical trial of formula feeding versus breastfeeding among women living with HIV in Kenya, 44% of perinatally transmitted HIV infection was attributed to breastfeeding.[97] Co-factors significantly associated with the risk of perinatal transmission include levels of maternal viral load,[98-101] timing of delivery after rupture of membranes,[102-104] mode of delivery,[9,105] and length of time breastfeeding.[56] No link has been established between perinatal transmission and maternal age, race/ethnicity, or history of giving birth to an HIV-positive child.[106]

Perinatal HIV Transmission Rates

The anticipated rate of perinatal transmission in the absence of preventive measures is estimated to be in the range 22–29%.[3,5,6] In 1994, the interim results of US Pediatric AIDS Clinical Trial Group Protocol 076 (PACT076) demonstrated that a combination of the oral administration of zidovudine (AZT) to HIV-positive pregnant women during their second and third trimesters, intravenous administration during labour and delivery, and oral administration to their infant for six weeks after delivery, could reduce this anticipated rate by

approximately two-thirds, from 25.5% to 8.3%.[3] Subsequent international studies of the administration of AZT in pregnancy confirmed these interim results or achieved even lower rates of perinatal HIV transmission.[51-56] In Canada, for example, one study completed in Vancouver, British Columbia found that

> *[i]n BC, between 1993 and 1996, the use of anti-retroviral therapy (AZT) reduced the likelihood of HIV transmission from mother to infant from 22% transmission among mother-infant pairs who had not received AZT, to 14% among mother-infant pairs who had received some AZT therapy and 5% among those who had received the full AZT protocol.*[5]

The choice of anti-retroviral therapy to treat the pregnant woman's illness and, or only, to reduce the likelihood that the virus will be transmitted to her foetus or infant has evolved over time and has impacted on perinatal transmission rates. In developing countries, recent clinical trials have demonstrated that a shorter course of monotherapy with AZT administered at 36 weeks gestation and during labour can reduce perinatal HIV transmission rates to less than 2%,[107-109] and even greater reductions have been achieved using single-dose nevirapine among breastfeeding African women.[110]

In Canada, prior to 1995, only monotherapy with AZT was used. However, data from the national surveillance programme of Paediatric Centres and HIV clinics in Canada, where 95% of diagnosed HIV-exposed infants are followed, show a steady increase in the percentage of pregnant women living with HIV whose anti-retroviral therapy comprises two or three drugs. In 1995, just 2% of HIV-treated pregnant women received combination therapy; in 1997, this proportion increased to 35%; and in 1998, the latest date for which data are available, 78% of HIV-treated pregnant women received two or three antiretroviral drugs. This change in treatment protocol has shown significant reductions in the rate of perinatal transmission among Canadian women from 4.8% among pregnant women living with HIV who received monotherapy with AZT to 2.5% among those women who received combination therapy.[111]

Perinatal AIDS[vi] in Canada

In Canada, the majority of reported cumulative AIDS cases with known exposure category among children under 15 years of age (paediatric AIDS cases) are attributed to perinatal transmission. Of the 208 cumulative paediatric AIDS cases reported to the Centre for Infectious Disease Prevention and Control (CIDPC) at Health Canada to the end of June 2002 (the latest date for which data are available), 164 (83%) are attributed to perinatal transmission. Fifteen percent occurred among children who had received blood or clotting factor, 1% was attributed to origin in an HIV-endemic country and 1% of reported cumulative AIDS cases among children under 15 years of age are attributed to other factors.[2]

Perinatal Positive HIV Test Reports in Canada

The long period of latency between infection with HIV and the onset of the clinical presentations of AIDS-defining illnesses, extended in recent years due to improvements in HIV treatment regimes, means that AIDS statistics no longer accurately represent the burden of HIV disease and thus the true extent of perinatally transmitted HIV infections. In fact, it is generally acknowledged that AIDS data can only contribute to an understanding of 10-year old trends in HIV infection.[15] HIV testing data are now increasingly used as an indication of the spread of the epidemic and of the changing profile of specific transmission routes.

Following the same exposure pattern of reported paediatric AIDS cases, the majority of cumulative positive HIV test reports with known exposure category among children under 15 years of age are attributed to perinatal transmission. Of the 652 paediatric positive HIV test reports reported to the CIDPC to the end of June 2002, 241 (68%) are attributed to perinatal transmission with the greatest proportion of remaining positive test reports (24%) occurring among children who had received blood or blood products.[2]

[vi] The Canadian surveillance definition of AIDS requires a positive HIV test result and the onset of one or more defined clinical diseases that characterise a weakened immune system.[2]

In addition to the data reported to the CIDPC, Canadian data on the number of positive HIV tests reported among infants known to be exposed perinatally to HIV infection are derived from the Canadian Perinatal HIV Database of the Canadian Perinatal HIV Surveillance Programme, coordinated by the Canadian Paediatric AIDS Research Group. The Canadian Perinatal HIV database contains data collected through a national non-nominal confidential survey of infants identified by paediatricians in tertiary care centres and by HIV specialists in HIV clinics across Canada as having been born to women living with HIV and AIDS.[112]

Table 1 shows, for the period 1984 to 2001, the cumulative number of Canadian perinatally HIV-exposed infants by geographic region and current HIV status. Québec reported the highest number of infants born to HIV-positive mothers at 516 of whom 169 infants have been diagnosed HIV-positive, followed by Ontario at 421 infants of whom 152 have been diagnosed HIV-positive. Atlantic Canada, which comprises all provinces east of Québec, had the lowest total number of infants born to HIV-positive mothers at 30, of whom nine have been diagnosed HIV-positive. However, examining the proportion of infants with a confirmed HIV positive diagnosis among infants with known HIV status, Ontario reported the highest proportion among all provinces. Thirty-eight percent of perinatally exposed infants in Ontario with known HIV status were confirmed HIV-positive compared with 35% in Québec and 31% in Atlantic Canada.[2]

Table 1

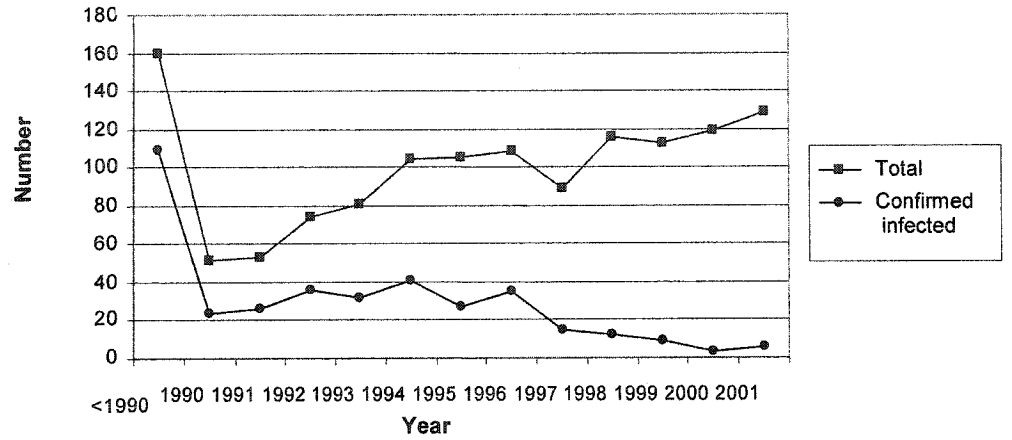
Cumulative Number of Canadian Perinatally HIV-exposed Infants by Geographic Region and HIV Infection Status 1984 - 2001

REGION	HIV INFECTION STATUS			TOTAL	
	CONFIRMED INFECTED	CONFIRMED NOT INFECTED	INFECTION STATUS NOT CONFIRMED	N	(%)
British Columbia	42	156	14	**212**	**15.2**
Alberta	25	112	16	**153**	**10.9**
NWT/Prairies	13	53	1	**67**	**4.8**
Ontario	152	247	22	**421**	**30.1**
Québec	169	313	34	**516**	**36.9**
Atlantic Canada	9	20	1	**30**	**2.1**
TOTAL	**410**	**901**	**88**	**1,399**	**100.0**

Overall, among the reported 1,399 infants born to Canadian women living with HIV and AIDS between 1984 and 2001, 30% have been confirmed HIV-positive. Among these 410 infants, 114 had died of AIDS, 199 were symptomatic, 46 remained asymptomatic, 13 had died of causes other than AIDS, and 38 had been lost to follow-up by the end of the study period. Sixty-four percent of the infants born to women living with HIV and AIDS were confirmed as HIV-negative, while the infection status of the remaining 6% could not be confirmed due to indeterminate HIV test results, death or loss to follow-up.[112]

In terms of temporal trends over the last decade, the annual number of infants born to women living with HIV or AIDS has increased from 56 infants born in 1991 to 138 infants born in 2001 as shown in Figure 1. However, the number of these infants with confirmed HIV-positive status has declined from a high of 41 infants in 1994 to three infants in 2000 and six infants in 2001 also shown in Figure 1.[113]

Figure 1
Reported Number of Canadian Perinatally HIV-exposed Infants
by Year of Birth and Current Status
< 1990 - 2001



The HIV-related behaviours, situations and structural factors associated with the HIV infection of the mothers of 1,384 of the infants born to HIV-infected women between 1984 and 2001 are shown in Table 2. The majority (68%) of known maternal HIV infections are attributable to sexual exposure, while almost one-third (30%) of cases among pregnant women who gave birth to a live infant are attributed to injection drug use.[112]

Table 2

Number of Canadian Perinatally HIV-exposed Infants
by Maternal Exposure Category
1984 - 2001

MATERNAL EXPOSURE CATEGORY												TOTAL	
Recipient of Blood Products		Recipient of Blood Transfusion		Sexual Exposure		Injection Drug Use		Other		Unknown			
n	%	n	%	n	%	n	%	n	%	n		N	%
1	0.07	24	2.0	907	68.0	403	30.0	2	0.15	47		**1,384**	**100**

Perinatal AIDS in Ontario

In Ontario, 44 AIDS cases, representing 0.6% of the total 6,918 AIDS cases reported to the Ontario AIDS Surveillance Programme by the end of 2000[vii], were attributed to perinatal transmission.[114]

Perinatal Positive HIV Test Reports in Ontario

A component of the larger Canadian Paediatric AIDS Research Group previously described, the Ontario HIV Paediatric Network was established in 1992 to collect information on infants born to women living with HIV and AIDS and receiving specialised care at hospitals in Ontario. The Hospital for Sick Children in Toronto, The Children's Hospital of Eastern Ontario in Ottawa, McMaster University Medical Centre in Hamilton, St Joseph's Health Centre in London and Hotel Dieu Hospital in Kingston have contributed cases to the Network to date which is co-ordinated by Dr. Susan King at the Hospital for Sick Children in Toronto.

To maintain the Ontario HIV Paediatric Network database, Network staff annually solicit information from the participating hospitals on newly diagnosed mother-infant pairs as well as updates on clinical information relating to previously reported cases. Data reported to the Network on newly diagnosed mother-infant pairs include:

- date of birth and sex of infant;
- maternal country of birth;
- maternal risk factors for HIV infection;
- history of prenatal zidovudine prophylaxis; and
- infection status of the infant: confirmed infected, confirmed uninfected, pending, unknown or lost to follow up.[114,115]

[vii] Provincial perinatal HIV transmission data are available for the year 2001.[118] However, these data exist only in draft form and, as national data are only currently (July 2003) available for the year 2000, provincial data are limited to the year 2000 for methodological rigour and also to allow for comparability with national data.

Data on 352 infants born to Ontario women living with HIV or AIDS were reported to the Network by the five participating hospitals between 1984 and 2000. These data appear under the "Provincial Data" column in Table 3. At the latest follow-up in 2000, the majority, 61% (204), of the 334 infants with known HIV status had been confirmed HIV-negative whereas over one third, 39%, (130) had been confirmed HIV-positive.[114]

Table 3

Status in 2000 of Children Born Between 1984 and 2000 to Ontario Women Living with HIV or AIDS

HIV STATUS										TOTAL	
Confirmed HIV-positive				Confirmed HIV-negative				Pending/ Unknown			
Provincial Data		National Data		Provincial Data		National Data		Provincial Data	National Data	Prov. Data	Nat. Data
n	%	n	%	n	%	n	%	n	n	N	N
130	39	**131**	38	**204**	61	**215**	62	**18**	**13**	**352**	**359**

For the same time period, 1984 to 2000, a slightly higher number of 359 infants born to Ontario women living with HIV or AIDS was reported to the Canadian Perinatal HIV Surveillance Programme. These data appear under the "National Data" column in Table 3. This higher number may reflect the fact that participating sites in the national programme are more extensive and varied than those in the provincial programme. Interestingly, although more HIV-exposed infants were identified, the positivity rate ratio in the national data set was somewhat lower than that in the provincial data set. Sixty-two percent of the HIV-exposed infants with known HIV status identified through the national programme have been confirmed HIV-negative and 38% confirmed to be living with HIV infection.[112]

In terms of provincial temporal trends of perinatal transmission, Table 4 shows the time period of birth of the 130 HIV-positive infants identified through the Ontario HIV Paediatric Network and the assigned exposure category of their mothers. The number of infants who contracted HIV perinatally rose steadily from the three-year period 1984-1987 when 19 infants were diagnosed HIV-positive to peaks of 27 and 29 respectively between the years 1992-1993 and between 1994-1995. However, commencing in 1996, as AZT was becoming increasingly recognised for its perinatal transmission-interruption properties, the number of infants born to women living with HIV or AIDS and diagnosed with HIV infection has been steadily declining to 10 infants between the years 1996 and 1997 and 11 infants between the years 1998 and 2000.[114]

Table 4

Number of Perinatally HIV-infected Infants in Ontario by Period of Birth and Exposure Category of Mother [a] 1984 – 2000

PERIOD OF BIRTH	EXPOSURE CATEGORY OF MOTHER									TOTAL
	IDU		HIV-endemic		Heterosexual		Transfusion		Unknown	
	n	%	n	%	n	%	n	%	n	n
1984-87	1	5.9	13	76.5	3	12.5	0	0.0	2	**19**
1988-89	1	7.1	5	35.7	7	50.0	1	7.1	3	**17**
1990-91	0	0.0	9	60.0	5	28.6	1	6.7	2	**17**
1992-93	1	4.0	17	68.0	7	28.0	0	0.0	2	**27**
1994-95	3	10.3	21	72.4	5	14.8	0	0.0	0	**29**
1996-97	0	0.0	9	90.0	1	12.5	0	0.0	0	**10**
1998-00	1	9.1	5	45.5	5	33.3	0	0.0	0	**11**
TOTAL	**7**	5.8	**79**	65.3	**33**	27.3	**2**	1.7	**9**	**130**

[a] Percentages based on total number of positive HIV test reports for which exposure category was reported.

As can also be seen from Table 4, the trend for the majority of perinatally HIV-infected infants in Ontario to have mothers born in an HIV-endemic country[viii] has been consistent since the Network first began collecting data, with the exception of the periods 1988-1989 and 1998-2000. Overall, between 1984 and 2000, of the reported perinatally HIV-infected infants in Ontario where maternal exposure category was known, 65% were born to women originating from an HIV-endemic country, 27% to women who reported sexual contact with a male partner as the most likely route of HIV transmission, and 6% to women who reported injection drug use.[114]

Consistent with documented regional variations in AIDS case reports and positive HIV test reports among Ontario women, the majority (88%) of the perinatally HIV-infected infants in Ontario were born in the region of the two health units comprising the two major urban centres of Toronto and Ottawa. As depicted in Table 5, 61% of perinatally HIV-infected infants in Ontario were born in the catchment area of the Metro Toronto health unit, 27% were born in the catchment area of the City of Ottawa health unit, and 12% of perinatally HIV-infected infants in Ontario were born in other areas of the province.[114]

[viii] In provincial HIV/AIDS reporting, the term HIV-endemic refers to origin in a country in which the population prevalence of HIV infection is above 1% and in which the predominant mode of transmission is heterosexual intercourse accounting for at least 50% of transmissions. As discussed later in this chapter, for Ontario women, this term largely applies to women born in the Caribbean or Africa[273].

Table 5

Location of Health Institution Reporting Perinatally HIV-infected Infants 1984 - 2000

LOCATION OF HEALTH INSTITUTION	PERINATALLY HIV-INFECTED INFANTS: NUMBER	PERINATALLY HIV-INFECTED INFANTS: PROVINCIAL PERCENTAGE
Ottawa	35	26.9
Toronto	79	60.8
Hamilton	7	5.4
London	8	6.2
Windsor	1	0.7
TOTAL	**130**	**100**

Limitations in Perinatal AIDS and HIV Surveillance Data

Data relating to AIDS case reports among perinatally infected infants at both the federal and provincial levels underestimate perinatal AIDS prevalence and perinatal AIDS incidence. Perinatal AIDS case reports only represent those infants who were presented for medical care, who were diagnosed with AIDS, and whose diagnoses were reported to either provincial or territorial public health officials for provincial/territorial surveillance and to the CIDPC for national surveillance. Thus, the cumulative and annual numbers of perinatal AIDS case reports are unlikely to reflect the actual number of perinatal transmissions or the rate at which new transmissions are occurring, both of which are likely to be higher.

Similarly, data relating to perinatal positive HIV test reports are limited to those infants who were tested, were diagnosed and reported HIV-positive to provincial/territorial health authorities, and whose positive HIV test result was reported voluntarily to the CIDPC by these authorities. These reported data are likely to be underestimates and do not represent true perinatal HIV prevalence or

HIV incidence. In fact, the CIDPC estimates that up to one third of prevalent HIV infections in Canada may not be diagnosed.[116] True perinatal HIV prevalence and incidence rates are therefore likely to be higher than those reported. A survey of provincial and territorial perinatal HIV surveillance reporting, carried out by Chevalier and colleagues in 2002[117], suggests other factors potentially impacting on accurate reporting at the federal level. Preliminary results document duplicate perinatal HIV test records due to multiple confirmatory testing; inconsistent reporting of maternal HIV risk; and, in three provinces, the absence of HIV surveillance data on children under two years of age.

The discussion in this section demonstrates a further minor limitation in perinatal HIV transmission data in that depending on the source of the data, final results may vary slightly. Additionally, as the data on perinatally exposed infants are restricted to infants born to women whose positive HIV status was known in the prenatal period, they do not reflect all perinatally transmitted HIV infections as the number of HIV-positive infants born to pregnant women whose HIV status was unknown at the time of delivery are not included. The calculation of perinatal HIV transmission rates from these data would therefore be invalid.

Implications for the Study of HIV Counselling and Testing among Pregnant Women in Ontario

The relevance and urgency of working with pregnant women in devising acceptable and accessible programmes for the prevention of perinatal HIV transmission is contextualised in the foregoing data. Despite the availability of antiretroviral therapy to reduce the possibility of a woman living with HIV giving birth to a child with HIV infection, perinatal transmission of HIV persists and, in Ontario in particular, assumes a high profile. However, it is clear that the incidence of perinatal transmission at both the federal and provincial level is declining, co-incident with the advent of interventions with perinatal transmission-interruption properties. Ensuring that as many women as possible have the opportunity to learn of their HIV status and thus be in a position to take

advantages of such treatments is clearly of paramount importance. This outcome can be accomplished by PHCT programmes which are maximally accessible and acceptable to pregnant women. Such programmes are more likely to evolve if they incorporate the perspectives of pregnant women on best practices in PHCT.

Although in absolute terms, the number of perinatally transmitted HIV infections in Ontario is clearly declining, the proportion of infants born to women living with HIV and subsequently confirmed HIV-positive is the highest in Canada. For example, Québec reported a higher number of births to women living with HIV but a lower proportion of these infants were subsequently confirmed to be HIV-positive. This finding suggests perhaps that PHCT programmes in Ontario may be less than optimally effective in reducing HIV transmission and highlights the relevance of further study of the policy and practice of PHCT in Ontario.

Perinatal HIV data also clearly demonstrate that women born in HIV-endemic countries and women who inject drugs may well have particular issues related to prenatal testing and this situation is of particular concern in Ontario. Including women from HIV-endemic countries and women who inject drugs as well as heterosexually active women in the study of PHCT among women in Ontario is clearly indicated. In addition, although arguably a population size effect, as the majority of perinatally HIV-infected Ontario children were born in Metro Toronto and Ottawa, the relative regional composition of the women in the study needs to reflect these ratios.

CANADIAN WOMEN AND HIV INFECTION

The risk of perinatal HIV transmissions increases as levels of HIV incidence and HIV prevalence among women increase. This second section of Chapter One discusses epidemiologic data defining and characterising the escalating HIV epidemic among Canadian and Ontario women. The section ends with a consideration of the inherent limitations in the data and the implications of the data for the study of HIV counselling and testing among pregnant women in Ontario.

AIDS among Women in Canada

In Canada, since the beginning of the HIV epidemic in the early 1980s, the number of reported AIDS cases among women (adolescent and adult women aged 15 years and over), and the proportion of all adult reported AIDS cases comprised by women has been increasing. Of the total 18,124 cumulative AIDS cases among adults reported to the CIDPC to the end of June 30, 2002, 1,437 (8%) were among women. However, in the context of significantly declining Canadian rates of AIDS incidence, Canadian women represent an increasing proportion of the total number of annual reported AIDS cases among adults in which gender and age are known. Prior to 1993, 6% of reported AIDS cases were among women. This proportion rose to 8% in 1995; to 15% in 2001; and has since increased to 17% in the first 6 months of 2002. Women make up the largest proportion of adult AIDS cases in the 15-29 years age group. In this age group, the proportion of women among reported AIDS cases rose from 10% before 1993 to 47% in 2001. The proportion was 43% between January and June 2002.[2]

The profile of HIV-related behaviours, situations and structural factors associated with reported AIDS cases among women has shifted over time. As shown in Table 6, the greatest proportion of AIDS cases diagnosed among adolescent and adult women prior to 1997 was attributed to sexual contact with a male partner at risk of HIV[ix]. For the next four years, from 1997 to 2000, injection drug use was the exposure category reported by the greatest proportion of women diagnosed with AIDS in each of the four years: 35%, 46%, 35% and 37% respectively. In 2001 however, the majority of AIDS cases (51%) among women was attributed to origin in a pattern II country, that is, a country in which HIV is endemic[x]. In the first half of 2002, the previous pattern of the greatest proportion of reported AIDS cases occurring among women who reported injection drug use as a risk factor resumes.[2]

[ix] In federal HIV/AIDS reporting, a heterosexual partner at risk of HIV is someone who is either HIV-positive or who is at increased risk of HIV infection such as an injection drug user, someone from an HIV-endemic country, or a bisexual male (women only).[2]

[x] In federal HIV/AIDS reporting, the term HIV-endemic country refers to a country in which the predominant means of HIV transmission is heterosexual contact.[2]

Table 6

AIDS Cases among Canadian Women ≥ 15 years by Exposure Category and Year of Diagnosis 1997 – 2002 (June)

	YEAR OF DIAGNOSIS												TOTAL	
	< 1997		1997		1998		1999		2000		2001		2002 (June)			
EXPOSURE CATEGORY	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%[a]**
IDU	194	18.9	34	35.4	41	46.1	25	34.7	17	37.0	3	7.0	5	45.5	319	23.0
Blood/blood products																
a) recipient of blood	105	10.2	2	2.1	2	2.2	3	4.2	0	0.0	2	4.7	0	0.0	114	8.2
b) recipient of clotting factor	13	1.3	1	1.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	14	1.0
Heterosexual contact/endemic																
a) origin in a pattern II country	299	29.1	22	22.9	19	21.3	22	30.6	13	28.3	22	51.2	3	27.3	400	28.9
b) sexual contact with a person at risk	374	36.4	26	27.1	22	24.7	13	18.1	11	23.9	9	20.9	1	9.1	456	32.9
Occupational exposure	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	0.1
No identified risk - Heterosexual	40	3.9	11	11.5	5	5.6	9	12.5	5	10.9	7	16.3	2	18.2	79	5.7
Other	1	0.1	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	0.1
No identified risk	38		4		4		5		0		1		1		53	
TOTAL	1,065	100	100	100	93	100	77	100	46	100	44	100	12	100	**1,437**	100

[a] Percentages based on total number minus those reports for which there was no identified risk.

Overall, of the cumulative 1,437 AIDS cases among Canadian women reported to the CIDPC by the end of June 2002, as shown in Table 6, the greatest proportion (33%) was attributed to sexual contact with a male partner at risk of HIV, the next highest proportion (29%) to origin in a pattern II country, 23% to injection drug use and 15% to other factors.[2]

HIV Infection among Women in Canada

Whereas AIDS data can contribute to an understanding of trends in HIV infections acquired some ten years ago, positive HIV test reports provide an estimate of more recent infections.[15] In Canada, HIV infection is now legally notifiable in all provinces and territories. A notifiable disease is one that is considered to be of such importance to public health that its occurrence is required to be reported to public health authorities. HIV reporting legislation has been in place since the mid-to-late 1980s in most provinces with the exception of Québec and British Columbia where HIV infection became reportable only in April 2002 and May 2003 respectively. The provincial and territorial health departments receive nominal or non-nominal information from their laboratories and physicians concerning the person testing positive which includes age, gender, HIV-related risks and in some provinces, ethnicity. The provinces and territories voluntarily share these HIV surveillance data with the CIDPC as HIV infection is not legally notifiable at the national level. All positive HIV test reports are provided non-nominally to the CIDPC.

By the end of June 2002, a total of 6,250 positive HIV test reports among women had been reported to the CIDPC by the provinces and territories, representing 15% of the cumulative number of positive HIV test reports with known age and gender.[15] Since 1996 the greatest proportion, 37%, of annual positive HIV test reports among adolescent and adult women has been reported among women aged 30 to 39 years of age with women aged 20 to 29 years of age representing the next highest proportion, 35%.[2] Examining temporal trends in HIV surveillance data, the pattern of increasing HIV infection among women seen in reported AIDS case data is replicated. Women account for a growing proportion of cumulative

positive HIV test reports with known age and gender among adults in Canada. Before 1996, adult and adolescent women represented just 11% of all reports of positive HIV test results among adults. This proportion increased sharply in 1998 to 22% and increased again to 25% in 2001. In the first half of 2002, this proportion increased slightly to 26% of all positive HIV test reports with age and gender classification.[2,15] The proportion of women among all adult positive HIV test reports varies considerably with age and is highest among adolescents and young adults. In 2001, women accounted for 45% of reports of positive HIV test results among adults aged 15 to 29 years, an increase from 41% in 2000. In the first half of 2002, this proportion decreased slightly to 43%.[2,15]

Table 7 depicts the relative contribution of HIV-related behaviours, situations and structural factors to this level of HIV infection among adolescent and adult women, demonstrating that, in contrast to AIDS case report data, the HIV-related risk exposure profile has been largely consistent since 1998.

At the end of June 2002, injection drug use accounted for the greatest proportion (40%) of cumulative HIV test reports among adolescent and adult women and since 1997, this has been the HIV risk-related exposure category reported annually by the greatest proportion of women receiving positive HIV test reports. Although sexual contact with a person at risk accounted for only 9% of cumulative HIV test reports due to earlier combining of this category with that of origin in a pattern II country, since 1998, with the exception of the year 2000, this exposure category has been reported by the second-highest proportion of Canadian women receiving positive HIV test results. Similarly, although origin in a pattern II country accounted for only 4% of cumulative HIV test reports, this is an exposure category that has been steadily increasing since 1998. Interestingly, the third highest proportion (12%) of cumulative HIV test reports among adolescent and adult women was among women who reported only heterosexual contact as a possible risk factor where nothing was known about the HIV-related factors associated with the male partner, an increasing trend since 1997.[2]

Table 7

Positive HIV Test Reports among Canadian Women ≥ 15 years by Exposure Category and Year of Test 1985 – 2002 (June)

	YEAR OF TEST														TOTAL	
	1985-96		1997		1998		1999		2000		2001		2002 (June)			
EXPOSURE CATEGORY	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%[a]**
IDU	692	38.8	126	45.2	98	38.7	126	47.9	95	39.7	87	32.6	44	35.5	1,268	39.5
Blood/blood products[b]																
a) recipient of blood/blood products	161	9.0	4	1.4	2	0.8	1	0.4	0	0.0	2	0.7	0	0.0	170	5.3
b) recipient of blood	n/a	n/a	n/a	n/a	7	2.8	2	0.8	3	1.3	2	0.7	2	1.6	16	0.5
c) recipient of clotting factor	n/a	n/a	n/a	n/a	0	0.0	0	0.0	1	0.4	0	0.0	0	0.0	1	0.0
Heterosexual contact/endemic[b]	691	38.8	89	31.9											780	24.3
a) origin in a pattern II country	n/a	n/a	n/a	n/a	16	6.3	27	10.3	30	12.6	33	12.4	20	16.1	126	3.9
b) sexual contact with a person at risk	n/a	n/a	n/a	n/a	75	29.6	62	23.6	46	19.2	82	30.7	30	24.2	295	9.2
No identified risk– HET	128	7.2	38	13.6	43	17.0	37	14.1	55	23.0	51	19.1	27	21.8	379	11.8
Other	111	6.2	22	7.9	12	4.7	8	3.0	9	3.8	10	3.7	1	0.8	173	5.4
No identified risk	347		16		15		18		20		12		10		438	
Not reported[c, f]	1,838		203		208		243		228		250		161		3,131	
TOTAL[d, e]	3,968	100	498	100	476	100	524	100	487	100	529	100	295	100	**6,777**	100

[a] Percentages based on total number minus reports for which exposure category was not reported or for which there was no identified risk.

[b] Prior to 1998, blood/blood products and heterosexual contact/endemic were combined exposure categories, but have since been separated where possible for reporting purposes.

[c] Information on exposure categories of individuals who have tested positive for HIV is not available for Québec.

[d] Prior to 1998, positive HIV test reports from Alberta were not available by both age group and gender. Therefore, paediatric data are included with adult data.

[e] Prior to June 2002, 11 positive HIV test reports between January and April 1998 were not reported for Alberta.

[f] Prior to 1998, HIV data from Prince Edward Island were not available by exposure category.

AIDS among Women in Ontario

Reporting of AIDS cases in Ontario was initiated informally in 1982 and expanded into the official surveillance system, the Ontario AIDS Surveillance Programme (OASP), when AIDS became a reportable disease in 1983. AIDS cases are reported to local public health units and forwarded to the Public Health Branch of the Ontario Ministry of Health and Long Term Care (OMHLTC).[118]

Of the 1,536 cumulative AIDS cases among all Canadian females (children, and adolescent and adult women combined) reported to the CIDPC by the end of June 2002, Ontario reported the second highest number, 471 cases, relative to all other Canadian provinces and territories as shown in Table 8. Québec reported the highest number of cases (696) and British Columbia the third highest (195), likely demonstrating an overall population size effect.[2]

As shown in Table 8, the average gender ratio of reported AIDS cases in Canada is 11 reported AIDS cases among males of all ages to one reported AIDS case among females of all ages. Together with Prince Edward Island and Nova Scotia, Ontario reported an above average ratio of 14 AIDS cases among males of all ages to each reported AIDS case among females of all ages. In contrast, females of all ages in the Yukon represented a much greater proportion of all territorial AIDS cases, with a gender ratio of two AIDS cases among males of all ages to each AIDS case among females of all ages.[2]

Table 8

AIDS Cases among Canadians of All Ages by Province/Territory and Gender to June 30, 2002

PROVINCE/TERRITORY	NUMBER OF CASES		RATIO
	MEN	WOMEN	MEN:WOMEN
British Columbia	3,002	195	15:1
Yukon	4	2	2:1
Alberta	1,034	69	15:1
Northwest Territories	17	5	3:1
Nunavut [a]	0	0	-
Saskatchewan	152	30	5:1
Manitoba	186	16	12:1
Ontario	6,663	471	14:1
Québec	5,247	696	8:1
New Brunswick	134	14	10:1
Prince Edward Island and Nova Scotia	275	20	14:1
Newfoundland	68	18	4:1
TOTAL [b]	**16,782**	**1,536**	**11:1**

[a] Data prior to 2000 are not available for Nunavut as it became a Canadian territory in April 1999 and began reporting in 2000.

[b] Numbers exclude 18 AIDS cases for which gender was not reported or was reported as transgender (15 in British Columbia, 2 in Alberta and 1 in Ontario).

At the provincial level of reporting AIDS cases to the OASP, since 1981 7,091 cases had been reported by the end of May 2002, of which 472 (7%) were among female children and adolescent and adult women (females)[xi]. However, reflecting the national trend of an increasing annual proportion of AIDS case reports among women of all ages relative to all AIDS case reports for which gender is known, the proportion of AIDS cases among Ontario females reported at the provincial level has increased from less than 11% for the period 1981 to 1996, to 19% of all

[xi] Unlike federal HIV/AIDS surveillance reporting, overall HIV/AIDS data for Ontario are not stratified by age into paediatric (<14years) and adult data (≥ 15years). The term female is used in this section of the thesis to describe female children and adolescent and adult women.

AIDS cases reported in 1998. In 2000, 12% of all AIDS cases reported were females, a proportion that increased dramatically to 18% in 2001[xii].[118]

The majority (54%) of the AIDS cases among females reported to the OMHLTC between 1981 and 2001 occurred among females from the two health regions comprising the major urban centres of Toronto and Ottawa. As shown in Table 9, 41% of all reported AIDS cases occurred among females residing in the catchment area of the Metro Toronto health unit, 13% were among females residing in the catchment area of the City of Ottawa health unit, and 46% of reported AIDS cases were among females from other areas of the province.[118]

Table 9

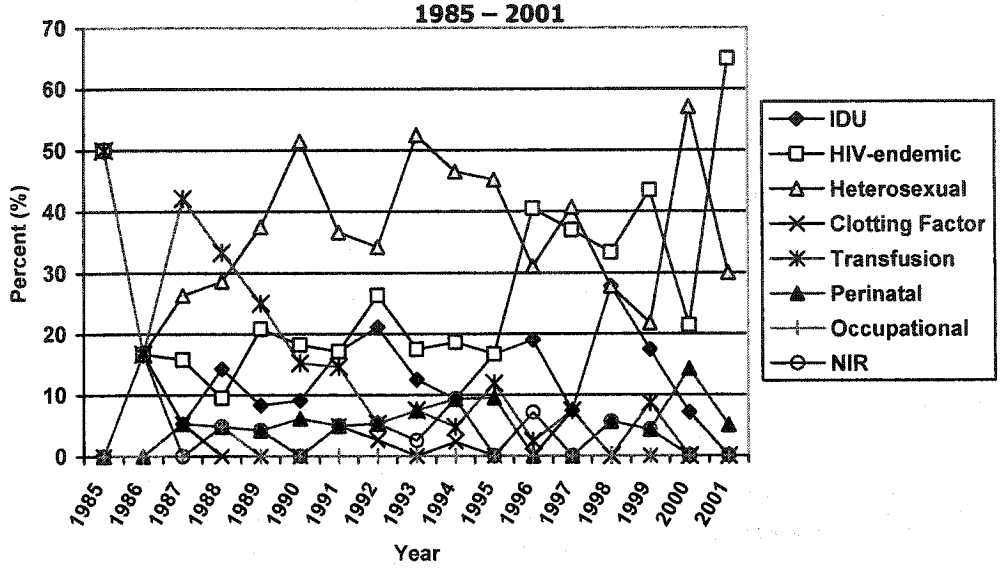
Location, by Public Health Unit, of AIDS Cases among Females in Ontario 1981 - 2001

LOCATION	NUMBER	PERCENTAGE
Northern	21	4.4
Ottawa	63	13.3
Eastern Other (Kingston)	19	4.0
Metro Toronto	194	41.1
Central East Other	82	17.4
Central West (Hamilton)	46	9.8
Southwest	47	9.9
TOTAL	**472**	**100**

[xii] Provincial data on AIDS cases and HIV-positive diagnoses for 2001 are in draft form[118] at the present time (July 2003) and should be treated with some caution pending confirmation.

Temporal trends in HIV-related risk exposures associated with these AIDS cases are shown in Figure 2 and are particularly interesting. Overall HIV-related risk exposures associated with cumulative AIDS cases for a slightly longer period, 1981 to 2001, are shown in Table 10.[118]

Figure 2
Temporal Trends in Exposure Category Associated with AIDS Cases among Females in Ontario 1985 – 2001



Overall, the greatest proportion (38%) of cumulative reported AIDS cases between 1981 and 2001 among females in Ontario was attributed to sexual contact with a male partner. However, cases attributed to this risk exposure category are perhaps the most unstable of any category as depicted in Figure 2. For example, a recent substantial increase to a proportion of 57% in 2000 was preceded by a smaller proportion (22%) in 1999 and followed by 30% in 1998. Proportions for the period overall ranged from 17-57%.

The next highest proportion of cumulative AIDS cases, 26%, was among females born in HIV-endemic regions with the proportion associated with this risk exposure category ranging between 20-40% from 1996 to 2000. However, 65% of cases was among females born in HIV-endemic regions in 2001 and this increase was statistically significant ($p<0.001$). The next highest proportion of cumulative

AIDS cases, 14%, was attributed to injection drug use, a proportion initially relatively stable over the period but which has also fluctuated between 0% and 28% over the last five years. The decrease in the last two years of 2000 and 2001 from previous years was borderline significant.[118]

Table 10

AIDS Cases among Females in Ontario by Exposure Category 1981 – 2001

EXPOSURE CATEGORY	NUMBER	PERCENTAGE
Injection drug use	66	14.0
HIV-endemic	123	26.1
Heterosexual	179	37.9
Clotting factor	8	1.7
Transfusion	51	10.8
Perinatal	26	5.5
Occupational	1	0.2
No Identified Risk (NIR)	18	3.8
TOTAL	**472**	**100.0**

HIV Infection among Women in Ontario

Of all the 6,713 cumulative positive HIV test reports among all Canadian females (children, and adolescent and adult women combined) reported to the CIDPC up to the end of June 2002, Ontario reported the highest number, 2,647, relative to all other Canadian provinces and territories as shown in Table 11. Québec reported the second highest number of positive HIV test reports (1,981) followed by British Columbia (1,400).

Considering the relative provincial gender composition of positive HIV test reports reported to the CIDPC, shown also in Table 11, Ontario reported a higher HIV-positive male-to-female ratio than the national average of six positive HIV test reports among males of all ages to each positive HIV test report among

females of all ages. Together with British Columbia and New Brunswick, Ontario had the highest HIV-positive male-to-female ratio of seven positive HIV test reports among males of all ages to each report among females of all ages. In the Yukon and Alberta, females of all ages represented a greater proportion of all positive HIV test reports, with a gender ratio of two positive HIV test reports among males of all ages to each report among females of all ages.[2]

Table 11

Positive HIV Test Reports among Canadians of All Ages by Province/Territory and Gender 1985 – 2002 (June)

PROVINCE/TERRITORY	NUMBER OF CASES		RATIO [a] MEN:WOMEN
	MEN	WOMEN	
British Columbia [b]	9,129	1,400	7:1
Yukon	24	11	2:1
Alberta [c,d]	508	233	2:1
Northwest Territories	26	6	4:1
Nunavut [f]	0	0	-
Saskatchewan	290	105	3:1
Manitoba	772	175	4:1
Ontario [b]	18,985	2,647	7:1
Québec [b, e]	8,341	1,981	4:1
New Brunswick	227	31	7:1
Prince Edward Island and Nova Scotia	500	77	6:1
Newfoundland	163	47	3:1
TOTAL	**38,965**	**6,713**	**6:1**

a Ratio based on those reports for which gender was reported.

b Data based on positive serology results for cases > 2 years of age only for Ontario (starting in 2000), Québec and British Columbia.

c Prior to 1998, positive HIV test reports with both age and gender information were not available from Alberta, therefore these reports are not included in this table.

d Prior to June 2002, 11 positive HIV test reports between January and April 1998 were not reported for Alberta.

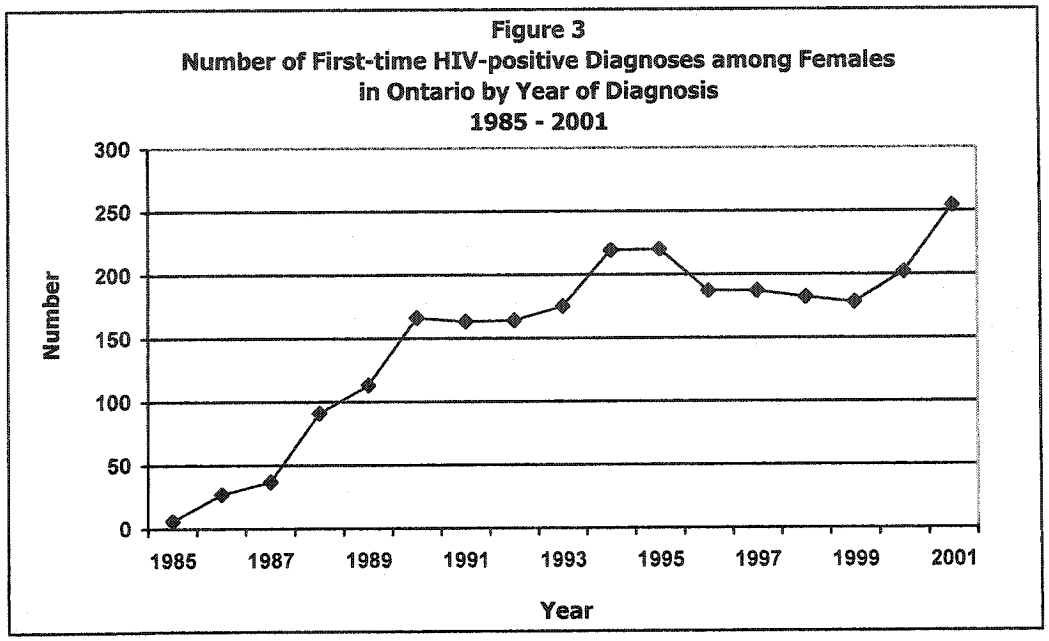
e For Québec, the number of positive HIV test reports is based on the minimum number of HIV positive individuals.

f Data prior to 2000 are not available for Nunavut as it became a Canadian territory in April 1999 and began reporting in 2000.

In terms of reporting HIV positive results at the provincial level in Ontario, legislation has been in place since 1985 requiring laboratories and physicians to report HIV infection to public health officials.[119]

The trend of increasing reported cases of HIV infection among women seen in national HIV data is reflected at the provincial level. Data from the HIV Laboratory, Central Public Health Laboratory, OMHLTC, indicate that among individuals newly testing positive for HIV, an increasing number and proportion are females. As depicted in Figure 3, the number of first-time HIV-positive diagnoses among females in Ontario has increased from six reported cases in 1985 to a high of 220 first-time HIV-positive diagnoses in 1995, declined slightly to just below 190 cases each year between 1996 and 1999 and increased again to 202 in 2000. In 2001, 254 females received first-time HIV-positive diagnoses, the highest number ever recorded.

Consistent with this increase in actual numbers of first-time HIV-positive diagnoses, the proportion of all first-time HIV-positive diagnoses comprised by females also increased. In 1985, approximately 2% of first-time HIV-positive diagnoses in Ontario was among females. This proportion increased to 12% in 1993; to 17% in 1994; and plateaued at approximately 20% in the three-year period from 1997 to 1999. In 2000, the proportion of all first-time HIV-positive diagnoses in Ontario comprised by females increased to 23% and in 2001, the latest year for which data are available, this proportion increased to 26% The increasing trend in the proportion of cumulative first-time HIV positive diagnoses comprised by females between 1985 and 2001 is strongly significant ($p<0.0001$).[118]



Of particular relevance to the study of perinatal HIV transmission in Ontario are the data in Table 12 showing the number and proportion of first-time HIV-positive diagnoses among females in Ontario by age group at diagnosis. Nearly three-quarters (73%) of all first-time HIV-positive diagnoses occurred among women in the primary childbearing years of 15 – 39.[118]

Table 12
First-time HIV-positive Diagnoses among Females in Ontario
by Age Group at Diagnosis
1985 - 2001 [a]

AGE GROUP	NUMBER	PERCENTAGE	AGE GROUP	NUMBER	PERCENTAGE
< 1	167	6.8	35 – 39	335	13.7
1 – 14	59	2.4	40 – 44	179	7.3
15 – 19	84	3.4	45 – 49	113	4.6
20 – 24	319	13.1	50 – 54	57	2.3
25 – 29	497	20.3	55 – 59	38	1.6
30 – 34	539	22.1	60+	57	2.3
			Unknown	127	
Total	**2,571**	**100.0**			

[a] Restricted to cases with known age at diagnosis.

Again, reflecting the regional variations documented in AIDS case reports among Ontario females, the majority (70%) of positive HIV test reports reported to the OMHLTC between 1985 and 2001 were among females from the two health units comprising the major urban centres of Toronto and Ottawa. As shown in Table 13, 51% of all first-time HIV-positive diagnoses occurred among females residing in the catchment area of the Metro Toronto health unit, 19% occurred among females residing in the catchment area of the City of Ottawa health unit, and 30% of positive HIV test reports occurred among females from other areas of the province.[118]

Table 13

Location, by Public Health Unit, of First-time HIV-positive Diagnoses among Females in Ontario [a]
1985 - 2001

LOCATION	NUMBER	PERCENTAGE
Northern	92	3.8
Ottawa	453	18.9
Eastern Other (Kingston)	70	2.9
Metro Toronto	1,26	50.8
Central East Other	178	7.4
Central West (Hamilton)	176	7.4
Southwest	209	8.8
TOTAL	**2,396**	**100**

[a] Excludes first-time diagnoses among those with unknown gender or for whom public health unit was not stated.

The HIV-related risk exposures reported to be associated with these positive HIV test reports reflect a markedly different profile from that associated with HIV prevalence among all Canadian women and a slightly different profile in relation to the exposures associated with AIDS case reports among females in Ontario. As shown in Table 14 and consistent with Ontario AIDS case report data, the greatest proportion (28%) of the 2,720 positive HIV test reports among females in Ontario

recorded between 1985 and 2001 was attributed to high-risk heterosexual contact, that is, sexual contact with a male partner at increased risk of HIV infection[xiii].

Table 14

First-time HIV-positive Diagnoses among Females in Ontario by Exposure Category [a] 1985 - 2001

EXPOSURE CATEGORY	NUMBER	PERCENTAGE
Injection drug use	510	18.8
Clotting factor	35	1.3
Transfusion	195	7.2
HIV-endemic	679	25.0
High Risk : Heterosexual	747	27.5
Low Risk : Heterosexual	363	13.4
Perinatal[b]	151	5.6
Other[c]	39	1.4
TOTAL	**2,720**	**100.0**

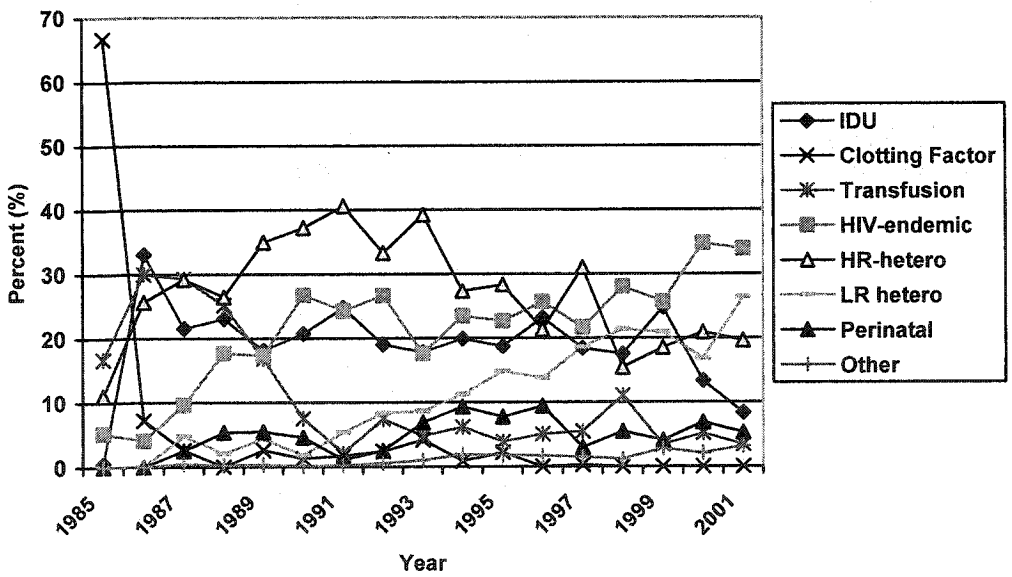
a Unknown gender assigned according to the distribution of those with known gender; unknown exposure category assigned according to proportion among the known.
b Includes infants with maternal HIV antibodies who are not infected.
c Includes needle stick, acupuncture, tattoo, etc.

Overall, cases attributed to injection drug use accounted for 19% of Ontario's cumulative first-time HIV diagnoses among females during this period. However, as shown in Figure 4, proportions have varied to some degree, but were mostly in the range of 18-25% from 1987 to 1999 but decreased to 13% in 2000 and 8% in 2001. This latter statistic is, of course, in sharp contrast to the much greater contribution of injection drug use to HIV prevalence among all Canadian women. Females from HIV endemic regions accounted for a quarter (25%) of Ontario's cumulative first-time HIV diagnoses. In contrast to injection drug use however, positive HIV diagnoses among these females have been increasing gradually to a

[xiii] In provincial HIV/AIDS reporting, a sexual partner at risk of HIV infection is someone who is known to be HIV-positive or who is at high risk of HIV infection such as a bisexual male (women only), an injection drug user, a clotting factor recipient or someone from an HIV-endemic region.[114]

plateau of 22-28% from 1990 to 1999. However, they accounted for about 35% of cases in the two most recent years. The difference was statistically significant ($p<0.00001$). Thirteen percent of first-time HIV-positive diagnoses among women are attributed to low-risk heterosexual contact, that is, sexual contact with a male partner not known to be HIV-positive or at increased risk of HIV infection. Low risk heterosexual women accounted for less than 10% until 1993, but increased to over 20% in the last four-year period. Clearly this is a newly emerging HIV risk exposure category and HIV risk-related practice among women in Ontario not yet reflected in AIDS case report data.[118]

Figure 4
Temporal Trends in Exposure Category Associated with First-time HIV-positive Test Reports among Females in Ontario 1985 - 2001



Limitations in AIDS and HIV Surveillance Data

The limitations in perinatal HIV transmission data previously discussed apply equally to AIDS case report data and positive HIV test report data at both the federal and provincial level. Levels of AIDS and HIV prevalence and among Canadian and Ontario women are likely to be higher.

Data describing the number of new HIV infections in each year are subject to further limitations. Not all women whose positive HIV results are reported in any given year would have become infected in the year in which their infection was reported, and only a proportion will have become infected in the year in which they are tested. In fact, using enhanced sources of data including AIDS case reports, provincial HIV testing databases, population-based surveys, targeted epidemiologic studies, and census data, the CIDPC has estimated that in 1996 and 1999, women accounted for more than one of every five infections in Canada, a proportion much higher than that documented using the more usual sources of surveillance data.[120]

Implications for the Study of HIV Counselling and Testing among Pregnant Women in Ontario

From absolute and relative measures of AIDS case reports and positive HIV test reports at the national and provincial levels, the picture emerges in Canada of a steady and rapidly increasing epidemic of HIV infection among women, suggesting increased potential for perinatal HIV transmissions.

From a national perspective, the high and increasing number of reported AIDS cases among women in Ontario, which is the second highest reported in Canada, and the even higher number of positive HIV test reports, which is the highest in Canada, point to the urgent utility and relevance of working with women in Ontario to assess their experiences of HIV counselling and testing in the prenatal context and their perspectives on best practices. From a provincial perspective, the dramatic increase in AIDS case reports and the statistically significant trend in

the increasing number of HIV positive test reports among females in Ontario further support the importance and relevance of the study to Ontario.

As the majority of AIDS diagnoses and the majority of first-time HIV positive diagnoses have occurred among women residing in Metro Toronto and Ottawa, the relative regional composition of the women in the study needs to reflect these ratios. It is also clear that an inclusive group of pregnant women need to be included in the study: women at higher risk of HIV infection through sexual contact with a male partner at risk of HIV; women born in HIV-endemic countries; and women at risk of HIV infection through their injection drug use practices. The experiences and perspectives of women whose only HIV-related risk appears to be heterosexual contact with a low-risk male partner also need to be included as the number of infections occurring among this group of women shows a recent increase. These women may well have specific HIV prevention needs in the prenatal context and may, in the absence of perceived or identified risk, either not be offered or may choose not to accept prenatal HIV counselling and testing.

WOMEN AT HIGHER RISK OF HIV INFECTION

This third section of Chapter One looks beyond the epidemiologic data previously described. One of the aims of my research is to throw light on the socio-cultural context within which information about HIV/AIDS in general, and PHCT in particular, is synthesised and thus the context in which decisions are made by pregnant women offered testing. Consequently, this section analyses the individual and collective behaviours, practices, situations, and structural factors associated with HIV infection among women who inject drugs, Aboriginal women, and women from HIV-endemic countries in Canada as a whole and in Ontario in particular.

Women and HIV Risk

Heterosexually active women confront what Lesley Doyal[121] has so eloquently termed the "biological sexism" of the human immunodeficiency virus with each act of unprotected heterosexual intercourse.

This contention of biologic disadvantage is grounded in the relative efficiency of male-to-female transmission of the virus in one single act of heterosexual contact compared with female-to-male transmission. A higher concentration of HIV in semen than in vaginal secretions; a greater transmitted volume of seminal fluid compared with vaginal fluid; and a comparatively larger area of mucous membrane in the vagina through which seminal fluid is absorbed[121-123] together construct for women a greater likelihood than men of being infected in one single act of penile-vaginal unprotected intercourse. Quantification of this differential risk varies across studies. A cohort study of risk factors for heterosexual transmission of HIV among 563 heterosexually active sero-discordant stable couples in thirteen centres from nine European Union countries suggests that male-to-female transmission is nearly twice as effective as female-to-male transmission (OR = 1.9, 95% CI: 1.1, 3.3).[124] Similarly, a cross-sectional study in 16 Italian centres with a larger sample of 730 heterosexually active sero-discordant stable couples also found the efficiency of male-to-female transmission to be twice as effective as female-to-male transmission (OR = 2.3, 95% CI: 1.1, 4.8).[122] Conversely, the latest findings of Padian and colleagues[125] suggest a much higher ratio. In their study of sero-discordant couples in Northern California, male-to-female transmission was approximately 8 times more efficient than female-to-male transmission (OR = 7.8, 95% CI: 1.97, 67.3) when controlling for consistent condom use. The authors argue for the validity of this current elevated rate premised on the facts that this study is the largest and longest study of the heterosexual transmission of HIV in the United States and the results have been consistent over the 10-year duration of the study.

Co-factors significantly increasing the risk of male-to-female transmission have been identified in longitudinal studies among stable monogamous couples discordant for HIV. These studies are arguably more methodologically rigorous than cross sectional studies of heterosexual transmission focussing on only one partner, as duration of exposure is a controlled factor and the possibility of biases related to the presence of multiple partners is lessened.[126] Identified co-factors from these studies include: advanced stage of HIV infection in the male partner (OR=2.7, 95% CI: 1.5, 4.9);[124] clinical diagnosis of AIDS in the male partner (OR=5.4, 95% CI: 1.2, 25.2),[127] (OR=2.6, 95% CI: 1.2, 5.4);[122] older age of the female partner (OR=3.9, 95% CI: 1.2, 13.0);[124] the practice of anal intercourse (OR=5.1, 95% CI: 2.9, 8.9),[124] (OR=5.8, 95% CI: 2.3, 14.8),[128] (OR=2.3, 95% CI: 1.4, 3.7),[122] (RR=1.4, 95% CI: 0.4, 4.8),[126] (OR=2.1, 95% CI: 1.1, 4.1);[125] recent or current history of sexually transmitted diseases (OR=3.1, 95% CI: 1.1, 8.6),[127] (OR=2.9, 95% CI: 1.2, 7.2),[122] (OR=2.6, 95% CI: 1.4, 5.1);[125] and frequency of vaginal intercourse more than twice a week (OR =2.0, 95% CI: 1.2, 3.3).[122]

Women who Inject Drugs and HIV

Heterosexually active women who inject drugs confront this inequitable transmission risk in their sexual lives and both equitable and inequitable gendered transmission risks in their drug-using lives.

People who inject drugs are at risk of HIV infection when they use injection equipment contaminated by the HIV-infected blood of another user. Previously used needles and syringes found, borrowed or bought from another user or dealer, pose significant risk for infection as efficient storers of the previous user's blood.[128-132] However, injection drug users (IDUs) confront other injection-related HIV risks even if they use their own individual sterile needle and syringe for injecting.[133-135] These risks occur in the practices that proceed injecting, in the practices of drug preparation and, in the case of collectively purchased drugs, in drug distribution. In the steps associated with drug preparation, these practices

include the shared use of water to mix with the drug which may already have been used by another user to rinse used syringes immediately after injection; cookers, spoons, bottle caps or other drug mixing containers; and cotton filters through which to draw up the drug from the cooker to remove undissolved particles in the drug solution which could clog the needle.[131,133-143] This communal use of injection-associated equipment has been termed indirect sharing.[139] Although the recent virological research of Shah and colleagues[144] has detected HIV-1 DNA in syringes, cottons, cookers and waters taken from shooting galleries in Miami, Florida, the potential risk of transmission of HIV from engaging in this practice of indirect sharing is not fully understood. However, it seems likely that if contaminated blood is transferred in these intermediate steps in the process of drug preparation, the potential for HIV transmission exists.[134,145] In the steps associated with the distribution of collectively purchased drugs, syringe-mediated drug-sharing practices include front-loading in which individual portions of the prepared drug are transferred from the communal syringe into the front of the IDU's own syringe by removing the needle,[137,145] and back-loading in which the drug is transferred to an individual's syringe by removing the plunger of that syringe.[138,145] Again, if the initial communal syringe is contaminated with HIV-infected blood, the potential for HIV transmission exists despite the subsequent use of sterile needles and syringes to inject.[133] For example, among 660 street-recruited IDUs in New York City, one quarter reported receiving drugs by back-loading, which was positively and significantly associated with HIV seropositivity.[138]

Heterosexually active women who inject drugs and whose sexual partners also inject drugs confront HIV-related risks associated with their own HIV risk-related injection practices described above, and also from the HIV-related risk conditions[xiv] constructed by their partner's HIV risk-related injection and sexual practices.

[xiv] In this thesis, risk conditions are considered to be those conditions which might create or contribute to a situation where HIV risk-related behaviours take place – i.e., the social construction of HIV risk.

Across many studies differentiated by time, country of origin and population of IDUs studied, the finding is consistent that women who inject drugs are significantly more likely than men who inject drugs to have a sexual partner who injects drugs, and are more likely to be living with another user.[146-157] Unprotected sexual intercourse within this relationship is therefore likely to carry elevated HIV-related risk for these women through their partner's possible unsafe injection and drug use practices. As a case in point, in a longitudinal study of 442 Northern Californian sero-discordant heterosexual couples, the risk of HIV transmission to uninfected women doubled if their heterosexual infected partner was an injection drug user (OR=2.0, 95% CI: 1.0, 4.2).[125]

Speculation as to why this unequal pattern of partnering persists among people who inject drugs is far ranging and equivocal. The strong disaffinity among men who inject drugs for women who inject drugs has been documented in ethnographic studies from the UK and is advanced as the reason why men IDUs may not be in a sexual relationship with a woman user.[152,153,158] The study by Barnard[153] suggests that this unequal partnering is simply a matter of statistical probability related to the greater numbers of men compared with women who inject drugs. The consistent finding that the initiation of women into drug and into alcohol use is directly associated with the presence of a substance-using male sexual partner suggests a different perspective on the issue.[153,159-161] Whatever the antecedent, the presence of sexual partners at risk of HIV through their own individual HIV risk-related injection and sexual practices comprises a risk condition mediated by gender. Freeman and colleagues[148] in fact conclude that the average Patterson, New Jersey woman IDU may be at greater risk for HIV infection as a result of involvement with a drug-using sexual partner than through her own HIV-related injection practices. Women in their study were significantly more likely than men IDUs to report injecting with a sexual partner in the previous six months and women IDUs with one sexual partner were more than twice as likely as men IDUs with one partner to report that this partner injected drugs.

With few notable exceptions,[162-164] little Canadian work has specifically addressed the gender-differentiated HIV risk-related behaviours practised, and the impact of HIV risk conditions experienced, by women and men who inject drugs. However, HIV prevalence data from one of my own studies (an insufficient number of seroconversions occurred during the period of the study to permit an analysis of HIV incidence), obtained during seven years of work with women in Ottawa who inject drugs, show the relevance of the above discussion of individual HIV risk-related injection and sexual practices and the impact of HIV-related risk conditions to women in Ontario who inject drugs.[165-167]

Table 15 shows crude odds ratios for risk factors for HIV infection among women IDUs that were significant at $p<0.05$ in univariate analysis. A history of injection drug use of three years or more had the greatest measure of effect (OR=10.56, 95% CI: 1.41, 78.95). Other injection-related risk factors also had significant effects. A history of injecting with a previously used needle (sharing) (OR=2.58, 95% CI: 1.20, 5.55) and a recent six-month history of injecting drugs with strangers (OR=2.35, 95% CI: 1.09, 5.08) were all significant factors. In terms of sexual practice-related risk factors, reporting sex in the past six months with only same sex partners was the only sexual practice variable affecting risk of infection and had the second largest measure of effect overall (OR=5.62, (95% CI: 1.09, 29.00). Accessing the services of The SITE, Ottawa's needle exchange programme, for seven months or more was the only significant sociodemographic variable and had the third largest measure of effect overall (OR=3.42, 95% CI: 1.28, 9.14). Injecting heroin in the six months prior to interview exerted a protective effect (OR=0.43, 95% CI: 0.18, 1.01) against HIV infection.[165]

Table 15

Risk Factors Associated with HIV Prevalence among Women in Ottawa who Inject Drugs (N=254)
1996 - 2003

RISK FACTOR	CRUDE ODDS RATIO (95% Confidence Interval)	*p*	ADJUSTED ODDS RATIO* (95% Confidence Interval)	*p*
Duration of drug use				
0-2 Years	1.00 (Reference)	.02	---	
3+ Years	10.56 (1.41, 78.95)			
Ever injected with someone else's used needle				
Yes	2.58 (1.20, 5.55)	.01	3.04 (1.30, 7.07)	.01
No	1.00 (Reference)		1.00 (Reference)	
Injected heroin in past six months				
Yes	0.43 (0.18, 1.01)	.05	0.34 (0.13, 0.91)	.03
No	1.00 (Reference)		1.00 (Reference)	
Injected drugs with strangers (people don't know well or at all) in past six months				
Yes	2.35 (1.09, 5.08)	.03	---	
No	1.00 (Reference)			
Only same sex partner(s) in the past six months				
Yes	5.62 (1.09, 29.00)	.04	10.37 (1.74, 61.81)	.01
No	1.00 (Reference)		1.00 (Reference)	
No sexual partners in the past six months	1.02 (0.22, 4.81)	.98	1.27 (0.14, 11.54)	.83
NEP** use ≥ 7 months				
Yes	3.42 (1.28, 9.14)	.01	3.54 (1.25, 10.02)	.02
No	1.00 (Reference)		1.00 (Reference)	

* Adjusted for all other variables in the equation.
** Needle Exchange Programme

Table 15 also presents the adjusted odds ratios and 95 percent confidence intervals from a logistic regression model including the same variables. In the multivariate model, the injection-related risk factors of duration of drug use for three years or more and injecting with strangers in the six months prior to interview were dropped from the model and their omission induced changes in the effects estimated for the other independent variables. All effects increased and remained significant. The following behaviours and practices remained significant risk factors among women with significant independent associations with HIV prevalence while controlling for all other variables in the equation. In the multivariate model, engaging in sex with only same-sex partners in the previous six months had the greatest measure of effect, elevating the risk of HIV infection among women IDUs ten-fold (AOR = 10.37, 95% CI: 1.74, 61.81). Interestingly, this study appears to be one of the few studies among Canadian women injection drug users to find a significant and independent association between reporting only same-sex partners and prevalent HIV infection.

Among women IDUs in this study, a history of injecting with used needles was a significant predictor of HIV infection. The risk of HIV infection increased three-fold among those women IDUs who had ever injected with a previously used needle borrowed, bought, or stolen from someone else or simply found (AOR = 3.04, 95% CI: 1.30, 7.07). Of course, injection with used needles is only risky if the needle is contaminated with the infected blood of another user. With the documented period prevalence of HIV among both women (18.1%, 95% CI: 13.6, 23.4) and men IDUs (21.3%, 95% CI: 18.5, 24.3) in Ottawa[167] the highest in Ontario,[168] the chances of being passed a contaminated needle are high. Accessing the service of Ottawa's needle exchange programme (NEP) was also a significant predictor of HIV infection among women in Ottawa who inject drugs (AOR=3.54, 95% CI: 1.25, 10.02). Although this may be an indicator of unintended consequences of NEP attendance in that networks of high risk IDUs may form around a NEP posing a risk condition for IDUs accessing the NEP, further analysis in this and other studies points to an alternative scenario in which higher risk IDUs access NEP services to maintain

engagement in protective HIV transmission injection practices. Injecting with heroin remained a significant independent protective practice when controlling for all other factors in the model (AOR=0.34, 95% CI: 0.13, 0.91). This confirms anecdotal reports from NEP nurses and counsellors that due to the reduced need for injections among heroin users compared with the intense frequency of injections required by cocaine users who are the majority of women IDUs in Ottawa, needle sharing is less prevalent.

The escalating consequences of the interplay of biologic disadvantage, individual HIV risk-related injection and sexual practices, and the impact of HIV-related risk conditions for Canadian women who inject drugs are evident in HIV incidence and prevalence data at the federal and provincial level.

Over time, there has been a dramatic increase in the annual proportion of positive HIV test results among adult and adolescent Canadian women attributed to injection drug use. Since 1996, approximately one-third to one-half of new HIV test reports among women has been attributed to injection drug use. Before 1995, 37% of new positive HIV tests among adult women were attributed to injection drug use,[15] whereas in 1999 that proportion had increased to the highest level recorded of 48%.[169] In 2001, the proportion of positive HIV tests among adult women attributed to injection drug use declined to 33% and rose slightly to 36% in the first half of 2002.[169] Examining new HIV test results by gender, the relative significance of injection drug use as a risk factor for Canadian women compared with Canadian men is revealed. Whereas in 2000, 40% of newly reported HIV diagnoses among women were attributed to injection drug use, the proportion among men was lower at 23%. This relative differential remained reasonably stable in 2001 with 33% and 22% of new diagnoses attributed to injection drug use among women and men respectively.[169]

The comparative significance of injection drug use as a risk factor for HIV among women compared with men, evidenced in national HIV data, is reflected at the provincial level. Data from the Ontario HIV Laboratory, Ministry of Health and Long Term Care, indicate that among all first-time HIV-positive diagnoses in Ontario from 1985 to 2000 where exposure category and gender are known, injection drug use accounted for 21% of all cases among Ontario women whereas only 6% of all cases among Ontario men were attributed to injection drug use.[118]

Aboriginal Women[xv] and HIV

While HIV data are generally considered a more rigorous and appropriate measure of recent trends in the HIV/AIDS epidemic, AIDS data, for the reasons discussed below, may be more relevant in the specific context of considering the HIV epidemic among Aboriginal women.

AIDS case report data, although providing information on HIV infections that occurred some ten years in the past, are nevertheless far more complete than HIV positive test report data in terms of the reported ethnic status of the person receiving the diagnosis. Of the total 18,336 AIDS cases reported to the Centre for Infectious Disease Prevention and Control, Health Canada (CIDPC) by the end of June 2002, 86% included ethnicity data.[170] In direct contrast, data on the ethnic status of the person who received a positive HIV test result are nowhere near as complete; in fact, at the end of June 2002 it was estimated that 71% of all positive HIV test results did not include data on ethnic status.[171] In the first six months of 2002, only 26% of positive HIV test reports included ethnicity data, the lowest proportion since ethnicity data for positive test results first became available in

[xv] The descriptor 'Aboriginal women' is used in this thesis to refer to the indigenous inhabitants of Canada. This terminology is used by the Royal Commission on Aboriginal Peoples and refers to First Nations, Métis and Inuit. First Nations: this term describes indigenous peoples and their descendants who are recognised and registered under Canada's Indian Act. Métis: this term describes individuals who are descendants of inter-married Aboriginal and non-Aboriginal people and are recognised by the Canadian Government as a distinct group. Inuit: this term describes indigenous people living in the Northwest Territories, northern Quebec and Labrador.[172]

Canada in 1998.[171] Overall, it is estimated that since the beginning of HIV/AIDS surveillance reporting, approximately 15% of reported AIDS cases and over 90% of positive HIV test reports did not contain information on ethnicity.[2] A number of factors combine to construct this incompleteness in ethnicity reporting in HIV data: not all provinces and territories routinely collect data on ethnicity; not all provinces and territories routinely report data on ethnicity to the CIDPC; and newly diagnosed HIV-positive people may well choose not to identify their ethnic background for fear of further collective stigmatisation of that community.

These limitations preclude any meaningful examination of HIV data estimating HIV prevalence or incidence among Aboriginal women or, in the context of this chapter, an examination of the associated HIV risk factors. These data limitations have further particular relevance to HIV surveillance among the Aboriginal community. Ontario and Québec, two provinces with high HIV prevalence and incidence rates, do not provide ethnicity data to the CIDPC resulting in possible systematic underestimates of the determinants and rates of HIV incidence and prevalence among Aboriginal peoples. Conversely, among those Western provinces and territories that do provide ethnicity data, such as Alberta, British Columbia, Manitoba, Saskatchewan and the Yukon, the Aboriginal population is higher than other parts of Canada, thus possibly inflating estimates of reports of HIV positive test results among the Aboriginal population. In view of these limitations in HIV data among Aboriginal people, AIDS data among Aboriginal women will primarily be considered.

The Aboriginal population in Canada comprises First Nations peoples, Inuit and Métis, each with different historical backgrounds and reflecting a myriad of cultures, languages, traditions, living circumstances and experiences. In 2001, Aboriginal people comprised 3% of the Canadian population yet accounted for 5% of reported cumulative AIDS cases with known ethnicity. Between January and June 2002, the latest date for which data are available, Aboriginal people accounted for 14% of reported AIDS cases with known ethnicity suggesting

Aboriginal people are overrepresented in the number of AIDS cases in which ethnic status is reported.[171] While these data are not reported by gender and ethnic status, there is evidence to suggest that among the Aboriginal population, the relative proportion of cumulative AIDS cases comprised by Aboriginal women compared with the proportion comprised by Aboriginal men is higher than that reported among non-Aboriginal women and men. Among cumulative AIDS cases with ethnicity identification reported to the CIDPC by the end of June 2002, women comprise 8% among non-Aboriginal AIDS case reports and 23% among Aboriginal reported AIDS cases.[170] There is general agreement however among Aboriginal AIDS Service Organisations, grounded in their own knowledge and experience, that these data are underestimates of true AIDS prevalence and incidence among Aboriginal peoples.[172]

It is clear when examining the risk exposure categories assigned to the 106 reported AIDS cases among Aboriginal women reported to the CIDPC by the end of June 2002, that the previous discussion concerning the individual HIV risk-related injection and sexual practices, and the impact of HIV-related risk conditions for women who inject drugs is especially relevant to Aboriginal women. The majority, 64%, of reported AIDS cases among Aboriginal women with known exposure was attributed to injection drug use, 32% was attributed to heterosexual contact, 2% to receiving blood or clotting factor and 2% to perinatal transmission.[170]

Another reason for using AIDS data to assess the extent of, and factors associated with, HIV infection among Aboriginal women is the comparative dearth of published reports of Aboriginal and Aboriginal gender-specific data relating to positive HIV test results. The national surveillance report on HIV and AIDS in Canada published semi-annually by the CIDPC,[2] documents the number of AIDS cases among Canadians of all ages by year of diagnosis and ethnic status, but fails to report HIV positive test results in the same manner, presumably due to the deficiencies in HIV surveillance data previously discussed. Similarly, in specifically reporting HIV/AIDS data among Aboriginal persons in Canada the

CIDPC[171] reports the risk exposure categories assigned to AIDS case reports among Aboriginal women as discussed above; however, no gender-specific information on the risk factors associated with the 688 positive HIV test reports among Aboriginal people reported to the CIDPC by the end of June 2002 is documented. However, what is significant about these prevalent HIV data is that Aboriginal women represent 45% of the total number of reported positive HIV test reports among Aboriginal people. Among non-Aboriginal HIV positive test reports the proportion comprised by women is 20%.

Despite a recommendation from the Aboriginal Working Group on HIV/AIDS Epidemiology and Surveillance and CIDPC to improve HIV/AIDS surveillance data and make it more accessible to the Aboriginal community by standardising Aboriginal HIV/AIDS surveillance data statistics by gender,[173] it is unfortunate too that the fact sheet subsequently produced by the Focus Group on Aboriginal HIV Estimates in conjunction with the Aboriginal Working Group on HIV/AIDS Epidemiology and Surveillance and CIDPC[174] does not report HIV prevalence and incidence data and associated risk factors on a gender basis.

These substantial limitations notwithstanding, positive HIV test report data appear to suggest that Aboriginal people are overrepresented in reports of new HIV diagnoses and that HIV infection is continuing to spread rapidly among this population. In 1998, 19% of positive HIV test reports with ethnicity information were among Aboriginal people. This proportion has risen steadily over the years such that between 1999 and 2001 close to one-quarter (24%) of new HIV positive test reports were among Aboriginal people, peaking at 27% in the first six months of 2002[175]. As Aboriginal women comprise close to half of all positive HIV test reports among Aboriginal people,[171] it may be reasonable to conclude that HIV infection is steadily increasing among Aboriginal women, although lack of documented identification of the risk factors associated with this increase is to be regretted, particularly in terms of lost prevention opportunities for Aboriginal women.

In the light of the differential exposure categories documented in national AIDS surveillance data among Aboriginal women, it may be reasonable to conclude that injection drug use continues to be a significant contributing factor to levels of HIV infection among Aboriginal women. Recent regional studies among women who inject drugs confirm this supposition. Among the more than 1,400 participants in the Vancouver Injection Drug Users Study, Tyndall and colleagues[176] report that 25% were Aboriginal, of whom the majority (54%) were Aboriginal women. In contrast, women accounted for 29% of non-Aboriginal participants. In a recent report of an investigation of elevated HIV incidence rates among women participating in the same study, Spittal and colleagues[177] found that Aboriginal status among women who inject drugs was significantly associated with new HIV infection.

However, rather than focussing on specific individual HIV risk-related behaviour in isolation, the experience of the wider social, psychological and structural context is frequently emphasised as a determining factor in engagement by Aboriginal peoples in HIV risk-related behaviours and practices.[178-180] As reported by the Focus Group on Aboriginal HIV Estimates in collaboration with the Aboriginal Working Group on HIV/AIDS Epidemiology and Surveillance and CIDPC,[174]

> *Aboriginal people are disproportionately affected by many adverse social, economic and behavioural factors (such as high rates of poverty, exploitation, racism and cultural oppression leading to substance abuse, sexually transmitted diseases, limited access to or use of health care services). These factors increase their vulnerability to HIV infection. Furthermore, the high rates of mobility of some Aboriginal people from rural communities to urban centres without appropriate education, prevention tools and resources is another factor which may increase the risk of HIV transmission.*

Findings from a 1996 investigation of the impact of HIV/AIDS on Aboriginal women in Canada prepared by the Aboriginal Nurses Association of Canada[180] support these general conclusions and document additional gender-specific HIV-

related risk conditions or contexts which increase HIV risk among Aboriginal women. For example, the report documents that many Aboriginal women experience physical and sexual abuse, low self-esteem and low self confidence leading to a lack of power in sexual relationships. The fear of abandonment and violence often precludes their insistence on safer sex practices, exacerbated by the subordinate gender role experienced by Aboriginal women. Similarly, in a recent paper addressing the connections between HIV and sexual violence among Aboriginal women, Neron and Roffey[178] include, in a description of the beliefs about social conditions affecting Aboriginal women underpinning their paper, the beliefs that sexual violence and HIV are major social and health problems which can potentially affect the lives of all Aboriginal women. They also state as a belief that societal barriers such as sexism, racism and colonialism affect the conditions of Aboriginal women's lives and may increase their risk of sexual violence. The authors argue that these conditions together create heightened HIV risk for Aboriginal women by decreasing access to education and employment and increasing poverty; increasing Aboriginal women's social and economic dependency on men; reducing Aboriginal women's power and choice in relationships; and contributing to low self esteem and poor health among Aboriginal women.

Interpreting the accounts of eight HIV-positive Aboriginal women from Northern Alberta participating in a small qualitative study, Mill[181] also emphasises the effect of social, psychological and structural factors in determining engagement in HIV-related risk behaviours and practices. She describes how these women responded to the effects of their shared early formative experiences of troubled family relationships, parental substance use, and physical, emotional and sexual abuse in their childhood years by engaging in injection drug and alcohol use, unsafe sex with physically abusive partners, and the commercial sex trade - all behaviours and practices associated with HIV infection and which Mill describes as survival techniques that the women had little choice in using to cope with their individual situations.

Ontario is one of the few provinces and territories that does not include ethnicity data in reports of HIV positive test results. Consequently, data on levels of HIV infection among Ontario Aboriginal women are not reported in provincial surveillance texts such as those produced by Remis in partnership with colleagues at the Ontario HIV Epidemiologic Monitoring Unit at the University of Toronto, the Central Public Health Laboratory, and the Public Health Branch of the Ontario Ministry of Health and Long Term Care.[114]

Although there are limited data on the level of HIV infection among Ontario Aboriginal women and men, data do exist on possible determinants of infection largely reflecting those previously described among Canadian Aboriginal women: low rates of safer sex practices; sexual and physical violence; low self esteem; alcohol and injection drug use; and poor health in general. Specifically, while rates of sexually transmitted infections, documented to be a significant co-factor for HIV transmission, are estimated to be four times more prevalent among Canadian Aboriginal people than among all Canadians, in certain parts of Northern Ontario these rates are even higher. Similarly, incidences of sexual assault among Ontario Aboriginal women are estimated by the Ontario Native Women's Association to be between five and eight times higher than in the non-Aboriginal community.[182]

In a paper developed to assist Aboriginal stakeholders, researchers and governments in formulating HIV/AIDS research priorities,[183] the paucity of data on the determinants of HIV incidence and prevalence among Aboriginal women and men in Canada is acknowledged. The paper strongly recommends further research studies to specifically address the broader social determinants previously described such as poverty, discrimination and marginalisation among Aboriginal women and men as social determinants impacting on engagement in HIV risk-related behaviours such as the commercial sex trade and injection drug use. However, while such research is being completed with the aim of identifying Aboriginal-specific and gender-specific intervention strategies, (aided by a

protected annual $800,000 from the Canadian Strategy on HIV/AIDS to support research on HIV/AIDS among Aboriginal people) the HIV epidemic among Aboriginal people, and Aboriginal women in particular, shows no sign of abating.

Women from Endemic Countries and HIV

In federal HIV/AIDS surveillance, reports of positive HIV test results and reports of diagnosed AIDS cases are assigned to a single exposure category according to a hierarchy of HIV-related risk factors, with the higher risk activities appearing at the top of the hierarchy. If more than one HIV-related risk factor is reported by the person receiving the diagnosis, an AIDS case report or the report of an HIV positive test result is assigned to the exposure category listed highest in the hierarchy. The underlying principle is that for people with multiple exposures, the most likely source of exposure is assumed to be that associated with highest HIV prevalence and incidence.

The exposure category, heterosexual contact/endemic appears well down in the exposure category hierarchy, fifth among ten exposure categories. Men who have had sex with men (MSM); men who have had sex with men and have injected drugs (MSM/IDU); injecting drug users (IDU); and recipients of blood, blood products and clotting factor are the first four exposure categories in the hierarchy.[2] Thus, the report of an HIV positive test result from a woman born in an HIV-endemic country in which injection drug use is reported as an HIV-related risk factor would be assigned the IDU category rather than heterosexual contact/endemic.

The exposure category heterosexual contact/endemic was a combined exposure category prior to 1998, but has since been separated into two subcategories: origin from a pattern II country and sexual contact with a person at risk. Origin from a pattern II country refers to people who were born in a country in which HIV is endemic – that is, a country in which the predominant mode of transmission is heterosexual contact.[2] Women born in an HIV-endemic country and assigned the

origin from a pattern II country risk exposure category are therefore considered to have contracted their HIV infection through heterosexual contact. It is unique in HIV/AIDS surveillance that country of origin should be considered synonymous with an HIV risk factor; however it emphasises that the most significant population determinant of HIV infection among women and men from HIV-endemic countries is heterosexual intercourse.

In provincial HIV/AIDS surveillance, the term HIV-endemic is further delineated,

> *The term HIV-endemic refers to populations in which the prevalence of HIV is high [generally above 1% and sometimes much higher] and in which the predominant mode of spread is heterosexual intercourse, accounting for at least 50% of infections.*

Countries that are classified HIV-endemic in the Ontario AIDS Surveillance Programme (OASP) database are those in Sub-Saharan Africa and the Caribbean. The 44 HIV-endemic countries in Sub-Saharan Africa listed in the OASP database include for example, Botswana, Cameroon, Gambia, Kenya, Somalia, South Africa, Uganda and Zimbabwe. The 24 HIV-endemic Caribbean countries in the OASP database include, for example, the Bahamas, Barbados, the Dominican Republic, Haiti, Jamaica, St Lucia and St Vincent.[184]

Whereas limited HIV/AIDS data exist pertaining to the impact of HIV and AIDS among the Ontario Aboriginal population as previously described, in recognition of the increasing significance of the risk exposure category HIV-endemic in contributing to rates of AIDS and HIV prevalence and incidence in Ontario, the Ontario Ministry of Health and Long Term Care commissioned a study to determine the epidemiologic characteristics of HIV infection among persons living in the province who were born in Sub-Saharan Africa or the Caribbean. Equivalent analyses among all Canadians living with AIDS and HIV infection originating from HIV-endemic countries are not available at the federal level.

Of relevance to a consideration of the HIV risk-related exposures (behaviours, situations, structural factors) associated with HIV infection among women from HIV-endemic countries in Ontario, the primacy of heterosexual contact in contributing to levels of HIV infection among Ontario women is confirmed in the published report of the study's findings. As the majority of people who immigrate to Ontario reside in metropolitan Toronto and the City of Ottawa regions, the study's analysis of the HIV epidemic among people born in HIV-endemic countries was stratified according to the health regions of Metro Toronto, the City of Ottawa and the rest of Ottawa defined as 'other'. As shown in Table 16, applying the risk exposure category hierarchy previously described, among women born in HIV-endemic countries the majority, 98%, of the 83 reported first-time HIV-positive diagnoses were assigned the exposure category HIV-endemic, indicating that the presumed route of HIV transmission was heterosexual contact. Only two cases in Metro Toronto, representing just 2% of the total cumulative HIV-positive diagnoses among women in Ontario from HIV-endemic countries, were attributed to injection drug use.[184]

Table 16

Number and Percentage of First-time HIV-positive Diagnoses among Women Born in an HIV-endemic Country by Exposure Category and Health Region of Residence
1985 – 1998

EXPOSURE CATEGORY	HEALTH REGION OF RESIDENCE								TOTAL	
	Metro Toronto		City of Ottawa		Other		Unknown			
	n	%	n	%	n	%	n	%	N	%
IDU	2	5.6	0		0		0		2	2.4
HIV-endemic	34	94.4	33	100.0	13	100.0	1	100.0	81	97.6
TOTAL	36		33		13		1		83	100.0

Continued detailed study of the HIV risk-related exposures (behaviours, situations, structural factors) associated with HIV incidence among women who inject drugs, Aboriginal women and women from HIV-endemic countries could improve prevention and intervention responses at the micro level. However, sustained worldwide initiatives confronting traditional gender role socialisation with its associated lack of status and power for women are required. Although a virus causes AIDS, unequal gendered risk conditions fuel its spread among all women: women who inject drugs, Aboriginal women, and women from HIV-endemic countries in particular.

FACTORS ASSOCIATED WITH PRENATAL HIV TEST UPTAKE

The fourth section of this chapter reviews the findings from studies from both the pre- and post-PACT076 eras which examine factors associated with a pregnant woman's decision or intention to accept or decline HIV counselling and testing in the prenatal period. The methodological and conceptual implications of this review for further research in this domain are discussed.

With few exceptions, studies examining factors associated with pregnant women's acceptance of screening for HIV in pregnancy, whether undertaken prior to, or following, the implementation of policy responses to the publication of protocol PACT076, use quantitative methods of enquiry[xvi]. These studies report statistically significant correlates of prenatal HIV testing uptake or delineate factors which significantly and independently predict pregnant women's decisions to undergo prenatal HIV testing. However, as discussed below, study results are inconsistent and often contradictory.

[xvi] Several qualitative theorists and practioners[261-263] take the position that historically it has been difficult for health service researchers to secure funding for qualitative research and to secure the publication of the ensuing findings in health service research journals. Due to these constraints, "*qualitative methods may not have been utilised as frequently as they could have been and research results may not have been disseminated as widely and effective as possible*".[264]

Several studies in the pre-PACTO76 era examined **demographic and behavioural characteristics of the pregnant women** associated with increased uptake of prenatal HIV testing. In one of the first studies to examine the determinants of acceptance of routine testing among 4,731 inner-city pregnant women in Atlanta, Lindsay and colleagues[20] found that pregnant women who accepted HIV testing (n=4,574, 97%) were more likely to be young, black and single ($p<0.001$) and less likely to have received education beyond high school ($p< 0.05$) than those pregnant women who declined testing. In almost direct contrast, Webber and colleagues,[21] working with 544 hospitalised postpartum women from a public hospital in the Bronx, New York City in the early 1990s, observed that while acceptance of testing (n= 430, 79%) was associated with younger age (Odds Ratio (OR) = 1.4, 95%CI: 1.0, 2.2) and younger age was an independent predictor of HIV testing (Adjusted Odds Ratio (AOR) = 1.5, 95%CI: 0.9, 2.3)[xvii], race/ethnicity, marital status and level of education were not. Conversely, Moatti and colleagues[22] found no association between acceptance of testing and any socio-cultural characteristics among 397 pregnant women attending for prenatal care in the late 1980s in two Paris-region maternity hospitals, demonstrating, the authors suggest, a socially uniform uptake of prenatal HIV testing. Other investigators similarly have found sociodemographic factors such as age, race or ethnicity, marital status, number of previous live births, level of income, and level of education to be significantly associated with acceptance or refusal of HIV testing during pregnancy[17,21,27] while other investigators have observed no such relationship.[17,27-29]

In terms of **attitudinal attributes** modifying pregnant women's HIV testing behaviour, self-perceived level of risk of HIV infection or self-perceived likelihood of being at risk of HIV infection were found to be variously associated with intention to test and test uptake. Meadows and colleagues[17] examined predictors of testing intentions among 318 women attending a London antenatal clinic in the early 1990s. Intention to be tested for HIV significantly correlated with the perceived

[xvii] The authors report age 25 and under as an independent correlate. However, as the confidence interval contains a value <1.0, the result approaches rather than reaches statistical significance.

likelihood of being infected with HIV (r=0.15, p<0.02) so that those pregnant women who felt themselves to be at greater risk of HIV infection had stronger intentions to test. This latter finding is supported in the French study by Moatti and colleagues[22] previously described, in which the investigators observed that the self-perceived level of risk of HIV infection was significantly higher (p<0.002) among pregnant women who accepted prenatal HIV testing than those women who declined. In contrast, in a later study among a sub-sample of 88 pregnant women participating in the study with Meadows as lead investigator earlier described, Meadows and Catalan[28] observed no significant difference among those pregnant women who did subsequently agree to be tested (n=32, 36%) and those who did not (n=55, 63%) in terms of their self-perceived likelihood of HIV infection.

A significant early finding concerning the impact of **health care provider's behaviour and attitudes** on pregnant women's decision to accept HIV testing is reported by Meadows and colleagues.[39] The investigators examined differences in HIV testing uptake rates according to counselling midwife among 788 pregnant women attending antenatal clinics at the West London Hospital in the UK between 1989 and 1990. Results showed that the uptake rate of the test varied considerably across midwives from 3% to 82%. Test uptake rate also varied to some extent by ethnic group of midwife: African and Caribbean midwives had 36% uptake, others 11%. However, the wide variation within ethnic groups suggests that ethnicity alone does not explain the differential test uptake rates which the authors suggest could be due in part to the differences in the midwives' counselling approaches and their attitudes to HIV testing.

With the ability to decrease the transmission of HIV from a pregnant woman to her foetus convincingly demonstrated in 1994 by the PACT076 protocol, studies among diverse populations of pregnant women proliferated in the mid-to-late 1990s. These studies were conducted with the objective of obtaining sufficient information to define the most effective and acceptable approach to prenatal HIV testing in order to

drive national and local efforts to bring the benefits of prenatal HIV testing and appropriate treatment to as many women as possible:

> *It is important to understand what influences women's decisions to accept or reject testing so that interventions to increase acceptance of prenatal testing can be developed.*[26]

In England, there was added urgency to these efforts. In 1999, the Ministry of Health (MOH) accepted the recommendations from an Expert Group set up to develop targets aimed at reducing mother-to-baby transmission of HIV:

> *The targets are aimed at increasing the uptake of antenatal HIV testing and the percentage of HIV infected pregnant women diagnosed at a sufficiently early stage so that women can be offered advice, treatment and interventions during antenatal care to reduce vertical transmission.*[185]

The MOH required all health authorities to have arrangements in place to achieve an increase in uptake of antenatal testing to 90% by the end of December 2002 to ensure that nationally 80% of HIV-infected pregnant women are identified and offered advice and treatment during antenatal care. Research to define acceptable and effective prenatal HIV testing protocols in the British context thus became an urgent priority.

Adopting the same methods of scientific enquiry as studies undertaken in the earlier pre-PACT076 era previously described, these later studies add little new knowledge and add little convincing clarity to the domain of determinants of acceptance of prenatal HIV testing as results continue to be conflicting and contradictory. For example, in terms of **demographic and behavioural characteristics of the pregnant women,** Simpson and colleagues[23] report that being unmarried and younger were significant independent predictors of testing uptake among 3,024 pregnant women attending the antenatal clinic of the main maternity hospital in the city of Edinburgh Scotland in the mid 1990s. Conversely, Carusi and colleagues[24], report that among 247 antenatal patients attending San Francisco General Hospital in 1996, HIV test acceptance was not associated with any demographic factors including race and ethnicity. However, Ethier and colleagues[25] report that test acceptance rates did differ by race and also by testing history among 2,135 pregnant

women attending community health centres and hospital clinics in Connecticut between 1995 and 1997. Among this group, 77% accepted a prenatal HIV test following pre-test counselling. Hispanic women were more likely than either Black or White women to accept a test (OR=1.74, 95%CI: 1.38, 2.2) and pregnant women who had not been previously tested were more likely than those who had been previously tested for HIV to accept an HIV test during pregnancy (OR=1.4, 95%CI: 1.03, 2.03). Support for the finding of Ethier and colleagues that test acceptance rates did differ by race, is provided in the study by Fernandez and colleagues.[26] Examining acceptance of prenatal HIV testing among a systematic sample of 1,357 women in prenatal care in Miami, New York City and Connecticut, the investigators report significantly higher rates of testing among Hispanic women (89%) than among Black women (83%), white women (84%) or women in the "other" category (81%) (p=≤0.005). However, Simpson and colleagues in the Scottish study described above,[23] counteract Ethier and colleagues' second finding with the observation that in their study a previous history of HIV testing was a significant independent predictor of accepting prenatal HIV testing (AOR=1.6, 95%CI: 1.2, 2.1).

Further studies by investigators working with diverse populations of pregnant women in the US, Canada, England and Scotland have found women's decisions to accept prenatal HIV testing to be significantly associated with demographic or behavioural characteristics such as age, race or ethnicity, marital status, number of previous live births, level of income, level of education and previous HIV test history.[23,26,29-35,36] However, as with other factors, other investigators have observed no such association.[24-26,30,31,37]

In terms of **attitudinal attributes** of the pregnant women, the association between test acceptance and self-perceived or assigned level of risk of HIV infection was examined by several investigators, again with differing effects. Highlighting four studies emanating from approximately the same time period in the mid 1990s illustrates the point. In the American study by Carusi and colleagues previously

described,[24] no statistically significant association emerged between self-perceived HIV risk and test acceptance or between provider-assigned HIV risk category and test acceptance. In this study, low-risk patients did not have a higher likelihood of accepting testing compared with patients of moderate or high risk (OR=0.63, 95%CI: 0.33.1.20). Similarly, Ethier and colleagues in the study previously described,[25] observed that among 2,135 pregnant women attending for prenatal care in Connecticut there was no significant difference in test acceptance rates associated with reports of HIV risk. In contrast, in a multisite study among 18,791 pregnant women attending five inner London maternity units in an area of documented high HIV seroprevalence, Gibb and colleagues[34] observed that uptake of HIV testing was significantly higher among pregnant women who disclosed an HIV-related risk factor than among those women who did not. In this study, pregnant women who believed their partner was at risk or that they were at risk had the highest rates of uptake. Similarly, perceiving oneself to be at some to high risk of HIV infection was a significant independent predictor of accepting prenatal HIV testing (AOR=1.4, 95%CI: 1.0, 1.9) in the Scottish study by Simpson and colleagues[29] among 1,817 pregnant women attending for prenatal care at an Edinburgh maternity hospital, one of the largest maternity hospitals in Scotland. Two further studies among diverse populations of pregnant women in the US have found women's decisions to accept prenatal HIV testing to be significantly associated with self-reported HIV-related risk factors.[32,35]

The effect of the individual **health care provider's behaviour and attitudes** first reported in the pre-PACT076 era persists. In the two studies by Simpson and colleagues previously described among large populations (1,817 and 3,024 respectively) of pregnant women attending prenatal care at an Edinburgh Scotland hospital,[23,29] the individual midwife had an important effect on uptake. Even though midwives had received the same training and prenatal HIV testing protocols, their uptake rates were significantly different ($p<0.001$), and in both studies the midwife seen was a significant independent predictor of uptake of HIV testing. The

investigators suggest that this finding challenges the prevalent assumption that the behaviour of health professionals is based on the extent of their medical knowledge.

Further evaluation of the impact of health care providers' attitudes is reported in the study by Fernandez and colleagues previously described.[26] In this tri-city study, the investigators observed that stronger perceived provider endorsement of HIV testing was associated with higher test acceptance than weaker perceived endorsement (AOR=1.24, 95%CI: 1.0, 1.40). Similarly, in an earlier report with Fernandez as the lead author[40] among a smaller sample of 830 pregnant women in the same study, women who perceived that their health care provider strongly believed in prenatal HIV testing (83%) were more likely to accept testing than those who believed their providers did not (71%) (p=0.003). These findings are supported by the results of Royce and colleague's[31] investigation of barriers to universal prenatal HIV testing among a representative sample of 1,362 women delivering in seven hospitals in 1997 in four locations in the US. Health care provider's recommendations strongly influenced women's decisions on prenatal testing independent of other factors. Among women who perceived that providers strongly recommended testing, 93% were tested, a proportion 2.2 times greater than that among women who perceived that providers did not recommend testing.

Demographic characteristics of prenatal providers have also been found to be associated with rate of prenatal HIV test uptake. Jones and colleagues[33] observed differing effects according to age, years of qualification and self-identified ethnicity of individual midwives. In their study among 3,359 women receiving prenatal care in London, prenatal HIV test uptake with midwives aged over 40 and those qualified more than 10 years (i.e., more experienced) was similar to that with the youngest and most recently qualified midwives (i.e., current training in HIV infection). However, testing was significantly less likely when offered by midwives of intermediate age (AOR=0.51, 95%CI: 0.35, 0.74) and experience (AOR=0.37, 95%CI: 0.28, 0.50). Tests offered by midwives describing themselves as white were about half as likely to be accepted as those offered by midwives from other ethnic

groups: Afro-Caribbean (AOR=2.52, 95%CI: 1.90, 3.33), Black African (AOR=2.01, 95%CI: 1.34, 2.98), "Other" (AOR= 2.04, 95%CI: 1.22, 3.41).

In terms of **health system variables**, the context in which the prenatal care was provided was found to be significantly associated with rates of uptake in Duffy and colleagues' investigation of HIV uptake among 789 women attending prenatal care in inner London.[36] Uptake was higher in hospital-based antenatal clinics (41%) than in six community clinics (30%) or in the midwifery group practice (10%) (p=0.0001). Similarly, Gibbs and colleagues[34] report that among 18,791 pregnant women attending five major maternity units in inner London with high rates of HIV infection, maternity unit had the greatest influence on the uptake of testing (p<0.0001). This finding is confirmed by Keane and colleagues[42] who reported that among 3,861 women accessing prenatal care in Cornwall, a rural county with low HIV incidence in the southwest of England, the range of uptake of prenatal HIV testing varied between 44% and 100% depending on the general practice.

Facility characteristics also had an impact on the uptake of prenatal HIV testing among 32,700 prenatal patients accessing care from the Kaiser Permanente Medical Care Program in North California. As Limata and colleagues report,[41] the most important facility characteristic predictor of testing uptake was the ease and accessibility of HIV testing (AOR=4.62, 95%CI: 2.31, 9.24), followed by assigning a designated educator to counsel patients on HIV testing (AOR=2.25, 95%CI: 1.28, 3.97), and the presence of a registered nurse in the HIV counselling team (AOR=2.11, 95%CI: 1.22, 3.63). Some studies examined test delivery methods in terms of the extent and character of the pre-test counselling offered with divergent results. Simpson and colleagues[23] found no difference in uptake of prenatal testing among 3,024 pregnant women participating in a randomised trial of four different methods of offering the HIV test; neither the style of the leaflet nor the length of the pre-test discussion had an effect on uptake (p=0.27). However, the length of time spent with a counsellor in pre-test counselling did affect uptake of testing among New York's Community Planning Council prenatal clients[32] and in the study by

Jones and colleagues previously described,[33] HIV testing was twice as likely if pre-test discussions lasted longer than 5 minutes (OR=2.19, 95%CI: 1.82, 2.62).

Health beliefs and attitudes, although shaped by demographic characteristics, are amenable to change. Acknowledging this potential, later investigators have examined and reported on these attributes more fully among pregnant women accepting and declining prenatal HIV testing with the objective of formulating policy and programme recommendations. Among the 1,357 women receiving prenatal care at clinics in Florida, Connecticut and New York City, Fernandez and colleagues[26] report that positive beliefs about the benefits of prenatal identification of HIV infection was a significant independent predictor of prenatal HIV test acceptance (AOR=1.25, 95%CI: 1.1,1.42). Simpson and colleagues[29] define the exact nature of the perceived benefits a little more precisely in their investigation among 1,817 pregnant women attending for prenatal care at an Edinburgh Scotland maternity hospital. Pregnant women who had accepted the offer of an HIV test in the prenatal context ('testers', n=642, 35%) were compared with those who had declined the test ('non-testers', n=1,175, 65%). Significant cognitive independent predictors of uptake were being in favour of the availability of HIV testing in the prenatal context i.e., positive attitude towards prenatal HIV testing (AOR=5.7, 95%CI: 3.1, 10.3); perceiving great benefits for the baby (AOR=1.8, 95%CI: 1.4, 2.4); and perceiving great benefits for research (AOR=1.4, 95%CI: 1.1, 1.8). In this study, perceived benefit to the mother was not predictive of uptake. Interestingly, this is in direct contrast with a study carried out in the early 1990s in the pre-PACT076 era in which perceived benefits to the mother prevailed as the most important predictor of test acceptance. In the British study by Meadows and colleagues previously described,[17] the most significant predictor of intention to test was the perceived benefit of the test to the woman herself ($p<0.0001$), whereas perceived benefit to the baby was not a significant predictor.

Investigators have also examined the association between **knowledge of treatment to reduce perinatal transmission** and HIV test acceptance. In the study by Carusi and colleagues previously described,[24] pregnant women who knew that a medical intervention exists to decrease perinatal transmission were significantly more likely to accept testing (OR=2.54, 95%CI: 1.11, 5.96), a finding supported in two other studies. Ruiz and Molitor[38] in their study among 850 pregnant or post-partum women accessing medical care in four counties in California with high rates of HIV among newborns report that, regardless of race/ethnicity, age, education or parity, women who knew about AZT therapy to reduce the risk of perinatal transmission were more likely to have had an HIV test (AOR=1.5, 95%CI: 1.0, 2.2) than women without this knowledge. In addition, among women who had already tested for HIV, knowledge of AZT increased the likelihood that they would test again during prenatal care. Similarly, in the study by Fernandez previously described,[26] greater knowledge about vertical transmission was an independent predictor of test uptake (AOR=1.41, 95%CI: 1.19, 1.67).

Methodological and Conceptual Implications for Further Research

The limitations of the data produced by these studies are discussed in detail in the Introduction in terms of the constraints of the methodological approach adopted and thus the methodological implications of this study. There are however conceptual implications for this study as discussed below.

The studies reviewed do provide some insight into potential modifying mechanisms involved in prenatal HIV test-acceptance behaviour, particularly for example, knowledge of perinatal HIV transmission as described above. However, the focus on only one of several components e.g., demographics, attitudinal attributes or knowledge fails to provide a cohesive analysis of the entire process as experienced by the pregnant women themselves. Irwin and colleagues[18] did address the multifaceted nature of the decision making process in an early analysis of the lessons learned in a decade of providing voluntary HIV testing in the US,

> *The decision to accept [HIV] counselling and testing is complex and highly personal and is influenced by many client, provider, and program characteristics which involve balancing diverse concerns about risks and benefits, including acknowledging socially stigmatized behaviours, fear of coping with test results, risk of discrimination, preventing transmission to partners and offspring, and having earlier access to medical and psychosocial services.*

However, in the studies reviewed, few investigators considered interrelationships, concentrating on an examination of discrete and isolated factors. As Beardsell and Coyle in their proposal for process-based studies in the HIV testing domain comment,

> *... rather than conceptualising HIV testing as a dynamic process which consists of interrelated elements, this body of work [research on HIV testing] has focused on discrete aspects of the HIV testing process.*

In contrast, therefore, to the conceptual approach underpinning much of the published literature to date, the current study interprets prenatal HIV counselling and testing as a complex interrelated process of making a decision to be tested, accessing testing services, test counselling and waiting for the test result. Thus, in conducting a qualitative, as opposed to a quantitative investigation, the study aligns itself with the sentiments voiced by Beardsell and Coyle[186] in their review of research on the nature and quality of HIV testing services,

> *... if research on HIV testing is to be of use in the development and improvement of HIV testing services, it should be able to identify and describe in detail the factors that might lead to various outcomes of testing. This requires an in-depth examination of all aspects of the HIV testing process and their interrelationships from the perspectives of those undergoing testing ... qualitative methods could be particularly appropriate as they are well-placed to chart in detail the varied aspects of the HIV testing process and their interrelationships.*

PRENATAL HIV COUNSELLING AND TESTING POLICY

This final section of Chapter One adds further context to the current investigation by critically discussing, through a review of international literature, the development and theoretical underpinnings of prenatal HIV counselling and testing policy approaches. Establishing this policy context provides a framework within which the policy and practice implications of this current study can be understood.

As previously described, the emergence of clinical and medical interventions with the capacity to significantly interrupt perinatal HIV transmission demanded an urgent public health response to detect and respond to the potential for perinatal transmission of HIV. The conceptual underpinning of existing messages in the HIV prevention domain exhorting individual HIV prevention behaviour and practices was no longer valid. A new paradigm of HIV prevention was needed to capture the emerging science of perinatal HIV risk reduction as, uniquely in the HIV prevention domain, the source of exposure is easily identifiable in advance and infants cannot themselves take steps to ensure that they remain free from infection.

The promotion of perinatal HIV risk reduction required the active development and implementation of policies to increase HIV counselling and testing among women in prenatal care in order to identify those women who could benefit from preventive interventions. Increasing HIV counselling and testing among pregnant women also provides an opportunity for seemingly healthy pregnant women unaware of their HIV-positive status to benefit from early diagnosis and thus be in a position to decide on the range of treatment options for themselves as well as the range of prophylactic interventions available to them to reduce transmission to their child. Less well emphasised in the prenatal HIV counselling and testing (PHCT) domain is the fact that the post-test discussion following the return of negative HIV test results presents a timely, and for some women unique[187], opportunity to discuss HIV prevention and risk reduction activities. Given these

clear benefits to sensitive and informative PHCT, there is however little consistency between countries, and within countries between states and provinces, as to the ideal policy approach to ensure that as many pregnant women as possible have the opportunity to learn of their HIV status in order to increase control over their own health and that of their unborn child.

In Canada, HIV testing programmes are the responsibility of provincial and territorial governments. There are no national recommendations or federal policy protocols[xviii] to inform these governments in their policy formulation efforts to address the emerging issue of the implementation of HIV testing for pregnant women. As a result, there exists a range in formal and informal prenatal HIV testing policies in each of the provinces and territories. However, notwithstanding the policy implemented, in all Canadian provinces and territories prenatal HIV testing remains the choice of the pregnant woman.[113]

Three different policy approaches to maximising the number of pregnant women who accept HIV counselling and testing in the prenatal context are currently in effect in Canadian provinces and territories. A selective or targeted policy, in which HIV counselling and testing is offered only in the presence of risk factors for HIV, is the prevailing policy in Saskatchewan. In contrast, under a universal voluntary or 'opt-in' policy approach, all pregnant women are offered the opportunity to test for HIV and testing completed if the woman chooses to accept or 'opts-in', and gives her informed consent to the test. This policy is in effect in British Columbia, Manitoba, New Brunswick, Nova Scotia, Ontario, Québec and the Yukon. Under a routine or 'opt-out' policy, all pregnant women presenting for prenatal care are routinely tested for HIV unless the pregnant woman specifically and actively declines to be tested, or 'opts-out' of HIV testing. This policy is in effect in Alberta, Newfoundland and Labrador, the Northwest Territories and Nunavut.[113] No Canadian province or territory has implemented the fourth policy

[xviii] Health Canada has however recently published "Guiding Principles" for prenatal HIV testing which emphasise that established principles in HIV testing of voluntarism, confidentiality and informed consent need to be upheld in the prenatal context.[235]

option of a mandatory policy approach to PHCT. Each of the four approaches to PHCT is characterised by real or perceived varying degrees of autonomy over diagnosis and treatment afforded to the pregnant woman and varying degrees of responsibility for testing, balanced between the health care provider and the pregnant woman. These differing policy approaches are critically reviewed in the next sections.

A Targeted or Selective Policy

A targeted or selective policy approach to prenatal HIV counselling and testing is driven by epidemiologic data relating to HIV prevalence rates or, more frequently, the determinants of HIV infection. This approach places emphasis on identifying HIV risk-related behaviours and practices among pregnant women as a prerequisite to offering only those identified women a prenatal HIV test. Reflecting an earlier development stage in the formulation of PHCT policies, and largely replaced in many countries by universal policies, it is now widely accepted, as documented in the international studies reported below, that HIV testing policies that target only selected pregnant women rather than all pregnant women, consistently fail to identify significant numbers of pregnant women living with HIV.

In the UK, in the early 1990s, the Department of Health (DoH) recommended that all women considered to be at significant risk of HIV infection[xix] should be offered antenatal HIV testing, as should those women living in high HIV prevalence areas such as Greater London.[188] However, data from unlinked anonymous HIV monitoring among neonatal specimens and surveillance through registers of diagnosed maternal and paediatric infections between 1988 and 1996, revealed that in 1996 this policy only identified a small percentage of pregnant women living with HIV. An estimated 15% of previously unrecognised HIV

[xix] A pregnant woman would be considered to be at significant risk if: she was from, or has had sexual partners from, countries where HIV is endemic; she or her partner was an injection drug user who had shared needles; or she has had bisexual male partners.[193]

infections were diagnosed in pregnancy while the remaining 85% of pregnant women living with HIV were unaware of their infection and unable to benefit from recent advances in HIV management.[189] Similarly, several studies in the mid-nineties among pregnant women in high HIV prevalence areas also documented low implementation of the DoH guidelines,[34,190] resulting in missed opportunities for early maternal diagnosis and missed opportunities for preventing perinatal transmission.[191] By the late 1990s PHCT in the UK was described as a lottery, access to HIV testing being dependent on where women live and which health care professional was responsible for decisions to offer PHCT,[192,193] a situation viewed by health care professionals as medically negligent,[194,195] professionally unethical[196] and unjust.[193] Subsequently, in 1999, the DoH moved from this restrictive selective policy to a universal voluntary policy, requiring all health authorities to offer and recommend HIV testing to all pregnant women.[197]

In the US, in the late 1980s, the Public Health Service (PHS) and the American College of Obstetricians and Gynecologists (ACOG) recommended a selective PHCT policy whereby pregnant women acknowledging an HIV risk-related behaviour or practice would be offered an HIV test. However, a review of various studies concluded that as many as 42-86% of HIV-positive women do not in fact report risk factors for HIV infection and would therefore be missed.[198] Such occurrences are considered to be due to the fact that some pregnant women do not choose to disclose engagement in HIV risk-related behaviour or are not aware either of the HIV status of their male sexual partners or those partner's engagement in HIV risk-related behaviours.[199-202]

Building on these US data documenting that implementation of a selective approach failed to identify a substantial number of pregnant women living with HIV infection (including data from one of their own earlier studies[203] that documented 47% of pregnant women living with HIV did not prenatally disclose HIV risk-related factors), Barbacci and colleagues[187] compared the detection rate under the recommended selective policy with that obtained under a policy

whereby HIV counselling and testing was offered to all pregnant women irrespective of their engagement in HIV risk-related behaviours or practices. Their study, carried out between 1987 and 1990 among close to three thousand pregnant women in an inner-city area of Baltimore, showed that if the guidelines for selective testing had been followed, only 57% of HIV-positive pregnant women would have been identified. By offering PHCT to all pregnant women, the detection rate was increased to 87%. The authors conclude that a selective policy was not effective in identifying pregnant women living with HIV and recommended a policy of universal counselling and an offer of an HIV test to all pregnant women. As discussed below, in 1995 the US Public Health Service subsequently replaced the earlier guidelines calling for a selective policy and introduced revised guidelines recommending universal counselling and voluntary testing for all pregnant women.[204]

New Zealand has implemented a selective policy since 1997, although the Ministry of Health recommends a discussion of the risk of HIV infection as a routine component of prenatal care for all pregnant women.[205] Similarly, in Australia, most states recommend that HIV screening should be *offered* to all pregnant women, but screening is *recommended* only for those recognised to be at risk of HIV, although there are calls for universal counselling and voluntary testing for all pregnant women.[13,206] In Canada, Saskatchewan is the only province that continues to operate under a selective policy approach to PHCT.[113] Pregnant women in this province are offered HIV testing only in the presence of HIV-related risk factors voluntarily disclosed by the pregnant woman or identified (or assumed) by her health care provider. Interestingly, it seems that there is a possibility that a Canadian province or territory implementing a restrictive policy of selected PHCT would be vulnerable to a negligence action by any woman whose HIV status was not diagnosed due to the narrow scope of the policy and where perinatal transmission subsequently took place. As Stoltz explains, a territorial or provincial government would need to be able to prove such a risk-

based policy was implemented following a full consideration of a universal policy and was based on rational, social, economic or political factors.[63]

A Universal Voluntary Policy: The 'Opt-in' Approach

Acknowledging the deficits of a targeted or selective policy approach in denying a significant number of pregnant women the opportunity to avail themselves of one or more HIV-prevention interventions, the vast majority of professional associations[xx], governments and other interested bodies in Canada and elsewhere have responded by endorsing or adopting a universal voluntary policy of PHCT. Whereas a targeted or selective approach is restrictive in terms of the number of pregnant women who are offered an HIV test, a universal voluntary approach involves counselling all pregnant women concerning the risks and benefits of a prenatal HIV test, offering the test to all pregnant women irrespective of the presence of HIV-related risk factors, and requiring the woman's specific informed consent before administering the test.

In 1995, the American Public Health Service (PHS) established guidelines to promote universal counselling and voluntary testing of all pregnant women.[204] The American College of Obstetricians and Gynecologists endorsed this policy in the same year. Results from a four-state study evaluating the effect of these guidelines in reducing perinatal transmission documented several positive outcomes. Between the years 1993 and 1996, the proportion of pregnant women newly diagnosed with HIV in the prenatal period increased from 68% to 81%. In the same time period there was an increase in the proportion of women living with HIV offered AZT therapy from 27% to 85%, and a 43% reduction in perinatal transmission between the years 1992 and 1996.[207] However, results from a much larger Pan-American study evaluating the 1995 PHS guidelines found that nearly half of the pregnant women participating in the study had not been tested during

[xx] Canadian professional associations such as the Canadian Medical Association, the Society of Obstetricians and Gynaecologists of Canada, the College of Family Physicians of Canada, the Collège des médecins du Québec and the Canadian Paediatric Society .

the period of study, 1994-1999.[208] More recently, the CDC examined HIV testing among pregnant women in the United States and Canada between 1998 and 2001 and report prenatal HIV testing rates of between 25-69% in those US states implementing a voluntary opt-in policy.[209]

In Canada, British Columbia, Manitoba, New Brunswick, Nova Scotia, Ontario, Québec and the Yukon have adopted this universal voluntary policy approach, often characterised as an opt-in policy.[113] In these provinces, the policy is that all pregnant women are offered the opportunity to test for HIV during pregnancy and HIV testing is only completed if the woman gives her "*voluntary and specific informed consent for the test to be carried out.*"[210] Following adoption of a universal opt-in policy in Québec in 1997, the proportion of physicians offering the test increased from 50% in 1997 to 83% in 1999,[210] in which year it is estimated that 83% of pregnant women received prenatal HIV testing.[209] However, later evaluation data have revised these figures on test offer downwards, such that the percentage of HIV tests offered to pregnant women has been fairly constant at approximately 60% between the years 1999 and 2001.[113] In British Columbia, the proportion of pregnant women tested for HIV increased in the years following adoption of a universal voluntary policy from an estimated 55% in 1995 to 80% in 1999.[113] The increase in prenatal HIV test uptake following the adoption of a universal opt-in policy in Ontario has been somewhat slower but nevertheless as successful. The proportion of pregnant women tested for HIV in the prenatal period before the adoption of the policy in 1999 was 33%. This proportion increased to 54% in 2001.[209] However, there has recently been a dramatic increase in the number of pregnant women presenting for other prenatal tests who also accepted a prenatal HIV test. Province-wide, for the last 6 months of 2002 and for the first three months of 2003, 80% of pregnant women undergoing other screening tests in pregnancy also underwent testing for HIV (Dr Robert S. Remis, University of Toronto: personal communication, September 2003). At the end of 2002, in only three Ontario health units was test uptake less than 70%.[113] The inclusion of a memo with the results of other prenatal screening

tests sent in September 2001 to those physicians who had not also ordered a prenatal HIV test, appears to have had a substantial impact on prenatal HIV test uptake.[211]

In contrast to the approach embodied in a voluntary opt-in policy, routine and mandatory policies inherently afford the pregnant women less latitude in terms of autonomy over acceptance of the test. A routine policy approach relieves the health care provider of the responsibility of specifically offering testing and shifts that responsibility to the pregnant woman to actively decline testing. Under the provisions of a routine policy of PHCT, a HIV test is routinely carried out on all pregnant women presenting for prenatal care unless the woman specifically declines to be tested. In contrast to all other approaches, a mandatory policy approach affords no leeway to the pregnant woman to decline HIV testing in her pregnancy. Should a pregnant woman decline to be tested, that choice would not be respected. The test would be performed against her will.

It is important to differentiate between characterising the actual *administration* of the test as mandatory, i.e., legislation is in existence at the national or provincial or state level that mandates health care professionals to perform an HIV test on all pregnant women, with the existence of legislation mandating health care professionals to *offer* the HIV test to all prenatal patients. In France for example, the 1993 French National Policy made it mandatory to offer HIV screening to all pregnant women who planned to give birth, although women remained free to decline the test.[212] Similarly, in 1996, the Texas legislature passed a law making it mandatory for health-care providers to verbally notify pregnant patients that an HIV test would be ordered unless it was expressly refused and upheld the requirement that pregnant women must give informed consent before the test can be implemented.[213] While no Canadian territory or province has implemented a mandatory prenatal HIV testing policy, Connecticut is the only US state to do so.

A Mandatory Policy

In this final section of the chapter, the rationale for a mandatory policy of PHCT is critically evaluated as a way of demonstrating the legal and ethical concerns surrounding PHCT policy debates. Particular and equal attention is also given to the conceptual underpinnings of a routine opt-out policy, not only because of the similar, but less stringent, perspectives it embodies, but also because of its relevance to the current PHCT policy debate evolving in Ontario. Through a plethora of recent articles in the medical press[69,70,71,214] and statements made by the Canadian Medical Association,[215] it is clear that there is strong mounting pressure for Ontario to adopt a routine opt-out approach. As my research on pregnant women's experiences and perspectives on prenatal HIV counselling and testing took place in Ontario, it is particularly important to understand the parameters of this debate to provide context to the research findings and to evaluate the merits of such a policy proposal from the perspectives of the pregnant women who worked with me on the research. In considering both mandatory and routine policies of PHCT in this thesis, reference is made to the conceptual framework and application of a voluntary policy approach to PHCT as proponents of more stringent policy approaches, such as a routine approach, ground their justification in the perceived failings of a voluntary opt-in approach.

The sentiment behind John Stuart Mill's statement that

> *[t]he only purpose for which power can rightly be exercised over any member of a civilised community against his will, is to prevent harm to others.*[216]

underpins much of the ethical and legal rather than medical or epidemiologic considerations of the debate concerning the optimal approach to prenatal HIV counselling and testing. Is State intrusion into the freedom of pregnant women justified in the interest of foetal health?

For AZT or any antiretroviral therapy to be of benefit in the prevention of perinatal HIV transmission, HIV-positive women need to be identified at a point in their pregnancy when preventive interventions are likely to have most effect. This overriding concern for prevention of perinatal HIV transmission rather than equal concern for the treatment and support needs of the newly-diagnosed HIV-positive woman, has foregrounded the issue of potential maternal-foetal conflict in the PHCT debate and has led, according to one public policy director, to the "*histrionic push for mandatory perinatal HIV testing.*"[217]

As representative of that push, Wilfert, in an AIDS commentary editorial in the journal *Clinical Infectious Diseases* a few months following the publication of the interim results of PACTG 076, addressed the efficacy of a policy of voluntary counselling and testing of pregnant women in identifying pregnant women who could potentially benefit from this innovative preventive therapy.[218] Citing the legislative mandates that were necessary to produce rates of childhood immunisation effective in reducing the occurrence of vaccine-preventable diseases as an example of mandated provision of health care, Wilfert suggests that such an exercise of state power is an option to control perinatal transmission,

> *The need for counselling and testing of all pregnant women should be recognised by all health care providers. However, this has not happened and is unlikely to be accomplished efficiently on a voluntary basis despite the fact that zidovudine has been proven to interrupt transmission of HIV. Legislation may be required to effect a universal change in the performance of HIV counselling and testing of pregnant women in the United States . . . Mandating such testing provides the impetus to alter provision of health care and will potentially result in a significant reduction in transmission of the [HIV] virus to children.*

In what is generally considered to be a pivotal text[xxi] in the debate around a mandatory policy approach to PHCT, Wilfert does suggest that if such legislation is enacted, appropriate health care will need to be provided to women thus identified. However, the thrust of her argument is driven by the need to decrease transmission of HIV to the infant as demonstrated in the text above.

In addition, her argument portrays securing the HIV testing of pregnant women as an end in and of itself,

> *HIV counselling and testing of pregnant women can now provide a definitive means for decreasing transmission of HIV from mother to infant.*

However, I would argue that the only way that prenatal HIV testing can lead to decreases in perinatal HIV transmission is if the newly diagnosed HIV-positive pregnant woman is in a position to make the decision on whether or not to accept therapy for herself and/or therapy to interrupt possible HIV transmission to her infant. Other proponents[219] of a mandatory policy similarly neglect to emphasise both components (identification and treatment) of the perinatal-transmission-prevention equation attributing all transmission interruption benefits solely to identifying, by mandatory means, pregnant women unaware of their HIV infection. These proponents, such as the paediatric specialist quoted below,[220] tend to express their perspectives in emotional terms,

> *With mandatory testing, we have the opportunity to prevent deaths in newborns who cannot speak for themselves. Not to do it is legislative murder by omission.*

Schoen and colleagues[221] however, base their support for a mandatory policy less on rhetoric and more on clinical evidence. Having implemented the 1995 US PHS Guidelines of universal counselling and voluntary testing, the percentage of pregnant women agreeing to voluntary HIV testing within the Kaiser Permanente Medical Care Program of Northern California increased from 50% to 76% during

---

xxi This is a pivotal text in the post-PACTG 076 era. One of the earliest texts retrieved is that by Listernick writing in 1989 on *The Case against Mandatory Prenatal Testing for HIV.*[265] Listernick raises many of the same issues as Wilfert, but, in the absence of effective perinatal prevention treatment at that time, the conclusions reached are, of necessity, different.

a five-year period from 1994 to 1998. However, 83 HIV-positive pregnancies occurred among 63 women, only 17 of which were identified by the voluntary testing programme. Despite the fact that almost 80% of pregnant women agreed to testing, the vast majority, 80%, of the newly diagnosed HIV-positive pregnant women were tested outside the voluntary prenatal testing programme, and were only identified by use of an independent intensive data surveillance programme. Without such a tracking programme, the authors contend, voluntary prenatal screening would fail to identify most HIV-positive patients. The authors conclude that the study findings confirm the desirability of not depending on voluntary prenatal HIV testing to prevent perinatal transmission and suggest that

> *a compulsory prenatal HIV screening program would result in earlier and more effective identification of prenatal HIV disease and more effective treatment and tracking.*

Two studies[222] published two years after Connecticut became the first US state to mandate HIV screening for pregnant women demonstrate, from the perspectives of the authors, the efficacy of the policy. The law which took effect in 1999 requires that pregnant women are screened for HIV and, if no documented HIV test is on file before delivery, the law mandates HIV testing for the newborn. In Magriples's study among pregnant women attending Yale's high-risk pregnancy clinic, 39% of women were tested before enactment of the law and 91% were tested following enactment. Studying the effects of the law during the first ten months of implementation among pregnant women at Stamford Hospital, Cusick concluded that without mandatory testing six of nine cases of HIV infection among pregnant women would have been missed.

Originally opposed to mandatory testing, the American Medical Association's House of Delegates voted by a very narrow margin in 1996 to call for mandatory HIV testing of pregnant women and newborn babies.[223] The American College of Obstetricians and Gynecologists (ACOG) and the American Academy of Pediatrics (AAP) strongly disagreed with this move.[223] The ACOG's main concern was that mandatory HIV testing would deter many pregnant women from

seeking and obtaining prenatal care and would therefore actually result in an increased number of infants born with HIV infection,

> *Mandatory testing [of pregnant women for HIV] may be a particular barrier for women at high risk for HIV, and the opportunity to provide counselling, treatment and other recognised benefits of prenatal care would be lost.*

Concern that forcing a pregnant woman against her will to undertake an HIV test would drive the most vulnerable women away from accessing prenatal care is an argument frequently cited by critics of mandatory testing.[224-226] These critics include, for example, state health officials in Connecticut who voiced their opposition to the 1999 bill that was eventually passed requiring mandatory testing of all pregnant women.[227] Interestingly, the AMA having been forceful in its support of mandatory testing in 1996 reversed its five-year-old policy in 2002.[228] The AMA, in now endorsing a policy of universal testing with notification of the right of refusal, took the very same position against mandatory testing that the ACOG and APA had taken some years earlier in opposing the AMA's own recommendation of mandatory testing. The AMA stated that the new approach would

> *prevent the problem in the mandatory approach to testing in which some women may decline prenatal care in order to avoid mandatory testing.*

Evidence for this contention of avoidance of prenatal care can be extrapolated from the recent US study by Dolbear and colleagues[229] who examined the impact of implementation of named reporting and mandatory partner notification on the percentage of patients not accepting prenatal HIV testing or deferring prenatal care. Among more than five thousand pregnant women admitted to a labour and delivery unit in New York State between December 1999 and March 2001, the percentage of patients who did not undergo prenatal HIV testing significantly increased after the institution of named reporting and partner notification from 2.9% to 6.1%. Similarly, the percentage of patients who did not receive prenatal care increased significantly following implementation from 0.3% to 1.9%. The authors conclude that there is strong indication that the institution of named

reporting and mandatory partner notification significantly impacted the willingness of pregnant women to undergo HIV testing and access prenatal care.

In my earlier discussion of Wilfert's text[218] proposing a mandatory policy,[230] I emphasise her lack of attention to the need for a pregnant woman to be in a position to be able to decide on antiretroviral treatment to reduce perinatal transmission, for acceptance of HIV testing does not and should not guarantee acceptance of treatment. A second argument frequently advanced against a policy of mandatory testing of pregnant women is that testing without assurance of therapy would be unethical.[231] If HIV testing is to be made mandatory, will acceptance of HIV treatment be mandatory? As Stoltz reasons,[63]

> *If one accepts the degree of intrusion necessary to justify mandatory HIV testing in the interest of foetal health, what principled approach justifies a refusal to authorise the further intrusions that would be necessary to compel the treatment of pregnant women in the interest of reducing perinatal transmission?*

Will a pregnant woman be mandated to adhere to the necessary intensive antiretroviral drug therapy regime also against her will in order to prevent HIV perinatal transmission even if such therapy may be contraindicated in the history of her own infection? In New York State, treatment for syphilis, which can also be transmitted perinatally and for which pregnant women are tested in the prenatal screen, is mandatory.[232] However, as Minkoff points out,[231] the treatment regimes for the treatment of syphilis and HIV are simply not comparable. Minkoff goes on to suggest, albeit in a semi-serious manner, that the only way to achieve mandatory HIV treatment adherence is by incarceration. However, this suggestion is not as unrealistic as it first seems and has had previous, if dubious, success in HIV prevention strategies. The successful identification and treatment of 80% of the HIV-positive people in Hungary has been attributed to that country's compulsory HIV testing programme in which the groups required by law to undergo HIV testing are largely captive: prisoners, arrested juveniles and arrested sex trade workers.[233]

Justifying a mandatory PHCT policy solely on medical-based outcomes, epidemiologic-based outcomes, or even evidence-based outcomes in terms of increased rates of test uptake, is insufficient as these data fail to take account of the substantial ethical and legal issues associated with adopting or implementing a mandatory approach to PHCT. As Downes succinctly explains,[234]

> *The underlying ethical dilemma has involved weighing risks and benefits of mandatory testing with consideration for the rights of privacy and self-determination of the pregnant woman versus the rights of the infant for protection and treatment.*

In Canada, a proposal to mandate pregnant women to involuntarily undergo HIV testing is considered unlikely to withstand constitutional challenge under the Charter of Human Rights and Freedoms. Of relevance to this particular issue, Stoltz[63] refers to a decision made in 1997 at the level of the Supreme Court of Canada in *Winnipeg Child and Family Services*. The decision taken in this case,

> *confirms the inviolability at common law of a pregnant woman's right to exercise informed consent to a proposed medical intervention that may benefit the foetus she carries, and accept or decline that intervention free of state compulsion.*

Interestingly, just last year (2002), perhaps in response to recent calls for more stringent policies of PHCT in other countries, Health Canada published 'Guiding Principles for Human Immunodeficiency Virus (HIV) Testing of Women during Pregnancy' in the *Canada Communicable Disease Report.*[235] In emphasising that the common principles of voluntarism, confidentiality, and informed consent have guided policy development at the federal, provincial and territorial levels with respect to HIV testing in general, Health Canada states,

> *This document serves as a reminder that these principles should also apply to policy development regarding HIV testing of women during pregnancy.*

Thus, while mandatory prenatal HIV testing is unlikely to be proposed in Canada, the following section examining a routine opt-out approach to prenatal HIV testing suggests that there may well be other circumstances in which a pregnant woman's right to informed consent to prenatal HIV testing is compromised.

A Routine Policy: The 'Opt-out' Approach

A routine approach to PHCT is an approach that synthesises several overall perspectives relating to PHCT: HIV should not be treated differently from other communicable diseases for which prenatal tests are routinely undertaken; HIV testing should be considered a routine or standard component of optimal prenatal care; and should be routinely administered alongside the standard prenatal blood screen for which formal consent or specialised discussion is not usually required. These perspectives together construct a policy whereby the standard procedure is for pregnant women to be routinely or automatically tested for HIV unless they explicitly decline[xxii] or, a term frequently employed in discussions of PHCT, 'opt-out'. This construction of the HIV test as routine is not to be confused with a different connotation which refers to the routine or standard practice of *offering* the HIV test alongside other screening tests in the prenatal context, which is quite different in intent and practice from characterising the actual *administration* of the test as a routine procedure. Examining the provincial PHCT protocols currently in effect in Ontario and Alberta serves to illustrate this essential difference.

In 1998, the Minister of Health for Ontario announced a revised PHCT policy whereby HIV testing would be offered to all pregnant women and women planning a pregnancy,

[xxii] It is interesting to note that the term employed in most discourses in the prenatal HIV testing domain is that the pregnant woman 'refuses' the HIV test. The use of the term 'refuses' seems to suggest an element of irrationality or irresponsibility. The term 'declined' will be used throughout this thesis as it suggests to the author a more reasoned, rational action.

> *[t]he Ministry of Health, in conjunction with physicians and midwives in Ontario, will make voluntary HIV antibody testing available for all pregnant women and women planning a pregnancy, either as part of routine prenatal screening or through the current HIV testing programme. Women should be counselled about the benefits and risks of HIV antibody testing and must give their informed consent before their physician or midwife orders the test.*[236]

The intent behind the Ontario policy is to make the *offer of the test routine*, not that pregnant women will be *tested routinely*. This subtle difference is illustrated by reference to the current policy in Alberta similarly announced in 1998,

> *All women presenting for prenatal care should be informed about HIV infection and testing. Pregnant women should be assured that testing for HIV is voluntary. All pregnant women should be advised that HIV testing is part of routine, good prenatal care and will be done unless a woman chooses not to be tested.*[237,238]

Although we see the same construction of HIV testing as a component of standard or routine prenatal care as embodied in the Ontario protocol, the intent of the Alberta policy is to routinely test pregnant women unless they decline, or opt-out.

Proponents of a routine approach, as exemplified in the Alberta guidelines, are often practicing health care professionals unconvinced of the merits of an existing voluntary 'opt-in' approach characterised by health care practioners such as themselves discussing an offer of the HIV test with the pregnant women in their care who then need to consent to its administration. This opt-in approach is experienced by these practioners as ineffective in engaging sufficient numbers of pregnant women in the HIV testing process. In the UK for example, early guidelines from the Department of Health in 1992 and 1994[239,240] stressed, albeit in the context of a selective policy approach, an opt-in approach emphasising the offer of an HIV test,

> *Clinics should offer named voluntary testing to all women in areas of known or suspected higher prevalence and elsewhere to those women with recognisable risk factors.*

Two years following the publication of the latter guidelines however, Smith and colleagues in a commentary in the British Journal of Obstetrics and Gynaecology,[241] argue that pregnant women attending for prenatal care in areas of

the UK with high HIV prevalence should be informed that they will be routinely tested for HIV unless they decline. This proposal, a departure from the current national guidelines requiring that a HIV test be offered, is based on their concern that in their hospital (Chelsea and Westminster Hospital, London, UK) only one in seven pregnant women accept PHCT when offered on an opt-in basis. Counselling pregnant women to opt-in to HIV testing in order to increase the rates of testing was judged to be less effective than establishing an opt-out policy to increase rates of testing to levels that would detect more than the current one-fifth of HIV-positive women diagnosed in the prenatal context in the UK.[xxiii]

This concern with low rates of test uptake associated with a voluntary opt-in policy leading to a call for a routine opt-out policy, has also been expressed in studies emanating from the United States. In 1995, the American Public Health Service (PHS) established guidelines to promote universal counselling and voluntary testing of all pregnant women.[204] However, among more than nine thousand women who gave birth in 66 Chicago-area hospitals between 1997 and 1998 and who participated in a study by Joo and colleagues,[242] only 58% reported receiving counselling and only 65% of the women were offered testing. Similarly, in a paper at last year's (2002) International AIDS Conference in Barcelona, Spain, Montgomery and colleagues[243] reported on the situation in California where state law mandates the universal offering of an HIV test to all women in prenatal care with appropriate documentation and counselling. Less than half of the 1,362 pregnant or recently delivered women surveyed in 1996 reported receiving counselling and 74% reported being offered a test of whom 90% accepted. The authors argue that as prenatal rates of HIV counselling and test offering are far shy of universal, the results lend support to a revised policy of routine testing where women have right of refusal.

[xxiii] Data from anonymous unlinked antenatal testing suggests that the majority of women living with HIV in England and Wales remain undiagnosed.[266]

Perhaps the most extreme example of a routine opt-out policy is that recently recommended by the US Institute of Medicine Committee on Perinatal Transmission of HIV (IOM).[244] Concern with the continued numbers of HIV-positive infants born to undiagnosed women living with HIV and AIDS despite the existence of authoritative PHS guidelines to decrease such occurrences, led the IOM in 1998 to convene a special committee to examine the success of the efforts by the US to reduce perinatal transmission and to identify existing barriers to further reduction. Specifically, the committee evaluated the implementation of the 1995 PHS Guidelines in identifying HIV-infected pregnant women through universal voluntary prenatal HIV testing following appropriate counselling. The 1999 report of the committee concluded that further reductions in the rate of perinatal transmission were impeded by the continued difficulty in fully implementing the PHS guidelines for the universal voluntary testing of all pregnant women. Identified barriers to implementation included: difficulties in accessing prenatal care; time constraints resulting in lack of counselling about the importance of the test; lack of resources to overcome linguistic and cultural barriers that may contribute to declining testing; and financial and logistic problems rendering testing and treatment problematic. The committee therefore recommended that the most direct way to ensure that all pregnant women would be tested for HIV in the prenatal context in order to further reduce the rate of perinatal transmission was to implement a

> *national policy of universal HIV testing with patient notification, as a routine component of prenatal care.*

Essentially the recommendation is to adopt a routine opt-out approach with health care professionals being required to inform all pregnant women that HIV testing is part of routine antenatal care and will be administered unless the woman specifically declines. Formalised prenatal counselling and written informed consent would no longer be required.[69,245]

The IOM recommendations, the most restrictive US guidelines to date, received mixed reviews. The American Academy of Pediatrics (AAP) and the American College of Obstetrics and Gynecology (ACOG) promptly issued a joint statement of support for routine universal prenatal testing[246] overriding ACOG's previous endorsement of the 1995 PHS guidelines promoting universal counselling and voluntary testing. The Adolescent Medicine HIV/AIDS Research Network (AMHERN)[247] acknowledged that in some situations the inability to provide adequate counselling may actually deprive a woman of the opportunity to be tested for HIV infection during her pregnancy, but were of the view that a woman should have the right to expect and receive the time and attention it takes to do pre-test counselling. Given these sentiments, AMHERN was less enthusiastic in its endorsement of the IOM guidelines stating that it *"reluctantly supports a mechanism that will allow more women to be tested without formal counselling."* In 2001, the Centers for Disease Control (CDC) subsequently published revised PHS recommendations for HIV screening of pregnant women based on consultations around the IOM's recommendations. Essentially these latest guidelines emphasise that HIV testing should be presented universally as part of routine prenatal services to pregnant women but, unlike the IOM recommendations, stress that confidential informed consent before HIV testing is essential and should be maintained.[248]

In Canada, Alberta, Newfoundland and Labrador, the Northwest Territories and Nunavut are the only provinces and territories whose prenatal screening programme includes routine opt-out HIV testing. In Alberta in 1997, a stakeholder committee co-chaired by the Alberta Medical Association and Alberta Health recommended to the Alberta Minister of Health and Wellness that a programme of routine testing for HIV during pregnancy be implemented.[249] A year later testing for HIV was added to the routine prenatal blood tests for all Alberta women and the test completed unless the woman actively declines.[210] The rationale for implementing a routine, opt-out programme in Alberta was to ensure that the majority of pregnant women had access to HIV testing as part of good

prenatal care, particularly women who may not be perceived as at risk of HIV either by themselves or their health care providers. Data documenting that prior to 1998, the majority of the approximately 60,000 women who become pregnant each year in Alberta were not being tested for HIV provided additional impetus for policy implementation of this kind.[237]

Documenting any potential increase in prenatal HIV test uptake following the implementation of a routine opt-out policy in Alberta is not possible as, prior to this policy implementation, information on whether HIV tests were performed as part of the prenatal screening was not provided consistently.[250] However, in 1999, the year following policy implementation, 96% of pregnant women were tested for HIV in the prenatal context and 98% in 2000.[237]

Newfoundland and Labrador was the first province in Canada to recommend universal voluntary prenatal HIV testing in 1992 based on a province-wide anonymous prenatal HIV prevalence study. It was also the first province to introduce it on an opt-out basis in 1997 due to perceived limitations in applying a voluntary opt-in approach. Following the 1992 recommendation of universal prenatal HIV testing, it was estimated that in 1993 nearly half of the pregnant women in the province accepted prenatal HIV testing under this opt-in voluntary approach, a proportion that subsequently rose to 66%. However, a further province-wide anonymous prenatal HIV prevalence study in 1996 indicated that HIV testing carried out on a voluntary opt-in basis might not include all pregnant women at risk of HIV. Consequently, in 1997, HIV testing was introduced across the province on a routine opt-out basis implemented by the Newfoundland and Labrador Advisory Committee on Infectious Diseases. The Committee recommended that HIV testing be added to the existing prenatal screen and that HIV testing would routinely be carried out as part of that screen unless the pregnant woman declined.[251] The most recent data on prenatal HIV test uptake in Newfoundland and Labrador document a significant increase in the proportion of pregnant women being offered and accepting prenatal HIV counselling and

testing. In 2000, all pregnant women receiving prenatal care were offered and accepted testing[210] with the rate declining slightly to 94% in 2002.[209,251]

Comparative evaluations of an approach to PHCT, in which an HIV test is routinely administered unless the woman specifically declines, or opts out, have been conducted in several countries including the UK and the US. These studies generally report increased prenatal HIV test uptake when a routine opt-out approach is implemented replacing an opt-in or targeted approach.

In Edinburgh for example, in 1998, Simpson and colleagues[252] compared the proportion of pregnant women who accepted HIV testing when it was presented as a routine prenatal procedure with emphasis on the fact that a woman could decline, with the results of test uptake obtained in their earlier study carried out between 1996 and 1997[23] which examined an opt-in approach in which women had to make an active choice to be tested for HIV. Presenting the HIV test as routine resulted in 88% of pregnant women accepting the test, more than double the rate (35%) achieved in the earlier opt-in study. The authors contend that, despite the effect of possible developments in the knowledge and attitude of the health care providers offering the test and the pregnant women accepting the test, the magnitude of the significant increase in prenatal HIV test uptake points to the relative efficiency of a routine opt-out approach.

Endorsement of a model of routine opt-out PHCT is also provided by Blott and colleagues[253] who report similar high rates of test uptake with a routine opt-out approach in a different environment in the UK among a deprived, multicultural London population with a high prevalence of HIV infection among pregnant women. Among this population, the rate of test uptake with an opt-in approach was documented at 33%, a rate reasonably comparable to that documented in the same approximate time period in other inner London institutions operating an opt-in policy such as the 42% reported by Dennison and colleagues in 1995,[254] 46% reported by Hawken and colleagues in 1994,[255] and the 41% reported by Mercey

and colleagues in 1996,[27] but considerably higher than the rate also reported in 1996 among the majority of London institutions by MacDonagh and colleagues.[191] However, in Blott and colleagues' study, for the first six months following the introduction of a routine opt-out policy the overall rate of HIV test uptake in the prenatal context increased dramatically from the 33% obtained under an opt-in approach to 90% under a routine opt-out approach.

Adapting the IOM's recommendations[256] to conform to Alabama Medicaid law (which mandates written consent for all HIV testing), Stringer and colleagues[257] report on an investigation of prenatal HIV test uptake obtained under the approach suggested by the IOM of universal routine prenatal HIV testing with patient notification and active refusal. The rate of test uptake obtained under this policy was compared with that obtained under the previous system of universal pre-test counselling and a voluntary opt-in approach consistent with the 1995 PHS Guidelines.[204] Following implementation in 2000 of a policy of routine testing with active patient refusal, HIV testing rates among the study's large urban obstetric clinic population increased significantly. Overall, the rate of HIV testing increased from 75% under the previous system to 88% in the year following institution of the revised policy. This documented increase in test uptake led the authors to suggest that a policy of routine HIV testing with patient notification and active refusal may be a more effective approach to HIV testing than the standard 1995 opt-in model of voluntary counselling and testing.

In a recently published investigation of HIV testing among pregnant women in the US and Canada carried out between 1998 and 2001, the US Centers for Disease Control[209] report that HIV testing rates among pregnant women were found to be dependent on which policy approach to PHCT was used. Prenatal test uptake rates in those US states implementing a voluntary opt-in policy ranged from 25-69%, and rates in Canadian provinces implementing the same approach were in the range 53-83%. In contrast, testing rates among pregnant women in Alberta and Newfoundland and Labrador, two provinces that have implemented a routine opt-

out policy, were 98% and 94% respectively. Tennessee, one of two states described in the report with an opt-out approach, had a prenatal testing rate of 85%. In an editorial to the main report, the CDC concludes that increases in prenatal HIV testing rates were in states that had shifted from an opt-in approach to either a routine opt-out approach or had implemented a mandatory policy of testing newborns and were probably associated with a greater likelihood that women were offered HIV testing during prenatal care. As a result, the CDC recommended that jurisdictions using a voluntary opt-in approach and that have low prenatal testing rates should re-evaluate their approaches.

Increased uptake of prenatal HIV tests in the prenatal context is the outcome indicator most frequently adopted in studies evaluating the comparative efficiency of the different approaches to PHCT and the indicator most frequently reported and emphasised. The experiences and perspectives of the pregnant women as recipients of these varying testing policies generally receive little attention. Three European studies and one American study did, however, include data on the acceptability, from the perspectives of the pregnant women, of a HIV test completed routinely in pregnancy in the absence of expressed dissent. Within the context of Simpson and colleagues'[23] evaluation of different ways of offering prenatal HIV testing previously described, Boyd and colleagues[258] undertook a complimentary qualitative study. Twenty-nine women attending Edinburgh's main maternity hospital between August 1996 and January 1997 completed semi-structured interviews on their experiences of the PHCT process. Most of the women in the study wanted the decision to accept HIV testing to be taken out of their hands and for the test to be carried out routinely. Nearly all of the nine hundred pregnant women who participated in Simpson and colleague's earlier study assessing a voluntary approach completed a questionnaire in which 80% endorsed a routine opt-out policy on PHCT. A slightly higher proportion (88%) of the participants in Blott and colleagues' British study[253] also endorsed a routine opt-out policy, although participation in the evaluation was much lower at 39% of 241 pregnant women. In Carusi and colleagues' study among pregnant women in

San Francisco,[24] there was similar endorsement by 69% of the pregnant women interviewed of a routinely administered opt-out HIV test. The proportion of pregnant women preferring elective HIV testing with a separate written consent at 27% was similar to that recorded for tests for other prenatal conditions such as rubella, syphilis and hepatitis B. Simpson and colleagues[252] included an additional measure of pregnant women's satisfaction with a routine approach to PHCT, an anxiety measure. Comparing anxiety levels reported by pregnant women participating in their investigation of an opt-out approach with the anxiety levels of those pregnant women participating in their earlier investigation of an opt-in approach, anxiety levels were significantly lower among pregnant women experiencing the routine opt-out approach.

In Stoltz's extensive examination of the legal parameters of the prenatal HIV testing debate[63] she suggests that a significant problem with an HIV testing policy for pregnant women that characterises the test as routine is the increased likelihood that women will be tested for HIV without pre-test counselling and therefore without their informed consent – in effect mandatorily. In their endorsement of a routine opt-out approach, Smith and colleagues'[241] assertion that requiring women to opt-out of a routinely administered test rather than counselling them to opt-in will result in an increase in test uptake begins to demonstrate the concern of opponents of a routine approach and confirms Stoltz's concerns. Characterising the test as routine may lead to a perception that pre-test counselling and discussions are no longer necessary (as hinted by Smith and colleagues) and informed consent is no longer a pre-requisite for testing. In an early paper by Almond and Ulanowsky,[259] this potential to dispense with pre-test counselling and securing informed consent when administering an HIV test that is considered routine is made even more explicit in their recommendations to health care professionals that women should be notified that HIV screening will take place, but in-depth counselling should be reserved for those with questions or who later return with positive results. Nicholl[192] similarly endorses Almond and Ulanowsky's view of the marginal necessity for pre-test counselling, suggesting

that scarce counselling resources should be reserved for discussing the return of positive HIV test results rather than *"being wasted on routine pre-test counselling"*. In their paper suggesting guidelines to facilitate routinely offering HIV testing in busy antenatal clinical settings, Miller and Madge[260] similarly argue to minimise the need for pre-test counselling. They take this position on the basis that, as many more women are now better informed about HIV, lengthy discussion about testing is not needed and take the paternalistic view that "*too much discussion about advantages and disadvantages of testing can make decision-making difficult.*"

In the US context, Stoltz's concerns have particular resonance when considering the sentiment behind the endorsement by the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists of the IOM recommendations.[246] Their joint statement of support for the IOM's recommendations demonstrates the perceived marginality of pre-test counselling,

> *The use of 'patient notification' provides women the opportunity to decline to be tested but eliminates the obligation to provide extensive pre-test counselling which has been a barrier to testing in many settings . . . we encourage our members and Fellows to include counselling as a routine part of care, but not as a prerequisite for and barrier to prenatal testing.*

Similarly, in Stringer and colleague's investigation of the applicability of the IOM recommendations among an urban maternity clinic population in Alabama,[245,257] they make two interesting comments regarding pre-test counselling and a routine opt-out approach:

> *The strategy allowed us to reduce the time spent on extensive pre-test counselling in a population where the prevalence of HIV infection is quite low.*
>
> *This approach to HIV screening is more time efficient because much of the pre-test HIV counselling process has been eliminated.*

From a Canadian legal perspective, characterisation of a test as routine does not relieve physicians of their obligation to secure voluntary, specific and informed consent to the diagnostic intervention through pre-test counselling and discussion

of the risks and benefits associated with the HIV test. Characterising the HIV test as routine may be an effective way to diminish apparent physician reluctance or even intransigence in offering HIV testing to all pregnant women in line with existing Canadian policy and recommendations from professional bodies. However, in view of the potential to diminish a pregnant woman's right to autonomy through failure to secure her informed consent to HIV testing following pre-test counselling, Stoltz suggests avoidance of the term routine to describe the HIV testing of pregnant women in Canada.[63]

This assertion is very interesting in the Ontario context, a province for which a routine opt-out policy is being actively canvassed.[69] In a recent editorial in the *Canadian Family Physician,* Remis and colleagues,[71] (all of whom members of the Ontario Ministry of Health and Long-Term Care Prenatal Evaluation Committee of which I am also a member), recommend that in order to ensure as many infected pregnant women as possible know their HIV status and to reduce mother-infant transmission in Canada,

> *All provinces should adopt routine HIV testing for pregnant women and take an opt-out rather than an opt-in approach.*

In the light of the previous discussion on the possibility of pregnant women being tested without the benefit of pre-test counselling and without their informed consent under a routine opt-out approach, Remis and colleagues address this possibility as a certainty in comparing an opt-in policy with a routine opt-out policy,

> *Policy makers in each province will have to decide whether they will accept preventable HIV transmissions to newborns as the inevitable and acceptable price to pay for a system [voluntary opt-in] that probably offers a higher level of informed consent.*

So, consideration of Mill's statement comes full circle with the recommended implementation across Canada of a routine opt-out policy of PHCT with the potential to permit the State, by default rather than by direct sanctioning, the authority to *"rightly exercise its power over members of a civilised community to prevent harm to others"'* – that is to restrict the rights of pregnant women to autonomy, self-determination and bodily integrity in the interest of foetal protection. It is clear that although a mandatory policy of PHCT has traditionally been characterised as creating clear potential for conflict between the mother and the foetus she carries, a routine opt-out policy, as currently recommended for the whole of Canada[70,71,214,215] and Ontario in particular,[69] also possesses that quality.

CHAPTER THREE

METHODOLOGY

This chapter describes how I undertook this research, or, as Rapp succinctly states,

> *How, where and under what conditions I came to know what I now claim to know.*[267]

It describes the construction of the investigation starting with the design, and situates myself, as the researcher, within the context of that design. The specific methods of the investigation are then described in terms of how I addressed the requirements of appropriateness and adequacy through the framework of the sampling strategy and the sample size. The collaborative work I undertook in engaging with pregnant women; the process of the interview; and the methods I used to interpret the women's narratives are then subsequently detailed. The chapter concludes with information on the ethical approval process and a discussion of my responses to personal ethical concerns related to interviewing women in general and specifically in the HIV prevention domain.

Study Design

The design of this investigation was driven by the need to describe the phenomenon from the emic perspective, that is the perspective of the pregnant women themselves. Thus, I selected a qualitative, inductive approach as the most effective way to document the women's experiences, perceptions and decision-making processes around HIV testing in their pregnancies.

In designing this qualitative enquiry, I selected semi-structured interviewing as the most effective strategy to achieve the active involvement of the women in the construction of data about their experiences and their perceptions of best practices in PHCT. My decision to adopt this strategy was based on two considerations. Firstly,

the choice of a semi-structured interview in preference to a more unstructured, open-ended interview. This decision was based on the fact that I knew the themes or issues that I wanted to cover during my time with the women and had developed associated questions to capture the women's responses. These themes were grounded in my knowledge of the HIV testing process and made salient by the responses of the women in the pilot to this study.[64,65] However, as I could not predict the answers, the interviews were semi-structured, leaving space for the pregnant women to indicate and voice their own issues during the interview process. In enabling access to people's ideas, thoughts and memories in their own words, feminist researchers have emphasised the particular importance of this approach in interviewing women who have been historically silenced in mainstream research.[73,268]

Secondly, the decision to work with women on an individual basis through personal interviews rather than working collectively through a focus group was grounded in experience. The decision to undertake personal interviews was based on the results of a comparison of both the depth of information disclosed, and the comfort levels of pregnant women participating in both a focus group and an individual interview in the pilot to this study. For example, some of the women participating in the pilot focus group revealed to me in an individual post focus group evaluation session that they had not disclosed that they had participated in an HIV test for fear of adverse reactions from other focus group members. Similarly, all the women commented that their participation in the individual interview allowed for a more in-depth discussion of their personal attitudes and feelings towards the whole issue of prenatal HIV testing - issues that they would be unlikely to discuss in such a deep personal context in the more public domain of the focus group.

The Researcher as Instrument[269]

Qualitative research is an interactive process shaped by the personal history, biography, gender, social class, race and ethnicity of both the interviewer and the interviewee.[270] Although qualitative research can capture the lived experience of the participants in the research, this lived experience is created in the social text written by the gendered researcher speaking from a particular class, racial, cultural and ethnic community perspective.

In elaborating my presence in, and acknowledging that my orientation to, this research is shaped by my socio-historical location including the values and interests that this location confers upon me, it is important to state that as a white, middle-class, educated, heterosexual woman, mother, feminist social worker and AIDS activist I can claim no objectivity to the analysis. Within the feminist interpretive framework, this is not a statement of bias, rather an explanation of my standpoint as a researcher.[73]

Study Methods

Two principles were used to inform the basis on which I made decisions as to how many pregnant women I would need to work with, and which characteristics those pregnant women needed to possess. The first principle, appropriateness, defined as working with participants who can best inform the research according to the theoretical requirements of the study[271] is considered in the next section on sampling strategy. The second principle of adequacy, relating to information saturation[271], is discussed in the subsequent section on sample size.

Sampling Strategy

Distinct among other studies in this area, this research was predicated upon a firm commitment to include and privilege the voices of those women frequently marginalised in research in the prenatal domain and for whom prenatal testing for HIV may raise special issues and concerns. As prenatal HIV testing programmes that fail to address the cultural and social contexts within which women's decisions to test for HIV occur, will similarly fail to engage maximum numbers of pregnant women, it was of vital importance to hear from pregnant women whose life situations may influence their attitudes towards, and experiences of, prenatal HIV counseling and testing. Making these choices was influenced by the pilot study. This preliminary research revealed the importance of listening to younger street-involved women and visible minority women who were under undue pressure from their health care providers to test with the potential consequence of failure to access or continue prenatal care. The pilot work had also revealed that women who inject drugs had significant issues in presenting for HIV testing in the prenatal context that required further investigation:

> *I know a lot of them that are pregnant that are drug users like me. And, and right away a lot of them are going to think Children's Aid's going to get involved. They're going to take my baby away. And all this you know. Because automatic – every, every girl I've talked to that was pregnant, they're afraid to go for help because they're going to get the Children's Aid calling on them. What are you going to do about that?*

In addition, if PHCT is to maximize its potential as an HIV prevention intervention, it is essential that the process is acceptable to, and easily accessible by, women whose engagement in HIV risk-related behaviours and experience of HIV risk-related conditions potentially place them at higher risk of HIV infection. It was important therefore to ensure inclusion of the perspectives of women with the exposure characteristics that represent the face of the HIV epidemic among women in Ontario.

In order to capture this diversity of pregnant women's life situations and experiences of HIV-related risk conditions described above and which I considered likely to impact on their experience of, and attitude towards, PHCT, I adopted the techniques of selective or criterion sampling[272] to satisfy the requirement of appropriateness. Although more usually employed based on demographic indicators (demographic variation), I selectively engaged women based on achieving variation in terms of the PHCT experience.

The sampling strategy was therefore initially constructed to achieve maximum phenomenal variation so that inclusive coverage of variables likely to be determinants of experiences of, attitudes towards, and perceptions of best practices in HIV counselling and testing in pregnancy could be obtained. As an iterative process, if analysis of initial interviews revealed other factors that impacted on pregnant women's experiences and attitudes to PHCT, theoretical sampling could be implemented in an ongoing manner to include the voices of pregnant women with those characteristics that required further clarification.

Personal Characteristics of the Pregnant Women

To identify those women with the exposure characteristics contributing to the HIV epidemic among Ontario women, I used the latest data available at the time of implementing the design of the study on the exposure category of first-time diagnoses among Ontario women.[115]

These data, depicted in Table 17, suggest that women at higher risk due to heterosexual contact with a partner at increased risk of HIV infection needed to be included in the study. As it is well documented that Canadians with risk factors for HIV are more likely to test for HIV than those without such risk factors[116], it was important to include women considered to be at lower risk of HIV infection and who accounted for 19% of Ontario's first-time HIV diagnoses. It was particularly relevant to include these lower risk women as they will be the

majority to be offered testing in any prenatal programme based on a universal offer of HIV testing. Also, it was important to include women among whom an increasing number of infections were occurring. Thus, from an examination of provincial data it was clear that women from HIV-endemic countries, who accounted for 21% of Ontario's first-time diagnoses, needed to be included in the study, and data at the federal level indicated the need to investigate the national trend of increasing levels of HIV infection among younger Aboriginal women.[171]

Table 17

First-time HIV-positive Diagnoses Among Females in Ontario by Exposure Category[a] 1985 - 1999

EXPOSURE CATEGORY	NUMBER	PERCENTAGE
Injection Drug Use	420	17.0
Clotting factor	60	2.4
Transfusion	168	6.8
HIV-endemic	520	21.1
High Risk: Heterosexual	718	29.1
Low Risk: Heterosexual	458	18.6
Perinatal[b]	108	4.4
Other[c]	12	0.5
TOTAL	**2,464**	**100.0**

a Unknown sex assigned according to the distribution of those with known sex; unknown exposure category assigned according to proportion among the known.
b Includes infants with maternal HIV antibodies who are not infected.
c Includes needle stick, acupuncture, tattoo, etc.

Although the composition of the final sample would be driven by the strategy of achieving information saturation across and within each sub-group of women, the initial parameters of the sample and associated recruitment strategy were to therefore include pregnant women in Ontario who:

- were younger and street-involved;
- were from a visible minority;
- were current injection drug users or who had injected drugs at some point in their history;
- were considered to be at higher risk of HIV infection either through their own or their partner's engagement in HIV risk-related practices or experience of HIV-related risk conditions;
- were born in an HIV-endemic country;
- self-identified as Aboriginal women; and
- were considered likely to be at lower risk of HIV infection.

Regional Composition

I combined two approaches to determine the location of the pregnant women to be interviewed. The first approach was to interview pregnant women in areas of Ontario where the level of HIV infection among women was highest and therefore, by extension, the possibility of increased rates of perinatal transmission was potentially highest. The second was to interview women in those areas of the province where perinatal HIV transmission appeared to be most frequently occurring.

To identify those areas of Ontario with the greatest number of women reported to be HIV-positive and those areas with the greatest rates of perinatal HIV prevalence and incidence, data documenting these variables by location of health unit and institution were examined and monitored on a regular basis throughout the period of the study.[114,274-275] Using these data, interviews would take place in

health regions based on the proportion each health region was contributing to the total number of first-time HIV-positive diagnoses among women of all ages in the province and to the provincial total of children living with HIV.

Table 18 depicts a synthesis of the two sources of epidemiologic data relating to the percentage determination of the location of interviews. From this synthesis, the implications for the initial locations of the interviews were:

> 56% of the women interviewed should be residing in Toronto;
> 23% of the women interviewed should be residing in Ottawa; and
> 21% of the women interviewed should be residing in other parts of the province.

Table 18

Synthesis of Data Relating to Percentage Determination of Location of Interviews with the Pregnant Women

DATA SOURCE	TORONTO	OTTAWA	ELSEWHERE
First-time HIV-positive Diagnoses among Women	50.0	20.0	30.0
HIV-positive Children	62.0	26.0	12.0
AVERAGE CUMULATIVE PERCENTAGE	**56.0**	**23.0**	**21.0**

This location framework was adopted at the start of the project and was successively modified to take account of new information regarding prenatal HIV test uptake. On an on-going basis throughout the period of this investigation, data from the HIV Seroprevalence Study among Women Receiving Prenatal Care in Ontario by Remis and colleagues at the University of Toronto became available.[115,276] It became clear from these data that, throughout the period of the study, Metro Toronto consistently showed lower levels of uptake of HIV testing among pregnant women and Ottawa consistently higher levels, suggesting perhaps that the experience for Toronto women may be qualitatively different than that of Ottawa women. While maintaining the diversity of the women's situations and personal contexts, the location protocol was adjusted over the course of the study to take account of these findings.

Sample Size

A qualitative study's strength derives from the insights and depth of understanding generated rather than from the volume of women interviewed. Prevailing ideas on acceptable sample size in qualitative research suggest that a sample size of thirty to fifty interviews would be adequate to address the study objectives.[277] I therefore initially adopted the upper limit of fifty interviews to respond to the parameters relating to the composition of the sample as determined by provincial epidemiological data, and to achieve a close approximation of the calculated regional locations described above. Planning to initially conduct the higher limit of fifty interviews would also allow for secondary selection sampling.[278] As I would be relying on pregnant women to self-select to meet with me, I would not be able to determine in advance which participants would be most forthcoming in working with me. In the event that the interview was not fruitful, or the woman was constrained in her responses, or technical problems in recording intervened, the interview could initially be set aside without necessarily adversely affecting the attainment of the study's objectives.

A sample size of 50 was adopted at the commencement of the interviews with the intent that final sample size would be derived in an iterative manner, controlled by ceasing or increasing recruitment dependent on overall theoretical and informational saturation of the themes addressed and dependent on theoretical and informational saturation within the specific groups of women interviewed. Adopting the concept of saturation ensured that the research adhered to the second of the guiding principles previously discussed, that of adequacy, defined by Morse and Field[279] as ensuring

> *enough data are available to develop a full and rich description of the phenomenon – preferably that the stage of saturation has been reached. That is, no new data will emerge by conducting further interviews...*

As the interviews progressed, it became clear that I needed to hear more from some women, for example, those without provincial health coverage. This applied to women on temporary visitor's permits applying for landed immigrant status, and to street-involved women without a permanent address. For these women lack of coverage was impacting on actual or perceived difficulties in accessing prenatal care or was constraining the provisions of some components of it, including HIV testing. Adopting the concept of theoretical sampling to ensure adequate coverage of these newly identified issues I ultimately completed interviews with 57 pregnant women.

Recruitment Strategy

To participate in the study, women needed:

- to be pregnant;
- to fit the demographic and location criteria I had established; and
- to be capable of giving their informed consent to participate.

The pregnant women could be of any age and may or may not have been tested for HIV in their pregnancies. I made the decision to work with only women who were pregnant in order to ensure an opportunity for HIV counselling and testing in the prenatal period should this be the woman's choice as a result of participation in the study.

Recruitment strategies were consistent with the sampling strategy to achieve maximum phenomenal variation within the sample and were based on my prior experience of establishing and evaluating recruitment strategies in the pilot to this project which examined the same issue with a similar, if smaller, group of pregnant women in Ottawa and Montréal.[64,65] To recruit pregnant women in Ottawa for the pilot study, I was able to negotiate to describe the pilot study to several diverse groups of women attending general and specialised information sessions and prenatal classes at the (then) main maternity hospital in Ottawa at which most pregnant women in Ottawa gave birth. However, following these sessions, only a few pregnant women responded to the distributed promotional and recruitment material by contacting me to arrange a mutually convenient time to meet or to arrange to participate in the planned focus group. Similarly, promotional posters describing the study's importance and recruitment procedures displayed at this hospital and community health centres in Ottawa's downtown core were unsuccessful in attracting pregnant women into the study. The most successful method of engaging women into the pilot study in both Ottawa and Montréal was by direct introduction by trusted community personnel who were familiar with the women's personal circumstances.

To facilitate this process for this study, the Ottawa Project Community Advisory Board and the Toronto Project Community Advisory Board were established to assist with recruitment into the study and, equally as important, to ensure that all elements of the project were grounded in the specific communities. The community members of these two Advisory Boards were solicited on the basis of their positions in community agencies likely to be accessed by pregnant women with the social and cultural characteristics established for the study. Membership of the Ottawa and Toronto Community Advisory Boards are detailed in Appendix 1 and Appendix 2, respectively.

Members of these Boards were very active in facilitating recruitment in a number of ways. Some Board Members contacted colleagues working as frontline staff in community social service and health agencies providing services to pregnant women matching the profiles of the women I wished to include in the study and informed them of the objectives of the project. This strategy prepared the way for direct contact between myself and the agency worker to further explain the study and to arrange the logistics of meeting up with the women. Other Board Members worked within their respective agencies in directly advising pregnant women of the study and, at the request of the pregnant woman herself, would assist in setting up the interview. I was also able to make direct contact myself with agencies in Kingston, Toronto and Ottawa whose services women from the specific sub-populations would be likely to access. In these agencies, a designated staff person was appointed to advise pregnant women of the study and to assist with recruitment as necessary.

In order to recruit women outside of the Toronto and Ottawa areas, I was able to contact colleagues I had met in the course of my HIV prevention research work. Colleagues in both Kingston and Hamilton, working within settings likely to be accessed by a diverse group of pregnant women, promoted the study both within their own agencies and other agencies providing services to women with the characteristics that I wished to engage in the study.

The tasks undertaken by the agency workers that I met in this way included: regularly recruiting pregnant women into the study; making arrangements to reserve appropriate interviewing space at their agencies; providing child care on site to allow the women quiet uninterrupted time to complete the interview; at the women's request offering the services of a cultural interpreter[xxiv]; and, in many cases, arranging transport for the women to and from the interview.

[xxiv] Interpreters were only used at the request of the pregnant woman herself. Using the agency's own interpreters meant that these women were experienced, knowledgeable translators, women who had been trained by the agency to translate rather than summarise, and were well aware of their role in protecting the confidentiality of the sessions.

A complete listing of the community agencies and individuals who assisted with recruitment is contained in Appendix 3.

In order to avoid working with women from the same social networks and thus perhaps losing divergent experiences and attitudes, I did not actively encourage snowball recruitment. Only one pregnant woman was referred into the study by another woman participant. "Karyne" suggested to one of the women attending her mothering class that she too should give her point of view:

> *I talked to her about this thing [research interview] today. She's like, "I have nothing to do tomorrow." And I'm like, "Well come here and give your point of view!"*

Promotional material was specifically designed and developed for this project and, following successful pilot testing, was widely distributed. This promotional material included an information letter that I developed for front-line workers and health care providers in community agencies (Appendix 4) and a promotional brochure which I prepared for distribution to the pregnant women outlining the parameters of the study and with location-specific information on how to contact me to arrange an interview (Appendix 5).

Data Collection: The Process of the Interview

I carried out the personal interviews with the 57 pregnant women recruited through the strategies outlined above over a 15-month period between November 1999 and January 2001 with one exception. One woman who miscarried just prior to completing an interview we had arranged contacted me again several months later when she was pregnant again. She was extremely keen to participate in the research, considering it to be a very important and relevant issue which required the input of pregnant women themselves. She felt that she had much to say of her varied experiences of PHCT. I subsequently interviewed this woman in January 2002 and her narrative is included with those obtained earlier.

Prior to commencing an interview, I gave each woman a copy of the information sheet and consent form which is included in this thesis as Appendix 6. I read out this information letter and consent form to the woman, and once I was assured that she understood the terms of her participation, I signed both copies, thus assuring the anonymous and confidential nature of the interview. The form included my name and phone number as principal investigator, the name and phone number of the chair of the Research Ethics Committee, and details of the MotherRisk phone line should women require more information about their participation in the study or further general information about their pregnancies.

With the woman's consent I audio-taped the interview which typically lasted between one and one and a half hours. I explained to the women that they were in charge of the tape recorder, which I placed near them, and which they could turn off at any time in the interview:

Lynne	*Okay. It's going. If you want to stop it, it's this button here.*
"Isabelle"	*Okay.*
Lynne	*All right? So if we're talking about something and you don't want it recorded, it's this button.*

Contrary to generally accepted practice for qualitative interviews as suggested by Morse and Field:[279]

> *... because the participants expect to be asked questions, begin by asking for demographic information,*

I did not ask specific demographic questions before or during the interview. I wished to avoid establishing an interview pattern of short questions from me setting up short answers from the women. I also wanted to avoid categorisation or positioning of the women early on in the interview process which could have influenced the subsequent direction of the interview. At the conclusion of the interview, I gave all the women the choice of responding to some basic socio-demographic questions. These questions were asked for the explicit purpose of

directing recruitment strategies to respond to the established sampling strategy of achieving an inclusive group of pregnant women with differing experiences of HIV-related practices, behaviours and experiences of risk conditions.

In contrast to posing socio-demographic questions, I started each interview with the question, *"How are you feeling in your pregnancy?"* Women interpreted this broad question in many ways and the question allowed women to answer at the level with which they felt most comfortable. For example, some women responded with details about their physical health, others with descriptions of the stresses in their pregnancies and others with details of significant worries and concerns. In addition, the women's answers also allowed me to establish some rapport with them having experienced more than one pregnancy myself, although some several years previously. I was able to empathise with many of their stories and thereby established insider privilege, a useful means of easing the women into the interview.

The subsequent themes and associated questions for the interviews were constructed around critical points in the prenatal HIV counselling and testing process. They related to exploring the women's experiences of the application in the prenatal context of the principles of HIV testing and were developed from the earlier work of the pilot. Examples of some of these themes and examples of some of the associated questions include:

- Prenatal blood work - was HIV testing mentioned
  Let's talk about any blood tests that you may have had in this pregnancy.
- Reactions to mention of the HIV test
  How did you respond when HIV testing was mentioned to you?
  How did you feel about what you were being told?
  (Elicit perception of personal HIV risk.)
- HIV pre-test counselling
  What were you told about being tested for HIV in pregnancy?
  (Elicit perception of: mother to child transmission risk; pros and cons of test for mother and baby; use of positive results – reporting; testing options; anything else)

- Voluntary nature of the HIV test
  What was your impression of what your (doctor/nurse practitioner/midwife) wanted you to do?
  (Elicit understanding of voluntary consent and was this requested and given.)

- Consent
  Did you feel you could have said, "No"?

- Responding to the HIV test
  So you decided to go ahead and have an HIV test. Let's talk a little about that. What helped you decide on testing?

- Waiting for test results
  How was it waiting for the results?
  (Elicit disclosure of self-identified risk.)

- Post-test counselling
  Let's talk about how you got your results.
  (Elicit content of post-test counselling.)

The final questions tapped into the pregnant women's experiences of the PHCT process and asked them to describe:

- Best practices in prenatal HIV counselling and testing

  If you were asked to suggest to doctors and other health care providers ***what they should be telling women about HIV in pregnancy*** *- what would you suggest?*

  If you were asked to suggest to doctors and other health care providers ***how they should be testing*** *pregnant women for HIV in their pregnancy – what would you suggest?*
  (Elicit attitudes towards selective, opt-in, opt-out, mandatory)

  If you were asked to suggest to doctors and other health care providers ***how they should be talking to pregnant women about the results of their HIV test*** *– what would you suggest?*

The questions and probes relating to these and other themes are contained in the Interview Guide reproduced as Appendix 7.

The women's responses determined the inclusion and the order in which I introduced the thematic areas and related questions, the time spent on each, and the introduction of additional issues.[280] As I could not, and did not, know the unique parameters of each woman's experience, the interview was an iterative process in that I added thematic questions, both within and between interviews, as unanticipated subjects emerged. For example, as it became clear that difficulties in actually finding and, in some cases, paying for prenatal care accounted for significant delays in testing, women were subsequently invited to speak about their experience of prenatal care. As illustrated above in the question about pregnancy, when I did pose questions, these were widely framed and understandable on many levels so that the women could respond in their own terms without feeling constrained or directed in their responses. I also tried to use the women's own vocabulary when framing supplementary questions.

At the end of the interview I offered each woman the opportunity to ask me any further questions that she may have had and I also reviewed any issues of concern to me, mostly in the HIV prevention domain. At the conclusion of this debriefing session I offered all the pregnant women a package containing prevention and treatment information relating specifically to Canadian women and HIV/AIDS and current details of local resources to access more information on HIV/AIDS prevention and supportive programming. A copy of the brochure on prenatal HIV counselling and testing, *Important News for Pregnant Women, HIV Testing,* produced by the Ontario Ministry of Health and Long Term Care and the brochure produced by the Canadian Public Health Association, *Important News for Pregnant Women*, were also included in the package. All the pregnant women accepted the packages with interest. Most of the women started to read the pamphlets straight away, commenting that such information was not widely available and some of pregnant women engaged me in extended discussion of some of the topics raised in the material.

All of the women were compensated $30 for their time spent away from their other tasks and activities. As an agreed and promoted strategy to make the interviews accessible to all women who wished to participate, child care, travel and parking expenses were reimbursed and local bus tickets provided.

Data Management and Interpretation

In preparation for data analysis, the women's interviews were transcribed verbatim according to a uniform protocol of transcription that I developed. The protocol outlined strategies to be followed in order to maintain the integrity of the data during the analytical interpretation stage. For example, it was important that pauses in the women's narratives were indicated and that an interpretation of the expressions the women gave to their stories were included in the text.

As previously described, data collection and data interpretation took place concurrently to promote the emergence of substantive themes and thereby guide theoretical sampling. In interpreting the narratives constructed by the women of their PHCT experiences, I used conventional methods of qualitative interpretation borrowed from the dominant approaches of grounded theory[xxv] and phenomenology. In using a broad content analysis approach combined with thematic analysis I have adopted a *"practical pragmatic stand"*[268], an approach increasingly utilised in applied social research and social policy evaluation.[281-284] In rejecting the belief that a qualitative researcher must align with a specific enquiry paradigm, Patton[285] advocates a paradigm of choices:

[xxv] In reality it is perhaps now more accurate to talk about grounded theories as the later writings of the original proponents of the approach Glaser[291] and Strauss and Corbin[292,293] have moved the method in somewhat conflicting directions.[294] In addition, grounded theory is being further developed within other paradigms of research enquiry. For example, grounded theory researchers such as Charmaz suggest constructivist grounded theory[294] while Wuest promotes feminist grounded theory[83,295] and participatory grounded theory.[296,297]

> *A paradigm of choices rejects methodological orthodoxy in favour of methodological appropriateness as the primary criterion for judging methodological quality. The issue then becomes . . . whether one has made sensible methods decisions given the purpose of the enquiry, the questions being investigated, and the resources available.*

As the intent of the study was to specifically examine pregnant women's experiences of PHCT within the described framework of Ontario prenatal policy and within the framework of the established Canadian principles of HIV testing, the descriptive content analysis approach was considered to have maximum utility in evaluating specific issues such as whether women felt that they had given their consent and the contextual issues which they took into account when giving or withholding consent. In order to formulate specific policy recommendations, in order for this research to be *for* women instead of simply research *about* women,[73-75] this approach was foregrounded. In addition to this approach, I also searched for and identified common analytic threads that extended throughout the interviews. The themes emerging from this second strategy of interpretive analysis would have value in identifying overriding and inter-connected concepts that needed to be addressed within the policy response, e.g., balancing the women's health needs with those of the baby's.

The first stage of the analytic interpretation process was immersion in the data[284] achieved by reading the transcript of each taped interview three times. The transcripts were initially read at the same time as listening to the audiotape of the interview to identify the women's affect (tone of voice, emphasis, hesitation, etc.) as well as to initially identify, and latterly to confirm, main categories and variations. I used the broad principles of content analysis to identify or code the content in the interview and devised category labels for each group of data. This approach was consistent with the design of this applied research. As general thematic areas were introduced into each woman's interview, these themes or topics became the primary categories or category labels. Initially, for ease of coding, these

categories were very broad in scope, for example, *"The Offer of the HIV Test"*. Subsequently, these data were further categorised into subcategories such as, *"HIV Offered as a Package of Tests"* or *"HIV Test Talked about Separately"*. In order to respect the principles of internal convergence and external divergence, the data and categories of data were searched for categories and subcategories that were internally consistent but distinct from one another. Sections of several interviews were coded by myself and another experienced qualitative analyst at different points. Coding categories were compared and adjusted to enhance consistency and reliability. Thematic interpretation, or analysis, of the women's narratives was essentially achieved by line by line coding through which I was able to identify additional themes indicated by the data.

Ethical Approval

The Ottawa Hospital Research Ethics Board granted approval to this project in June 1999. Application to this Board for renewal of ethical approval was made and granted on an annual basis throughout the period of the study. A copy of the original approval letter from the Research Ethics Board and copies of the subsequent renewals are contained in Appendix 8.

In addition, some agencies required additional approval from their respective ethics boards and committees. For example in Ottawa, the Health Department of the (then) Regional Municipality of Ottawa-Carleton required and subsequently granted additional approval of the protocol from the Region of Ottawa-Carleton Public Health Research Board. A copy of this approval is contained in Appendix 9. In Toronto, the Central Toronto Community Health Centres (CTCHC) have a research policy and procedure protocol in place. Under this protocol proposed research involving Community Health Centres in central Toronto is evaluated by a Research Committee and by a separately convened Ethical Review Committee. Approval through this system was obtained in August 2000 before interviews were commenced in Community Health Centres in Toronto.

Ethical Considerations

Previous experience of conducting qualitative interviews with women in the context of practices and behaviour that have the potential to so seriously affect their lives and those of other people[286], made me aware of two issues in particular that required me to take an ethical position. The two issues are the role-related concepts of the qualitative interviewer as stranger or friend to the interviewee, and the issue of helping or supporting the interviewee. Discussion around the former is particularly associated with a feminist approach to interviewing and thus relevant to this study and the latter, for me, the most significant issue in a situation where women describe and discuss behaviour which has the potential to place them at higher risk of HIV infection or HIV transmission. Over time and through a process of reflective analysis I have come to develop a personal style of interviewing to address theses issues and which, in large measure, I applied to this study.

Friend, stranger, neither, both?[73] In describing the merits of carrying out qualitative research, proponents of the approach frequently cite friendship with the research participants as a benefit to the person carrying out the research. For example, Morse[287] contends that,

> *[Qualitative] researchers get to know the participants in their studies as real people, become part of their lives and often make life-long friends in the process.*

Similarly, in describing their model for qualitative interviewing, Rubin & Rubin[288] point to the friendship role of the interviewer as a feature of some feminist researchers,

> *Some feminists emphasise the need to be collaborators and perhaps friends with the interviewee...*

I have difficulty with the view that researchers need to become friends with research participants in order to talk meaningfully with them about their lives as Morse suggests. I am very clear that I am intentionally joining with participants so

that they can tell me their stories. They know I want to hear these stories and that I will compensate them for the time spent in the telling. To suggest any element of friendship in such a negotiated behaviour seems to mystify and obscure the true basis of the relationship for the women involved and could generate expectations that I, as a researcher in that situation, would not be able to fulfil. This latter point is extended by Stacey[84] who challenges the concept of interviewer as friend and suggests that an attempt at friendship,

> *... represents an intrusion into a system of relationships, a system of relationships that the researcher is far freer than the researched to leave.*

Reinharz[73] acknowledges the controversial nature of the interviewer as friend or stranger as a feature of both feminist and mainstream interviews. In considering how feminist researchers have negotiated this issue, she compares the approach described by Denise Segura in her 1989 study of a Chicano community with that described in Mary Zimmerman's 1977 interview-based study of abortion. Segura suggests that the researcher needs to be established in the community, needs to have close relations with participants before the interview takes place as

> *... [women] are likely to feel more comfortable talking to someone who is known within their social network rather than to an unknown researcher.*

Zimmerman on the other hand, posits that it was the very lack of a relationship that encouraged women to take part in her study,

> *The interviewer was a stranger - not a part of the women's world and someone she would be likely not to see again. The interviewer was also a professional who would not discuss the interview with anyone else.*

I have come to acknowledge that my own approach is much more aligned with that of Zimmerman. Indeed, the comments that I received from the women with whom I had been talking speak to the somewhat counter-intuitive concept, the idea of distance creating good conditions for trust in research relationships:

One Voice	*I feel better when I think about these things with somebody like you. I mean, I don't know you like. You know. I like to talk to a person I trust. I get everything out. I start crying. I feel more better, more lighter you know?*
Another Voice	*It's been very helpful to get this off my chest to a non-judgemental stranger.*
Another Voice	*I don't have a problem about being open. I've got nothing invested in what you think of me.*

While very sure that working towards a friendship relationship with the women I was meeting was ethically unjustifiable, I nevertheless came to accept a relationship that demonstrated and offered empathy. Initially I had set out to be a non-intrusive listener to the women's stories. I did not want to detract from the women's ownership of the construction of their life experiences or distract them from their task by any comments from myself. Neither did I want to engage in inappropriate rescuing as women sought to find expression for their pain and difficulties. It soon became clear that this was a role that I could not sustain and indeed did not want to sustain. Low-intrusion level expressions such as *Aha; I see; Yeah, yeah*, seemed specious and demeaning as women relived the horrors of rape and physical assault. Women recounting their daily struggles to maintain their HIV protective behaviour in the context of overwhelming demands and situational conflicts deserved more from me.

I am now more comfortable with a style that can be termed "empathic listening". Such a personal style, I feel, seems to generate the respect deserved by the women without the danger of me imposing my personal perspective too directly on their stories. Two examples will illustrate this point.

In this first snapshot, empathic listening had the effect of acknowledging the struggle in which the woman was engaged. "Janice"[xxvi], who had earlier described herself to me as an alcoholic, described at length, on different occasions during our time together, her fear of contracting HIV through unprotected sex with the many men she was sleeping with while her husband was in jail:

> *My husband, he's in jail right now, for a year. But I'm having sex beside, you know? While, I shouldn't, you know, but - . Like I said, I don't care when I have a few beers. Six or seven beers and I just kinda want, I just jump into bed with this guy with no safe [condom] or anything and it scares me. When I'm drinking I don't care about nothing. But the next morning I feel guilty. I get scared. I get worried. I do, I do. I get paranoid. I gotta get smart. I gotta start using safes and getting them to.*

It seemed essential to validate this struggle, so I said,

> *But it's hard. It's very hard when other things are going on, particularly if alcohol gets in the way.*

In the second situation described below, the style gave permission by example for the woman to engage with me at a deeper level of meaning. In this interview, or interviewee-guided discussion, a woman described in deep sequential detail her journey from the depths of despair as an injection drug user involved in sex trade work, to a woman who could manage her life without the aid of drugs. She told her story however in a mechanical, instrumental manner with little indication of the meaning for her of her behaviour. I offered,

> *"Connie", I think that must have taken a huge amount of courage, a huge amount of strength to achieve...*

This indication of my reflection, of my emotion on hearing her story served as a validation or a permission for "Connie" herself to engage in a reflective account of this journey, full of personal meaning.

In attempting to evaluate whether this empathic approach was successful in facilitating joining with the women as trusted collaborators in the interview

[xxvi] All names are ascribed pseudonyms.

process, I discovered a possible indicator of a successful collaborative empathic interview. This indicator marked an instance of the interviewee and I having an equal understanding of the discourse in which we were engaged to the extent that when I hesitated, the interviewee could continue my line of thought:

Lynne	*What I think I am hearing you say "Anne" is that - this dramatic event of the assault - you know - really was some sort of - almost like a -*
"Anne"	*Focus point! Yeah, yeah, as a focus point for me to turn myself around . . .*

Secondly, the issue of offering support and help to the interviewee. I was very clear that I had an ethical responsibility to the women I was talking with to answer questions about, or suggest, context specific risk-reduction techniques if they described situations in which they were placing themselves, or others, at risk of HIV. As an experienced social worker of some thirty years standing with twelve years experience in the field of HIV prevention, I felt capable of taking up this position. However, I attempted to balance this profoundly felt obligation with an understanding that my role with the women was not as counsellor or therapist. It would be very unfair to the women to slide into such a role (which comes naturally to me due to my clinical training) in a situation that had been negotiated on the basis of a completely different agenda. Equally, as with the friendship dilemma, to do so would be setting up expectations that I was in no position to carry out in the long-term.

To resolve the tension created by these two discordant rules of operating, I decided initially to conduct a debriefing session at the end of the interview which would include answering any questions that the woman may have had during or after the interview. During this debriefing session, with the women's permission, I would, if further counselling on a short or long term basis was agreed to be appropriate, or, if additional information resources were required, initiate a referral to the relevant community agency.

However, it quickly became clear that suggesting I would answer a direct question or respond to requests for further information at the end of our time together impeded the flow of our conversation and impeded the thought processes of many women. These women were left in the uncomfortable position of speculating on their question rather than being able to move on in their narrative. Equally as important however, it suggested different rules for the two of us as to when we would answer questions. The women always tried to answer any question of mine, even though they knew from the consent form that they could choose not to, and certainly never suggested that they would only answer certain questions at the end of the interview session.

I decided eventually therefore, that I would answer questions as sensitively and fully as I could as and when they arose in the interview, and to respond to any anxiety they produced. In framing my responses however, I was careful to say that I was responding as a woman interested in, and with some knowledge of, women's HIV protective behaviour and not as a health professional. I would not have all the answers but could certainly work with the woman at the end of the interview to suggest resources for her.

In reviewing other researchers' responses to this dilemma, Reinharz[73] provides some thoughtful extracts from Christine Webb's work on feminist methodology in nursing research which I found further consolidated my approach. Although arriving at the same point as myself, through a similar iterative, reflective process, Christine Webb decided that simply answering questions as they arose

> *...did not go far enough. I, as an "expert", had access to wider information than they did, and I could not justify keeping this to myself. Therefore I would give information and advice whenever I detected a need or opportunity during the interview. The effect of this has been at times I talked more than the women but this seems an inevitable consequence of my decision.*

I, however, am comfortable that the sequencing of responding to direct questions and requests for information that I am offering does go far enough. I feel that the "expert" approach described here is prone to the difficulties that I have already discussed.

Arriving at a level of professional and ethical comfort in deciding at what point and in what depth to answer direct questions was a swifter process than deciding at what point to intervene to suggest techniques and strategies to modify high HIV risk-related behaviour.

Initially, as before, I attempted to do this piece of work at the end of the interview. However, stripped of immediate context and emotion, the impact of our discussions was diminished and the salience of the modifications suggested equally reduced. Also, in reviewing some of the interviews, I saw with dismay any number of wonderfully rich opportunities actually occurring within the interview where, with very little prompting, the women themselves could have arrived at and experienced their own awareness of the importance of HIV-related risk behaviour change in their lives.

I subsequently decided that if such a situation presented itself again, I would indeed make a brief intervention. This intervention would be warranted so long as it was with the intention of reducing the risk of HIV infection for the woman involved. For example, "Mary" had described several instances of engaging in behaviour that did indeed confer a high level of HIV risk for her and she had decided to get herself tested for the virus. Her descriptions of the pain and suffering she endured while waiting for her test results and the experience of relief and exhilaration when she was told she was, in her words, "100% risk free", were vivid and powerful. I attempted to do something with her descriptions:

Lynne *It sounds like that experience really shook you up.*

"Mary" ***Oh yeah!!***

Lynne *You really remember those feelings.*

"Mary" *Oh man,* ***do I ever!!***

Lynne *I wonder then, I wonder then if there's any way that you can remember those feelings so that when you get in situations where it looks like, where it looks as though you are not going to use condoms, you could just remember how you felt when....*

My experience of interviewing women about behaviour that has the potential to so seriously affect their lives and those of other people, has led me to agree wholeheartedly with Brewer[289], who concludes from his own research on police work in Northern Ireland, that,

> *. . . in the real world researchers often have to make pragmatic compromises that depart from the text book portrayal of research practice...when the research involves sensitive locations or topics, the pragmatic compromises tend to increase in number and in the magnitude of their departure from ideal practice.*

So, through a process of reflective analysis, I have come to develop a personal style of interviewing which, in large measure, I applied to this current study. However, conducting qualitative research is an iterative process in all aspects of the undertaking. Therefore I recognise that this style will become modified "along the way" as Healy[290] suggests in this interesting metaphor:

> *The researcher who searches for and discovers a research method is similar to a traveller who sets out on a journey with an anticipated itinerary; sometimes things go to plan and sometimes things change according to contingencies along the way.*

CHAPTER FOUR

RESULTS

This chapter opens with a descriptive profile of the pregnant women participants who worked with me on this study. The detailed description of the women's experiences of their pregnancies lays out the context within which they made decisions around prenatal HIV testing and the context in which they would experience the results of HIV testing. The chapter is then divided into three further sections each related to the women's experiences of the interconnected components of the prenatal HIV counselling and testing experience.

The second section describes the application of Ontario's prenatal HIV testing policy in terms of the women's experiences of the offer of the HIV test and details the nature of the women's decision making in response to that offer. For those women who did undergo testing, their experiences of waiting for the test results are described. This section is followed by an analysis of the women's experiences in terms of the established Canadian principles of HIV counselling and testing. The issues examined are the voluntary nature of the offer of the HIV test; informed consent and pre-test counselling; and post-test counselling. The chapter concludes with a description of the pregnant women's perspectives on best practices in prenatal HIV counselling and testing. Specifically, an interpretation of the pregnant women's recommendations in terms of when HIV counselling and testing should be offered; by whom; the way in which it should be offered; and what the experience of prenatal HIV counselling and testing (PHCT) should comprise.

Firstly however, a note on how I have chosen to present the narratives of the women whose voices are the substance of this investigation. In reading the written reports of the qualitative work of other researchers, both declared feminist researchers and others who do not explicitly situate themselves within a specific theoretical framework, I have formed the opinion that from my perspective it is more respectful, dignified and of greater assistance to comprehension to refer to

the women by an allocated name and to ground the women's narratives by sharing some information on the speaker. In this context I needed to be acutely aware of the intersection between enhanced understanding of the texts and the need to ensure women have the degree of anonymity with which they are comfortable and which is required in research on human subjects.

In Rapp's excellent work with women experiencing offers of prenatal diagnosis for a variety of foetal disorders[267], she

> *promised and delivered confidentiality via pseudonyms for any pregnant woman or mother or child or their supporters [she] interviewed.*

Rapp adopted this approach as she felt that the topic on which she was working was highly charged, particularly in terms of the stories of painful decision making. I, however, have adopted a slightly different approach. Rather than assuming or taking responsibility for assigning a pseudonym to each woman myself, I left that responsibility with the women. During the consent process prior to commencement of the interview, I told each woman that she could *"choose any name you would like to be known by for the interview."* At the end of each woman's interview I asked her to choose a name for herself which I would then use in writing up the report of my investigation. Most women wanted me to use their own name. In cases where women asked me to choose a name for them I attempted to choose 'mainstream' names, deliberately avoiding any cultural ascription by choice of names. However, in respecting the woman's choice to use her own name, perhaps more identifying information is included for some women than for others, as for some women their cultural identity was embedded in their name. All names therefore appear in quotation marks, are followed by a brief description the first time the women makes a comment, and city of residence is omitted. For each woman a brief descriptive profile is provided in Appendix 10.

I have attempted to walk the intersection between practicing respect for the women's words by faithful representation rather than paraphrasing, and the need to prevent the reader from doing all the work of interpretation. The excerpts from the women do allow the reader to form their own analysis while also considering

mine.[73] In particular, in representing their views on best practices it was important to let the women's words speak. I have sometimes included more than one excerpt to illustrate each point in order to show the range of perspectives. I have followed Reinharz's[73] strategy in opting for the voice of the woman not yet included in the thesis when I had the choice of several appropriate excerpts.

In order to retain some of the spoken meaning in the representations of the women's voices, I have adopted the method used by British psychologist Liz Kelly[298] and suggested by others.[271] Where a dash (-) appears in the women's text, this signifies a pause or hesitation. Three dots (. . .) indicate a passage of speech is not reproduced. Words appearing in the text in **bold** signify that these words were stressed by the woman. Emotional expression is recorded in UPPER CASE in [square brackets] either within or following the passage of speech to which it refers. In addition, in some instances where it was integral to the women's account, I have reproduced my part of the discussion. In so doing I hope that the interactive nature of the interviews is portrayed and I am perceived as more than a disembodied data gatherer.

Profile of the Pregnant Women

Social and Cultural Characteristics

Specific demographic questions were not asked during the interview. This strategy avoided categorisation or positioning of the women early on in the interview process which could have influenced the subsequent direction of the interview. At the conclusion of the interview, women were given the choice of responding to some basic socio-demographic questions.

The socio-demographic questions had utility in driving recruitment for the study and helped to ensure adequate coverage of the parameters established for the sample of pregnant women. However, do the women's responses to these

questions have a place in the results section of this thesis? Glaser[272] notes that in qualitative research, demographic characteristics should not be considered significant, and presumably therefore worthy of report, until they emerge as significant in the analytic stage. Similarly, Morse[271] cautions that our compulsion to report the sociodemographic characteristics of the sample may be inherited from our quantitative colleagues and have little to do with reporting for the purpose of replicating the study. I, however, have chosen to present a descriptive profile of the women participants with whom I worked not only to demonstrate that the lived-situation parameters established at the conception of the project were achieved, but also to provide a context within which to interpret the voices of the women.

Descriptively, rather than statistically, reporting the situations which establish these women as comprising an exceptionally diverse sample and therefore comprising an inclusive sample, serves to emphasise the commonality of their PHCT experience. All of the women shared the experience of the phenomenon of confronting the issue of HIV infection in their pregnancy and needing to make an important decision which could have a myriad of personal and not so personal consequences. The following paragraphs of this section therefore provide selected descriptions of the women whose experiences and perspectives contributed to this study. Further details are contained in Appendix 11.

Driven by the concept of theoretical saturation, 57 women took part in the interviews. Twenty-four of the women were from Toronto, 25 from Ottawa, four from Hamilton, and four from Kingston. With one exception, a post-partum woman, all the women were pregnant, with the majority in their third trimester. The youngest women were 16 years old and the oldest woman was 41 years old. The majority of the women were in their twenties, one quarter were younger than 20, and one quarter of the women were in their thirties. The majority of women in the study had been born in Canada, the second highest proportion in the Caribbean and the third highest in each of Africa and Asia.

Similar proportions of women participants with whom I worked were unmarried as were married or living with a partner at the time of the interview. Some women were in high school at the time of their interview. Of those women who had completed their schooling, fairly equal proportions had either completed high school in Canada or in their country of birth; had not completed high school; had completed some college or university or had undergraduate or graduate degrees.

There was substantial variation in the women's sources and levels of income from high school students with no independent income supported by one or both of their parents or their partner; to single mothers and married women on welfare; to women living on their own or their partner's illegal source of income or panhandling; and women who reported single and dual incomes ranging from $32,000 to amounts in excess of $100,000.

Most women were in stable accommodation of their own, or were living with their family, friends or partners. A minority were unstably housed in shelters or had been living on the street before taking up residence in a maternity home. Close to the majority of women were unemployed, while the professions of those employed included retail, law, social work, catering, domestic work, the sex trade, public health, and administration.

In terms of the individual HIV-related risk behaviours or the more collective HIV-related risk conditions the women may have been experiencing and which may have led to different experiences of, and different perspectives on, the PHCT process, women could be considered under one of eight discrete descriptors as shown in the first section of Table 19, according to the following schema:

- Aboriginal: women who self-identified as Aboriginal;
- Aboriginal IDU: women who self-identified as Aboriginal and who were currently injecting drugs or had a history of injection drug use;
- HIV-endemic[xxvii]: women born in an HIV-endemic country;
- IDU (non-Aboriginal, non-visible minority): women who were currently injecting drugs or had a history of injection drug use;
- Visible minority[xxviii]: visible minority women born in non HIV-endemic countries;
- Visible minority IDU: visible minority women who were currently injecting drugs or had a history of injection drug use;
- Higher risk[xxix]: women not in previous categories and at higher risk of HIV infection due to their own sexual behaviours, their partner's injection practices or sexual behaviours, or their partner's seropositive HIV status;
- Lower risk: women not in previous categories and for whom heterosexual intercourse was possibly the only HIV-related risk behaviour.

[xxvii] A woman was identified as HIV-endemic if she was born in a country in which the prevalence of HIV infection is high (generally about 1%) and in which the predominant mode of spread is heterosexual intercourse, accounting for at least 50% of HIV infections[273].

[xxviii] A woman was identified as a member of a visible minority if the researcher perceived the woman to be a member of a visible minority who had not been born in a country identified as HIV-endemic.

[xxix] A woman was identified as at higher risk of HIV infection if she disclosed instances of her own sexual behaviour or her partner's sexual or injection behaviour recognised as placing her at risk of HIV infection. Women were therefore assigned to the higher risk category if any of the situations below applied:

- the woman herself described episodes of unprotected sexual intercourse with multiple partners;
- the women's husband/partner/baby's father had a history of unprotected sexual intercourse with multiple partners;
- the women's husband/partner/baby's father had disclosed unprotected sex with an HIV-infected partner;
- the women's husband/partner/baby's father was an injection drug user; or the women's husband/partner/baby's father had been diagnosed HIV-positive.

However, in practice, the assigned descriptors were not discrete. Some Aboriginal or visible minority women for example, could also be considered under the lower or higher risk descriptors. Similarly, a woman injecting drugs could also be considered under the higher risk descriptor if her sexual partner was HIV-positive. The final section of Table 19 shows the multiplicity of HIV-related risk factors and HIV-related risk conditions experienced by 38 of the 57 women.

Table 19

HIV-related Risk Behaviours and HIV-related Risk Conditions Associated with the Pregnant Women

HIV-RELATED RISK BEHAVIOUR/RISK CONDITION SINGLE CATEGORY (N = 57)	n	(%)
Aboriginal	4	7.0
Aboriginal IDU	4	7.0
Higher risk	11	19.3
HIV-endemic	10	17.5
IDU (non-Aboriginal, non-visible minority)	4	7.0
Lower risk	11	19.3
Visible minority	12	21.1
Visible minority IDU	1	1.8
HIV-RELATED RISK BEHAVIOUR/RISK CONDITION MULTIPLE CATEGORIES (N = 38)		
Aboriginal	8	
IDU	9	
HIV-endemic	10	
Visible minority	13	
Higher risk	37	
Lower risk	20	

Experiences of Pregnancy

The specific demographic questions did not capture the fuller context in which women were experiencing their pregnancy. For most of the women I spoke with, irrespective of the social and economic parameters of their personal lives, their pregnancy was largely experienced as a time of stress and anxiety as they adjusted to their new health status. The unexpected nature of the pregnancy exacerbated this situation. For many women, both those in stable long-term relationships and women with relationships of very recent duration, pregnancy was something of an unexpected event. "Fatimah", a 26 year-old lower-risk visible minority woman in her third trimester, explains her reaction on learning of her pregnancy:

> ***Surprised! To say the least!*** *Both me and my husband were very surprised because we were not at all trying to have another baby for at least another - maybe until my daughter was two and a half. We were trying to wait. Um - so, I think, when I found out I was pregnant, she was eighteen months old. So we were shocked.*

"Desirée", a 21 year-old lower-risk Aboriginal woman, was also surprised to learn of her pregnancy after she had broken up with her boyfriend:

> *Quite surprised, actually. I didn't think I could get pregnant. So it was like, whoa! I had tried to get pregnant before, when I was younger, and I was with a person for a year. Nothing happened. And then I met a new guy. I was with him for the next six months. And I broke up with him and moved out here and found out I was already gone . . . Yeah, a bit surprised. But I was very happy. Because thinking you can't get pregnant, then all of a sudden being pregnant, it's like, wow!!*

Other women were similarly surprised or described the stronger emotion of shock on having their pregnancy confirmed. For "Amanda", a 25 year-old Aboriginal woman in her ninth pregnancy, confirmation of her pregnancy had other health-related concerns:

> *I was kind of shocked! ... Because I was on the pill and we've been trying really hard not to get me pregnant. And with my health at the time, they [health care professionals] thought it was best that I didn't ... I was thinking I'd have a baby in about a year and a half. Like, we'll get pregnant in a year and a half.*

Other women such as "Tammy", a single teenager born in a HIV-endemic country and "Christie", a 21 year-old lower-risk woman, share Amanda's feelings although not her use of birth control:

> *I was surprised, shocked! Because I never knew it would happen unexpectedly. I don't really use condoms, right? And nothing ever happens - so I never thought that anything would happen.*
>
> *I was shocked.* [LENGTHY PAUSE] *I was hollow inside.* [SOUNDING SHAKEN] - *'cause I was using protection, so. I figure condoms don't work these days.*

Shock and surprise often lead to not knowing what to do as "Claire", a lower-risk visible minority high school student, explains:

"Claire" *I was - shocked. Because I shouldn't have been, but I was.* [SMALL LAUGH] *And I was – I didn't know what to do.* [QUIETLY] *It's hard to explain.*

Lynne *Tell me a bit more about it.*

"Claire" *Well, um, like, I knew that I probably was. But then, when I went to a doctor's and he told me that I was, and it was like - It felt like everything was gone. I had to think of what to do. I didn't know.*

Similarly for "Karyne", a lower-risk teenager in her third trimester, the shock and surprise developed into confusion:

> *I was totally confused. It was totally the opposite um, reaction of what my fiancé* [LAUGHS] *did. Um, before I found out I was pregnant - when* ***I thought*** *I was pregnant, I was like good, you know? Like, "Oh, I'm so happy!" And when* ***I found out*** *I was pregnant, it was like, shock. I was like shocked for four months. I didn't know what to do ...*

Not expecting to become pregnant led to "Dana", a 38 year-old visible minority lower-risk professional woman, *"initially avoiding coming to the realisation that I might be pregnant."* The unexpected nature of her pregnancy had later consequences for her when faced with the offer of an HIV test in her pregnancy:

> *Yeah, I wasn't really planning to get pregnant this fast. It was - it made me realise that no wonder teenagers have problems! Now I'm over 35, so I should know better! But I didn't think it was going to be that easy to get pregnant. So I probably would have done a lot more reading [about the HIV test] prior to going in there, and do a lot more talking with more people to find out what my options were, what would happen, like talk to*

family, friends who have gone through the experience . . . But it really was a shock for me to get pregnant so fast! Maybe my doctor could've discussed the test - we did sort of discuss that I was potentially thinking of getting pregnant within the year. But we didn't really go through all the "what to do" beforehand. We just talked about folic acid!

The unexpected nature of the pregnancy required a period of painful adjustment and for many women a change in previous plans to take account of the birth of their child. "Claudine", a lower-risk visible minority teenager in her second trimester, describes her reaction to her pregnancy and explains the consequences in terms of her personal plans:

Scared. I was scared. Just scared. Because, you know, I'm young. I – I'm young, and um, you know, I want to go to school and stuff. But I think I can still do it. But it's going to be harder. I know it's hard raising a child...

In some cases, adjustment to the confirmation of their pregnancy necessitated reflection on whether to continue the pregnancy, as "Deborah", a 16 year-old lower-risk Aboriginal woman in her first trimester explains:

I felt shocked and I thought I couldn't get pregnant because I only had a baby not too long ago. And I was kind of happy, sort of. And I was in between the options of getting an abortion and keeping it and giving it up for adoption. Then I decided I would keep it and go through with the pregnancy.

Deciding to continue with her pregnancy was only one of the stressors in this woman's pregnancy. "Jacquie", a 23 year-old woman from a Caribbean HIV-endemic country, explains her feelings and the personal context in which she learned of her pregnancy:

I'm okay. My pregnancy, after I found out [I was pregnant], was a little hard. Umm, 'cause at first I didn't know if I wanted a baby, a child, or whatever? 'Cause was living a lifestyle which – which I'd have to stop, to accommodate to my baby's needs ... Uh, it was hard, 'cause they took the test, then they told me that I was pregnant. I didn't know who to turn to after that or what to do. Because the baby's father, he was happy at first, but now he's no longer in our lives. Because he found somebody else – which is okay. Doesn't bother me, but - I'm a – I'm a single mom. There are a lot of issues that I need to work on. And I needs to work on those, like I need more time, for the safety of my babies... [TRAILING OFF]...

The next visits were the hardest, 'cause it was kind of sinking in that I have no job, I'm not in school, I'm on ODSP [Ontario Disability Support Plan], and I was having thoughts of having an abortion. 'Cause I didn't – I didn't think I could stop my lifestyle.

"Jacquie's" one source of support in her challenging life, her boyfriend, the one person she could turn to, is no longer with her. The lack of, or instability in, personal supportive relationships during pregnancy described by "Jacquie" was mentioned by several women as a significant stressor in their pregnancies. "Caroline", a lower-risk visible minority teenager in her first trimester and living in a woman's shelter, has no support from either her family or her boyfriend. Soon to be a nurturer herself, "Caroline" receives no nurturing of her own; she is alone and poor:

Yeah, I'm scared. Because the thing is, I'm all alone. My family are not going to be there for me in my life, for sure. Because I'm cut off from my family. But the thing is I'm all alone. I'm worried about me, I'm worried about the baby - how am I going to do that? I'm worried about how nobody's helping me out. I'm worried if my boyfriend's staying or not. Because it would be so much helpful if he stays because I really love him. And if he doesn't want to stay, I don't even know how I'm going to deal with it. Because I have no money, I have no job, no money at all. And to buy clothes and stuff, you know how expensive it is. So I think if I had a job and had some money. But I have nothing at all, so I really need it. And now I'm pregnant, I have to definitely get those clothes, no matter what.

For some women, their partners were most likely or definitely out of the picture. "LisaLee", a higher-risk teenager living in a shelter, had yet to speak with the baby's father but was pessimistic of the outcome:

Umm, I haven't seen him, but I left a message with his best friend. I don't know if he got it yet, though. He hasn't tried calling yet or anything. So, I guess he doesn't care!

Whereas "Christie" was clear about her partner's reaction:

Oh, I told him [I was pregnant]. And he didn't believe me. So I haven't talked to him since.

For other women, their partner's reaction was placing some strain on the relationship. "Sally", a higher-risk teenager living in a woman's shelter, recognises and responds to her boyfriend's reaction:

> *So, my boyfriend's kind of iffy about it. He's not too impressed with the thought, but he is there for me. I told him if there is any time during this that he thinks he needs a break and wants to go home and take some time - I'm not going to pressure him. I understand it's hard.*

While "Claire" explains that her indecision regarding the continuation of her pregnancy affected her relationship with her boyfriend:

> *'Cause my boyfriend was like, he wanted it from the very beginning - I didn't know if that's what I wanted. So we had a lot of stress on our relationship for a while.*

Whereas "Vivianne", a 25 year-old lower-risk woman from a Caribbean HIV-endemic country, broke up with her boyfriend over her decision to continue with her pregnancy:

> *I bought the home ones [pregnancy testing kits]. And I bought four.* [GIGGLING] *And I took all four to make sure it wasn't lying. And then I called Doctor here at the [name of clinic]. And when I came, she [the doctor] said it was positive. I am pregnant. Yeah! And then I told the dad. And he said, like um, he wanted me to have an abortion and I don't believe in that. So, I didn't want to do that one ...That's mean. I said I can't. 'Cause - I don't know. It must be a once in a lifetime chance. And I get it. I'm holding on to it. He [the boyfriend], he gonna go free. Tough. He will have to. Me and my baby.* [SPEAKING QUICKLY, FIRMLY] *Ya. So here I am! Eight months!* [SOUNDING DELIGHTED]

For women who did have the support of their partners, the unanticipated pregnancy was easier to adjust to, as "Morning Star", a lower-risk Aboriginal teenager in her first trimester explains:

> *I have a lot of support. I'm not alone. I'm not married, but my boyfriend is with me. And he's there and supportive and all that stuff. It wasn't a plan, but we always talked about if it did happen, what we would do about it.*

And "Mariah", also a lower-risk Aboriginal teenager, acknowledged that she may be unusual at her age in having the support of her boyfriend:

[I was feeling] overwhelmed, scared, nervous - all those things. I didn't know what I was going to do. The good thing though, was that the father was still around. So I had lots of support. Because I'm from [name of town]. I have no family down here ... Yeah, it's easy. It's a lot easier than - I know a lot of girls my age don't exactly get it that easy because the fathers of their babies don't stay around, and they have more problems. So I was lucky.

In addition to making personal adjustments to an unplanned pregnancy, immigrant women described the additional challenges they faced. For "Jennifer", a 28 year-old lower-risk woman from a Caribbean HIV-endemic country, it was the lack of family members in the same country:

Well, it was a shock. And I was depressed. And I was going crazy like. And I don't have family here, so you know like.

Whereas for "Grace", a 17 year-old lower-risk visible minority woman in her third trimester, it was concern that she had let her parents down in failing to fulfil their immigration hopes and plans for her:

Um, I was a bit - I wasn't upset, but it was just such a surprise, such a shock that at the time I wasn't feeling too happy about it. But I wasn't depressed you know, but I got used to it. About after a month I got used to it. There was nothing really I could do, I just had to make the best of it . . . 'Cause at first you panic. You're like, "What am I going to do?" It's expensive for a baby. It's expensive to take care of a baby. And you know, I didn't have – I was still in school, I was still working, you know, just doing regular stuff . . . I think the only thing I was worried about was letting my parents down, okay? I wasn't born here. They brought me from another country for me to have a better education, to have a better life, and all that. And to tell them that I was pregnant and that I might not be going to school for a while was something that I knew that they really wouldn't like. And I was really worried about school because I was only, like I just finished grade eleven right now, and I heard so many girls that they don't go back to school, and I was so scared because I didn't want that to happen to me.

In addition to the challenges of overcoming the surprise, shock and confusion on learning of their pregnancy, to adjusting to the changes in their lives necessitated by their pregnancy and loss of relationships, and to overcoming concerns in disclosing their pregnancies to their partners and their parents, women expressed

an overriding concern about their personal capabilities as future mothers to the children they were carrying. "Kristina", a 16 year-old higher-risk woman, represented the views of many of the women in the study when she responded to a question about how she was feeling in her pregnancy by alluding to her worry about becoming a "good mother":

> *How am I feeling? I'm kind of a bit upset and a bit happy. And I'm just worried that I'm not going to be a good mother. That's why I'm taking – I'm doing "Baby Time" just to get some help and advice.*

The concept of being a good mother, what the pregnant women felt was needed to be a good mother, what they were prepared to do to become a good mother, has direct relevance to how women viewed decisions around HIV testing in their pregnancies. In some cases, this desire to be a good mother, to do everything necessary for their child to be healthy, was played out by pregnant women accepting every medical intervention available. As "Mariah" explains:

> *I'd grab any kind of flyer to see about pregnancy and testing for this and that. I'd grab it. And my doctor phoned and told me about this [research interview]. He gave me a flyer about cord blood, just different tests they do in pregnancy. I went to have an ultrasound and they had a thing on the wall in the room that said they're doing a new test - it's a vaginal ultrasound, to see if you have premature labour. And stuff like that. That's all interesting stuff. I would have done that. I would have done it all. Anything that can better my pregnancy, make it healthier, make my baby healthier, anything.*

Similarly, "Caroline" explains how her own health-seeking behaviour is directed towards taking care of her baby and how she places her concern for her baby over her own needs:

> *I'm trying to get everything I can get. I'm looking there. I'm asking for this information, what's that, and whatever is in my best interest. Not for me, it's for the baby. Now I got to think about the baby, not what's bothering me or what's good for me. Because it's not going to be for me. It's going to be for my kid.*

"Carole", a 35 year-old single Aboriginal woman, also talks about privileging the needs of her unborn baby in her thoughts, feeling and behaviour. She describes how she now is thinking and behaving for two and includes responding to

knowledge on the baby's health status as part of her preparations for the baby's healthy start to life:

> *I think it is because, for me, I felt that, uh, I can care about another spirit more than I care about myself. And so that the baby will grow to be healthy, I take care of myself and be a good little girl so that the baby will be healthy ... Because it's not just me, it's both of us. It's like this little body and I'm building a home for another little baby. I'm beginning to eat healthy, and I don't smoke and I don't drink. I do everything to protect that baby, so the baby will grow up healthy, and that baby will have a healthy beginning and um, certainly, it becomes a priority. Yeah, absolutely. It's not just me ... So it becomes a priority to look after myself even more when I'm pregnant, such as testing, eating. Personally, I feel I would want to know if there was a risk that the baby might get sick. That's something I would want to know, especially if I could prevent.*

For some women, the desire to be a good mother played out in the extreme behaviour changes they were able to impose on themselves in order to ensure the health and safety of the children they were carrying. "Sally", for example, in order to avoid feeling guilty about giving birth to a child with a birth defect, has made substantial changes in her behaviour including moving away from potential triggers to her previous behaviour:

> *I can't smoke weed any more at all. Because they explained to me that a lot of women that smoke a lot of weed or cigarettes while they're pregnant, their babies are really stunted, like they're small. One thing I have already over my head is, if my child is born with a birth defect, what would I do? I wouldn't want to give him away, but it would be twice as hard on me. So I'm trying to take every precaution I can – like staying away from drugs. If my friends want to smoke weed, they just don't do it near me. I cut down on my cigarettes. My boyfriend quit smoking because I'm pregnant ... And with me moving here to this hostel has really helped me a lot because it's gotten me away from the downtown centre where all my friends and all the drugs are, and it keeps me out of trouble. I figure I'm just going to be done with everything now. I'm done with the drugs, I'm done with the alcohol ...*

The women in this study not only wanted to be "good mothers", but desperately wanted to avoid being "bad mothers', mothers whose children might be removed by the Children's Aid Society (CAS). The child welfare system, it has been argued, reproduces the binary opposites of "good mothers"/ "bad mothers" which are internalised by all women but affect particularly poor single mothers who are

subjected to surveillance and control.[299] "Jacquie" has been able to make substantial changes to her life to take account of her status as mother and her desire to protect her babies from any sickness, but the spectre of CAS is present in her thoughts:

> *I used to party a lot. Used to drink a lot. And basically stuff like that. I used to socialise with the wrong people, get in wrong relationships. Um, just do stuff I'm not really proud of. It made me think, what kind of mother am I gonna be? What do I need to prove to myself that when these kids were born, that they're the biggest part of my life? What my kids need first has gotta be my biggest priority right now. I haven't drank since I was pregnant, and I've done no drugs. I haven't even been to a party since I've gotten I was pregnant ... I had to change. 'Cause I'm getting older, I'm not getting younger. I'm 23 and I'm just starting a family, which I don't want anything to happen to my babies. I don't wanna get them sick in any way or I don't want to give them to the CAS or stuff like that. I* ***had*** *no choice, I* ***had*** *to change.*

"Karyne" sensitively describes how, despite withdrawals, she was able to give up smoking marijuana in consideration of her baby. Interestingly, although she does not believe that smoking marijuana can actually harm her baby, she gives it up rather than impose her actions on her baby. Even in the womb, her baby, described as innocent and with no decision-making power, exerts upon her a strong feeling of guilt when she does smoke again in her pregnancy:

"Karyne" *I've smoked marijuana before, and uh, when I found I was pregnant, I was like, well it's not good. So I quit smoking cigarettes, uh, marijuana, and quit drinking.*

Lynne *Good for you. Good for you.*

"Karyne" *I had withdrawals. Well, you gotta do it, for the baby . . . Um, to tell you the honest truth, marijuana was the hardest - marijuana was the hardest . . . Uh, it happened once [smoked marijuana in pregnancy]. It made me sick, and I cried and I cried and I cried for days. I was really depressed and it was my choice if I want to do it or not, and I said, "Why not?" I felt like, well, how about the baby? My baby doesn't need that. Doesn't need to inhale that, he doesn't have a choice, you know what I mean? Like, so I decide for him you know . . . Yep. I think about the baby. He's, he doesn't have any choice, I mean, he's harmless, he can do nothing, he's innocent. He's innocent; he's not even a year yet. He can't talk, he*

can't, you know, so I just even, my point of view on marijuana anyways, is like, I don't think it would really harm the baby, like, really hurt the baby, but it's still a decision that if I can not do it, then good. It's better not to do it than do it - It was hard, but I did it for the baby.

"Karyne's" story illustrates a very important theme that we shall subsequently see played out in the prenatal HIV testing arena. "Karyne" sees her baby as a subject who cannot express his own choices. Thus, she, the mother, must act in the baby's interest to be a "good mother". In her case, this involves giving up behaviours which she believes cannot harm the baby but which are seen as incompatible with social expectations that "Karyne" has internalised about what is involved in being a "good mother".

In conclusion, we see pregnant women overcoming substantial challenges in emotionally adjusting to being pregnant. We see pregnant women imposing substantial behaviour changes on themselves ranging from giving up junk food to giving up cigarettes, alcohol and drugs. All of this is explained as a component of being a "good mother" to the "innocent dependent baby" whose interest is foregrounded and privileged.

This drive to be a "good mother" and the ensuing development and maintenance of appropriate mothering behaviour, often in the context of enormous personal challenges, is clearly experienced very early on in the pregnancy. By the time the HIV test is introduced to these women, if indeed it is, the need to be a good mother by putting the health and safety needs of the baby first is well established and deeply embedded.

The next section considers the offer, if any, of an HIV test to these women in their pregnancies, and their reactions and responses to the offer and to the period of waiting for the return of test results.

The Offer of the Prenatal HIV Test

Ontario's PHCT policy requires health care providers to offer an HIV test to each pregnant woman in their care. Is this what was experienced? In the pregnant women's experience, did health care providers consistently apply this policy to the care of all their prenatal patients? Did every pregnant woman experience the offer of an HIV test as a component of her prenatal care?

Table 20

Pregnant Women's Experiences of the Offer of the Prenatal HIV Test

	n	%
OFFERED HIV test/HIV test mentioned in prenatal context	39	68.4
REQUESTED HIV test in prenatal context	5	8.8
NOT OFFERED HIV test in prenatal context	10	17.5
UNSURE if offered/tested in prenatal context	3	5.3
TOTAL	**57**	**100**

Offered Prenatal HIV Test

In describing blood tests that were mentioned to them as part of their prenatal care, there was divergence in the women's experience of an offer to have an HIV test. As shown in Table 20, 39 women, that is, approximately two-thirds of the 57 women participating in the study, were clear that testing for HIV had at least been spoken about by their health care providers in their pregnancy. Whether this was experienced as an offer is discussed later. Ten women were also equally clear that an HIV test had not been mentioned in the context of their prenatal care, three women were unsure and five women had taken the initiative in requesting a prenatal HIV test.

For most of the pregnant women, the HIV test was first mentioned in the context of all the other prenatal blood work the pregnant woman was required to complete. It was one of a number of tests marked off on the requisition form for which little information was provided beyond naming the tests themselves. "Lisa", a higher risk teen with a partner at increased risk of HIV, describes:

"Lisa" *They took blood for six different tests. I can't remember all of them. They did hepatitis and they did one for HIV and I can't remember the rest. There were a bunch of things checked off and there was a couple of writing things . . . [She told me] nothing. She just said go downstairs and get a blood test done and that I would get the results in a week. She didn't really say much about it [the HIV test]. She just gave me the paper with everything marked off and the blood test place was just downstairs in the building so I had to do that.*

Lynne *Ummm - So, an explanation of what the blood tests were?*

"Lisa" *No, she didn't really say.*

Some women were able to query the nature of this undifferentiated blood work, but received little information as to the purpose of the ordered tests in response. "Elizabeth", a teenager at higher risk of HIV, does however appear to end up getting an offer of the HIV test but still no information:

> *She just, she just pretty much, she gave me the sheet and she was like, "Here, take this downstairs for blood work." And I asked her what kind of blood work it was cause I wanted to know how many of bottles I was going to have blood taken out of me. And she just said, "Well, okay, we are doing this [one] and we are doing this one." And she goes, "If you want this one we can do it." I said, "Okay." So that's pretty much what it was. Kind of like, if you want, this, this and this. If you don't, too bad.*

Presenting the HIV test as part of a package with other prenatal tests sets the woman up to accept all the tests as one package. "Claire" explains:

> *He's like, uh, "Well, since we're doing all this other work, maybe we should take an HIV test." I was like, okaaaay. I said, "Yeah, might as well get it all done with" So he took one . . . [He didn't explain about] the HIV test. Nothing. He just said it was an HIV test* [LAUGHING]. *Like, I didn't think I had HIV, you know? So I was like, I don't need to but, like, what if I do? I should take it.*

"Fatimah's" experience also involved receiving a complete package of undifferentiated prenatal tests for which she was given no explanation. However, like many other women whose voices we will come to hear, she was able to find a justification of her doctor's actions:

> *I really wasn't told. I wasn't told anything. I wasn't told anything specific about the [HIV] test. It was - this test was sort of lumped in with all the other tests. Um, like [the] RH test. And all the other different tests were just lumped together. Oh, you have an HIV test as well. So uh, I just thought that, I chalked that up to her thinking that because my last test was negative, that was over two and a half years ago, she obviously thought I'd be negative, and she didn't really make a big deal about it. And that's why I didn't think that anything was really mentioned specifically about that test.*

Requested Prenatal HIV Test

Five pregnant women requested an HIV test either in the absence of an offer from their health care provider or before an offer may have been made. In both situations, the pregnant woman took the initiative to request testing. None of these women had been tested for HIV in their past, although they were all concerned about circumstances that may have constructed a higher risk of HIV for them. Concern for their baby enabled them to overcome previous fear and reticence in presenting for an HIV test. As "Jacquie" explains:

> *I knew about it [HIV testing] but I never thought about getting tested. For one, the lifestyle I was living, and for two, I was scared. But having the babies - it helped me to want to get tested, to protect them.*

For example, "Mary", a single woman at higher risk of HIV, knew that she had had some blood tests completed in her pregnancy although she, as many other women in the study later reveal, was unclear as to which ones. She did however know that HIV had not been mentioned:

"Mary" *I've just had blood tests, just the normal blood tests that they do ... I don't know the names of the tests. They don't really tell you the names. They just give you a sheet for the blood work and tell you to go get it.*

Lynne *So did you know what they were testing for?*

"Mary" *No, they just test for the normal stuff I guess, like your, you know, I don't know what it is ... But I know they didn't mention HIV at the time.*

However, in the absence of any offer from her physician, as "Mary" perceived herself to be at risk of acquiring HIV due to her boyfriend's HIV-related behaviours, she was able to request a test for HIV:

> *Yeah, it was my idea to have it. I don't think too many doctors ask if you want an HIV testing. I think you actually have to ask the doctor for it . . . Yeah, I don't think doctors come out and say, "Do you want an HIV test?" . . . I don't know why they don't. Unless they know your background and your history, I don't think they'll ask you. I don't know why they don't ask; they should.*

"Sarah", a 41 year-old sex trade worker and current injection drug user, was also able to request a test for HIV during her first prenatal visit with a family physician. Although acknowledging that her behaviour potentially placed her at higher risk of HIV, she had not previously requested or been offered testing for HIV. Testing only became salient in the context of her pregnancy and enabled her to have the courage to request testing, to initiate what she described as, *"the search for bad news"*:

> *I asked them to test for HIV because my boyfriend is HIV. I was suspecting I had HIV, because of him. 'Cause when I started going out with him, uh, he didn't tell me he was HIV, 'cause he was afraid I'd walk out on him or something ... Oh yeah, I asked right away. I told her [family physician], I said [name of boyfriend] was HIV-positive and I really needed the test right away.*

Absence of Offer of Prenatal HIV Test

Ten pregnant women were very clear that they had not been offered HIV testing by their health care providers at any time during their pregnancies. For example, "Claire", accepted her obstetrician's offer to undergo testing for Down's syndrome, but the option of HIV testing was never presented to her:

> *I don't remember him mentioning that at all. I remember yesterday I was reading this paper that he gave me, and it said, like, every appointment that I would go to, what he would talk about or what he would do. And he never said anything about HIV.*

"Suzanne", a 26 year-old lower-risk married professional woman in her third trimester also receiving prenatal care from an obstetrician, was offered a standard Ontario prenatal screening test but was not offered an opportunity to test for HIV:

> *Ah, he talked to me about the maternal serum screening if I wanted that done. And I don't think he did any other blood tests with that. Like, I know he didn't do the HIV test. But I don't think he even did like anaemia or anything. I know I went for the maternal serum screening at sixteen weeks ... I thought it was maybe something that he would've asked... And it, it is kind of surprising I think. Because I do work in an HIV field and I thought, I thought that everybody was supposed to be screened at that point. So, I was just kind of like, oh, okay!* [LAUGHING].

One pregnant woman, "Natasha", a 32 year-old married medical practitioner from the Sudan was also not offered the test. However, as she perceived herself to be at lower risk, she did not feel it was necessary to initiate a discussion about the issue in the absence of an offer from her health care provider:

> *Neither she [the obstetrician] nor my family physician mentioned anything about HIV at all. I don't know if that's the normal, but they never mentioned it. And I never asked.*

In comparison with the above three women who were in their third trimester and had not been offered an HIV test, are three women who were very early in their pregnancy and intended to accept the offer when and if it was made to them. For example, "Kristina" has not yet been offered testing because, as she explains, at five weeks pregnant at the time of the interview, she had yet to have her first "formal" prenatal appointment beyond the initial confirmation of her pregnancy. If asked to undergo HIV testing, she said she would agree. She felt comfortable accepting the test because she had tested negative three months previously. However, she expresses a perspective on prenatal HIV testing which was shared by many others. Her confidence in her assessment of her own negative HIV status is mediated by her concern for her child. It is this concern which in the end determines her intention to accept prenatal HIV testing:

I know it's going to come out negative. I'm not gonna worry about something about that no more. 'Cause I know I'm clean ... Yeah, I'm gonna go get it done 'cause, like, I don't want to be carrying a baby and then, just in case I do have AIDS or anything, I don't want to bring a life into this world having AIDS.

Only one newly-pregnant woman remained undecided as to whether she would accept the offer when and if it was made to her. "Kedesha", a 21 year-old higher-risk visible minority woman, at six weeks pregnant has only visited her doctor once for the pregnancy test, but has further prenatal appointments scheduled. She has had a negative HIV test in her recent past and assumes that any future tests will be negative as well. However, agreeing to be tested puts her in the position of having to hear her test results. Her distress is palpable:

Well, I don't know, just – I'll have to tell them that I'll think about it. 'Cause, like, I don't know. Lately, I have been thinking about wanting to – I don't know. I've been really concerned about my body 'cause it's been through a lot, so my body means more to me than it did before, right? So that's why I'm always going to the doctor's and getting tested for this and that. And, yeah, the testing for HIV. I thought about it too. But I'm just - Like, I want to do it again, 'cause, you know? You never know who you slept with, and you know? But, um, I'm just scared because I just don't want to hear, "Oh, you have AIDS." I'll feel like my life is over and, so I'm just - and that's what's holding me back.

Two women had not been offered an HIV test in their pregnancy because they had yet to obtain a health care provider for their prenatal care. For example, "Seiko", a 30 year-old lower-risk woman, plans on being tested for HIV during her pregnancy. However, as a visitor to Canada from another continent she did not have health insurance and, by the third month of her pregnancy, had not yet found a doctor or midwife for her prenatal care:

Lynne *Have you had an HIV test since you've been pregnant?*

"Seiko" *No. I will.*

Lynne *You will.*

"Seiko" *In case - Because it makes sure, for baby, make sure I am not HIV positive. Be good, because if I am positive, the baby might get some things. It's very important I think.*

One woman's physician had not offered her the HIV test by the end of her second trimester because he assumed she would be tested elsewhere at a facility where she was receiving treatment for another disease. "Sandra", a 34 year-old higher-risk woman, explains,

> *He [the physician] said, "Well, I know you don't have HIV." Because I get tested all the time...I always had [the HIV test] done at the [name] Clinic, because my blood was being done there. So, he's never really done anything. He always got them to do everything.*

Unsure if Offered Prenatal HIV Test

Three pregnant women, all visible minority women, were not sure whether they had been offered the test or if they indeed had already been tested for HIV, as the purpose of their blood work had not been explained to them. "Caroline" describes her experience of the blood tests taken in her pregnancy:

> *They really didn't tell me anything - Because when they were testing me, all they told me was, the first time they took my blood, "Oh we need to take your blood test to see if there's anything wrong with you." And that was it. That's all he said. I'm like, "Okay." I can't really stop him. I want the best for me, so I have to let him do it.*

As a consequence "Caroline" does not know whether she was tested for HIV:

> *I'm not really sure. The thing is, I don't really know about that one [HIV]. I'm not sure. Because I just remember I had two blood tests. He came twice.*

And "Betty", a 34 year-old woman originally from a Caribbean HIV-endemic country, also does not know if she was tested for HIV in her pregnancy, although she clearly remembers that her blood was drawn for testing for sickle cell anaemia:

> *I know sickle cells is one of them . . . I wasn't told so [if I was being tested for HIV]. So, if I was, I don't know . . . But I wasn't told that I was tested for it before. So if I was tested, I have no idea. Do you think that they have tested already? . . . I got lots of tests. I can't tell you what kind and what for. So much things. But, lots.*

Responding to the Offer of the HIV Test

The responses of those women whose health care providers did mention HIV testing as a component of their prenatal care were couched in a range of reactions which varied along a continuum of benign acceptance to initial feelings of shock and offence. Knowledge that an HIV test was going to be offered and knowledge of why it was offered seemed to determine which of these emotions was uppermost and points to the utility of informed pre-test counselling.

For example, "Deborah" relates her feeling of comfort that HIV testing was mentioned by her physician to the fact that she is quite well informed about HIV and thus perceives herself to be at low risk:

> *It wasn't actually a big thing for me because I heard a lot about HIV and I was pretty happy that I was pretty healthy. And I'm not the kind of person that sleeps around a lot and that. And, I was pretty comfortable with the subject. I was comfortable that it was brought up.*

However, in the absence of awareness about HIV and perinatal HIV prevention, and in the context of inadequate pre-test counselling, some women were upset by the offer. For example, "Claudine" felt shocked and was left to wonder the purpose of the test to which she had agreed:

> *It was just shocking. But when I sat down and thought to myself, and said, "Obviously you've had unprotected sex to get pregnant, right? So, maybe that's why they're doing it." It was just shocking though that they'd ask me it. I didn't even know you could do the test when you're pregnant either. 'Cause they don't explain this stuff in school. They don't.*

Similarly unsure about the purpose of the offer of the HIV test in her pregnancy, "Zenny", a 17 year-old lower risk woman, is able to reframe her initial offence at the offer to concern for health:

> *I was kind of - it kind of made me feel like they were telling me this because I got pregnant and they felt that I wasn't being careful so that I could have anything. It kind of made me feel like dirty. And it was like well, just because I'm pregnant doesn't mean that I would sleep with unreputable people. I mean, sure a number of people who are quite reputable have AIDS, but usually the way you get it is from sleeping*

around. So, I kind felt like that's what they were trying to say. And it kind of offended me at first. But then I just realised that they were trying to look out for me and wanted to make sure that I knew what was available and stuff like that.

In contrast, in the context of an offer made with information about the risks and benefits of the test, "Elizabeth" was able to appreciate the value of the additional health information she would have available to her:

I was kind of, like - I kind of appreciated more that they asked me about it and talked a bit about it because, instead of leaving it and not telling you about that option. Like, the fact that, if I did end up having it, what would happen. If they didn't ask me and I didn't do anything about it and didn't find out 'til years down the road - .

Decision-Making

What contextual factors did women take into account in their decision-making around the offer to test for HIV as a component of their prenatal care? Interpreting the women's construction of their decision-making process in response to a perceived offer of an HIV test, four distinct themes emerged. The themes were: maximising the health of their baby; maximising feelings of personal comfort about a serious disease; perceptions of the role of their health care providers and a personal assessment of their own risk factors for HIV infection. The personal saliency of each of these factors underpinned each of the women's decisions to accept or decline HIV testing in the prenatal context. The next section examines these factors among women who accepted the offer, were intending to accept the offer, and who declined the offer.

Accepting the Offer

Of the 39 pregnant women who were offered the opportunity to test for HIV in their pregnancy, the majority, 28 pregnant women, accepted their health care provider's offer, as shown in Table 21.

Table 21

Pregnant Women's Responses to the Offer of Prenatal HIV Test

	n	%
OFFERED HIV TEST IN PRENATAL CONTEXT	**39**	**100**
Accepted offer	28	71.8
Intend to accept offer	5	12.8
Declined offer	6	15.4
TOTAL	**39**	**100**

The reasons most frequently cited for accepting the offer of the test were related to wanting the best for their baby, ensuring the health of the child they were carrying, and taking responsibility for the baby – a continuance of the need to behave as a good mother. As "Karyne" explains, she accepted her doctor's offer wanting the best for her baby:

> *I just said, I want the best for my baby, and I'll do everything the doctor asks me to, to make sure my baby's healthy.*

"Claudine" explains further this need to know about the baby's health. Just wanting to know provides reassurance:

> *[I accepted] you know, because – you just wanna know. You know? It's just like your baby, you gotta know everything's fine. I'm going to the doctor's right now and I'm sure I'm gonna ask him a hundred questions, you know? You want to know everything's fine with the baby, you want to know everything. And just with your body, 'cause your body's - your baby's part of your body so - you want to know everything's perfect in your body. Well, not perfect, but good enough.*

"China", a 24 year-old lower-risk single woman, adds a different perspective to the need to know the baby is fine. She accepted the HIV test *on behalf* of the child she was carrying and explained in some depth the responsibility she felt towards making decisions for her "innocent" child:

"China" *Yeah [I accepted to be tested]. Because, because, um, you know, it's not fair to the baby really, because they have no say, because they're still innocent, right? And, um, so, you know? The mother has to take care of the child because the child cannot take care of himself. So, in doing the HIV testing, you're not only doing it for yourself, you're also doing it for the baby. Because then that way you'll know what the results are, and then you know, like, for example, if the results are negative, obviously your baby's okay. Butt then if it's positive, then you can do something about it to prevent the baby from having it.*

Lynne *To reduce...*

"China" *Yeah, 'cause every child they, you know, supposed to have a chance at life. For me it's really important because I lost my baby before and I just don't think it's fair. So - yeah.*

"Eliza", a 35 year-old visible minority woman with a history of injection drug use, echoes the sense that pregnancy requires the construction of decision-making for two, in this case accepting HIV testing for two:

> *And I was like, I'm pregnant, it's not only me. You know? I have to think about the baby. So I wanted to know if there's something wrong, what can I do about it for the baby.*

"LisaLee", also foregrounded the health of her baby in guiding her decision to be tested even though she herself felt she was not at risk:

"LisaLee" *I'll get tested when I get my MSS [maternal serum screening]. See if the baby's okay. But I don't think I have it.*

Lynne *What's persuaded you to get it done?*

"LisaLee" *Uh, I always want to make sure - everything.*

Lynne *Okay. Has it been different during, in pregnancy?*

"LisaLee" *Yeah, because now there's a baby to worry about.*

Lynne *Mm-hmm.*

"LisaLee" *I want to make sure it's okay.*

Lynne *Mm-hmm. What about yourself?*

"LisaLee" *All that matters is the baby.*

Accepting the HIV test for or on behalf of the child was often a direct consequence of the manner in which the test was presented to the pregnant women. For some of the pregnant women, hearing that the test was for the benefit of the baby, they clearly were going to accept. Their own health care needs, the likelihood of themselves being infected and everything that might entail were not part of the discourse. As "Dana" explains:

> *The doctor explained that it's more of a safety thing for the child...So that you could get some care and treatment for the child... So, in any test that was offered to me I was going to do. Because I wanted the baby to be in a good environment.*

"Angelica', a 26 year-old visible minority woman, describes her similar experience:

> *Dr. [name] told [me] that if I wanted to do this, this kind of test was to see if there was nothing wrong with the baby, no infection, no nothing with HIV. And [I] agreed to do that just to be safe with the baby.*

In fact, concern for the baby's health often overshadowed the woman's assessment of her own susceptibility to HIV infection. For example, "Desirée" was very sure that none of her previous experiences could have put her at risk of acquiring HIV infection, yet nevertheless she agreed to be tested:

> *I didn't feel I was really at risk. It was just more of a precaution [for the baby] than anything. That's mainly what it was for me.*

Whereas for other women, their own health was also part of the equation. For some women it was their own physical health as "Pebbles", a 35 year-old street-involved Aboriginal woman with a history of injection drug use explains:

> *I chose [to accept the HIV test]. I wanted to know for myself. I mean, I don't need this child coming into this world, and then for them to tell me the child is HIV positive. Oh, well then I guess I must be, too! I don't need that. That'd be too much of a shock – way too much.*

For other women like "Claudine", it was their own mental health related to reassurances about the safety of the child she was carrying:

> *[I accepted] because – to calm my nerves* [LAUGHS]. *To make me feel better. And just to know that my baby's 100% safe. Even though I know, but, just to,* ***really know,*** *like - have the proof* [LAUGHS].

"Lual", a 26 year-old woman from an African HIV-endemic country now in her third trimester, also accepted the test to stop her worrying about the health of her baby:

> *I have to make any tests I could take just to make sure, okay? So I can be comfortable instead of being worried.*

"Sally" also speaks of her need for reassurance that her baby is safe that led her to accept testing, a theme echoed by many women:

> *I just see it as I know I'm safe; I know my baby is safe. It helps me a lot knowing that I haven't put myself and my child at risk, because just I find that having a baby and having a complications with it would be twice as hard when you're young, let alone having a child. It's going to be hard and there's no doubt in my mind that it won't be easy, but having it with extra complications, coming out HIV positive, any birth defects from it – it would be a lot. It would be hard. So I think knowing that I'm safe and so is my child, even if I decided after that two months, to go back and check one more time, I know that I'm safe and that everything should be okay.*

A woman's assessment of her own level of HIV risk factored into her decisions around HIV testing, with differing effects. In making their decisions on whether or not to accept HIV testing, or whether or not to request HIV testing, women took account of their perceived level of risk of HIV infection.

For some women, their self-perceived low risk of acquiring HIV infection led them to accept the offer almost as a matter of routine. A perception of low HIV risk aligned with attaching little significance to the outcome for themselves but reassurance concerning their baby. As "Morning Star" explains:

> *Well, I had decided to go ahead and get it because I can't think of any way I would have been at risk to get HIV, but I decided to go ahead and get it just to make sure, I guess.*

"Leslie", a 23 year-old higher-risk street-involved woman, has recently tested negative for HIV outside her pregnancy and feels that she does not have HIV. However, she too accepts testing, perceiving no risk to herself of a positive test result, but in pregnancy, just to "be on the safe side" becomes salient:

> *Um, she just basically asked me if I think I'm at risk of having HIV, and I told her "No", because me and my boyfriend have been together for like a year and a half. We've been together for a year and a half, but I've known him for three years. And we've never used protection, but I had gone for a test before seeing her for HIV. It came out negative. I didn't have it. And I just knew that I didn't have it. But I told her I'd go with it anyways . . . You know, I really didn't need to, but I figured, "Yeah", why not?" – just to be on the safe side.*

Whereas many studies on PHCT examine a women's perceived level of HIV risk, some of the women in this study also took account of their partner's risk in their decision-making. For example, "Caroline" assessed both her own behaviour and that of her boyfriend. Concluding that neither she nor her partner had put themselves or her at risk of HIV she nevertheless accepted her physician's offer perceiving she had nothing to lose:

> *I don't do no drugs. Like my boyfriend, he's healthy. And I'm healthy. He was the first guy I ever slept with, so I'm very sure I'm healthy. And he was healthy. So I wouldn't sleep with him if he were unhealthy. Some women are like - they don't know. But the thing is I trust him, and he's healthy. He does weed and stuff, but he's not with HIV or anything. I don't think there's anything wrong with me; but why wouldn't I do it when there's a chance to?*

Interestingly, "Christine", a 31 year-old married professional woman from an African HIV-endemic country, who accepted her family physician's offer to test because she was confident that she didn't have HIV, uniquely explains how, had she thought she was at risk, she would not have accepted the offer:

> *[I agreed] because I was confident that I don't have this disease. Maybe, if I hadn't confidence, I would think first and say, "No" . . . . I have a husband. I trust him. He trusts me. And I think, "Oh, I don't think that it's going to be positive." That is why I say, "Oh, it's okay, [I'll have it]." But if I was wondering about my sex life, I don't think I'm going to have [it]. I think I would think about it twice. Maybe more* **[LAUGHS]**.

In contrast to accepting the offer based on a low perceived level of risk, for other women however, the offer was accepted as they perceived there was some chance that they could have acquired HIV infection. For "Isabelle", a sex trade worker who also injects drugs, her assessment of her need to have the HIV test was based on her perceived susceptibility to HIV infection through her own behaviours:

> *She just asked me if I wanted to have one. And I said, "Yeah." Because I was working on the street and doing intravenous drugs. I agreed to do it.*

Similarly, for "Eliza", it was her concern that her sexual practices may have placed her at higher risk of HIV infection that directed her prompt decision to accept her physician's offer of an HIV test in her pregnancy:

> *But when she mentioned that, uh, I agree right away. Because of the fact, you know, I mean, different partners, you know, different times without protection.*

For other women, like "Lisa", a realistic appraisal of the HIV risk conditions constructed by their partner's behaviours and practices led to a need to accept the offer of the HIV test:

> *Well, she just asked me if I wanted it done. And I said, "Yeah", because of my boyfriend's history and stuff. Every time he's gotten a test, he's never gone back for the results. So we're not really sure whether he actually did have anything or not. So, I did want it done. And he was into crack and stuff like that. He sold himself for crack and stuff . . . he has done that while we were going out and I didn't like that. 'Cause it was only to men . . . 'Cause of my boyfriend and him selling himself and stuff, and you never know. He says most of the people are married, but that doesn't make a difference. And one person that he had done stuff with before, died of HIV, AIDS actually. And he had done stuff with him without using protection before. So that got me pretty worried. And he didn't tell me that until like a year after we had been doing stuff without protection. So, that kind of bothered me a bit. But everything seemed to turn out all right, so* [LAUGHS].

"Amanda" also perceived that her previous boyfriend's behaviour may have created a HIV-related risk condition for her even though her own behaviours did not:

> *Well, I just wanted to make sure. I hadn't been tested since my last pregnancy. Like, I haven't used drugs or anything for five years. But my*

boyfriend, it's been a different story. Added to that, my last boyfriend was a [drug] user before I got with my boyfriend I have now. So, I just wanted to know.

Intending to Accept the Offer

Five women who were offered the HIV test had not yet been tested during their pregnancies but intended to accept the offer at some point in the future. For example, "Deborah" was offered the HIV test by her physician and intends to undergo testing during her next prenatal appointment:

"Deborah" *She recently, at my last doctor's appointment she asked me about the HIV screening and she sat me down and she said, "It's up to you whether you want to have it or not have an HIV screening." But I said, "Sure." Because I'm pretty confident that I'm okay because I've been with the same partner for the last few months. So I'm okay with that. And so my next doctor's appointment, she said she'd do it.*

Lynne *Okay. So you haven't taken it yet.*

"Deborah" *No.*

Declining the Offer

As we have seen, women who perceived themselves at lower risk of HIV infection were among those who accepted testing. Similarly, other women such as "Deborah" discussed above, intend to accept testing feeling confident of their lower risk. Conversely, a perception of being at lower risk of having HIV was what all six women took into account when they decided to decline the offer of HIV testing in pregnancy. Two of these women had previously tested negative for HIV outside of their pregnancy and thus had recent confirmation of their status. "Linda", a 25 year-old lower-risk married professional woman, explains:

So I didn't go get tested. No. I've been tested in the past and I've been in a monogamous relationship for almost eight years and I had been tested before that and I had been tested since then. Also giving blood, when they test your blood and you fill out that little form that they, you know, and things like that. So I'm not concerned about having HIV.

Regular HIV testing through blood donation procedures was the reason "Bobbie", a 30 year-old visible minority married professional woman in her third trimester, declined the offer of HIV testing in her pregnancy perceiving it to be redundant in providing any additional information on her health status:

> *I'd given blood about, less than three months before I had found out I was expecting. So I, automatically when you give blood I get an HIV test done, so I thought I'd been negative because they accepted my blood. So. ... Because I give regularly, I get tested regularly, and I know I'm negative. Generally, like within any year, I'll give blood like at least four times. So then I know, probably on average every three months, that I'm still negative.*

Other women relied on a self-assessment of risk as "Jessica", a 28 year-old lower-risk professional woman, explains:

> *I would say that [the HIV test] was very easy to decline. I wasn't worried about it at all. It was a risk perception thing. I felt quite comfortable about being low risk and I decided not to get tested.*

Most women considered themselves to be at low risk for HIV because they had never injected drugs and were currently in monogamous relationships as "Polly", a 29 year-old woman originally from a Caribbean HIV-endemic country explains:

> *I don't junk [inject drugs]; I don't smoke; I have one partner. My partner doesn't sleep around. So that's why I decided [I'm not going to take it].*

After discussing with her midwife the information package on prenatal screening which included details of the HIV test, "Jessica", declined the test immediately:

> *I had said I didn't want an HIV test and, um, the way I sort of arrived at that decision was I felt that I was at low risk...I had made up my mind pretty much and quite quickly. I didn't ask her for any opinions.*

In contrast, other women required some time after the offer of an HIV test was made to come to a decision, as "Eglamtina", a 21 year-old lower-risk married Eastern European refugee stated:

> *No, he, um, she was very good. She said, "It your choice, you can decide it. If you want it you can take it or no." And I think about myself, and I read at home the booklet, so I - for now, "No."*

Unlike many women who wanted the peace of mind afforded by a negative test result, "Polly" did not feel that it was worth the anxiety associated with testing:

> *I asked him if I had to do it. He said no, it's up to me if I wanted to do it. So he said if I take it and found out you have HIV, they can give you treatments to prevent the baby from getting it. I don't have AIDS. I'm not going to take it. So I decided I'm not going to take it. Because I told him, I know I don't have to, so why worry myself?*

Declining the test based on a self-assessment of personal risk of HIV clearly requires some basis for that assessment of risk. For example, in recognising that she was declining the test based on her own perception of her current risk of acquiring HIV infection, "Linda" explains that had she felt she was at risk of having acquired HIV then she would have accepted her physician's offer of the HIV test as previously she had been concerned and had voluntarily gone for HIV testing:

> *Although being myself with my personality, if I had felt – when I had felt that I had put myself at risk I had gone and gotten tested. So, I don't know how to explain that exactly. If I felt that I was at a high risk I probably would have been tested anyway, regardless of the pregnancy and recently. You know, I mean if I felt that I'd incurred a risk in that last year or something.*

"Eglamtina" had also declined the offer based on her assessment of her personal risk of acquiring HIV as she described above. However, later on in the interview she revealed a limited knowledge of HIV transmission routes, causing the cultural interpreter to break into our conversation to highlight this limited knowledge and to make a plea for increased HIV prevention information for women coming from countries where such information is less available:

"Eglamtina" *. . . but for me [the HIV test] is not important. For other women maybe who had, uh, more sexual with another mans, for them maybe is important. For me, no, 'cause he the first man . . . but I really, I was sure what for me, is not important, and for my husband. Because I know that he, maybe he has a friend, girlfriend, but maybe not a sexual relationship. 'Cause if you don't have a sexual relationship, you can't have this virus.*

Interpreter *Now, there are some other ways - Can I add something? . . . Some women do not understand the importance of this test. Especially the newcomers that are coming from countries where they have a limited information, they don't know importance of this test. If they have some more information for sure they will ask them to do this test.*

None of the women who declined their health care provider's offer felt that their decision to decline the test was received negatively, as exemplified by the comments of "Jessica":

> *I would say that was very easy to decline...I didn't feel that I was judged by her at all.*

However, one woman's physician put a condition on accepting her decision not to be tested. "Linda" was "not concerned about *having HIV*" perceiving herself to be low-risk having recently been tested including as a blood donor. However, she was concerned about *testing for HIV*. She had significant concerns about the confidentiality of test results in the context of a notifiable disease. Explaining this to her physician, her physician then changes the purpose of the offer of the prenatal HIV test from providing information to the pregnant woman herself to facilitate her health care decisions, to concerns over occupational exposure. As "Linda" explains:

> *So when she offered it to me I said, "Well, if you really want a result, I'll go to one of the community clinics to get tested and bring you back a result." And she said, "Well, are you saying you don't want to be tested or what's going on?" I said, "I don't mind bringing back a result for you, but I'm not letting you test me." So she asked why. And I said, "Because I make a big point of encouraging anonymous testing among people that I know, among clients, among everyone. I make a big point of telling people if they can't, um, I mean, if you have to get tested at the doctor, that's fine. But the doctor does have to tell the public health department and they keep records of it and I've seen cases of discrimination because of it later on. Employers get their hands on it, insurance companies get their hands on it. It's messy. So I said, "I'm very fine with bringing you back a result but I'm not letting you touch me." We talked a little bit about my history. I guess she was trying to sort of feel out if I was in a high risk group and kind of decided that I wasn't I guess, and she said, "Well I don't really care if you go and get tested or not." But we sort of made a deal that if something happened, for example an emergency C section or something,*

and there was blood spattered and someone who worked at the hospital had blood on them, could they test that - do you know what I mean? If they get splashed with my blood, would I object to them testing my blood just to make sure? And I said, "No, I didn't mind that at all." So, in any kind of emergency situation I didn't mind being tested. So she said that was fine. She trusted my feeling. ... And that was the end of it. She never brought it up again.

Interestingly, it would perhaps seem that the discrimination that "Linda" was concerned about and which led to her decline of the offer may well be embedded in her physician's request for testing compliance as a component of her care.

"Bobbie's" physician went along much more directly with her decision not to accept an HIV test. This was acceptable to "Bobbie" as she would not have appreciated any further discussion of her decision:

And I wouldn't have wanted her to pursue it further either. . . I mean – just like with the other tests, once I've made a decision, I don't want to feel that I am being coerced, especially by somebody who's going to be providing me with care at a fairly, um, critical time for me. I don't want to feel that they're questioning my decisions.

In contrast, "Jessica" ponders whether it was helpful to have her midwife accept her decision not to be tested. Should the midwife have worked with her on her reasons for feeling an HIV test was not necessary for her?

I have this whole mind-set: "I am so low risk, it doesn't matter." [LAUGHING] *I don't know if you find that? Which was sort of an overriding factor. And maybe it is the duty of the health care system to dissolve that a little bit more and getting you to think about it a little bit more. But, again, would it make me anxious? Would it consume a whole lot of resources unnecessarily?*

Waiting for the Results

With few exceptions, for the 33 pregnant women who had undergone an HIV test, the time between the prenatal appointment in which the test was taken and the next visit when the results were given was characterised as one of stress and anxiety. Pregnant women who had agreed to take the test based on their perception of their lower risk of HIV infection experienced the same emotions as those women who agreed to HIV testing because they did feel that they had put

themselves, or had been put, at higher risk of HIV infection and therefore a positive test result was a possibility.

"Pebbles" is still waiting for her results. As an injection drug user she is concerned that a positive result might be a possibility:

> *I got tested for HIV and I am still waiting! It's driving me nuts!* ***It's driving me nuts and I'm scared.*** *Because I used to share needles. Ten years ago. And if I'm HIV, I'll freak. I will. Not too much for myself, because even 10 years ago, I knew what I was getting into. I knew it wasn't right. But I had never thought about getting pregnant again.*

Aware of her possible susceptibility to HIV, "Mary" was nervous and worried:

"Mary" *I was nervous for the first, for the waiting period, until you get the results.*

Lynne *What was going through your head at that time?*

"Mary" *Uh, I was just praying to God that I didn't have it.*

Lynne *How many times do you think you thought about it during the waiting period?*

"Mary" *Um, not too many times, just a couple of times. Mostly when I was sleeping. I'd wake up and I was like, "Oh my god!" Freaked a little.*

Even though "Zenny" did not feel that she had put herself at risk she too worried until she received her negative results:

> *I was nervous. I was scared. Sometimes I didn't care, 'cause I didn't think it would come back with anything wrong, so I just put it out of my mind. But as it got closer, I got more nervous and I really wanted to know what she [her doctor] had to say. So I was so nervous. But then she told me that I was okay. And I was like, "Oh, thank God!" [LAUGHS]*

Similarly, although "Bridge", an Aboriginal 17-year old street-involved woman who is also an injection drug user, feels she does not have HIV she is also similarly relieved to hear of her negative results to resolve her continuing worry about her HIV status. She describes herself as one of the lucky ones:

> *Oh yeah, just a little bit [anxious]. It wasn't a big huge jump, 'cause I* ***just knew*** *I didn't have it. Even if I did know whether I had it or not, that worriness is still there.* ***Because you're not sure.*** *And I'm just a lucky one that came out HIV negative.*

As one of the very few women who did not think about her results during the waiting period, "Lisa" is also very sure that she will not receive a positive HIV test result. It is only when she receives her negative result that she realises that she may in fact have invested some emotion in the result:

> *I don't even think I gave it [return of her results] another thought. Except when I came back in and the results were there. And she had the results there, and she said, "[Name], this looks good. The RH is good, you're, you know, you don't have this" . . . And she says, "Oh, and HIV is negative." And when she said that - it was interesting because I knew that I was negative. I'm thinking, I know that I am. I've been negative for ten years, you know, like, since my last test, I've been married, you know, for so long, and my husband never had any partners before we were married so I'm thinking, I know I'm negative! But even when she said, "You're negative." It was, "phew" - like it was relief. It was like, okay! And then I'm like, what are you talking about you know you are! So, you know? So, you know, there is still, some relief when you hear HIV negative. You're thinking, "Okay, good!" Even though if you know.*

Principles of HIV Counselling and Testing

Having described the experiences of the pregnant women in terms of the offer, if any, and the request for a prenatal HIV test; the issues that were personally salient to the women as they made their decisions around HIV testing; and the experience of waiting for the return of HIV test results, the next section considers the women's experiences in terms of the established Canadian principles of HIV counselling and testing. The issues examined are the voluntary nature of the offer of the HIV test, informed consent and pre-test counselling, and post-test counselling.

Principles of HIV Testing: Voluntary Nature of the HIV Test

The first underlying principle in testing for HIV referred to in the Guidelines is that,

> *Testing for HIV should always be voluntary...*

This principle is alluded to many times in the Guidelines, in particular in the discussion of the principles of pre-test counselling:

> *The decision to be tested should always be the choice of the individual patient.*

Similarly, the principle is reflected in the letter from the Ontario Minister of Health and Long Term Care to Ontario physicians announcing the HIV Prenatal Testing Programme:

> *The Ministry of Health will make voluntary HIV testing available.*

The voluntary nature of the prenatal HIV test is not however specifically emphasised in the Ontario Counselling Checklist although emphasis is placed on the concept of an offer of an HIV test:

> *All pregnant women in Ontario and all women planning a pregnancy will receive HIV counselling and be offered HIV antibody testing as part of routine prenatal care ...*

The concern exists that HIV testing may become so well integrated in the practice of routine prenatal care that pregnant women may have, or believe they have, no meaningful choice to make. For example, when very high rates of acceptance are reported by individual physicians or specific health units, one obvious concern is that the consent process may not have been adequate and that women may not have realised that they could refuse, i.e., that prenatal HIV testing in Ontario is voluntary. From the experiences of the pregnant women, many felt that they did not have the option to voluntarily participate in testing, that they had no choice. "Emily", a higher risk woman living in a maternity home, explains:

> *Umm, she [the doctor] didn't tell me exactly what blood-work she was doing. All she said was they had to take so many vials, and she wouldn't tell me what they were for . . . Yeah I asked her, and the only thing she did tell me was that it was the AIDS or HIV blood test and the hep blood test, and that's all she told me - Nothing was explained to me - I thought I had no other choice.*

Many of the women were very clear that they had not, in fact, given their consent to be tested, as "Tammy" explains:

No, not really [my decision]. Because like I said, he does it as a procedure, right? So basically he didn't even tell me what he was doing. I was asking the questions. I'm like, "What are you doing? What are these tests for?"

"Bridge" believed that HIV testing during pregnancy was mandatory, and that she had to be tested even if she didn't want to be:

Lynne — *Now you said before that she [family physician] had told you you had to have it.*

"Bridge" — *Yes, it's a mandatory thing. Uh, it's not just HIV, it's all STD testing. You have to have them all done, even though you may think you don't have something, it could always develop in you. Um, so I had to do it whether I liked it or not.*

Lynne — *And you said that she had told you that was because you're pregnant?*

"Bridge" — *Yep. Because of the pregnancy, you have to have the STD and AIDS testing done, whether you want to or not.*

Lynne — *How did you feel about that?*

"Bridge" — *Uh, with me, it didn't really bother me, 'cause I knew I was clean, and I knew it was also a safety precaution to help the baby. For when it was born, if I did have something. So I was like okay, you know. Like I'm not going to argue with the doctor that's telling me I have to take this.*

As we hear from "Bridge", health care providers appear to have the potential to influence or shape their prenatal patients' decisions and thus render the opportunity of testing less than a voluntary experience. Other women shared their perceptions of their health care providers' influence on their decision-making, as "Yvonne", a 30 year-old visible minority woman in her second trimester explains:

Through the interpreter, the doctor explained to me that it is my choice whether I want to have this test done or not, but it's better that I have it done.

Similarly, "Angelica", felt that the choice to be tested was not hers to make:

Dr. [Name of Doctor] says she recommend it and she make me feel it is very important to have this test. And I couldn't say no.

The narratives of some of the women do suggest however that it is possible to achieve at least a minimal threshold of voluntariness in a clinical setting, providing health care professionals are sufficiently committed to communicating to pregnant women their respect for patient choice. "Dana" explains:

> *She's very non-judgemental. And she's not pushy. She provides you with the information you need. And it's your decision to make of what you want done. And she gives the options you have in terms of that. But she didn't push me one way or the other. To have it done was my choice.*

Similarly, "Deborah" describes how the information presented to her by her physician made her feel comfortable with the whole idea of the test, which helped her in her decision to accept the offer at her next appointment:

> *She just asked me if I was comfortable with having an HIV test. And I said, "Yeah, okay." And she told me what about would happen if there was a good chance that it was positive. And I felt rather comfortable with it after she explained the stuff to me . . . She just asked me after our session we had, after the check up and she asked me if I wanted to or, if I didn't want to, or if I had to think about it . . . She said, "Don't feel that I am pressuring you" . . . And I said, "All right."*

Principles of HIV Testing: Informed Consent

A major emphasis in the Ontario Counselling Checklist is the concept that while all pregnant women in Ontario and all women planning a pregnancy should be *offered* HIV antibody testing as part of routine prenatal care, the pregnant women need to consent to the test before it can actually be administered:

> *The test will not be done without informed consent.*

Similarly, in addition to stipulating that testing for HIV should always be voluntary, the Guidelines clearly state that testing for HIV should always be carried out only after the patient has given informed consent:

> *Testing for HIV should always be voluntary and carried out only after the patient has given informed consent.*

Based on the narratives shared by the women with whom testing for HIV had been raised in their pregnancy, how well do their experiences measure up to these protocols? Did health care providers fulfil their professional obligation to seek

informed consent before testing a pregnant woman for HIV? Was HIV testing in these women's pregnancies always carried out with the informed, specific consent of the women being tested? Did any of the women who had been tested for HIV in their pregnancy feel that they had given their informed consent to be tested?

Principles of HIV Testing: Pre-test Counselling

The key question is whether the consent was informed consent. In a discussion of the legal and ethical concerns and prerequisites in HIV testing, the Guidelines emphasise that informed consent cannot be implied or presumed. The process of obtaining informed consent for testing for HIV during the pre-test counselling session is laid out in the Guidelines and is seen as involving:

- educating;
- disclosing advantages and disadvantages of testing for HIV;
- answering questions; and
- seeking permission to proceed through each step of counselling and testing.

The importance of pre-test counselling in ensuring the woman is giving her consent to HIV testing as required by Ontario law is explained in the Ontario Counselling Checklist:

> *The purpose of counselling women about HIV antibody testing is to give women the information they need to understand the benefits and risks of the test. Only when women understand the benefits and risks are they able to give their informed consent for the test.*

This necessity of understanding the implications of an HIV test before agreement to test can be given is also stipulated in the Guidelines which emphasise the necessity of preparing a patient for the possibility of a positive result:

> *Take time to examine and discuss the issues raised by testing so that the patient has the opportunity to weigh the advantages and disadvantages of being tested and prepare for the potential consequences of a positive or negative result.*

This concept of the necessity of information before informed consent can be given is well described by "Marion", a 33 year-old lower risk married health professional. "Marion" addresses the necessary requirement for adequate information before informed consent can be given or indeed accepted:

> *Well, I went along with it. She didn't really come out and ask for a consent the way I know consent should be asked for. Because there was no discussion about the test, because there was no information given about the test, I certainly couldn't - I did not give* ***informed*** *consent. I gave my agreement. I gave consent to do it - but she gave me no information. So how can that be informed consent?*

Even when physicians explained, and women understood, that agreeing to the test was their decision, information on which to base that decision as described above was often lacking, as "Leslie" explains:

> *Well, no, she didn't really explain that much to me about it. She just basically told me that she just wanted to make sure that I don't have it, just to test me. Also, she said because if I have it, there's also the chance the baby can have it. But she never really gave me any pamphlets or anything. She never really said a lot about it. She just basically asked me, "Do you want to have this test or not?" And I said, "Okay"... But I didn't really get like all kinds of information on it. She just basically told me that she wants me to have a blood test done for HIV, but it's up to me; she's not going to force it on me, but she feels that it's best that I do just to be on the safe side. Basically, that was it – point blank, that was it, yeah... But I figured like, she's the doctor. It's kinda her job to inform me on this stuff. But she didn't really...She didn't offer me the information. She just offered me the blood test, and told me she felt I should take it but that it's up to me. Like I said, I didn't get no information. I don't really feel like I need it because I know I don't have it. But if I did want it, yeah, I would want to see another doctor to get some information, because I didn't get it from her. And I shouldn't have to ask. She should tell me, right off the bat. Like even when she offered me the test – okay, this is the information on it. But she didn't, no.*

In explaining her need for more information before accepting the test, a theme expressed by many of the pregnant women, "Tammy" explains the importance of preparing women for a positive test result:

He should have explained it more. And explain the consequences - and all the things that could happen. He didn't even explain anything. He should have explained. He should have just told me more about it. And he should have just explain like if somebody had it, the different things that they could do, and if there's any programmes you could go to or anything. It wouldn't be good if the results were positive then I wouldn't know about anything you know. Then I'd be going to him asking questions. Instead he should tell me in advance.

Of particular interest is the fact that written information was seldom used in the pre-test context. Although most of the pregnant women interviewed subsequently voiced that they had wanted far more information than they received at the time of the offer of their HIV test, very few had seen, or more importantly been given, any written information on the prenatal HIV test. Seeing the Provincial Ministry's PHCT brochure in my binder reminds "Linda" that she has seen these brochures in her doctor's office but has not been given one by her doctor:

I'm just looking at your binder there. There's ones like that all over her office. Yeah. They're in the waiting room, and I've been to two or three different little examining rooms or whatever, and they're in all of them. And the reason is 'cause now I recognise them, so I think it sort of flashes. But she didn't give me one. She offered the [HIV] test first.

In contrast, the offices of "China's" obstetrician do not appear to have copies of the Ministry's brochure available and she too had not been given any written information about PHCT:

Lynne — *Have you seen anything in your family physician's office or the obstetrician's?*

"China" — *No, nothing.*

Lynne — *Did he give you anything to read to take away?*

"China" — *Nothing about HIV, no. No, I think he gave stuff about the Cord Blood Programme. Tons of literature, but nothing on HIV. No. No. Like they gave stuff about the Cord Blood Programme, tons of literature. But nothing HIV-related . . . He's [Obstetrician], he's affiliated with the hospital. So, you'd think there'd be a bit more. But most of the information in his office is like magazines, like Expecting Magazine, or Parent's Magazine. They all come in like little plastic pouches with the diaper sample that kind of thing. And then the only other things that I remember seeing are the Cord Blood Programme, or if you want to have your child's name on a*

star on the wall, like those kinds of things. Like there wasn't, wasn't a lot about like, medical brochures kind of thing. It was more fun kind of stuff.

The women's experiences of receiving limited information on the HIV test thus precluding their ability to give informed consent is often in direct contrast to the detailed information they were given on other tests on offer during the prenatal period. "Grace" was not offered an HIV test by her obstetrician. However, although a teenager, she had been provided with a package of information on the maternal serum screening. She speculates that if she had had similar information on HIV testing her perspective on the test may have been different:

'Cause that's how I - for the test for the Down's Syndrome and all that. It was in that package. It was like, a little pamphlet and I read it and I was like, "Okay, this is a good test that I'll have done." But there was no pamphlet for HIV or nothing like that. So it never crossed my mind, I never thought about it. But if it was in the package, I would have been, "Okay, I'll have that done too." . . . So if pregnant women knew that it [HIV testing] was important, and if they knew more, like if they knew that there are things you can do to reduce the chances - Like, see, I never thought there was anything you could do to reduce the chances. I thought it was, once it was done, there's really nothing you can do. 'Cause I don't really know that much about it, I've never read about it or - .

"Suzanne" for example, who also was not even offered an opportunity to test for HIV, similarly describes the information she was given concerning maternal serum screening:

"Suzanne" *He [obstetrician] explained to me that it was a test to test for any genetic problems, or that kind of thing. And that it was completely up to me, if I wanted to have it done or not. And because I was young, I was at a lower risk, but it's still up to me. If it's something that I want to do, then the option is there. So, he gave me the lab requisition and said, "If you want to get it done, then go at sixteen weeks." So, I just went to the hospital lab at that point and did it . . . The information that I had was pretty good. Like he drew charts and graphs and said, "This is your risk because of your age and if you're interested or whatever." The information for that was pretty good.*

Lynne *But he didn't mention HIV?*

"Suzanne" ***No!***

Principles of HIV Testing: Pre-test Counselling: Equal Benefits for Mother and Child

In describing the content of pre-test counselling at the first prenatal visit, the Guidelines emphasise that pre-test counselling should comprise a discussion of

> *the advantages and disadvantages of testing for HIV for both mother and child.*

Similarly, the Ontario Counselling Checklist requires health care providers, in discussing the benefits of being tested, to emphasise that there is equal benefit to HIV testing for both the pregnant woman and her child:

> *[One of the benefits of being tested, if the test is positive] is earlier diagnosis and treatment, which may lead to better health outcomes for both the woman and infant.*

An emerging theme in the women's narratives however, is apparent evidence of an imbalance between concerns for potential future infection of the child compared with possible current infection of the pregnant woman. Despite the fact that the Guidelines stress that the pre-test discussion of the risks and benefits of testing for HIV should apply both to the mother and the child, there appears to be an emphasis on foetal benefits, on reducing the risk of HIV infection to the child and a neglect of the needs of the possibly positive mother. As "Fatimah" explains:

> *It wasn't presented in a way that was saying, we want to get HIV testing so that **you** can be aware if **you're** HIV-positive – it was so that the **baby** is safe. So that, you know, your care can be assessed so that we can understand what's happening with the baby so that you know, because I think that she was saying that there's new things that they can do to reduce the risk of transferring HIV to the baby through the delivery. So she was saying that's important for us to know, you know, so we have that. I don't think it was really presented in a way that was um, so that **you** can be aware of it and that type of thing...*

"Leanne", a 23 year-old higher risk woman living in a maternity home echoes this experience which was representative of that of many of the women in the study:

> *She just said it was important, and that was all that she said. 'Cause we gotta know and we gotta find out sooner because, so this baby doesn't get it. They didn't say nothing about me, just the baby though...*

Similarly, "Polly" was told about prophylactic treatment to prevent perinatal transmission, but not about treatment that would be available to her:

> *[They told me] I take the treatments - they kind of prevent the baby from getting it. But they didn't talk about treatments for me.*

Principles of HIV Testing: Post-test Counselling

The Ontario Counselling Checklist provides little guidance to health care providers on the post-test session beyond emphasising the importance of assessing the "window period"[xxx] and the statement that all test results should be given in person not over the phone. However, the Guidelines contain explicit details on the procedural process as well as the content of the session to follow the completion of the HIV test:

> *Post-test counselling involves working with the patient to understand the test result, address psychological reactions to it, promote behaviour changes and assess the need for follow-up and care.*
>
> *The patient should be informed of the test result in a direct manner at the beginning of the post-test session.*

The return of the test results for most of the women in the study did not measure up to the procedure outlined in the Guidelines. For many women, the results were alluded to very briefly with little or no discussion of the issues suggested in the Guidelines, or an assessment of the window period as suggested in the Ontario Counselling Checklist. "Beverly", a woman perceived to be at lower risk of HIV, explains:

> *Um, she was just flipping through the pages and, um, she said - I had just come back from my ultrasound actually, they had the ultrasound results, and she was telling us, you know, all the important parts of the ultrasound and she looked at me and said, "Did you have an HIV test?" And I said,*

[xxx] The window period describes the seroconversion period, the period of time it usually takes to develop detectable antibodies to HIV following infection with HIV. In 75% of cases, antibodies are produced in 4 to 8 weeks; in almost all cases antibodies are produced within 14 weeks. The window period is very significant in relation to the timing of HIV tests. A person who is tested during the window period may receive a negative HIV test result although they may be infected with HIV. People disclosing HIV-related risk factors in the 14 weeks prior to testing negative for HIV are encouraged to retest at the end of the window period.[300]

"Yeah." And she flipped through and said, "Oh yeah, here it is. It's negative." And that was the end. And she went on talking about something else, so, there was no big issue made of anything.

"Elizabeth" describes her similar experience:

Everything came back negative [LAUGHING]. *That was all she told me about any of the results. Everything was fine and everything came back negative. Well, she pretty much, didn't specifically say this one came back negative. She said all of them came back negative and everything is okay. So, I was like, I figured everything was okay.*

which is echoed by "Mary":

He's like, "Everything's fine." That's all he said. "Everything's fine, you don't have to worry."... Looked through my file, told me that the results were negative. He's like, "You don't have to worry."

For some women however, this limited discussion was appropriate to their needs as "Lisa" explains:

Lynne	[Repeating "Lisa's" last comment]
	She looked through your results and said, "Everything is fine."
"Lisa"	*I think that was good enough for me because if there had been anything wrong she would have said what was wrong. She doesn't have to go into big detail, "Well, you don't have this or this or this or this or this, so you're fine." As long as she says what's wrong if there is anything wrong or just says everything's good, that's enough.*

A few women in the study had not received their results, as "Leslie" describes:

No, nothing's been mentioned. I mean, I figure it's her job to tell me, but she hasn't. I mean, it's also my job to ask, but still she's the doctor; she's supposed to tell me if I have it or not. But she hasn't, so. I don't know if she just forgot or what. I don't know...She said, well actually, I went to go see her - ah how long did I go see her after that - I think I went to go see her like, two weeks after that for another appointment. And also I never bothered asking, but I had the blood test done, and I went to go see her two weeks after, and she never told me about the results coming back. I figured that they would have the results in two weeks. I mean, they can't take that long. But I mean, she never mentioned anything to me, so I just kind of figured, well, maybe she's not going to because I don't have it. But she never mentioned anything to me yet. Like, not even now, she hasn't brought it up...Yeah, I probably will ask her. I mean I will ask her,

next time I go I will. But I just know I don't have it. It's basically like I'm just waiting for her to tell me.

"Marion" feels very strongly that her physician should have initiated a discussion around the return of the results:

> *I got my maternal screening results, and nothing was mentioned about it [HIV test] at all. And I didn't ask. I wanted to see if I would get an official result, and I never did. So, it hasn't been brought up since... I think she should have said, "Your results were negative." I think we should have had a discussion about it. Because I was totally focussed on the maternal screening results, it was up to* ***her*** *to bring in the HIV, and she never did. And, as I said, I assumed I was negative, so it wasn't a priority for me. But as a physician, she should have said, "Okay that's that test, your other test results are blah, blah, blah," and gone on from there. But no, there was no mention of it at all. I never even actually saw the results on the lab report, nothing. I saw nothing.*

The stipulation that the results should be given in a direct manner at the start of the interview was not always followed, with unpleasant consequences for the pregnant women, as "Zenny" explains:

> *And when I went into have the results, she didn't tell me right away. She sat me down and she goes, "I'm going to read your results and I want to make sure that you're okay with this and that you understand that this is a test, and it's accurate and that's why it's taken so long," right? And just the way she said it made me think that, "Oh, no! She's going to tell me I'm positive" right? So I was so nervous. But then she told me that I was okay... Well, I think if she'd just come into the room and said that it was negative, that would have been easier instead of explaining to me that the test was accurate and... If she'd had said...just come out and said it, I think it would have been easier. 'Cause the way she put it made me think that, Oh no, it's bad news.*

Similarly, "Mariah" described the anxiety she experienced as she was left waiting for her test results:

> *I was sitting there, I was emotional because I was pregnant. I was just looking at the clock and then, 45 minutes passed by and I started crying. I'm sitting here all alone and they're scaring me. I was waiting for the results, so it was like, okay, something's wrong because they're taking so long. But then, the doctor came in finally an hour and maybe ten minutes later and told me my results and said he was sorry they took so long. He told me my results – they were negative... And I was sitting there in like a*

hospital gown type thing, and just being emotional, being alone, making me wait an hour, I just felt like they didn't care – nobody cared... Well, they could have come in and said they'll be a few minutes and to hold tight, or just to let me know, reassure me that they know I'm here. Like, I thought they just totally forgot about me. And I was too nervous to walk out the door to say, "Hey, I'm still in here." I'm not a very outspoken person in that way. But I sat down alone and cried, and looked at the walls – what about me, I'm still here.

Indicators of Best Practices

Based on their own recent experiences, all the pregnant women participating in the study were asked to describe the content of an effective prenatal HIV screening programme and to describe the process whereby it would be offered to women in Ontario. Specifically, women were asked when HIV testing should be presented to women; who should present HIV counselling and testing to women; how HIV counselling and testing should be presented to women; and what the experience of prenatal HIV counselling and testing should comprise.

WHEN Should HIV Counselling and Testing be Presented to Women?

Not in Pregnancy

The Ontario prenatal HIV screening policy states that the Minister of Health will make voluntary HIV antibody testing available for all pregnant women and women planning a pregnancy. It would appear that the last sentiment needs to be pursued more actively as the general consensus among the pregnant women was that pregnancy was not the appropriate time to raise with women the issue of HIV infection or to offer testing. "Christine" explains:

But, is best if you talk to someone before she's pregnant. And just try to explain everything. Because, it is very difficult. You are pregnant. You see that now I have HIV, what I supposed to do? I have to keep my baby, not to keep my baby. What? That is a stress, eh?

Several women explained that had they had a greater awareness of HIV in general and perinatal transmission in particular, they would have chosen to have been tested prior to pregnancy as knowledge of their status would have been a factor in their decision to become pregnant. "Gillian", a 34 year-old visible minority lower-risk married woman, explains the utility of a pre-conception diagnosis:

> *No, I think before is better, because if you have that risk, you can prevent bringing a child, right? But if, for me it was better they do it before, because I prevent if I have that infection. Maybe I don't try to bring a child. Sure they have a little risk, but they have it, right? But I think is better before...*

Clearly, pre-conception testing maximises a woman's choice and prevents having to make life-altering decisions after the fact, as "Christine" further explains,

> *To explain to people that it is better to do that [testing for HIV] before [becoming pregnant]. Because when you do that before, you can say, now I know. If we have HIV, we have this disease and we decide we're going to have a baby, we know that we are responsible for that. But sometime you can be pregnant and you know that after. You know that it's going to be a great big stress. I don't think [that] I can handle that.*

The Guidelines suggest that HIV testing should be offered routinely at visits for pap tests and consultations about contraception or STDs. "Morning Star" has the same suggestion:

> *Um, maybe you know how at the doctor's, after you become sexually active, you're supposed to get a pap smear or whatever, just to make sure you're not at risk for cervical cancer – so maybe they should also say that you should think about getting the [HIV] test. Like they should mention that, too, at that time... Yeah, because when you get a pap smear, they check to make sure you're not at risk for cancer; then get the blood test, too, so you can find out if you're not at risk of AIDS.*

"Marion" also emphasises that both men and women should be offered HIV testing regularly:

> *I think testing should be voluntary definitely, and that it should be offered to men and women and not just because you're pregnant. For women, that's usually part of the physical – a pap test – and have a [HIV] blood test done then. I think that would be reasonable. But with men – where are we going to capture men in that? And that's where I don't fully agree that it should just be pregnant women who are tested.*

Discussion of HIV Test Should Take Place over Several Early Prenatal Visits

If a policy of prenatal HIV testing is to continue, the pregnant women had suggestions of when in pregnancy HIV counselling and testing should take place.

The Ontario policy, as outlined in the Ontario HIV Counselling Checklist, requires counselling to be completed during the women's first visit and states that *women must be given the option of being tested at the first visit or at a subsequent prenatal visit.* However, it is clear that this directive is acting against some women accepting the test as "Rosie", a 36 year-old Ottawa woman considered to be at lower risk for HIV explains:

> *I wasn't expecting to be asked. So my husband and I hadn't actually discussed it beforehand. So we said no. I think it would have been more helpful to actually know that that was one of the things I was going to be asked about at my next visit. I hadn't even thought about it.*

The policy as stated in the Guidelines that counselling *should be carried out over several prenatal visits* appears to be more appropriate and was suggested by several women including "Marion". However in the light of the benefits of early diagnosis and treatment, these would need to be early visits.

> *I think because you see the physician so many times when you're pregnant, there's enough opportunity to – say, the first visit your pregnancy test comes back and she talks about the process. Well then in that process – then the next visit you'll talk about the HIV testing that's offered. So at the second visit you talk about the testing, then maybe at the third visit you actually do the test. So it gives people a bit of time to talk about it, or even think about it.*

"Linda" adds an interesting point. She explains how you really need to adjust to your pregnancy before you can start thinking about a decision for yourself and your baby. She recommends delaying the offer, while at the same time recognises that delaying the offer is also not optimal:

> *... because I don't think the best interests of one, they actually, they very much don't coincide there. Well, - not very much, just parts of it that don't, that conflict there. So, yeah, it's a little strange. And it's very strange early on because you can't feel anything and at least for me, because I was still sort of in shock mode, I was still thinking very much*

about myself. Um, and that's probably until very recently. I mean, I thought, you know, "Yes, I'm pregnant, I can't fit into my jeans," I know that. But all I felt was like I'd eaten too much turkey or something, you know. [LAUGHS] *I didn't feel - and I felt sick, so you don't feel sort of that idea that they - oh the wonderfully glowing mother.* [LAUGHS]. *My face hasn't broken out like that since I was twelve, so it's strange. I don't know if maybe they should give you some time to think about it. But then on the other hand, I mean the best time to find out would be early on. Right?*

Interestingly, the salience of allowing pregnant women time to adjust to the idea of talking about disease in pregnancy and allowing time for adequate on-going discussion was played out in the actual interview situation. Of the six women who had previously declined the offer of the test with their health care provider, participation in the interview acted as a catalyst for further consideration for four of them. "Linda", for example, speaks directly to a longer time for reflection after she had declined the test and the effect of the interview:

I think I thought about it more after really . . . I mean, it doesn't keep me up at night, but a little, like us talking about it. I think, maybe did I do something wrong, you know.

"Polly" similarly queried her decision to decline the test and asked me if it was too late for her to be tested:

I was sometimes saying, "I should have taken the AIDS test." But now – it's not too late? So maybe, Dr [name]? Maybe I might talk to him about it?

Neither the family physician nor the obstetrician providing care for "Grace" had offered her the opportunity to test for HIV during her pregnancy. However, as she explains, discussing prenatal HIV testing with me during the interview made her think that she would like to be tested:

I wouldn't mind having it done. Now I think, like after talking about it and stuff, I was thinking like, it is important to me, like, even though I'm scared to find out, it is important to me. Because it's not just for me, it's for the baby too.

Discussion of HIV Test Should Not Be Integrated with Discussion of Other Prenatal Tests

Many women wanted more attention paid to the HIV test in the prenatal context, as "Grace" explains:

> *They should, like the doctor should stress those HIV tests more. The way they stress, like, you know, your weight, like eat healthy and nah, nah, nah, nah, nah. Yeah, they should just stress those kinds of tests the way they stressed everything else. If the woman doesn't want to, fine, but he should at least talk about it a little bit more, just so it's not something he mentions and you forget about it. It's something that he actually talked about and that either just didn't do or not, or you wasn't interested in it. But he should talk about it more, not just mention. He should actually talk about it.*

Based on her own professional knowledge, "Marion" feels very strongly that an HIV test is not a standard test:

> *Well, because it gets sort of just lumped in and slammed in there as a standard test. Well, it's not. Based on my occupation, I know it's not a standard test. And if the results are positive, it takes on a whole other meaning to people. And there's no way my experience would have prepared me to deal with that. I can work in HIV for the next 20 years, and still not be prepared to hear my own positive results.*

In particular, some women suggested that it should be discussed separately from the maternal serum screening as "Marion" explains:

> *I was kind of curious why she waited four months. I thought - that's the other thing. When I went for my pregnancy test (it was a urine test), I thought they might have offered me some [HIV] testing at that time. Why did they wait? Why was it lumped in to the maternal [serum] screening time? And is it just because it's easy just to take all the blood at once? But I think it could have been offered a lot earlier. Especially with what I know about medication and the benefits of it. Why did I not get tested sooner? Then it could have been separate from the maternal [serum] screening, because the maternal [serum] screening is way too important. As a pregnant woman, that's the test you want to know about. Do it much earlier than four months, not the day you get the pregnancy results, that's not the time to do the test, but maybe it's the next obstetrical check which is about a month later.* ***I think HIV testing should be a focus of the discussion. I think that should be separated from the maternal [serum] screening or anything else, because it needs to have much more importance than it does.***

WHO Should Present HIV Counselling and Testing to Women?

For most women, their doctor was considered to be the best person to inform them about HIV and to offer testing.

"Dana" explains the importance of the existence of a level of trust in her relationship with her physician in facilitating the discussion of the HIV test:

> *She was the best person for me. Because I trust her, I like her, I find her very sensitive. She listens to what I say. But that's the way she's always been. When I first met her, we clicked right away. And I've had two female family physicians, and I changed the first one because she just walked in, did my blood pressure, did my tests and then walked out. Whereas this one, sits there and asks why I'm there, listens to what I say. It doesn't matter whether I'm a nurse or not. She asks whether I need more information about this and whether she can help me with any problems I may be having, and how she can be supportive. So she's, for me, I've already trusted her before. She's just a gem... Because she's very good at what she does. She's got great bedside manners that are ideal for that situation. She's very sensitive and she listens. She actually looks at you when you've something to tell. She's not worried about what's happening in the waiting room. You're there; you're her concern. Her knowing you're there – that's important... Yeah! It's very rare in a doctor, but she's just great. And she's got a good office staff, too. Like they're all very good. So I think complements it. It does. I would recommend, if all family doctors are like that, then that would probably be the ideal person for that. Because when you're going into a situation with an obstetrician, and you've met him or her for the first time. Certainly when I went in there to meet [Name of Doctor], he was very nice and very presentable, and just took the time and spent time with me. He also wanted to know if I had my blood tests. I reassured him that it was all done. But I don't know how comfortable he would have been, or how comfortable I would have been, to hear about what blood tests that needed to be done and why they were being done. But with my family doctor, there was a lot more trust there.*

"Marion" also points to the necessity of a close relationship in enabling a discussion about HIV:

> *So I would say yes, she [the doctor] would be the one. I would like her to do it more than any other, like even if she had given me the option of anonymous testing, I still like to deal with the person who I know across the table from me instead of a stranger. So I would have still liked to have had her do the test. But anonymously.* [LAUGHS] *You know what I mean. So I still think yes, the physician should be the one to do it. But I would have still liked her to have talked about it. This is what's going to happen*

if it's positive and where does that result go and the implications it has. Because otherwise, you know, out of the blue, because you're not thinking, you're not thinking about HIV and if you're not given any information, why would you even think you'd be at risk for it? You're thinking about this pregnancy and this baby and if the baby is physically all right. So you're in no capacity to be able to assess your own risk for that. So if somebody has to take charge, and I think it should be a physician who has that intimate relationship with you, to go down that road. And yeah, it might be difficult for some people, but who else but your physician should have that discussion with you about that.

Whereas, "Fatimah" emphasises the necessity of sensitive training and experience in presenting the offer of the HIV test to pregnant women. She vividly describes the consequences for women of the lack of this counselling experience among health care providers which could result in the pregnant woman no longer accessing prenatal care:

Because if you, I'm telling you now, if you go into, having some background in counselling myself, go into a situation which a woman is dealing with all kinds of different factors, you know, she doesn't know what's going to happen. She has no idea, you know, this pregnancy is the last thing that you know, she maybe, you know, there may be drugs involved, you know, there's so many different factors, to put somebody in a situation, where they're with a person who's not trained, or not experienced to deal with those kinds of things, to say, okay, you need to get tested for HIV because you're pregnant. You know, if they're not at all trained to deal with that, it's a time bomb. Not only will they not want to get tested, but they probably won't even want to have, seek any more care because they're so afraid that they may be HIV positive, they may not know. Rather than to deal with that, they'll forego any prenatal care at all because they may think that it's mandatory. You know, if it's not explained properly. So, you know, I think there needs to be definitely some sort of training module for physicians and clinicians and different people to be able to offer the test to pregnant women. Uh, regardless of if they're no risk at all or they're higher risk. So, I think that that needs to be in place.

However, some women also felt that their doctor was too rushed to answer their questions fully or to be concerned about their feelings and their fears. Midwives, nurses and counsellors rated higher than doctors in this respect and family physicians rated better than gynaecologists, as "Lisa" explains:

Like she's [her gynaecologist] always in kind of a hurry it seems. But at least everything gets done that needs to be done, so it's not that much of a problem. If it was anything, if I had problems or anything like that, and I wanted to try and talk to her and she was just rushing through it, I don't think I would be too happy. But as it is, everything is fine, so it doesn't bother me that much that she wants to get things done and get on to the next patient.

"Suzanne" similarly experiences her appointments with her obstetrician whom she is seeing for all her prenatal care as speedy encounters. However, as "Lisa" did, "Suzanne" is also prepared to accept this practice as she feels she herself has a lot of the answers:

Lynne	*And how is that [care with obstetrician] working out for you?*
"Suzanne"	*Very good. He's very quick at what he does. But he's pretty good.*
Lynne	*Very quick meaning what?*
"Suzanne"	*The appointments are five minutes* [LAUGHING] *that kind of quickly. You go in and you take your blood pressure and your weight and screen your urine. And he goes, "Anything wrong?" And I go, "No." He says, "Okay, see you in two weeks." Like it's very quick.*
Lynne	*What do you think about that?*
"Suzanne"	*Sometimes, I like, because I'm in the health profession it's fine because like I already know a lot of the answers to what I would have had questions to. But if I wasn't then it would kind of concern me, being my first pregnancy.*
Lynne	*Yeah.*
"Suzanne"	*Because, like, I know a lot of the things and the stages now. But if I didn't know that and I went in and it was quick it would be a little different.* [LAUGHING] ... *He's really quick* [LAUGHING] *Really quick ... it's not so much of an issue for me but I think that it would be if I didn't know or didn't have access to like the internet or whatever. Like, whatever I need to know I search through there instead.*
Lynne	*Yeah, But relying on him -.*
"Suzanne"	*I don't.* [LAUGHING] *I don't so much.*

HOW Should HIV Counselling and Testing be Presented to Women?

Approaches to Prenatal HIV Counselling and Testing

In the context of our discussion, most of the pregnant women reflected on how they would have liked HIV testing to have been raised with them during their prenatal care. In these cases I was able to extend the discussion around the various policy options. For women who had not initiated the discussion, I asked them directly how they would have liked the test to have been presented to them and supplemented the questions with explanations of the various approaches where necessary.

Only a few women, such as "Natasha", favoured a targeted or selective approach. As a physician, her concerns centred around the cost of a universal rather than selective testing policy:

> *But just doing tests for the sake of, I mean just doing HIV test on every pregnant lady. I'm not really sure if it's worth it for any pregnant lady because some of them don't. For example, I don't really see myself as needing it at all . . . I would take it, yeah, but I don't know, if you consider like a, from a policy point of view, I think some of the money could be used, I think it is better to decide which patients need it, and which patients don't. I mean - that's how I see it.*

Most women were concerned about the stigmatisation inherent in such a selective approach as "Linda" explains:

> *Of all of them, that's the worst one. Um, I think that's - you're opening the door wide open for stereotypes to come in. I have a friend who, um, ah, worked in Thailand for two years teaching English, and the second they find out she's been in Thailand, HIV tests come offered out their wazoo or whatever. So really, really, that really irritates me because they would see people who they think look like they would be at risk, um, just racism, um, just if someone looks like, like they use drugs – "Well mmmm, we'd better test," you know? And someone like who looks like me would never be offered the test. Do you know? I shouldn't say never but much less frequently be offered the test.* ***So no!*** *That's a* [LAUGHS] *bad - for me, that's* ***a bad option.***

Many of the pregnant women were really torn in their opinions about whether it should be a mandatory test or if women should have a choice. In describing this dilemma "Kathy", a 17 year-old woman with a history of injection drug use, illustrates the ambivalence expressed by many women:

"Kathy" *It really **should** be an offer, but in a way I think it should be compulsory. But it's kind of up in the air, because some women are like, "No, I'm not getting it." But they might have it, so they're risking themselves and their child. But you can't **force** it on somebody like, "Okay, we're doing an HIV test." But in a way I want to think there's a way around it. Because the doctors come in and they'll do six vials of blood and you don't know what any of them are. I always ask, "What's that?" And she'll tell me just so I know. But they could just do it without you knowing.*

Lynne *How would you feel about that?*

"Kathy" *Better.*

Lynne *You'd feel better.*

"Kathy" *Yeah, if somebody did that, I'd be like okay. I didn't just spend two weeks worrying about it.*

Concern for the health of the baby led many of the pregnant women to support mandatory prenatal HIV testing as "Beverly" explains:

> *Absolutely [testing should be mandatory]! Without a doubt. Anybody, everybody, maybe not for your second or third pregnancy that's with the same parent, like, father, but um, absolutely everyone. There should almost be a government law to do it, I think.* [PREVIOUS SENTENCES SPOKEN STRONGLY, WITH CONVICTION] *And as it's spreading more and more, it should be, and especially if it's as treatable as it sounds like it is. I mean, my knowledge of that isn't great because obviously I don't need to know; but certainly if they can prevent it, HIV coming in the baby, then it should be mandatory. There's nothing else for me to say.*

Other women in the study however were equally as firm in their conviction that mandatory testing was unacceptable. In discussing mandatory prenatal HIV testing, "Bobbie" talks of women losing autonomy over their bodies once pregnant:

> *You're saying to a woman, "Well, now your body's not your own. We're going to screen you regardless of whether you like it or not." **There's no equivalent situation.***

Later in the interview she talks again of the need to leave decision making where it belongs with the pregnant women herself, suggesting that even a recommendation to accept testing removes women's autonomy:

> *I think it's unreasonable to force **anybody** to be tested for **anything**, even though there are treatment options, though there are options of prevention of transmission. I think that there are – you can't force a woman not to drink in pregnancy, you can't force a woman not to smoke in pregnancy, or do drugs in pregnancy. How can you force her, how can you force anybody to make decisions? You can't take decisions away from a person when it comes to their own body and their own health. I think it has to be offered appropriately and in a partnership mentality. Not in, "This is my recommendation to you." I think it's paternalistic to offer it that way and it's definitely paternalistic to **insist** on screening somebody.*

And "Marion" speaks sensitively of the unfairness in making a pregnant woman undergo an HIV test with little support infrastructure in place:

> *I totally disagree. I disagree with mandatory testing unless you can guarantee that your physicians are going to do a proper counselling job. And that we have the proper supports in place, for **everyone**, and that we don't have any discrimination any more against people who are HIV positive. As long as we don't have those, it can't be a mandatory test. For the health of the baby, it would be nice if it was mandatory, but there's no point in doing that if the mother then carries the baby to term with an undue amount of stress and lack of support and family breakdown. There are huge things there. Again, that's why it troubles me that the test is offered during pregnancy. It puts a tremendous amount of pressure on the pregnant woman, that if it does come positive, she could lose everything. Why do that while she's pregnant? That's terribly unfair. A couple or an individual should go through that kind of testing way before the pregnancy. So, I know in terms of opportune moments, that's when physicians get to see women, but I think it's a lot of stress. And therefore, if you make it mandatory, I think that's really setting people up, **really setting them up.***

The majority of the women however were in favour of an offer of an HIV test that was made to women as a standard component of her prenatal care. An offer that was fully discussed with them and to which they needed to actively consent. The importance of having the opportunity to agree to the test, to having the knowledge that they themselves had played a full part in decisions about their prenatal care was emphasised by many of the women. As "Carole" explains:

I don't like to be told what to do, I like to have choices. And I'd like to know it was my decision, to know that I have a healthy baby, that I'm doing anything I can to have a healthy baby . . . To agree, yeah, like a choice. Give me the information and I - I like to be able to decide. It is my baby, it is my body, and, um, I'd like to be in charge of that. I just think it's really empowering for moms to think of their priorities and make those healthy decisions on their own, instead of being forced to do it. Not everybody is able to make those kinds of decisions on their own. But I really feel that they need power enough to know, like give them what they need to know. Having the information is really important.

"Tammy" summarised the sentiments of many of the pregnant women on the issue of a routine test which may or not require counselling and informed consent to complete:

I think you should be offered to agree to it or not. Because if the doctor just does it routinely he's not really going to explain it to you from my experience. He's just going to do it because that's his routine, that's how he was trained or whatever. He's going to do it with his routine of what he knows. But if it's a matter of you asking the person you want to do the test or not, then they'll explain the consequences, they'll explain the different treatments if you have it, they'll give you more information. And if he just does it through the procedure, he won't really explain anything. That's what I've experienced. But like if they ask you and you say, "No," he'll probably say, "Why not?" And then you know there'll be a conversation when he'll find out your reasons and then he'll explain to you. Yeah! So that's what I think!

WHAT Should the Experience of Prenatal HIV Counselling and Testing Comprise?

Components of the Pre-test Session

In describing how the HIV test was offered to them, it was abundantly clear that, almost without exception, the pregnant women wanted more information than they had been given at the time of the offer of the test. I was able to ask at this point what sort of information they would have liked to have. In essence, what should pre-test counselling comprise?

The topics mentioned by the women were mostly those absent from their own discussions and which, on refection, they felt they would have liked to have known about before accepting or declining the offer to test. "Claire" succinctly summarises what most of the pregnant women suggested:

> *Um, they should tell you what they're testing you for; why they're testing you for that; and if you have an option for getting tested, then you could check in like a little box if you wanted to be tested for that particular thing.*

Specifically, the topics raised by the women as essential to allowing an informed decision regarding testing included:

- the reasons for taking the test in the prenatal context – early diagnosis and treatment for the mother, prophylaxis for reduction of risk to foetus and child;
- emphasis on the universality of the test offer and that no fee is charged;
- the nature of the test – what's involved, the timing of the test – including discussion of the window period, discussion of the range of testing options;
- when and how the results will be discussed and offer of support while waiting for results; and
- an offer to know the implications of a positive test result.

This last component was based on the divergent views held by the pregnant women on whether the consequences of a positive result should be told in this session before the test is completed and in advance of a positive result. The

divergence of views on this topic suggests the necessity of including this as an option and thereby specifically addressing preparation for a positive HIV test result to the individual needs of each pregnant woman.

For example, "Kathy" has an impressive knowledge of HIV transmission and infection, and was very clear that the consequences of a positive result have no place in the pre-test session:

> *No! Don't talk to them about a positive result* ***before*** *they get the results back, because they're just going to stress themselves out. Because like, with all this information, they're like, "What, am I positive? Okay, what's going on, blah, blah, blah?" and with their nerves breaking out. And they're marking on their calendar for the two weeks to be up, so they can go to their doctor for the results. And it's just bad. It's awful.* ***You wait,*** *and then get the results, and* ***then talk about it****. So you know, "You're not [positive] - okay, this is what you can do." Or. "You are [positive], so this is what you can do - make a decision, whatever" . . . Before [the test] like just basically, if you are HIV positive, that there is medication to help it for you and the baby. Don't get into* ***detail****. Just leave it short and simple. If it comes out positive, then you ought to go into detail with them – well, obviously!*

Similarly, "Lisa", who had considerable concerns going into her own HIV test because of her partner's behaviour which had potentially placed them both at high risk of HIV, was not told about or offered the opportunity to discuss the consequences and implications of a positive test. She however was quite comfortable with that, preferring to deal with it if and when she had to:

> *[I didn't need more information], not really. Because we would have been able to talk about it afterwards, if there would have been anything wrong. I didn't really need to know that much ahead of time. Just if anything does end up showing up then it's better to talk about it then. But why would you need to know all about it, if you're not going to need the stuff anyways? You know?*

"Amanda", like "Lisa", also preferred to think about a positive result only if it happened. However, she recognised that there would be other women who would want more information:

For me? I just wanted it [the HIV test] over with and think about when it happens. There's probably a fair number of people like that and a fair number of people who want to know everything right away. So, a range of options - Like, depending on what the woman wants. They just say, "Do you want to know what's going to happen if - ?" And if they say, "No," "Okay, we'll tell you if we need to."

"Nancy", a 22 year-old higher-risk woman, is one of those women alluded to by "Amanda" who wanted to know more about the implications of a positive result at the time of agreeing to take the test. "Nancy's" partner is a man living with HIV and she has always disclosed his HIV status to her health care providers. Having had an "unbearable" experience in the Emergency Department of the local hospital where she was encouraged to have an abortion in the absence of a HIV test, "Nancy" was subsequently told by a friend about a family physician who would be more able to help her. This physician was able to discuss the offer of an HIV test in her pregnancy in a more balanced way and was able to talk to her about treatment for herself if necessary and for her baby to reduce transmission. Reflecting with me on the two experiences, "Nancy" consolidated her feelings into recommendations for other pregnant women:

"Nancy" *Um, yeah, they need to know more about it. The doctors need to give them the information before they find out the test results. About how they can treat the baby and how they can treat the mother and tell them that there is a good chance, 'cause there is a good chance of the baby not catching it. It puts the person more at ease, than not knowing that. Like they know if it comes back positive, they know, hey, the baby, the baby takes the medication, and stuff is okay, things would be, there's more of a chance that things would be okay. It's better to explain the different options when you're doing, when you give them the test, explaining those options to them.*

Lynne *So even before the results come back.*

"Nancy" *Yeah. So they know. So then when they're waiting for three weeks wondering, "Well, what would happen if the baby catches it and stuff?" Because nowadays, in this world, there are so many negative people that if you don't know that stuff, it's kind of hard to talk about it. 'Cause you don't know what type of answer you're gonna get from people and it's too hard to talk to family about it and stuff. So I found it easier for me knowing that there is an outlook for me and the baby, if it is positive, there's an outlook and*

> *ways of helping me and know that there's a good chance that the baby would be fine. I found that helped me out a lot knowing that. 'Cause it didn't put as much stress on me. It didn't worry me as much as it did not knowing what they can do and what chances that things are gonna help, so...*

Sadly, "Nancy's" reflections on the optimal way of helping women prepare for a positive result did not play out in the experience of "Sarah", the only woman who took part in the interviews and who did receive a positive test result:

> *And when she saw how upset I was when she gave me the positive results, that's when she told me about the medication . . . [it would have helped to have known about that beforehand] because I wouldn't have been so upset . . . **Oh yeah, because I didn't know**. Like most people are naïve. Like, they think, oh it's gonna happen to someone else, not me.*

Support While Waiting for Results

For many women, waiting for the results of their HIV tests was a time of acute stress and anxiety, not always related to their perception of their risk of receiving a positive result. In order to respond to this difficult waiting time, several women talked about the necessity to provide some support until they saw their health care provider again for their results. "Sally" suggests the offer of a counsellor:

> *[Doctors should say], "Would you like a counsellor during this process, or would you like to wait until afterwards?" And if they say, "Oh, well I'd like [to wait] until afterwards," there you go. If they don't want it, then it shouldn't be given to them because it makes it more frustrating.*

Universality and Importance of PHCT Must be Emphasised

Many of the women in the study were very aware that introducing an HIV test in the context of regular prenatal care and in the absence of little general awareness of the rationale behind the offer was a sensitive issue as "Kathy" bluntly explains:

> *You need to explain it to them. Yeah, it is [difficult]. Because you could have somebody pissed off at you. Because they could think, "What, you think I'm a drug addict, that I'm positive?" Because they just think automatically when it comes to HIV, people think of drug addicts and prostitutes and gays. When the most people with HIV now is women - that's a high number.*

In the context of acknowledged limited awareness, "Linda" takes up the importance and necessity of explaining the universality of the offer to test for HIV:

> *I do think it should be offered to everybody. But I think it has to be explained. Yes, and I think it should be made clear to them that everyone is offered the test, um, so that people don't feel stigmatised and they don't feel - because again, people, friends of mine who have had children four or five years ago who were offered the test sort of would take them aback and say, "Well, do I look like I need the test?" like, "Well, why would you be asking me?" kind of thing. So if you're not informed, I assume people, a lot of people, would react like that. So, I think it should be made clear to people, that everyone's offered the test. "And this is why we are doing it, and here are the risks, and here's..." Even give stats on HIV and say, "You know, you may not think that you might be at risk but, you know..."*

Health Care Providers Need to Reassure Pregnant Women that Standard of Care Will Remain the Same Whether or Not They are Tested

Many women alluded to future implications for their prenatal care if they declined the offer to test. For some women the concern was the interpretation of their reasons for refusal as "Fatimah" explains:

> *I guess because I didn't want to cause any problems. I didn't want to like, fight her on it and you know, if she thought it was very important, I didn't want to say, "No, I'm not having it. I refuse on moral grounds." I didn't know what to say, other than say, I don't want to have the test. But I knew that I was negative, so I was saying, what's the big deal, I'm gonna have it. I guess somehow in my mind I'm thinking, just by having the test, I'm confirming that there could be a risk that I have it. But then I thought, but if I don't have the test, she's gonna wonder the whole time, why didn't she have the test and they're gonna, you know, think about why didn't I want to have the test. So I just decided to have it.*

While for other women the concern was for the continuance of their prenatal care if they did not take up their health care provider's suggestion to test for HIV in their pregnancy, as "Linda" explains:

> *It very clearly wasn't a huge deal for her. She was sort of doing it because she felt like she was supposed to. Because after I turned her down she said, "Well, you know, I don't feel - some doctors feel that everyone should be tested, but I don't see that as all that necessary." And so after I had sort of* [LAUGHS] *blown my top, she very much put me at ease with*

that and she really made it clear to me that this wasn't going to affect how she was going to treat me, or that she was going to worry around me or anything like that...I sometimes worry that if you turn doctors down for stuff that they feel is very important they, you know - I mean I want her to trust my judgement as well. I mean, I trust her judgement but she has to know that somewhere inside me I must have whatever brain I had before I was pregnant so...

"Christine" describes the positive affect she experienced on being reassured by her health care provider that the care she would receive could not be affected by any treatment decisions she took:

Yeah, because she told me, different kind of decision you can take. If you refuse something it cannot change anything, the way the treatment going. She told me that. She say, "You are free to say yes when they ask you to do some test. If you say no, you are free, but you cannot change the way you are my patient." I say, "Thank you."... It made me feel that I am an adult. I can take decisions. I can, because, if someone just pushing you, it's like you are a kid. You don't know anything. Now, this one is indirectly pushing you. But if you feel like making decision for yourself and you're big, you are already powered to do that.

CHAPTER FIVE

SUMMARY AND DISCUSSION OF MAJOR FINDINGS

This final chapter discusses the main findings of the study and the resulting implications for PHCT policy re-evaluation and re-development. The chapter begins with an assessment of the study limitations within which the findings can be considered. The strategies of triangulation and transferability applied to enhance the validity and credibility of the findings are described. Methodologic and empirical conclusions are discussed. The final section of this chapter speaks to the fundamental objective in carrying out this research, namely that advancements in prenatal HIV testing policy are enabled through the integration of the perspectives and recommendations of the experts in prenatal HIV counselling and testing, the pregnant women themselves. This section therefore focuses on specific recommendations for policy and programme development derived directly from the analysis of the experiences of the pregnant women and their own perspectives on best practices in HIV counselling and testing in the prenatal context. In this way, this research can claim to be for women instead of simply research about women.

Study Limitations

The practice of research involves making positive choices to work in a particular way, to use a particular method, to follow a specific interpretative path. Such choices however, also point to roads not travelled, investigations not undertaken, data not collected. The imperatives of choice-making always point to the limitations of every research project. The identification of limitations enables us to grasp an understanding of the context of the research. It is for this reason that I begin this section of the thesis with a discussion of its limitations.

From the perspective of the application of Ontario's prenatal HIV testing policy, it is possible that the reported uptake of the prenatal HIV test, and the offer of the test itself, are overrepresentations. Although the majority of the women reported that they had been

offered a test and that testing had been carried out, it is possible that not all women were in fact offered a test or were tested. O'Campo and colleagues[301] reported that less than half of the pregnant women (42%) in their study had their self-reports of previous HIV testing at the hospital confirmed through comparison with data maintained in the hospital's centralised hospital laboratory database. In explaining the high rate of discrepancies, the investigators suggest that some pregnant women may have assumed that they were being tested for HIV as part of routine prenatal blood work when in fact they were not. It is probable that this situation may apply to the pregnant women in this study thereby inflating the reported rate of prenatal HIV test acceptance. In fact, in one recent case of perinatal HIV transmission in Ontario, the woman was under the impression that she had indeed agreed to prenatal HIV testing, and that the test was carried out. Subsequent review, after the birth of her child later confirmed to be living with HIV, revealed that in fact the test had not been carried out.[69]

It is possible, although perhaps not probable, that the women's responses were subject to social desirability bias. As no illegal or embarrassing situation was involved in the context of a confidential and anonymous interview with an interviewer unconnected with their care in any way, and as there were no sanctions for "incorrect" answering, social desirability bias is likely to be minimal. However, the deep-rooted drive to demonstrate the behaviour of a good mother may have carried over into the interview situation.

Other factors known to impact information collection such as misunderstanding of any questions, minimal engagement of the participant or being under the influence of alcohol or drugs were minimised in this study by the expertise of the interviewer and by the exclusion from the study of any pregnant woman unable to give informed consent due to alcohol or drug use.

However, it is quite probable that the class and language differences among the pregnant women have influenced the way in which they spoke about their experiences, the depth of their reflective self-analysis and their familiarity with technical and medical vocabulary. It may well be therefore that reported differences, for example in the

information they were given about HIV screening in pregnancy, may be due to these verbal presentation differences in the interview rather than actual differences in experiences.

The sharp policy focus on evaluating the application of Ontario PHCT policy, and the implementation of established principles of HIV counselling and testing in the prenatal context in order to formulate grounded concrete policy recommendations, has of necessity resulted in less attention on other aspects of the pregnant women's experience of prenatal HIV counselling and testing. Similarly, my decision to use semi-structured interviews to focus on certain discrete aspects of the HIV counselling and testing process, although driven by the results of the pilot to this larger study, may also have constrained the focus of the investigation.

Enhancement Strategies

Strategies were used to enhance the validity and credibility of the findings from this study. Triangulation is a process whereby the researcher can guard against the accusation that study findings are simply an artefact of a single source by checking findings against other sources and other perspectives. The purpose of triangulation is to make use of multiple data sources, investigators, methods or theory to the extent possible to provide corroborating evidence.[264]

Triangulation of Data Sources

In this study, triangulation of data sources was achieved by using purposeful sampling to engage a diverse sample and multiple referral sites in that pregnant women were recruited into the study by a number of different means, in a number of different venues, in a number of different cities at a number of different time periods. In addition, analyst triangulation was achieved by more than one experienced qualitative researcher analysing the data within and between study sites to enhance the quality and credibility of the data by reducing systematic bias. Credibility of the findings was further enhanced by a

convenience sample of three participants reviewing the findings to confirm their consistency with their own experience.[302]

Methods Triangulation

In terms of methods triangulation, it was possible to analyse the findings from my own study in the context of a study by Guenter and colleagues[303] examining the practices and attitudes of Ontario family physicians, obstetricians and midwives in prenatal HIV counselling and testing which took place at the same time as my own study. This analysis revealed substantial congruity between the reported practices and attitudes of the 622 family physicians, obstetricians and midwives participating in the study by Guenter and colleagues and the reported HIV counselling and testing experiences of the pregnant women in my study. For example, many pregnant women in my study experienced the offer to test as less than voluntary and did not feel that the choice to be tested was theirs to make. This finding is supported by data from the quantitative study in which nearly a quarter (22%) of all providers surveyed were not adhering to the provincial policy in always explaining to women that the HIV test is optional, and by the fact that one third (34%) of all providers did not believe that pregnant women in any case should have a choice in whether to be tested for HIV.

As described, many of the pregnant women in this study went along with prenatal HIV testing in the absence of any meaningful pre-test discussion concerning the risks and benefits of testing, thus precluding their ability to give informed consent. The women's perceptions of this lack of pre-test information is mirrored in the findings from the quantitative study which revealed that just over one-third (37%) of all providers surveyed did not always counsel their prenatal patients on the reasons, risks and benefits of HIV testing, two-thirds (69%) did not always provide education about HIV transmission, and the majority (89%) did not always give pregnant women written information about the HIV test. Most significantly, 24% of providers did not in any case agree that HIV testing should include special counselling about the test.

Transferability

Rather than the positivist criteria of generalisability most commonly used in quantitative research to assess the extent to which results could be extended to a population or to phenomena across time and place, the post-positivist concept of transferability is more commonly used as a criterion in qualitative research. Transferability refers to the extent to which findings from this study hold up in other settings or situations.[304] A review of the prenatal screening literature in general, and the prenatal HIV test literature in particular, addressing pregnant women's attitudes and behaviours towards prenatal testing does indeed suggest that the findings from this study do hold up in other settings or situations.[305-324] In particular, the concepts of accepting testing for the sake of the baby and accepting testing without adequate information to give informed consent were dominant.

For example, in the Ontario context of prenatal screening, Carroll and colleagues explored the ideas, opinions, feelings and experiences of women regarding prenatal genetic screening and maternal serum screening (MSS) in particular.[305] A strong need for reassurance as a motivation for having prenatal genetic screening and the overriding theme that women wanted informed choice are some of the areas of convergence with the findings of this study. In the Ontario context of prenatal HIV counselling and testing, Tharao and colleagues examined this issue among 29 black women and women of colour in Toronto.[306] Their results bear considerable similarities to those emanating from this study. Most women did not receive the necessary information or counselling to permit informed decisions and most had limited information on HIV transmission, testing and treatment. Women accepted the test because of their doctor's recommendations or insistence; for the sake of the baby; and because they were told that something could be done (but not what) to save the baby.

In the Canadian context, findings from the qualitative work of Katz have particular relevance, demonstrating a great degree of congruency with the findings of this study.[325] Although the 32 women in her study of women's experiences of PHCT, all of whom had been offered screening, were quite different from those in this study as they were

predominately white, middle class and well educated women, the main theme of foetal supremacy identified in this study was also the overriding theme in her study. As Katz describes, the central concept in her study is that women readily agree to have an HIV test because they want what is best for their babies and want to be seen to be doing what is best. However, as in this study, this is accomplished without realising the impact of an HIV diagnosis on their own lives.

Methodologic Conclusions

Qualitative research has been described as a process of "researching the parts other methods cannot reach"[326]. Qualitative methods were particularly suited to this exploratory study as relatively little is known about women's experiences of the PHCT process and even less of their perspectives on PHCT best practices. The use of qualitative methods also enabled me to conceptualise and carry out the interview as an interviewee-led discussion and conversation thus allowing issues relating to the women's experience and ideas relating to their perspectives to emerge which had not previously been identified.

Qualitative methods emphasise context as part of the phenomenon under study.[287] This was of particular relevance in the domain in which this study was undertaken where HIV risk-taking behaviour, and health-seeking behaviours need to be situated in the context of the meanings participants themselves have ascribed to this behaviour. For instance, through utilisation of qualitative methodologies in this study, it is clear that when pregnant women did not accept HIV testing in their pregnancies they acted for reasons that made sense in their lives. They did not irrationally refuse, they thoughtfully declined.

Empirical Conclusions

How are we to hear the voices of the women who have spoken in this thesis? At first, perhaps, we hear what is different in each voice, how unique each woman's narrative of pregnancy is. We are struck by the diversity of the experiences and the interpretations of these experiences which women offer up to us. This is not surprising. The women with

whom I worked on this project reflect a great diversity of social and economic locations. They differ in their experiences of class, culture, ethnicity, and exposure to different kinds of risk of which HIV infection is only one of many. The risk of the consequences of poverty, loneliness and abandonment haunts the stories of many of these pregnant women. However, alongside the diversity of stories we can hear the refrains of what the women have in common: their pregnancy, their anxiety surrounding their expected baby, their desire to be good mothers, their sharp, expert reflections on HIV counselling and testing and their willingness to speak about difficult things.

What the women most commonly speak about is the stress and anxiety generally experienced in their pregnancy and made, in many cases, more emotionally destabilizing by the shock and surprise they suffered when they discovered that they were pregnant. We hear some women speak of their conflicting and ambiguous responses to this discovery: how they knew, through a process of self-reflection, that they were pregnant, but still experienced shock and fear when their pregnancy was medically confirmed. Pregnancy was, for most of the women whose stories we hear, a turbulent time of strong emotions made stronger for some by their social relations and their material conditions. For some, the father of the expected baby has disappeared from their lives and for others what is overwhelming is the desperate loneliness and poverty of their existence: "no money, no job" and living in a women's shelter. In all this turmoil, the women speak of their determination to be "good mothers", to do everything they could "for the baby". Their baby's needs are more important than their own. "I can care about another spirit more than I can care about myself" one woman says, while another reminds us that the dreaded opposite of the "good mother" is the "bad mother", a dread which haunts so many women. It is into these experiences of fear and uncertainty generated by their pregnancy that the women are faced with HIV testing.

The HIV testing process with which the women were confronted increased, for most of them, the stresses they were already experiencing in their pregnancy. Was the official policy requirement of informed consent upheld in the practice of pre-test counselling through the provision of relevant information and with sensitivity to the temptations of

exerting pressure to test within a professional interpretation of the best interests of the patient? Some women speak of an experience which reflected all of the requirements of informed consent, women whose health care provider practiced with respect for the patient, who possessed the interpersonal skills though which respect was communicated and who saw the pregnant woman as engaged in a joint enterprise of health care with the professional. However, this is not the dominant story which is expressed through these women's voices. Many women paint a different picture of what they experienced in the HIV testing and counselling process. These women speak of lack of information, of a pressure to test, of an ambiguity concerning their right to decide against being tested. Many women speak, in effect, of being unable to resist the subtle pressure to accept, without much questioning, the perceived wishes of the health care provider. Their stories about what happened before the test show, perhaps, a pattern of general compliance to the professional authority and knowledge of the health care provider, a compliance which is strongly linked to wanting to be, and be seen as, a good, responsible mother.

Wanting to be a "good mother", giving priority to the baby, a powerful emotional drive during pregnancy, is now re-enforced in the encounter with the prenatal care system of blood work and counselling. We hear many women speak approvingly of their health care provider's emphasis on "what's good for the baby" and so accept, in effect, that their own needs as women must be subordinated to the more important needs of their babies. The women's support or compliance to this internalised discourse of foetal supremacy is hardly surprising. It is a discourse matched by a taken-for-granted set of wider patriarchal beliefs that being a "good mother" involves a relatively uncomplicated set of feelings, practices and instincts uncontaminated by the mother's own needs and rights. We hear in the women's voices one barrier to fully achieving the principle that in offering voluntary HIV testing the needs of the woman and her baby should be given equal priority.

Central to the women's narratives was the concept of 'foetal supremacy'. The connecting theme running through the description of their own pregnancy behaviours and apparent in all the components of the HIV counselling and testing process was the foregrounding of the foetus. Pregnant women described in many different ways how their thinking, feeling

and behaviours were directly a consequence of the responsibility they felt for an "innocent" child. The women described in detail the enormous changes they made in their lives to ensure the health of the baby they were carrying and how this was grounded in their desire to be a "good mother". These understandings carried over into accepting HIV testing in pregnancy for the sake of the baby. Their own concerns as women were secondary.

This theme was not only evident in the perspectives of the pregnant women as consumers of the HIV test, but also in how women describe the practices of the providers of the test. Despite the policy requirement that the balance in the pre-test session should be evenly placed between risks and benefits for the woman and her baby, the test was all too frequently presented as a test for the sole benefit of the baby. An overriding desire to prevent perinatal HIV transmission not balanced by an equal desire to identify and treat HIV infection in the woman herself led to less than optimal practices in HIV counselling and testing. The pre-test counselling session was reported to be often absent and often only limited to a comment that the test was not a required test. Women talked about frequently being made to feel they had no choice in undergoing HIV testing if they were to be "good mothers". This lack of choice was constructed either explicitly from the information given by their health care providers or the way in which their health care providers presented the test. In addition to this perceived external pressure, the pregnant women described internal pressures to accept. The pregnant woman's own sense of responsibility towards her child was manifested in the perceived primacy of the baby's needs over her own and her guilt should she decline. This emphasis was magnified by a lack of information on prenatal HIV prevention treatments and left many of them with no option but to accept testing.

In a foot note on the first page of thesis I stated that I would be using the term perinatal HIV transmission as this is the term used in Canadian HIV/AIDS surveillance. I also explained that the more usual term in use world-wide is MTCT or mother-to-child-transmission. Rosenfield and Figdor[329] in a recent article considering the international impact of MTCT pose the question, "Where is the M in MTCT?" In an attempt to adjust

the balance between concern for the potential of HIV transmission to the foetus with concern for actual HIV infection in the woman herself, the policy and programme implications from the women's perspectives on best practices are described next. The most effective way to prevent perinatal HIV transmission is of course to prevent HIV infection among women. As Bassett so eloquently states [330],

> *If we take care of women, we will take care of mothers. If we take care of mothers we will take care of infants.*

Enactment through policy re-development of the women's perspectives on best practices may work towards improving HIV testing for women, including in the prenatal context; and in taking care of women, and women who are mothers, we will act to reduce perinatal HIV transmission.

Policy Implications

Timing of the Offer to Test for HIV

Specific policy formulation and enactment directed towards providing HIV counselling and offering HIV testing to women in the prenatal context works to construct the higher emphasis on the HIV prevention needs of mothers rather than of women. Promoting the offer of an HIV test in pregnancy can interrupt the transmission of a fatal disease to someone not able to protect themselves against transmission. However, emphasising an HIV test in pregnancy has severe consequences for women and limits a woman's options, as argued by the women in the study.

It has been reported that among women undergoing prenatal genetic testing, maternal-foetal bonding can be demonstrated at 10 weeks gestation.[327] Such early bonding clearly compounds a pregnant woman's difficulties in deciding whether to continue with a pregnancy in the light of her own newly diagnosed HIV infection. In addition it may well contribute to behaviour in which the needs of the baby are privileged over the women's own, resulting in considering only the needs of the baby in undergoing prenatal HIV testing. Promoting HIV testing in the prenatal context also limits women's choices over their own health care. Specifically, any woman who is diagnosed HIV-positive in her

pregnancy has lost the ability to choose not to become pregnant in the first place. Any woman diagnosed later than 14 weeks in her pregnancy would be precluded from following the full PACT 076 protocol and faces heightened risks in terminating her pregnancy should this be her choice.[63]

The pregnant women in this study gave consideration to the issue of timing, to when HIV counselling and testing should be presented to women. The general consensus was that pregnancy was not the most appropriate time to raise with women the issue of HIV infection or to offer testing. The sentiment of the majority was that HIV counselling and testing should be initiated before conception if possible.

The Guidelines suggest that HIV testing should be offered routinely at visits for pap tests and consultations about contraception or STDs. Similarly, the Ontario policy requires the offer of an HIV test not only to pregnant women but also to those women planning a pregnancy. From the perspectives of the pregnant women participating in this study it is clear that these recommendations need stronger promotion and enactment. Pre-conception testing maximises a woman's choice and precludes her from having to make life-altering decisions after the fact, as we have heard pregnant women in the study describe. Placing discussions around HIV in general and offering HIV testing in particular in the wider sexual health context firmly places the focus of concern initially on the woman herself and not solely on her role as a reproductive being.

Presentation of the Offer to Test for HIV

It was the experience of the majority of the pregnant women in this study that any mention of the HIV test was generally "lumped in" with other screening tests regularly performed in pregnancy, but tests which do not impart or reveal significant, incurable and fatal infection in the pregnant woman. From the experiences of the pregnant women in this study, HIV testing was subsumed conceptually as well as procedurally under the rubric of routine prenatal screening care by their health care providers. Consequently, it was internalised as such by the pregnant women for whom the unique personal

significance and implications of the results of this test were obscured. HIV testing for women was thus largely transformed in the prenatal context from a specific diagnostic test with significant consequences for the pregnant woman testing positive to a routinised component of good, prenatal care, a component which the pregnant woman had little option but to accept.

Some of the pregnant women in this study felt very strongly that downplaying the personal significance of an HIV test was a disservice to pregnant women. Primarily based on their professional knowledge of the serious personal, social and legal consequences of an HIV-positive diagnosis, these women suggested that the HIV test needed more attention than it was currently accorded by health care professionals and that it should not be discussed in the context of other prenatal screening tests that do not involve information on maternal infection status.

Maintaining the Established Principles of HIV Counselling and Testing in the Prenatal Context

It was the experience for many pregnant women in the study that the offer of an HIV test in pregnancy does not always play out in practice to be of a voluntary non-coercive nature. Rather, the experience has the potential for regulating women's behaviour, albeit with the worthy goal of preventing the birth of HIV-infected children. Similarly, resting the ethical, legal and constitutional legitimacy of the testing programme on the requirement that health care providers obtain informed consent is in practice an inadequate safeguard for pregnant women's autonomy.

We have heard several women speak of the attraction of mandatory testing as a perinatal HIV prevention strategy. It is attractive as it embodies the fact that, uniquely in the HIV/AIDS domain, the source of infection is known in advance and the infant cannot take steps to protect herself. However, we hear from the majority of women that being empowered to make their own informed decision about prenatal HIV testing as a component of their regular prenatal care is their preferred policy option. An offer of an

HIV test with the recommendation that it is accepted and in the absence of pre-test counselling falls far short of what women want and what they are entitled to under the established principles of HIV counselling and testing. The UNAIDS Policy on HIV Testing and Counselling addresses this issue and makes the explicit recommendation that

> *[r]egardless of the presence of risk factors or the potential for effective intervention to prevent transmission, women should not be coerced into testing, or tested without consent. Instead they should be given all relevant information and allowed to make their own decisions about HIV testing, reproduction and infant feeding.*[328]

Aligned with the concept of the voluntary nature of the HIV test and the concept of choice is the requirement for informed consent before the test can take place. Among the pregnant women in this study who were offered testing in their pregnancy, some pregnant women reported that they had not in fact given their consent to be tested or were not aware if they had been tested for HIV as the nature of their blood work had not been explained to them. A critical review of the medical, legal and ethical evidence reveals no support for the notion that removing the informed consent requirement in an HIV testing programme for pregnant women will achieve higher rates of uptake than a fully implemented voluntary programme that respects informed consent requirements.[63]

It is clear, from the experiences of the pregnant women in this study, that the re-development of provincial policy guidelines for health care professionals providing prenatal care to assist them in upholding the established Canadian principles of HIV testing relating to the voluntary nature of the HIV test is indicated. A particular emphasis in the Guidelines to support health care providers in always obtaining informed consent and ensuring that the decision to test for HIV in pregnancy remains the woman's choice is indicated. As well as providing an optimal experience for the pregnant women in their care, enactment of such guidelines may well be vital for health care providers' own professional continuance as Stoltz explains below.

Although the Guidelines were not developed to represent a standard of care for HIV testing, it has been reasonably argued that they do represent a standard against which a physician's conduct could be measured by a Canadian court in establishing whether or

not the physician has been negligent. In her extensive review of the subject, Stoltz[63] warns that *"informed consent is not considered a frill by the Canadian courts, to be abandoned because it is perceived as too burdensome by physicians."* With specific reference to HIV testing in pregnancy, Stoltz concludes that

> *[g]iven the relevant jurisprudence, together with the seriousness of the consequences of HIV testing for persons so tested, there is little question that a physician who conducts an HIV test on a patient without meeting the basic elements of the doctrine of informed consent as prescribed in detail in the CMA Guidelines would be vulnerable to both a civil action for damages, as well as prosecution for professional misconduct by his or her licensing body for a failure to meet the adequate standards of practice.*[63]

A requirement to include in the medical record the written acknowledgement by the pregnant woman that she has received information about HIV transmission and prevention appropriate to her needs, has had the opportunity to ask any questions that she may have had, and has been offered an HIV test and has either declined testing, or has given her informed consent to test for HIV, may possibly resolve the unsatisfactory situation where some of the pregnant women interviewed in this study were not sure whether or not they had been tested. In addition it would serve as an opportunity for those women intending to be tested to ensure that these intentions are noted and thus prevent other mothers learning through the birth of their child with HIV that the HIV test to which she thought she had consented had not in fact been carried out.

Many pregnant women in the study alluded to future implications for their prenatal care if they declined the offer of an HIV test. For some women the concern was their health care provider's interpretation of their reasons for refusal, while for others the concern was for the continuance of their prenatal care if they did not take up their health care provider's suggestion to test for HIV in their pregnancy. These perceptions of the consequences of declining the test need to be dispelled by the health care provider at the time the offer to test is made. Pregnant women need to receive an assurance that the standard of care will remain the same whether or not they accept the offer of an HIV test in the prenatal context. Appendix 13 formulates the recommendations from the pregnant women into a suggested prenatal HIV counselling and testing checklist for health care providers.

Aligned to the issue of consent is the requirement for pre-test counselling in order to ensure that the consent that is given by the woman is informed consent. It is clear from the findings of this study that some pregnant women are accepting, or going along with, testing with little or no information about the reasons for, or the implications of, an HIV test for themselves, their family and their unborn children. In addition to the absence of informed pre-test counselling from their health care provider, pregnant women reported a lack of information in the popular press or the widely used standard pregnancy books. Women who had access to the Internet fared better in accessing information on HIV/AIDS in general and prenatal HIV transmission in particular. In this respect, in conjunction with the need to raise the level of awareness of all components of the HIV test and the requirements for its conduct among health care providers, similar strategies to more closely inform pregnant women and women planning a pregnancy are suggested by the women in the study.

Of particular concern is the fact that the provincial Ministry of Health and Long Term Care has produced and distributed a brochure intended for distribution by physicians to women in their practices. In view of the fact that such a very small number of pregnant women in the study reported that they had seen or had been given a copy of the brochure, distribution strategies of future brochures need to be re-evaluated in the context of a comprehensive communications plan directed to health care providers and to all Canadian women. Support for a comprehensive communications strategy for pregnant women and women planning a pregnancy is clearly indicted from the experiences of the pregnant women in this study. The communications strategy should encompass the development and comprehensive dissemination of brochures and posters, and public service announcements in the media tailored to the specific diverse needs of pregnant women and women considering pregnancy.

Appendix 12 contains a report of the suggestions made by the women in the study in terms of the content of a brochure for women and suggested distribution strategies.

Nearly all the pregnant women experienced the waiting period between the completion of the HIV test and the return of their results as a period of stress and anxiety. It was a period characterised by women thinking back over instances in their lives when they may have put themselves at risk of HIV or may have experienced risk conditions constructing high risk for HIV. The return of their results at the end of this period was often restricted to a simple statement that the woman was "fine", that the results were "fine" and that the pregnant woman had "nothing to worry about". Given the initial heightened personal awareness of HIV risk during the waiting period, and the considerable relief subsequently experienced by most women it is unfortunate that health care providers did not make more of this "teachable" moment. For many women, consultations for prenatal care may be their only occasions of access to medical care. This is likely to be the case among the most marginalised women who comprise those women at increased risk of HIV infection. The potential in post-test counselling to provide an important and unique prevention opportunity for HIV-negative women requires greater programme emphasis. Post-test counselling offers the opportunity to raise awareness of HIV risk and prevention strategies among women testing HIV-negative who may have been previously unaware. It represents an important and unique opportunity to provide pregnant women who have tested HIV-negative with the information they may need to remain HIV-negative. It also represents an opportunity for the health and safety of the pregnant woman herself to be foregrounded in a process in which these concerns are often subjugated.

Ensuring as many pregnant women as possible agree to HIV testing in the prenatal context does not reduce or prevent perinatal HIV transmission. Among prenatally diagnosed pregnant women, reduction of perinatal HIV transmission is only possible by the strict adherence by the pregnant woman to a treatment regime that may not be congruent with her own treatment needs and for which equivocal results in terms of side effects have been documented. It is essential therefore that the pregnant woman is enabled, through comprehensive and tailored pre-test counselling, to give her informed consent to undertake an HIV test, to be treated as partner in the management of her care. Sensitive and effective pre- and post-test counselling are the first steps in providing a caring experience on which pregnant women may build in order to access the most

appropriate care both for themselves and their children. Similarly, it is an important step in providing pregnant women with the opportunity to learn of HIV prevention strategies for themselves and their family. Enabling as many women as possible, through the PHCT process, to adopt and maintain HIV prevention strategies to keep themselves free from infection remains the most effective strategy to reduce perinatal HIV transmission. In this respect, the perspectives of the pregnant women in terms of the content and process of prenatal HIV counselling and testing are particularly key.

I leave it to the voice of one of the pregnant women to conclude this thesis:

If we are going to do it,
let's take the time to do it,
and let's take the time to do it right!

REFERENCES

1. Tudiver N. *Universities for Sale: Resisting Corporate Control over Canadian Higher Education.* Toronto: James Lorrimer & Company; Canadian Association of University Teachers, 1999.

2. Health Canada. *HIV and AIDS in Canada: Surveillance report to June 30, 2002.* Ottawa: Division of HIV/AIDS Epidemiology & Surveillance, Centre for Infectious Disease Prevention & Control, Health Canada, 2002.

3. Connor EM, Sperling RS, Gelber R, Kiselev P, Scott G, O'Sullivan MJ et al. Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. *New England Journal of Medicine* 1994; 331(18):1173-1180.

4. Lapointe N, Samson J, Ag Bazet A, Boucher M, Fauvel M, Tran T et al. Mother-to-child HIV transmission, treatment and circumstances of delivery. *Canadian Journal of Infectious Diseases* 1995; 6(Suppl B):23B.

5. Forbes J, Burge DR, Money D. Pregnancy outcomes in HIV infected women in British Columbia: The impact of anti-retroviral therapy on maternal-infant HIV transmission. *Canadian Journal of Infectious Diseases* 1997; 8(Suppl 1A):31A.

6. Postma MJ, Beck EJ, Mandalia S, Sherr L, Walters MDS, Houweling H et al. Universal HIV screening of pregnant women in England: cost effectiveness analysis. *British Medical Journal* 1999; 318:1656-1660.

7. Centers for Disease Control. Administration of zidovudine during late pregnancy and delivery to prevent perinatal HIV transmission - Thailand, 1996-1998. *Morbidity and Mortality Weekly Report* 1998; 47(8):151-154.

8. Dunn DT, Newell ML, Mayaux MJ, Kind C, Hutto C, Goedert JJ et al. Mode of delivery and vertical transmission of HIV-1: A review of prospective studies. *Journal of Acquired Immune Deficiency Syndromes* 1994; 7(10):1064-1066.

9. International Perinatal HIV Group. The mode of delivery and the risk of vertical transmission of human immunodeficiency virus type 1: A meta-analysis of 15 prospective cohort studies. *New England Journal of Medicine* 1999; 340(13):977-987.

10. Read J. Mode of delivery and vertical transmission of HIV-1: A meta-analysis from fifteen prospective cohort studies (The International Perinatal HIV Group) [Abstract #23275]. Geneva, Switzerland: 12th World AIDS Conference, 28 June - 3 July 1998, 1999.

11. Mayaux MJ, Teglas J-P, Mandelbrot L, Berrebi A, Gallais H, Matheron S et al. Acceptability and impact of zidovudine for prevention of mother-to-child human immunodeficiency virus-1 transmission in France. *Journal of Pediatrics* 1997; 131(6):857-862.

12. Mandelbrot L, Le Chenadec J, Berrebi A, Bongain A, Benifla JL, Delfraissy JF et al. Perinatal HIV-1 transmission: Interaction between zidovudine prophylaxis and mode of delivery in the French Perinatal Cohort. *JAMA* 1998; 280(1):55-60.

13. Ziegler JB. Antenatal screening for HIV in Australia: time to revise policies? *Medical Journal of Australia* 1999; 171:201-203.

14. Ioannidis JP, Abrams EJ, Ammann A, Bulterys M, Goedert JJ, Gray L et al. Perinatal transmission of human immunodeficiency virus type 1 by pregnant women with RNA virus loads <1000 copies/mL. *Journal of Infectious Diseases* 2001; 183:539-545.

15. Health Canada. *HIV/AIDS Epi update: HIV and AIDS Among Women in Canada.* Ottawa: Division of HIV/AIDS Epidemiology & Surveillance, Centre for Infectious Disease Prevention & Control, Health Canada, 2003.

16. Cafferkey M, Philbin M, McDonnell E, McKenna P. Screening for HIV-1 in pregnancy [Letter]. *Lancet* 1998; 351:1893-1894.

17. Meadows J, Catalan J, Gazzard B. "I plan to have the HIV test" - predictors of testing intention in women attending a London antenatal clinic. *AIDS Care* 1993; 5(2):141-148.

18. Irwin KL, Valdiserri RO, Holmberg SD. The acceptability of voluntary HIV antibody testing in the United States: A decade of lessons learned. *AIDS* 1996; 10(14):1707-1717.

19. Sorin MD, Tesoriero JM, LaChance-McCullough ML. Correlates of acceptance of HIV testing and post-test counseling in the obstetrical setting. *AIDS Education and Prevention* 1996; 8(1):72-85.

20. Lindsay MK, Adefris W, Peterson HB, Williams H, Johnson J, Klein L. Determinants of acceptance of routine voluntary human immunodeficiency virus testing in an inner-city prenatal population. *Obstetrics & Gynecology* 1991; 78(4):678-680.

21. Webber MP, Schoenbaum EE, Bonuck KA. Correlates of voluntary human immunodeficiency virus antibody testing reported by postpartum women. *JAMWA* 1997; 52(2):89-92.

22. Moatti JP, Le Gales C, Seror V, Papiernik E, Henrion R. Social acceptability of HIV screening among pregnant women. *AIDS Care* 1990; 2(3):213-222.

23. Simpson WM, Johnstone FD, Boyd FM, Goldberg DJ, Hart GJ, Prescott RJ. Uptake and acceptability of antenatal HIV testing: Randomised control trial of different methods of offering the test. *British Medical Journal* 1998; 316:262-267.

24. Carusi D, Learman LA, Posner SF. Human immunodeficiency virus test refusal in pregnancy: A challenge to voluntary testing. *Obstetrics & Gynecology* 1998; 91(4):540-545.

25. Ethier K, Fox-Tierney RA, Ickovic JR. Prenatal HIV counseling and testing: Rates and determinants among women at public health clinics [Abstract #43111]. Geneva, Switzerland: 12th World AIDS Conference, 28 June - 3 July 1998, 1999.

26. Fernandez MI, Wilson TE, Ethier KA, Walter EB, Gay CL, Moore J. Acceptance of HIV testing during prenatal care. *Public Health Reports* 2000; 115:460-468.

27. Mercey D, Helps BA, Copas A, Petruckevitch A, Johnson AM, Spencer J. Voluntary universal antenatal HIV testing. *British Journal of Obstetrics and Gynecology* 1996; 103:1129-1133.

28. Meadows J, Catalan J. Why do antenatal attenders decide to have the HIV antibody test? *International Journal of STD & AIDS* 1994; 5:400-5404.

29. Simpson WM, Johnstone FD, Hart GJ, Boyd FM, Goldberg DJ. To test or not to test? What makes pregnant women decide to take an HIV test? *Psychology, Health and Medicine* 1998; 3(3):327-335.

30. Jha S, Gee H, Coomarasamy A. Women's attitudes to HIV screening in pregnancy in an area of low prevalence. *British Journal of Obstetrics and Gynecology* 2003; 110:145-148.

31. Royce RA, Walter EB, Fernandez MI, Wilson TE, Ickovics JR, Simonds RJ. Barriers to universal prenatal HIV testing in 4 US locations in 1997. *American Journal of Public Health* 2001; 91(5):727-733.

32. Molano LF, Farley DE, Lane RD. Voluntary prenatal testing as an alternative to mandatory testing [Abstract #43147]. Geneva, Switzerland: 12th World AIDS Conference, 28 June - 3 July 1998, 1999.

33. Jones S, Sadler T, Low N, Blott M, Welch J. Does uptake of antenatal HIV testing depend on the individual midwife? Cross sectional study. *British Medical Journal* 1998; 316:272-273.

34. Gibb DM, MacDonagh SE, Gupta R, Tookey PA, Peckham CS, Ades AE. Factors affecting uptake of antenatal HIV testing in London: results of a multicentre study. *British Medical Journal* 1998; 316:259-261.

35. Cardonick E, Daly S, Elles K, Silverman NS. Determinants of antepartum human immunodeficiency virus testing in a non-Medicaid obstetric population. *Infectious Diseases in Obstetrics & Gynecology* 1998; 6:209-213.

36. Duffy TA, Wolfe CDA, Varden C, Kennedy J, Chrystie IL, Banatvala JE. Antenatal HIV testing: current problems, future solutions. Survey of uptake in one London Hospital. *British Medical Journal* 1998; 316:270-271.

37. Dobson S, Burdge D, Money D, Patrick D. Screening for HIV in pregnancy: Improvement in rates of testing in an area of low prevalence [Abstract #60596]. Geneva, Switzerland: 12th World AIDS Conference, 28 June - 3 July 1998, 1999.

38. Ruiz JD, Molitor F. Knowledge of treatment to reduce perinatal human immunodeficiency virus (HIV) transmission and likelihood of testing for HIV: Results from two surveys of women of childbearing age. *Maternal and Child Health* 1998; 2(2):117-122.

39. Meadows J, Jenkinson S, Catalan J, Gazzard B. Voluntary HIV testing in the antenatal clinic: differing uptake rates for individual counselling midwives. *AIDS Care* 1990; 2(3):229-233.

40. Fernandez MI, Wilson T, Moore J, Ethier K, Walter E. Acceptance of HIV testing among women in prenatal care in Miami, New York City, and Connecticut [Abstract #43142]. Geneva, Switzerland: 12th World AIDS Conference, 28 June - 3 July 1998, 1999.

41. Limata C, Schoen EJ, Cohen D, Black SB, Quesenberry CP. Compliance with voluntary prenatal HIV testing in a large health maintenance organization (HMO). *Journal of Acquired Immune Deficiency Syndromes* 1997; 15:126-130.

42. Keane FE, Neale J, Phillips T, Heard L, Jones R, Guttridge B et al. Offering routine antenatal testing for HIV and hepatitis B in the rural setting of Cornwall. *Sexually Transmitted Infections* 2002; 78:133-134.

43. Hunter MS, O'Dea I, Britten N. Decision-making and hormone replacement therapy: A qualitative analysis. *Social Science and Medicine* 1997; 45(10):1541-1548.

44. Cohen M. Gender issues in family medicine research. *Canadian Family Physician* 1991; 37:1399-1405.

45. Jürgens R, Palles M. *HIV Testing & Confidentiality: A Discussion Paper.* Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996.

46. Holman S. HIV counselling for women of reproductive age. *Bailliére's Clinical Obstetrics and Gynaecology* 1992; 6(1):53-68.

47. Lindgren S, Bohlin AB, Arneborn M, Ottenblad C, Lidman K, Anzén B et al. Screening for HIV-1 antibodies in pregnancy: Results from the Swedish national programme. *British Medical Journal* 1993; 307:1447-1451.

48. Goldberg DJ, Johnstone FD. HIV testing programmes in pregnancy. *Bailliére's Clinical Obstetrics and Gynaecology* 1992; 6(1):33-51.

49. Macquart-Moulin G, Harion D, Auquier P, Manuel C. Vertical transmission of HIV - a rediscussion of testing. *AIDS Care* 1995; 7(5):657-662.

50. Field MA. Testing for AIDS: Uses and abuses. *American Journal of Law and Medicine* 1990; 16(1/2):34-106.

51. Sperling RS, Shapiro DE, Coombs RW, Todd JA, Herman SA, McSherry G et al. Maternal viral load, zidovudine treatment, and the risk of transmission of human immunodeficiency virus type 1 from mother to infant. *New England Journal of Medicine* 1996; 335(22):1621-1629.

52. Fiscus SA, Admora AA, Schoenbach VJ, Wilfert CM, Johnson VA. Can zidovudine monotherapy continue to reduce perinatal HIV transmission? The North Carolina experience 1993-1997 [Abstract #33162]. Geneva, Switzerland: 12th World AIDS Conference, 28 June - 3 July 1998, 1998.

53. Kind C, Rudin C, Siegrist CA, Wyler CA, Biedermann K, Lauper U et al. Prevention of vertical HIV transmission: Additive protective effect of elective Cesarean section and zidovudine prophylaxis. *AIDS* 1998; 12(2):205-210.

54. Lindegren ML, Byers RH, Fleming PL, Thomas P, Notley P, Gwinn M, Ward J. Status of the perinatal HIV epidemic in the United States: Success in perinatal prevention [Abstract #23306]. Geneva: 12th World AIDS Conference, June 28-July 3, 1998.

55. Paul S, Cross H, Dimasi LG, Costa SJ, Beil JK, Morgan DH. Evaluation of ZDV administration to pregnant women and their children born in 1993 through 1996 in New Jersey [Abstract #23287]. Geneva, Switzerland: 12th World AIDS Conference, 28 June - 3 July 1998, 1999.

56. Dunn DT, Newell ML, Ades AE, Peckham CS. Risk of human immunodeficiency virus type 1 transmission through breast feeding. *Lancet* 1992; 340:585-588.

57. Bayer R. Editorial Review - Ethical and social policy issues raised by HIV screening: The epidemic evolves and so do the challenges. *AIDS* 1989; 3:119-124.

58. National Advisory Committee on AIDS. Human immunodeficiency virus antibody testing in Canada. Recommendations. *Canada Diseases Weekly Report* 1989; 15(8):37-43.

59. Parliamentary Ad Hoc Committee on AIDS. *Confronting a Crisis: The Report of the Parliamentary Ad Hoc Committee on AIDS.* Ottawa: The Committee, 1990.

60. Ontario Law Reform Commission. *Report on Testing for AIDS.* Toronto: The Commission, 1992.

61. Canadian Public Health Association. *HIV & AIDS: A Public Health Perspective.* Ottawa: The Association, 1993.

62. Canadian Medical Association. Counselling Guidelines for HIV Testing. Ottawa: The Association, 1995.

63. Stoltz L, Shap L. *HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate.* Ottawa: Health Canada, 1999.

64. Leonard L, Shap L. A different kind of risk? Pregnant women's experience of HIV testing in pregnancy. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 5(1):18-21.

65. Leonard L, Shap L, Pelude L, Hotz S. Pregnant women's experiences of screening for HIV in pregnancy: What they have to say about what constitutes an appropriate policy for the HIV testing of pregnant women in Canada - A Pilot Study. In: *Perinatal HIV Transmission: Study Results and Implications for Policy and Programme Development.* Ottawa: Health Canada, 1998.

66. Schabas R. *Message from the Chief Medical Officer of Health on HIV Testing for Pregnant Women,* 1995.

67. Jürgens R. Testing of pregnant women: Issues and options. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3):1,54-60.

68. Remis RS, King S, Vernich L, Vermeulen M. Preventing HIV transmission from mothers to infants in Ontario 1994 to 1996: A missed opportunity [Abstract #23288]. Geneva, Switzerland: 12th World AIDS Conference, 28 June - 3 July 1998, 1999.

69. Bitnun A, King SM, Arneson C, Read SE. Failure to prevent perinatal HIV infection. *Canadian Medical Association Journal* 2002; 166(7):904-905.

70. Walmsley S. Opt in or opt out: what is optimal for prenatal screening for HIV infection? *Canadian Medical Association Journal* 2003; 168(6):707-708.

71. Remis RS, Guenter D, King S. Testing pregnant women in Canada for HIV: How are we doing? *Canadian Family Physician* 2001; 47:2193-2195.

72. Olesen V. Feminisms and models of qualitative research. In: Denzin NK, Lincoln YS, editors. *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage Publications, 1994: 158-174.

73. Reinharz S. *Feminist Methods in Social Research.* New York: Oxford University Press, 1992.

74. Harding S. Conclusion: Epistemological questions. In: Harding S, editor. *Feminism and Methodology.* Bloomington, Indiana: Indiana University Press, 1987: 181-190.

75. Hall JM, Stevens PE. Rigor in feminist research. *Advances in Nursing Science* 1991; 13(3):16-29.

76. Bunting SM. Applying a feminist analysis model to selected nursing studies of women with HIV. *Issues in Mental Health Nursing* 1997; 18(5):523-537.

77. King KE. Method and methodology in feminist research: What is the difference? *Journal of Advanced Nursing* 1994; 20(1):19-22.

78. Ussher JM. Eclecticism and methodological pluralism: The way forward for feminist research. *Psychology of Women Quarterly* 1999; 23:41-46.

79. Russo NF. Feminist research: Questions and methods. *Psychology of Women Quarterly* 1999; 23:i-iv.

80. Crawford M, Kimmel E. Promoting methodological diversity in feminist research. *Psychology of Women Quarterly* 1999; 23:1-6.

81. Campbell JC, Bunting S. Voices and paradigms: Perspectives on critical and feminist theory in nursing. *Advances in Nursing Science* 1991; 13(3):1-15.

82. Harding S. Introduction: Is there a feminist method? In: Harding S, editor. *Feminism and methodology.* Bloomington, Indiana: Indiana University Press, 1987: 1-14.

83. Wuest J. Feminist grounded theory: An exploration of the congruency and tensions between two traditions in knowledge discovery. *Qualitative Health Research* 1995; 5(1):125-137.

84. Stacey J. Can there be a feminist ethnography? *Women's Studies International Forum* 1988; 11(1):21-27.

85. Rosser SV. Are there feminist methodologies appropriate for the natural sciences and do they make a difference? *Women's Studies International Forum* 1992; 15(5/6):535-550.

86. Klein RD. How to do what we want to do: Thought about feminist methodology. In: Bowles G, Klein RD, editors. *Theories of Women's Studies.* London: Routledge & Kegan Paul, 1983: 88-104.

87. Mies M. Toward a methodology for feminist research. In: Bowles G, Klein RD, editors. *Theories of Women's Studies.* New York: Routledge & Kegan Paul, 1983: 117-139.

88. Hartsock NC. The feminist standpoint: Developing the ground for a specifically feminist historical materialism. In: Harding S, Hintikka MB, editors. *Discovering Reality.* Holland: Reidel, 1983: 283-310.

89. McCormick KM, Bunting SM. Application of feminist theory in nursing research: The case of women and cardiovascular disease. *Health Care for Women International* 2002; 23:820-834.

90. Ehrnst A, Lindgren S, Dictor M, Johansson B, Sönnerborg A, Czajkowski J et al. HIV in pregnant women and their offspring: Evidence for late transmission. *Lancet* 1991; 338:203-207.

91. Luzuriaga K, McQuilken P, Alimenti A, Somasundaran M, Hesselton R, Sullivan JL. Early viremia and immune responses in vertical human immunodeficiency virus type 1 infection. *Journal of Infectious Disease* 1993; 167:1008-1013.

92. Martin N, Ammann AJ, editors. *Timing of transmission.* Montréal: Proceedings of the Conference on Global Strategies for the Prevention of HIV Transmission from Mothers to Infants, September, 1997.

93. Newell ML, Gray G, Bryson YJ. Prevention of mother-to-child transmission of HIV-1 infection. *AIDS* 1997; 11(Suppl A):S165-S172.

94. Martin N, Ammann AJ, editors. *Current status of breastfeeding studies on preventing HIV transmission.* Montréal: Proceedings of the Conference on Global Strategies for the Prevention of HIV Transmission from Mothers to Infants, September, 1997.

95. Fowler MG, Simonds RJ, Roongpisuthipong A. Update on perinatal HIV transmission. *Pediatric Clinics of North America* 2000; 47:21-38.

96. Bertolli J, St.Louis ME, Simonds RJ, Nieburg P, Kamenga M, Brown C et al. Estimating the timing of mother-to-child transmission of human immunodeficiency virus in a breast-feeding population in Kinshasa, Zaire. *Journal of Infectious Diseases* 1996; 174:722-726.

97. Nduati RW, John G, Mbori-Ngacha DA, Richardson BA, Overbaugh J, Mwatha AK et al. Effect of breastfeeding and formula feeding on transmission of HIV-1: A randomized clinical trial. *JAMA* 2000; 283(9):1167-1174.

98. Mofenson LM, Lambert JS, Stiehm ER, Bethel J, Meyer WA, Whitehouse J et al. Risk factors for perinatal transmission of human immunodeficiency virus type 1 in women treated with zidovudine. *New England Journal of Medicine* 1999; 341(6):385-393.

99. Garcia PM, Kalish LA, Pitt J, Minkoff HL, Quinn TC, Burchett SK et al. Maternal levels of plasma human immunodeficiency virus type 1 RNA and the risk of perinatal transmission. *New England Journal of Medicine* 1999; 341(6):394-402.

100. Shaffer N, Roongpisuthipong A, Siriwasin W, Chotpitayasunondh T, Chearskul S, Young NL et al. Maternal virus load and perinatal human immunodeficiency virus type 1 subtype E transmission, Thailand. *Journal of Infectious Diseases* 1999; 179:590-599.

101. John GC, Nduati RW, Mbori-Ngacha DA, Richardson BA, Panteleeff D, Mwatha AK et al. Correlates of mother-to-child human immunodeficiency virus type 1 (HIV-1) transmission: Association with maternal plasma HIV-1 RNA load, genital HIV-1 DNA shedding, and breast infections. *Journal of Infectious Diseases* 2001; 183:206-212.

102. Simonds RJ, Steketee RW, Nesheim S, Matheson P, Palumbo P, Alger L et al. Impact of zidvudine use on risk and risk factors for perinatal transmission of HIV. *AIDS* 1998; 12(3):301-308.

103. Landesman S, Kalish LA, Burns DN, Minkoff HL, Fox HE, Zorrilla C et al. Obstetrical factors and the transmission of human immunodeficiency virus type 1 from mother to child. *New England Journal of Medicine* 1996; 334(25):1617-1623.

104. Stoto MA. Natural History, Detection, and Treatment of HIV Infection in Pregnant Women and Newborns. In: Stoto MA, Almario DA, McCormick MC, editors. *Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States.* Washington, D.C.: National Academy Press, 1999: 45-53.

105. European Mode of Delivery Collaboration. Elective caesarean-section versus vaginal delivery in prevention of vertical HIV-1 transmission: A randomised clinical trial. *Lancet* 1999; 353:1035-1039.

106. Remis RS, Vandal AC. Cost-effectiveness of universal and selective HIV screening of pregnant women in Quebec. *Canadian Journal of Infectious Diseases* 1995; 6(Suppl B):23B.

107. Shaffer N, Chuachoowong R, Mock PA, Bhadrakom C, Siriwasin W, Young NL et al. Short-course zidovudine for perinatal HIV-1 transmission in Bangkok, Thailand: A randomised controlled trial. *Lancet* 1999; 353:773-780.

108. Wiktor SZ, Epkini E, Karon J, Nkengasong J, Maurice C, Severin ST et al. Short-course oral zidovudine for prevention of mother-to-child transmission of HIV-1 in Abidjan, Côte d'Ivoire: A randomised trial. *Lancet* 1999; 353:781-785.

109. Dabis F, Msellati P, Meda N, Welffens-Ekra C, You B, Manigart O et al. 6-month efficacy, tolerance, and acceptability of a short regimen of oral zidovudine to reduce vertical transmission of HIV in breastfed children in Côte d'Ivoire and Burkina Faso: A double-blind placebo-controlled multicentre trial. *Lancet* 1999; 353:786-792.

110. Guay LA, Musoke P, Fleming T, Bagenda D, Allen M, Nakabiito C et al. Intrapartum and neonatal single-dose nevirapine compared with zidovudine for prevention of mother-to-child transmission of HIV-1 in Kampala, Uganda: HIVNET 012 randomised trial. *Lancet* 1999; 354:795-802.

111. King SM, Singer J, Forbes J. Trends in antiretroviral therapy (ART) in pregnant women in Canada. *Canadian Journal of Infectious Diseases* 2000; 11:57B.

112. Health Canada. *HIV and AIDS in Canada: Surveillance report to December 31, 2001.* Ottawa: Division of HIV/AIDS Epidemiology & Surveillance, Centre for Infectious Disease Prevention & Control, Health Canada, 2002.

113. Health Canada. *HIV/AIDS Epi update: Perinatal Transmission of HIV.* Ottawa: Division of HIV/AIDS Epidemiology & Surveillance, Centre for Infectious Disease Prevention & Control, Health Canada, 2003.

114. Remis RS, Major C, Wallace E, Schiedel L and Whittingham, E.P *Report on HIV/AIDS in Ontario: 2000.* Toronto: Ontario Ministry of Health and Long Term Care, 2001.

115. Remis RS, Major C, Wallace E, Schiedel L and Whittingham, E.P *Report on HIV/AIDS in Ontario: 1999.* Toronto: Ontario Ministry of Health and Long Term Care, 2000.

116. Health Canada. *HIV/AIDS Epi update: Prevalent HIV Infections in Canada: Up to one-third may not be diagnosed.* Ottawa: Division of HIV/AIDS Epidemiology & Surveillance, Centre for Infectious Disease Prevention & Control, Health Canada, 2003.

117. Chevalier C, Miron M, Smith J, Reid D, Tudin B. Perinatal surveillance in Canada: A situational analysis. *Canadian Journal of Infectious Diseases* 2003; 14(Suppl A):323P.

118. Remis, R. S., Swantee, C., Major, C., Wallace, E., Schriedel, L., Merid, M. F. *Report on HIV/AIDS in Ontario 2001 [Draft].* Toronto: Ontario Ministry of Health and Long Term Care, 2002.

119. Health Canada. *HIV/AIDS Epi update: HIV Infection Reporting in Canada.* Ottawa: Division of HIV/AIDS Epidemiology & Surveillance, Centre for Infectious Disease Prevention & Control, Health Canada, 2003.

120. Geduld J, Archibald C. National trends of AIDS and HIV in Canada. *Canada Communicable Disease Report* 2000; 26:193-201.

121. Doyal L. *What Makes Women Sick. Gender and the Political Economy of Health.* London: MacMillan Press; 1995.

122. Nicolosi A, Leite MLC, Musicco M, Arici C, Gavazzeni G, Lazzarin A. The efficiency of male-to-female and female-to-male sexual transmission of the human immunodeficiency virus: A study of 730 stable couples. *Epidemiology* 1994; 5(6):570-575.

123. Zierler S. Women, sex, and HIV. *Epidemiology* 1994; 5(6):565-567.

124. European Study Group on Heterosexual Transmission of HIV. Comparison of female to male and male to female transmission of HIV in 563 stable couples. *British Medical Journal* 1992; 304:809-813.

125. Padian N, Shiboski SC, Glass SO, Vittinghoff E. Heterosexual transmission of human immunodeficiency virus (HIV) in Northern California: Results from a ten-year study. *American Journal of Epidemiology* 1997; 146(4):350-357.

126. Saracco A, Musicco M, Nicolosi A, Angarano G, Arici C, Gavazzeni G, Costigliola P, Gafa S, Gervasoni B, Luzzati R, et al. Man-to-woman sexual transmission of HIV: Longitudinal study of 343 steady partners of infected men. *Journal of Acquired Immune Deficiency Syndromes* 1993; 6(5):497-502.

127. European Study Group on Heterosexual Transmission of HIV. Risk factors for male to female transmission of HIV. *British Medical Journal* 1989; 298:411-415.

128. Kaplan EH, Heimer R. A model-based estimate of HIV infectivity via needle sharing. *Journal of Acquired Immune Deficiency Syndromes* 1992; 5(11):1116-1118.

129. Nicolosi A, Leite ML, Musicco M, Molinari S, Lazzarin A. Parenteral and sexual transmission of human immunodeficiency virus in intravenous drug users: A study of seroconversion. *American Journal of Epidemiology* 1992; 135(3):225-233.

130. Patrick D, Strathdee SA, Glass SO, Vittinghoff E. Determinants of HIV seroconversion in injection drug users during a period of rising prevalence in Vancouver. *International Journal of STD & AIDS* 1997; 437-445.

131. Koester SK. Following the blood: Syringe reuse leads to blood-borne virus transmission among injection drug users. *Journal of Acquired Immune Deficiency Syndromes* 1998; 18(Suppl 1):S139-S140.

132. Vlahov D, Munoz A, Anthony JC, Cohn S, Celentano DD, Nelson KE. Association of drug injection patterns with antibody to human immunodeficiency virus type 1 among intravenous drug users in Baltimore, Maryland. *American Journal of Epidemiology* 1990; 132(5):847-856.

133. Needle RH, Coyle S, Cesari H, Trotter R, Clatts M, Koester SK, Price L, McLellan E, Finlinson A, Bluthenthal RN, et al. HIV risk behaviours associated with the injection process: Multiperson use of drug injection equipment and paraphernalia in injection drug user networks. *Substance Use & Misuse* 1998; 33(12):2403-2423.

134. Koester SK, Booth R, Wiebel W. The risk of HIV transmission from sharing water, drug mixing containers and cotton filters. *International Journal of Drug Policy* 1990; 1(6):28-30.

135. Koester SK, Booth RE, Zhang E. The prevalence of additional injection-related HIV risk behaviours among injection drug users. *Journal of Acquired Immune Deficiency Syndromes* 1996; 12:202-207.

136. Power R, Hunter GM, Jones SG, Donoghoe MC. The sharing of injecting paraphernalia among illicit drug users. *AIDS* 1994; 8(10):1509-1511.

137. Grund JP, Kaplan CD, Adriaans NF. Drug sharing and HIV transmission risks: The practice of frontloading in the Dutch injecting drug users population. *Journal of Psychoactive Drugs* 1991; 23:1-10.

138. Jose B, Friedman SR, Neaigus A, Curtis R, Grund JP, Goldstein MF, Ward TP, Des Jarlais DC. Syringe-mediated drug-sharing (backloading): A new risk factor for HIV among injecting drug users. *AIDS* 1993; 7(12):1653-1660.

139. Koester SK, Hoffer L. "Indirect sharing": additional HIV risks associated with drug injection. *AIDS Public Policy Journal* 1994; 9(2):100-105.

140. McCoy CB, Metsch LR, Chitwood DD, Shapshak P, Comerford ST. Parenteral transmission of HIV among injection drug users: Assessing the frequency of multiperson use of needles, syringes, cookers, cotton, and water. *Journal of Acquired Immune Deficiency Syndromes* 1998; 18(Suppl 1):S25-S29.

141. Hagan H, Theide H, Weiss NS, Hopkins SG, Duchin JS, Alexander ER. Sharing of drug preparation equipment as a risk factor for hepatitis C. *American Journal of Public Health* 2001; 91(1):42-46.

142. Loimer N, Werner E, Presslich O. Sharing spoons: a risk factor for HIV-1 infection in Vienna. *British Journal of Addiction* 1991; 86:775-778.

143. Nemoto T. Behavioural characteristics of seroconverted intravenous drug users. *International Journal of Addiction* 1992; 27(12):1413-1421.

144. Shah SM, Shapshak P, Rivers JE, Stewart RV, Weatherby NL, Xin KQ, Page JB, Chitwood DD, Mash DC, Vlahov D, et al. Detection of HIV-1 DNA in needles/syringes, paraphernalia, and washes from shooting galleries in Miami: A preliminary laboratory report. *Journal of Acquired Immune Deficiency Syndromes* 1996; 14(3):301-306.

145. Grund JP, Friedman SR, Stern LS, Jose B, Neaigus A, Curtis R, Des Jarlais DC. Syringe-mediated drug sharing among injecting drug users: Patterns, social context and implications for transmission of blood-borne pathogens. *Social Science & Medicine* 1996; 42(5):691-703.

146. Ross M, Wodak A, Miller M, Gold J. Sexual partner choice in injecting drug users from a "critical incident" measure: Its implications for estimating HIV spread. *Sex Reviews* 1993; 1:77-92.

147. Gollub EL, Rey D, Obadia Y, Moatti JP, Manif 2000 Study Group. Gender differences in risk behaviours among HIV+ persons with an IDU history: The link between partner characteristics and women's higher drug-sex risks. *Sexually Transmitted Diseases* 1998; 25(9):483-488.

148. Freeman RC, Rodriguez GM, French JF. A comparison of male and female intravenous drug users' risk behaviours for HIV infection. *American Journal of Drug & Alcohol Abuse* 1994; 20(2):129-157.

149. Latkin CA, Mandell W, Knowlton AR, Doherty MC, Vlahov D, Suh T, Celentano DD. Gender differences in injection-related behaviours among injection drug users in Baltimore, Maryland. *AIDS Education & Prevention* 1998; 10(3):257-263.

150. Davies AG, Dominy NJ, Peters AD, Richardon AM. Gender differences in HIV risk behaviour of injecting drug users in Edinburgh. *AIDS Care* 1996; 8(5):517-527.

151. Gossop M, Griffiths P, Strang J. Sex differences in pattens of drug taking behaviour: A study at a London Community Drug Team. *British Journal of Psychiatry* 1994; 164:101-104.

152. Klee H. HIV risks for women drug injectors: heroin and amphetamine users compared. *Addiction* 1993; 88:1055-1062.

153. Barnard MA. Needle sharing in context: Patterns of sharing among men and women injectors and HIV risks. *Addiction* 1993; 88:805-812.

154. Donoghoe MC. Sex, HIV and the injecting drug user. *British Journal of Addiction 1992*; 87:405-416.

155. Hartel D. Context of HIV risk behaviour among female injecting drug users and female sexual partners of injecting drug users. *NIDA Reseearch Monograph* 1994; 143:41-47.

156. Dwyer R, Richardson D, Ross MW, Wodak A, Miller ME, Gold J. A comparison of HIV risk between women and men who inject drugs. *AIDS Education & Prevention* 1994; 6(5):379-389.

157. Brown V, Weissman G. Women and men injection drug users: An updated look at gender differences and risk factors. In: Brown BS, Beschner GM, editors. *Handbook on Risk of AIDS: Injection Drug Users and Sexual Partners.* Westport, CT: Greenwood Press; 1994, p. p. 173-194.

158. Taylor A. *Women drug users: An ethnography of a female injecting community.* Oxford: Oxford University Press; 1993.

159. Powis B, Griffiths P, Gossop M, Strang J. The differences between male and female drug users: Community samples of heroin and cocaine users compared. *Substance Use & Misuse* 1996; 31(5):529-543.

160. Hser Y-I, Anglin MD, Booth MW. Sex differences in addict careers. 3. Addiction. *American Journal of Drug & Alcohol Abuse* 1987; 13(3):231-251.

161. Roy E, Haley N, LeClerc NP, Boivin JF, Frappier JY, Cedras L. Drug injection among street youth: The first time. *Canadian Journal of Infectious Diseases* 1999; 10(Suppl B).

162. Bruneau J, Lamothe F, Soto J, Lachance N, Vincelette J, Vassal A et al. Sex-specific determinants of HIV infection among injection drug users in Montreal. *Canadian Medical Association Journal* 2001; 164(6):767-773.

163. Spittal P, Tyndall MW, Li K, Laliberte N, Wood E, Craib KJ et al. Risk factors for HIV among female and male injection drug users: Does sexual transmission explain why female IDUs are being disproportionately affected by HIV in Vancouver? *Canadian Journal of Infectious Diseases* 2001; 12(Suppl B):301.

164. Leonard L, Navarro C, Hankins C, Birkett N. Gender differences in sexual and injection practices among injection drug users in Ottawa. *Canadian Journal of Infectious Diseases* 2001; 12(Suppl B):351P.

165. Leonard L. Injecting Gender: The Importance of a Gendered Analysis in Working with Women and Men who Inject Drugs. In: Rowe W, Csiernik R, editors. *Addiction Issues for Canadian Social Workers.* Toronto: Canadian Scholars Press, 2002.

166. Leonard, L. The Urgent Need to Scale-up Successful Harm Reduction Interventions: First Harm Reduction Conference, Ottawa, March 19-20, 2003.

167. Leonard, L. and Navarro, C. *A gendered analysis of sexual and injection practices associated with high levels of HIV prevalence among injection drug users in Ottawa-Carleton 1996-2000: Issues for HIV prevention programming and policy development.* Ottawa: Community Health Research Unit, University of Ottawa, 2001.

168. Remis, R. S., Millson, M., and Major, C. *The HIV epidemic among injection drug users in Ontario: The situation in 1997.* Toronto: AIDS Bureau, Ontario Ministry of Health and Long Term Care, 1997.

169. Health Canada. *HIV/AIDS Epi update: HIV/AIDS Among Injecting Drug Users in Canada.* Ottawa: Division of HIV/AIDS Epidemiology & Surveillance, Centre for Infectious Disease Prevention & Control, Health Canada, 2003.

170. Health Canada. *HIV/AIDS Epi update: Ethnicity Reporting for AIDS and HIV in Canada.* Ottawa: Division of HIV/AIDS Epidemiology & Surveillance, Centre for Infectious Disease Prevention & Control, Health Canada, 2003.

171. Health Canada. *HIV/AIDS Epi update: HIV/AIDS Among Aboriginal Persons in Canada: A Continuing Concern.* Ottawa: Division of HIV/AIDS Epidemiology & Surveillance, Centre for Infectious Disease Prevention & Control, Health Canada, 2003.

172. McLeod, A. *Aboriginal Communities and HIV/AIDS.* Ottawa: Canadian AIDS Society, 1997.

173. Fayant AY, Andersen F, Greer D, Masching R, Nguyen M. National estimates of HIV infections among Aboriginal populations: Understanding the information. *Canadian Journal of Infectious Diseases* 2001; 12(Suppl B):383P.

174. Focus Group on Aboriginal Estimates. *HIV and Aboriginal People in Canada: A Report on the Estimated Number of HIV Infections Among Aboriginal People in Canada.* Ottawa: Division of HIV/AIDS Epidemiology & Surveillance, Centre for Infectious Disease Prevention & Control, Health Canada, 2001.

175. Canadian Aboriginal AIDS Network Inc [Pamphlet]. 2000. Ottawa, Canadian Aboriginal AIDS Network Inc.

176. Tyndall MW, Craib KJ, Currie S, Li K, O'Shaughnessy MV. Impact of HIV infection on mortality in a cohort of injection drug users. *Journal of Acquired Immune Deficiency Syndromes* 2001; 28(4):351-357.

177. Spittal PM, Craib KJ, Wood E, Lailiberte N, Li K, Tyndall MW et al. Risk factors for elevated HIV incidence rates among female injection drug user in Vancouver. *Canadian Medical Association Journal* 2002; 166(7):894-899.

178. Neron C, Roffey R. HIV, sexual violence and Aboriginal women. *Native Social Work Journal* 2000; 3(1):57-72.

179. Ship SJ, Norton L. "It's hard to be a woman!" First Nations women living with HIV/AIDS. *Native Social Work Journal* 2000; 3(1):73-89.

180. Aboriginal Nurses Association of Canada. *HIV/AIDS and Its Impact on Aboriginal Women in Canada.* Ottawa: Health Canada, 1996.

181. Mill JE. HIV risk behaviours become survival techniquest for Aboriginal women. *Western Journal of Nursing Research* 1997; 19(4):468-489.

182. *Ontario Aboriginal HIV/AIDS Strategy.* Ottawa: Ontario Aboriginal HIV/AIDS Strategy, 2000.

183. Northern Health Research Unit, University of Manitoba. *Research on HIV/AIDS in Aboriginal People: A Background Paper.* Ottawa: Medical Services Branch, Health Canada, 1998.

184. Remis, R. S. and Whittingham, E. P. *The HIV/AIDS epidemic among persons from HIV-endemic countries in Ontario, 1981-98: Situation report* Toronto: Department of Public Health Sciences, University of Toronto, 1999.

185. NHS Executive. *Health Services Circular HSC 1999/183.* London: National Health Services Executive, 1999.

186. Beardsell S, Coyle A. A review of research on the nature and quality of HIV testing services: A proposal for procedure based studies. *Social Science and Medicine* 1996; 42(5):733-743.

187. Barbacci M, Repke JT, Chaisson RE. Routine prenatal screening for HIV infection. *Lancet* 1991; 337:709-711.

188. U.K. Department of Health. *Guidelines for offering voluntary named HIV antibody testing to women receiving antenatal care.* London: U.K. Department of Health, 1994.

189. Nicoll A, McGarrigle C, Brady AR, Ades AE, Tookey PA, Duong T et al. Epidemiology and detection of HIV-1 among pregnant women in the United Kingdom: Results from national surveillance 1988-96. *British Medical Journal* 1998; 316:253-258.

190. MacDonagh SE, Masters J, Helps BA, Tookey PA, Gibb DM. Why are antenatal HIV testing policies in London failing? *British Journal of Midwifery* 1996; 4:466-470.

191. MacDonagh SE, Masters J, Helps BA, Tookey PA, Ades AE, Gibb DM. Descriptive survey of antenatal HIV testing in London: Policy, uptake, and detection. *British Medical Journal* 1996; 313(7056):532-533.

192. Nicoll A. Antenatal screening for HIV in the UK: What is to be done? *Journal of Medical Screening* 1998; 5(4):170-171.

193. Ottewill M. Antenatal screening for HIV: Time to embrace change. *British Journal of Nursing* 2002; 9(14):904-914.

194. De Cock KM, Johnson AM. From exceptionalism to normalisation: a reappraisal of attitudes and practice around HIV testing. *British Medical Journal* 1998; 316:290-293.

195. 39 D. Antenatal HIV testing: Has been done badly in Britain and needs to improve. *British Medical Journal* 1998; 316:241-242.

196. Anonymous. Unethical to not offer voluntary HIV screening to all pregnant women. *New Zealand Medical Journal* 2001; 114(1131):216.

197. Department of Health. *Reducing Mother to Baby Transmission of HIV. Health Service Circular 183.* London: Department of Health, 1999.

198. Minkoff HL, Holman S, Beller E, Delke I, Fishbone A, Landesman S. Routinely offered prenatal HIV testing. *New England Journal of Medicine* 1988; 319:1018.

199. Landesman S, Minkoff HL, Holman S, McCalla S, Sijin O. Serosurvey of human immunodeficiency virus infection in parturients: Implications for human immunodeficiency virus testing programs of pregnant women. *JAMA* 1987; 258(19):2702-2703.

200. Krasinski K, Borkowsky W, Bebenroth D, Moore T. Failure of voluntary testing for human immunodeficiency virus to identify infected parturient women in a high-risk population [Letter]. *New England Journal of Medicine* 1988; 318(3):185-185.

201. Minkoff HL, Landesman S. The case for routinely offering prenatal testing for human immunodeficiency virus. *American Journal of Obstetrics and Gynecology* 1988; 159(4):793-796.

202. Lindsay MK. A protocol for routine voluntary antepartum human immunodeficiency virus antibody screening. *American Journal of Obstetrics and Gynecology* 1993; 168(2):476-479.

203. Barbacci MB, Dalabetta GA, Repke JT, Talbot BL, Charache P, Polk F et al. Human immunodeficiency virus infection in women attending an inner-city prenatal clinic: Ineffectiveness of targeted screening. *Sexually Transmitted Diseases* 1990; 17(3):122-126.

204. Centers for Disease Control. U.S. public health service recommendations for human immunodeficiency virus counseling and voluntary testing for pregnant women. *Morbidity and Mortality Weekly Report* 1995; 44(RR-7):1-15.

205. Eberhart-Phillips J, Dickson N, Williams S. Asking pregnant women about HIV risk. *New Zealand Medical Journal* 1998; 111:175.

206. Doherty RR. Preventing transmission of HIV from mothers to babies in Australia. *Medical Journal of Australia* 2001; 174:433-434.

207. Centers for Disease Control. Success in implementing public health service guidelines to reduce perinatal transmission of HIV - Louisiana, Michigan, New Jersey, and South Carolina, 1993, 1995, and 1996. *Morbidity and Mortality Weekly Report* 1998; 47(33):688-691.

208. Lansky A, Jones JL, Frey RL, Lindegren ML. Trends in HIV testing among pregnant women: United States, 1994-1999. *American Journal of Public Health* 2001; 91(8):1291-1293.

209. Roome A, Birkhead GS, King S, Archibald C, Schrag S, Lansky A et al. HIV Testing Among Pregnant Women --- United States and Canada, 1998--2001. *Morbidity and Mortality Weekly Report* 2002; 51(45):1013-1016.

210. Health Canada. *Perinatal Transmission of HIV.* Ottawa: Division of HIV/AIDS Epidemiology & Surveillance, Centre for Infectious Disease Prevention & Control, Health Canada, 2001.

211. Remis R, Swantee C, Major C, Fearon M, Wallace E, Palmer RW et al. Increasing HIV testing of pregnant women in Ontario: Results from the HIV Seroprevalence Study to September 2002. *Canadian Journal of Infectious Diseases* 2003; 14(Suppl A):322.

212. Rey D, Carrieri MP, Obadia Y, Pradier C, Moatti JP. Mandatory prenatal screening for the human immunodeficiency virus: the experience in south-eastern France of a national policy, 1992-1994. *British Journal of Obstetrics and Gynecology* 1998; 105:269-274.

213. Grimes RM, Helfgott AW, Watson JR, Eriksen NL. For children's sake: New law mandates HIV testing of pregnant patients. *Texas Medicine* 1996; 92(1):36-40.

214. O'Connor KS, MacDonald SE. Aiming for zero: preventing mother-to-child transmission of HIV. *Canadian Medical Association Journal* 2002; 166(7):909-910.

215. Anonymous. CMA urges prenatal HIV tests. *Canadian Medical Association Journal* 2002; 165(5):523a.

216. Mill JS. *On Liberty.* London: John W. Parker and Son, 1859.

217. Hansen E. The histrionic push for mandatory perinatal HIV testing. *GMHC Treatment Issues* 1997; 11(7/8):33-34.

218. Wilfert CM. Mandatory screening of pregnant women for the human immunodeficiency virus. *Clinical Infectious Diseases* 1994; 19:664-666.

219. Patrick DM, Burdge D. Compulsory HIV tests [Reply]. *Canadian Medical Association Journal* 1999; 160:1286-1287.

220. Kuvin S, Stryker J. Should AIDS tests be mandatory for pregnant women? *Health* 1996; 10(1):28.

221. Schoen EJ, Limata C, Black SB. Unsuccessful voluntary prenatal testing for human immunodeficiency virus infection. *Pediatric Infectious Disease Journal* 2001; 20(1):81-79.

222. Anonymous. Two studies find Connecticut mandatory HIV screening law is a success. *Reuters Health* May 3, 2001.

223. Rovner J. U.S. specialists object to AMA's call for mandatory HIV testing. *Lancet* 1996; 348:330.

224. Peckham CS, Newell ML. Controversy in mandatory HIV screening of pregnant women. *Current Opinion in Infectious Diseases* 1997; 10:18-21.

225. Nakchbandi IA, Longenecker C, Ricksecker A, Latta RA, Healton C, Smith DG. A decision analysis of mandatory compared with voluntary HIV testing in pregnant women. *Annals of Internal Medicine* 1998; 128(9):760-767.

226. World Health Organization. *Pregnancy and HIV/AIDS.* Geneva, Switzerland: WHO, 2000.

227. Anonymous. Groups oppose bill to require HIV testing of pregnant women. *Newsday Online* 3-3-1999.

228. Anonymous. AMA unit says "no" to mandatory HIV testing. *AIDS* 2002; 16(9):N5.

229. Dolbear GL, Wojtowycz M, Newell LT. Named reporting and mandatory partner notification in New York State: the effect on consent for perinatal HIV testing. *Journal of Urban Health* 2002; 79(2):238-244.

230. Wilfert CM. Duke researcher calls for mandatory HIV testing of pregnant women. *AIDS Weekly* 1994; November 7:16-17.

231. Minkoff HL. Point/counterpoint: II. The case against mandatory prenatal HIV testing. *Obstetrical and Gynecological Survey* 1995; 50(1):2-3.

232. Acuff KL, Faden RR. A history of prenatal and newborn screening programs: Lessons for the future. In: Faden RR, Geller G, Powers M, editors. *AIDS, Women, and the Next Generation.* New York: Oxford University Press, 1991: 59-93.

233. Danziger R. Compulsory testing for HIV in Hungary. *Social Science and Medicine* 1996; 43(8):1199-1204.

234. Downes J. The ethical dilemmas of mandatory prenatal and newborn HIV testing. *NursingConnections* 1995; 8(4):43-50.

235. Health Canada. Guiding principles for human immunodeficiency virus (HIV) testing of women during pregnancy - 2002. *Canada Communicable Disease Report* 2002; 28(13):105-108.

236. D'Cunha D. Letter to Ontario physicians. 1998.

237. Howard Research & Instructional Systems Inc. *Alberta Routine Prenatal HIV Screnning Program: Final Evaluation Report.* Edmonton: Alberta Medical Association and Alberta Health & Wellness, 2001.

238. Doherty MA, Leonard LE, Mykietka K, Gahagan J. Preventing Perinatal Transmission of HIV : Pregnant Women's Experiences and Perspectives on Best Practices. Alberta Report (Unpublished). 2001.

239. Department of Health. *Offering voluntary named HIV antibody testing to women receiving antenatal care.* London: Department of Health, 1992.

240. Department of Health. *Guidelines for offering voluntary named HIV antibody testing to women receiving antenatal care.* London: Department of Health, 1994.

241. Smith JR, Barton SE, Boag FC. Antenatal testing for HIV: to opt in or opt out, that is the question. *British Journal of Obstetrics and Gynecology* 1996; 103:1059-1060.

242. Joo E, Carmack A, Garcia-Buñuel E, Kelly CJ. Implementation of guidelines for HIV counseling and voluntary HIV testing of pregnant women. *American Journal of Public Health* 2000; 90(2):273-276.

243. Montgomery ET, Kropp R, Hill DW, Ruiz J, Maldonado YA. Assessment of universal HIV voluntary counseling, test offering and testing for prenatal women in California [Abstract ThOrD1399]. Barcelona: XIV International AIDS Conference, July 7-12, 2002.

244. Stoto MA. Implementation and Impact of the Public Health Service Counseling and Testing Guidelines. In: Stoto MA, Almario DA, McCormick MC, editors. *Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States.* Washington, D.C.: National Academy Press, 1999: 68-108.

245. Stringer EM, Stringer JS, Cliver SP, Goldenberg RL, Goepfert AR. Evaluation of a new testing policy for human immunodeficiency virus to improve screening rates. *Obstetrics & Gynecology* 2001; 98(6):1104-1108.

246. Joint Statement of the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists. *Pediatrics* 1999; 104(1):128.

247. D'Angelo LJ, Belzer M, Futterman D, Perlata L, Sawyer M. "Reducing the Odds" at what cost: Will routine testing of pregnant adolescents decrease perinatal transmission of HIV? *Journal of Adolescent Health* 2000; 27:296-297.

248. Centers for Disease Control. Revised recommendations for HIV screening of pregnant women. *Morbidity and Mortality Weekly Report* 2002; 50(RR-19):59-85.

249. Ketchum P. Routine prenatal HIV screening program launched. *Canadian Family Physician* 1999; 45:700-702.

250. Jayaraman GC, Preiksaitis JK, Larke B. Mandatory reporting of HIV infection and opt-out prenatal screening for HIV infection: effect on testing rates. *Canadian Medical Association Journal* 2003; 168(6):679-682.

251. Mossman CL, Ratnam S. Opt-out prenatal HIV testing in Newfoundland and Labrador [letter]. *Canadian Medical Association Journal* 2002; 167(6):630.

252. Simpson WM, Johnstone FD, Goldberg DJ, Gormley SM, Hart GJ. Antenatal testing: assessment of a routine voluntary approach. *British Medical Journal* 1999; 318(1660):1661.

253. Blott M, Yearwood J, Gerval M, Welch J, Zuckeman M. Routine antenatal testing – Is acceptable to women. *British Medical Journal* 1999; 319(1069):1070.

254. Dennison B, Kennedy J, Tilling K, Wolfe CD, Chrystie IL, Banatvala JE. Feasibility of named antenatal HIV screening in an inner city population. *AIDS Care* 1998; 10(3):259-265.

255. Hawken J, Chard T, Jeffries DJ, Costeloe K, Grant K, Ward F et al. Evaluation of an antenatal HIV testing programme in an inner London health district. *British Journal of Obstetrics and Gynecology* 1994; 101:960-964.

256. Stoto MA. Recommendations. In: Stoto MA, Almario DA, McCormick MC, editors. *Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States.* Washington, D.C.: National Academy Press, 1999: 109-133.

257. Stringer E, Stringer J, Cliver S, Goldenberg R, Goepfert A. Active refusal increases human immunodeficiency virus screening in an urban prenatal clinic system. *Obstetrics & Gynecology* 2001; 97:S58.

258. Boyd FM, Simpson WM, Hart GJ, Johnstone FD, Goldberg DJ. What do pregnant women think about the HIV test? A qualitative study. *AIDS Care* 1999; 11(1):21-29.

259. Almond B, Ulanowsky C. HIV and pregnancy. *Hastings Center Report* 1990; 20(2):16-21.

260. Miller R, Madge S. Routine HIV testing in antenatal care: Time to move on. *The Diplomate* 1997; 4(1):26-31.

261. Jones R. Why do qualitative research? It should begin to close the gap between the sciences of discovery and implementation [editorial]. *British Medical Journal* 1995; 311(6996):2.

262. Britten N, Jones R, Murphy E, Stacy R. Qualitative research methods in general practice and primary care. *Family Practice* 1995; 12(1):104-114.

263. Fitzpatrick R, Boulton M. Qualitative research in health care: I. The scope and validity of methods. *Journal of Evaluation and Clinical Practice* 1996; 2(2):123-130.

264. Devers KJ. How will we know "good" qualitative research when we see it? Beginning the dialogue in health services research. *Health Services Research* 1999; 34(5):1153-1188.

265. Listernick JI. The case against mandatory prenatal testing for HIV. *Clinical Obstetrics and Gynecology* 1989; 32(3):506-515.

266. Department of Health. *Unlinked Anonymous HIV Seroprevalence Monitoring Programme in England and Wales: Report from the Unlinked Anonymous Surveys Steering Group. Data to the end of 1997.* London: Department of Health, 1998.

267. Rapp R. *Testing Women, Testing the Fetus: The Social Impact of Amniocentsis in America.* New York: Rutledge, 2000.

268. Greene JC. Qualitative program evaluation: Practice and promise. In: Denzin NK, Lincoln YS, editors. *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage Publications, 1994: 530-544.

269. Willms DG, Johnson NA. *Essentials in Qualitative Research: A Notebook for the Field.* Hamilton: McMaster University Faculty of Health Sciences, 1993.

270. Denzin NK, Lincoln Y. Introduction: Entering the field of qualitative research. In: Denzin NK, Lincoln YS, editors. *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage, 1994: 1-17.

271. Morse JM. *Qualitative Research Methods for Health Professionals.* 2nd ed. Thousand Oaks, CA: Sage, 1995.

272. Glaser BG. *Theoretical sensitivity: Advances in the methodology of grounded theory.* Mill Valley, CA: Sociology Press, 1978.

273. Remis, RS and Whittingham, EP. *The HIV/AIDS epidemic among persons from HIV-endemic countries in Ontario, 2000: Situation report.* Toronto: Department of Public Health Sciences, University of Toronto, 2001.

274. Remis RS, Major C, Bangura H, Wallace E, Vermeulen M. *Report on the HIV/AIDS Epidemic in Ontario: 1981 – 1996.* Toronto: Ontario Ministry of Health and Long Term Care, 1998.

275. Remis RS, Major C, Wallace E, Schiedel L, Whittingham EP. *Report on HIV/AIDS in Ontario: 1997 – 1998.* Toronto: Ontario Ministry of Health and Long Term Care, 1999.

276. Remis RS, Major C and The HIV Seroprevalence Research Team. *HIV Seroprevalence Study among Women Receiving Prenatal Care in Ontario.* Toronto: Public Health Sciences Department at the University of Toronto, 2000.

277. Morse JM. Designing funded qualitative research. In: Denzin NK, Lincoln YS, editors. *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage, 1994: 220-235.

278. Morse JM. Strategies for sampling. In: Morse JM, editor. *Qualitative Nursing Research: A Contemporary Dialogue.* Newbury Park, CA: Sage, 1991: 127-146.

279. Morse JM, Field PA. *Qualitative Research Methods for Health Professionals.* Thousand Oaks, CA: Sage, 1995.

280. Aisenberg N, Harrington M. *Women of Academe: Outsiders in the Sacred Grove.* Amherst, MA: University of Massachusetts Press, 1988.

281. Howe KR. Against the quantitative-qualitative incompatibility thesis or dogmas die hard. *Educational Researcher* 1988; 17(8):10-16.

282. Patton MQ. Paradigms and pragmatism. In: Fetterman DM, editor. *Qualitative Approaches to Evaluation in Education: The Silent Scientific Revolution.*. New York: Praeger, 1988.

283. Pitman MA, Maxwell JA. Qualitative approaches to evaluation: Models and methods. In: LeCompte MD, Millroy WL, Preissle J, editors. *The Handbook of Qualitative Research in Education.* New York: Academic Press, 1992: 729-770.

284. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG, editors. *Analyzing Qualitative Data.* London: Routledge, 1994: 173-194.

285. Patton MQ. *Qualitative Evaluation and Research Methods.* Newbury Park, CA: Sage, 1990.

286. Leonard L. High risk women's understanding of HIV. In: *Determinants of Risk for HIV: Findings from Eight Qualitative Community-Based Research Studies.* Ottawa: Canadian Strategy on HIV/AIDS, Health Canada, 2000.

287. Morse JM. *Qualitative Health Research.* Newbury Park, CA: Sage, 1992.

288. Rubin HJ, Rubin IS. *Qualitative Interviewing: The Art of Hearing Data.* Thousand Oaks, CA: Sage, 1995.

289. Brewer JD. Sensitivity as a problem in field research: a study of routine policing in Northern Ireland. In: Renzetti CM, Lee RM, editors. *Researching Sensitive Topics.* Newbury Park, CA: Sage, 1993: 125-145.

290. Healy B. In doing you learn: Some reflections on practice research on an advocacy project. In: Fook J, editor. *The Reflective Researcher: Social Workers' Theories of Practice Research.* Sydney: Allen & Unwin, 1996: 70-83.

291. Glaser BG. *Basics of grounded theory analysis: Emergence vs. forcing.* Mill Valley, CA: Sociology Press, 1992.

292. Strauss AL, Corbin J. Grounded theory methodology: An overview. In: Denzin NK, Lincoln YS, editors. *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage, 1994: 273-285.

293. Strauss AL, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory.* 2nd ed. Thousand Oaks, CA: Sage, 1998.

294. Charmaz K. Grounded theory. Objectivist and constructivist methods. In: Denzin NK, Lincoln Y, editors. *Handbook of Qualitative Research.* 2000: 509-535.

295. Wuest J, Merritt-Gray M. Feminist grounded theory revisited. In: Schreiber R, Stern P, editors. *Using Grounded Theory in Nursing.* New York: Springer, 2001: 159-176.

296. Wuest J, Merritt-Gray M. Participatory action research: Practical dilemmas and emancipatory possibilities. In: Morse J, editor. *Completing a Qualitative Research Project: Details and Dialogue.* Thousand Oaks, CA: Sage, 1997: 283-306.

297. Wuest J, Merritt-Gray M, Berman H, Ford-Gilboe M. Illuminating social determinants of women's health using grounded theory. *Health Care for Women International* 2002; 23:794-808.

298. Kelly L. *Surviving Sexual Violence.* Minneapolis, MN: University of Minnesota Press, 1988.

299. Swift K. *Manufacturing "Bad Mothers": A Critical Perspective on Child Neglect.* Toronto: University of Toronto Press, 1995.

300. Ontario Ministry of Health. *HIV antibody testing: Guidelines for pre- and post-test counselling in anonymous testing.* Toronto: 1995.

301. O'Campo P, de Boer M, Faden R, Kass N, Gielen A, Barbacci M. Confirmation of self-report of HIV testing among a cohort of pregnant women. *Journal of Clinical Epidemiology* 1997; 50(1):57-61.

302. Sandelowski M. The problem of rigor in qualitative research. *Advances in Nursing Science* 1986; 8(3):27-37.

303. Guenter D, Carroll J, Kaczorowski J, Sellors J. Prenatal HIV testing in Ontario: Knowledge, attitudes and practices of prenatal care providers in a province with low testing rates. *Canadian Journal of Public Health* 2003; 94(2):93-97.

304. Guba EG; Lincoln YS. *Fourth Generation Evaluation.* Newberry Park, CA: Sage; 1989.

305. Carroll JC, Brown JB, Reid AJ, Pugh P. Women's experience of maternal serum screening. *Canadian Family Physician* 2000; 46:614-620.

306. Tharao E, Massaqoui N, Brown M. What is wrong with this picture? Preventing maternal HIV transmission amongst black women and women of color in Toronto, Canada [ThPeC7429]. Barcelona: XIV International AIDS Conference, July 7-12; 2002;

307. Press N, Browner CH. Why women say yes to prenatal diagnosis. *Social Science and Medicine* 1997; 45(7):979-989.

308. Pryde PG, Drugan A, Johnson MP, Isada NB, Evans MI. Prenatal diagnosis: Choices women make about pursuing testing and acting on abnormal results. *Clinical Obstetrics and Gynecology* 1993; 36(3):496-509.

309. Sanden ML, Bjurulf P. Pregnant women's attitudes and knowledge in relation to access to serum-alpha-fetoprotein test. *Scandinavian Journal of Social Medicine* 1988; 16:197-204.

310. Ruiz JD, Molitor F, Prussing E, Peck L, Grasso P. Prenatal HIV counseling and testing in California: Women's experiences and providers' practices. *AIDS Education and Prevention* 2002; 14(3):190-195.

311. Meadows J, Catalan J, Gazzard BG. HIV antibody testing in the antenatal clinic: The views of the consumers. *Midwifery* 1993; 9:63-69.

312. Kvam BM, Aavitsland P, Nilsen O, Lystad A. Attitude of pregnant women to routine voluntary antenatal HIV testing. [Norwegian]. *Tidsskift for Den Norske Laegeforening* 2000; 120(24):2895-2900.

313. DeMatteo D. Canadian women's experiences of testing "positive" for HIV in pregnancy: Psychosocial and ethical issues. *Can.J.Infect.Dis.* 2001; 12(Suppl B):420

314. Napravnik S, Royce R, Walter E, Lim W. HIV-1 infected women and prenatal care utilization: Barriers and facilitators. *AIDS Patient Care & STDS* 2000; 14(8):411-420.

315. Mawn B. Integrating women's perspectives on prenatal human immunodeficiency virus screening: Toward a socially just policy. *Research in Nursing and Health* 1998; 21:499-509.

316. Green J, Statham H, Snowdon C. Screening for fetal abnormalities: Attitudes and experiences. In: Chard T, Richards MPM, editors. *Obstetrics in the 1990s: Current Controversies*. Cambridge: Mac Keith Press; 1992; p. 65-89.

317. Press NA, Browner CH. Collective silences, collective fictions: How prenatal diagnosis testing became part of routine prenatal care. In: Rothenberg KH, Thomson EJ, editors. *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*. Columbus, OH: Ohio State University Press; 1994; p. 201-218.

318. Lippman A. The genetic construction of prenatal testing: Choice, consent, or conformity for women? In: Rothenberg KH, Thomson EJ, editors. *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*. Columbus, OH: Ohio State University Press; 1994; p. 9-34.

319. Gates EA. Prenatal genetic testing: Does it benefit pregnant women? In: Rothenberg KH, Thomson EJ, editors. *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*. Columbus, OH: Ohio State University Press; 1994; p. 183-200.

320. Hyde B. An interview study of pregnant women's attitudes to ultrasound scanning. *Social Science and Medicine* 1986; 22(5):589-592.

321. Statham H, Green J, Snowdon C. Psychological and social aspects of screening for fetal abnormality during routine antenatal care. *Conference Proceedings: Research and the Midwife* 1992; p. 44.

322. Evans MI, Pryde PG, Evans WJ, Johnson MP. The choices women make about prenatal diagnosis. *Fetal Diagnosis & Therapy* 1993; 8(Suppl 1):70-80.

323. Lippman A. Mother matters: A fresh look at prenatal genetic testing. *Issues in Reproductive and Genetic Engineering* 1992; 5(2):141-54.

324. Lippman A. Prenatal genetic testing and screening: Constructing needs and reinforcing inequities. *American Journal of Law and Medicine* 1991; 17(1/2):15-50.

325. Katz A. *HIV screening in pregnancy.* Winnipeg: University of Manitoba, 2000.

326. Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *British Medical Journal* 1995; 311(6996):42-45.

327. Caccia N, Johnson JM, Robinson GE, Barna T. Impact of prenatal testing on maternal-fetal bonding: Chorionic villus sampling versus amniocentesis. *American Journal of Obstetrics and Gynecology* 1991; 165(4):1122-1125.

328. UNAIDS. *UNAIDS Policy on HIV Testing and Counselling.* Geneva: UNAIDS, 1997.

329. Rosenfield A, Figdor E. Where is the M in MTCT? The broader issues in mother-to-child transmission of HIV. *American Journal of Public Health* 2001; 91(5):703-704.

330. Bassett MT. Keeping the M in MTCT: Women, mothers, and HIV prevention. *American Journal of Public Health* 2001; 91(5):701-702.

APPENDIX 1

OTTAWA PROJECT COMMUNITY ADVISORY BOARD MEMBERS

Lucie Carriérre	John Howard Society Ottawa-Carleton Detention Centre
Hannah Cowan	Clinical Nurse Specialist for HIV Oasis
Kathy Crowe	Supervisor, Reproductive Health Programme City of Ottawa Health Department
Danielle Dorschner	Programme Manager, HIV Prevention Programme City of Ottawa Health Department
Lesley Fleming	National Programmes Consultant Canadian AIDS Society
Mary Martha Hale	Director, Centre 454 Anglican Social Services
Corrine Langill	Public Health Nurse, School Based Sexual Health Programme City of Ottawa Health Department
Linda Pelude	Public Health Nurse, HIV Prevention Programme City of Ottawa Health Department
Susan Tolton	Executive Director Oasis
Zhaida Udden	Coordinator, Women's Project AIDS Committee of Ottawa

APPENDIX 2

TORONTO PROJECT COMMUNITY ADVISORY BOARD MEMBERS

Susan King	Physician, HIV/AIDS Comprehensive Care Clinic Toronto's Children's Hospital, Toronto
LaVerne Monette	Provincial Coordinator Ontario Aboriginal HIV/AIDS Strategy
Carol Roberts	Assistant Professor, School of Nursing Queen's University
Janet Rowe	Women's Community Development Coordinator AIDS Committee of Toronto
Louise Shap	Senior Policy Analyst Ontario Ministry of Health and Long Term Care
Esther Tharao	HIV/AIDS Educator Women's Health in Women's Hands

APPENDIX 3

COMMUNITY AGENCIES AND INDIVIDUALS ASSISTING WITH RECRUITMENT

Toronto

Lorraine Barnaby	Queen's West Community Health Centre
June Carroll	Mount Sinai Hospital
Leanne Cusitar	HIV Prevention Programme, Toronto Public Health
Mary Grondin	St Michael's Hospital
Shaun Hopkins	The Works
Lora Kucenty	Shout Clinic
Margaret Leslie	Breaking the Cycle
Janet Rowe	AIDS Committee of Toronto
Esther Tharao	Women's Health in Women's Hands Community Health Centre
Janis Tripp	Ontario Ministry of Health and Long-Term Care

Ottawa

Donna Bowers	Somerset West Community Health Centre
Hannah Cowan	Oasis
Jackie Joynt	
Lianne MacDonald	Wabano Centre for Aboriginal Health
Michelle McNeil	HIV Prevention Programme, Public Health and Long Term Care
Wendy Muckle	Sandy Hill Community Health Centre
Rita Peschka	Street Outreach Programme, Sandy Hill Community Health Centre
Linda Pelude	HIV Prevention Programme, Public Health and Long Term Care
Bev Soulier	Wabano Centre for Aboriginal Health

Shelley Van Keffle	St Mary's Home
Pat and Emily	The Well, Woman's Day Centre

Hamilton

Dale Guenter	North Hamilton Community Health Centre
Suzanne Newmark	Hamilton Public Health Department

Kingston

Ron Shore	Street Health Centre

APPENDIX 4

INFORMATION LETTER FOR FRONT-LINE WORKERS

Women, Pregnancy and HIV : What Women in Canada Have to Say

What This Study is About

Health Canada and the Ontario Ministry of Health and Long-term Care are looking at the best ways to carry out prenatal HIV counselling and testing.

The opportunity for HIV counselling and testing in pregnancy is being introduced as part of a prevention strategy to reduce the number of babies born in Canada who are infected with HIV and to offer treatment options to the mothers as soon as possible.

The Importance of the Voices of Pregnant Women

Effective antenatal screening programmes have the potential to successfully increase the number of pregnant women who accept testing as the first step in accessing, if necessary, the choice of treatment and interventions for themselves and the range of interventions to prevent transmission to their unborn child.

However, in order for such programmes to be maximally accessible to as many women as possible, it is essential that pregnant women's perspectives of best practices in antenatal HIV testing, based on their own experiences, are reflected in the development or re-examination of these programmes. For example, it is essential to understand and document from the experiences of pregnant women, those components of the programmes which facilitate the decision to accept testing and those which act against agreement.

Antenatal screening programmes which fail to address the cultural and social context which impacts on a woman's agreement to test will also similarly fail to engage maximum numbers of women. It is important therefore that not only should women be given a voice in re-examining existing programmes, but that voice must be inclusive of those women whose social and cultural context is likely to impact on their attitudes to, and experiences of, HIV testing in their pregnancy. In addition, in order to work towards lowering the HIV infection rate among newborns, it is essential that HIV counselling and testing programmes are easily accessible by those women whose life style places them at higher risk of acquiring HIV infection.

Participants

We are looking for pregnant women from a variety of backgrounds to participate in the study who may, or may not, have been tested for HIV during their pregnancy.

What's Involved

- Pregnant women meet with a woman researcher for a personal interview that takes about an hour.
- There is no testing involved in the interview - just talking.
- The interviews are confidential and anonymous- names and addresses are not asked for.
- The interviews are tape recorded and the tapes destroyed once the project is completed.
- Participants are compensated $30 for their time spent away from other activities and travel and child minding expenses are reimbursed.

Why It Is Important to Participate

The federal and provincial governments will have new knowledge, based on the perspectives of pregnant women themselves, of the essential components of an accessible and effective prenatal programme. This knowledge will be used to formulate a federal position on antenatal HIV counselling and testing and will be used to evaluate existing provincial policies.

Funding

The Women, Pregnancy and HIV Study is funded by the HIV Prevention and Community Action Programme of Health Canada and by the AIDS Bureau, Ontario Ministry of Health and Long Term Care. The study has received ethical approval from The Human Research Ethics Committee of the Faculty of Medicine at the University of Ottawa.

Study Team

Principal Investigator

Lynne Leonard, MA., CQSW	University of Ottawa

Co-Investigators

MaryAnne Doherty, PhD	University of Alberta
Jacqueline Gahagan, PhD	Dalhousie University
Cate Hankins, MD.,MSc.,CCFP., FRCPC	McGill University
Stephen Hotz, C.Psych., PhD	University of Ottawa
Abby Lippman, PhD	McGill University

For more information about the study, please feel free to contact one of the people running the study.

Her name is Lynne Leonard. You can call Lynne at the University of Ottawa (613) - 562 - 5800 extension 8286

APPENDIX 5
PROMOTIONAL BROCHURE FOR WOMEN PARTICIPANTS

MAKE
YOUR
VIEWS
COUNT

CALL TODAY!!!

For more information
and
to book your interview,
please call

LYNNE LEONARD
at (613) 562 - 5800
extension 8286

Should you have questions
about your pregnancy,
or would like more information
about HIV counselling and testing,
please contact
your health care provider.

You may also choose to call the
HIV Healthline and Network at
1-888-246-5840.

This hotline is run by the
Children's Hospital in Toronto
and is especially for
pregnant women.

There is no charge for this call.

HIV Testing During Pregnancy

What do women
in Canada think?

What do YOU think?

Health Canada and the Ontario Ministry of Health are looking at the best ways to carry out HIV testing among pregnant women such as yourself.

The opportunity for HIV testing in pregnancy is being introduced as part of a prevention strategy to reduce the number of babies born in Canada who are infected with HIV, the virus linked to AIDS, and to offer treatment options to mothers as early as possible.

Be part of a Health Canada study to let the provincial and federal governments know what pregnant women in Canada think about HIV counselling and testing during their pregnancy.

Tell us your thoughts and views about what you think pregnant women such as yourself need.

Share your experiences in a confidential private interview with a woman researcher. A personal interview will be arranged for you at a time and place to suit your needs.

To participate:

- You are now pregnant.
- You may or may not have been tested for HIV in your pregnancy.

What's involved:

- There is no testing involved in the interview - just talking.
- The interviews are anonymous and confidential - you will not need to give your name or address.
- The interviews will be tape recorded and the tapes destroyed once the project is complete.
- The interviews take about an hour.
- You will be compensated $30 for your time spent away from your other activities.

Be one of the pregnant women in Canada to let the government know what pregnant women need in a prenatal HIV testing programme

To book your interview in your area, see over.

For more information about the study, please feel free to contact one of the people running the study.
Her name is Lynne Leonard.
You can call Lynne
at the University of Ottawa
(613) 562 - 5800 extension 8286.
Outside the local calling area, you can also place a collect charge call to Lynne at
(613) 562 - 5449.

APPENDIX 6

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Université d'Ottawa · University of Ottawa

Faculté de médecine
Épidémiologie et médecine sociale

Faculty of Medicine
Epidemiology and Community Medicine

PARTICIPANT INFORMATION AND CONSENT FORM
National Study
(To be read to the participant before the commencement of interview.)
(Sign and date two copies. Participant receives one copy.)

A group from the University of Ottawa is working with Health Canada to understand womens' needs for HIV testing in pregnancy. This information will help the federal government to give people the information and advice they need.

We will be asking pregnant women like you to talk about your ideas on testing for diseases in pregnancy, including HIV, that may be passed on to your baby. If you have already had a screening test for HIV in your pregnancy, we will ask you to describe the experience in detail. In addition we will be asking you to talk about any behaviours that may have put you at risk for getting HIV, the virus linked to AIDS. It is possible that talking freely about these things may be uncomfortable and embarrassing at times for some women.

These conversation sessions are completely confidential and anonymous. Your name and address will not be asked for. You may choose any name you would like to be known by for the interview. The interview will be tape recorded. The tapes will only be identified by a number so that no one will ever be able to link your answers, thoughts or opinions back to you. Only people directly involved in the study will have access to the tapes which will be kept safe so that no one can steal or copy them. All records will be destroyed when the study is finished. When we publish the results or present them at scientific meetings, no names or other information that could identify you will be published or released.

All information given to us in these conversations will be kept confidential within the research team. There are two exceptions to this. If the interviewer feels that there is a danger that you might seriously hurt yourself, a person who could keep you safe will be alerted. If the interviewer feels that you might hurt someone else, the person at risk will be alerted and steps taken to keep you safe. Information regarding an abuse having taken place will also be kept confidential. However, the interviewer will need to

451, ch. Smyth
Ottawa (Ontario) K1H 8M5 Canada

451 Smyth Rd.
Ottawa, Ontario K1H 8M5 Canada

(613) 562-5410 • Téléc./Fax (613) 562-5465

report to the Children's Aid Society if there is reasonable grounds to suspect that any person under the age of 16 may be suffering from, or has suffered abuse.

The conversation sessions will last about an hour and a half. At the end of that time you will have a chance to talk about any worries that you might have and to ask questions.

During the conversation sessions you may :

- choose not to answer any question;
- choose to stop the conversation at any time;
- and choose to stop the tape recorder at any time.

Your right to treatment at any agency will not be affected by whether you choose to take part in the study or not.

We very much appreciate honest and accurate answers to the questions asked. If you agree to take part in the conversation sessions, you will receive $30 in cash to cover the time you spend away from your other commitments.

Should you have any questions or need more information about anything to do with the study, please feel free to contact one of the people running the study. Her name is Lynne Leonard. You can call Lynne at the University of Ottawa, (613) 562 - 5800 extension 8286. Outside the local calling area, you can also place a collect charge call to Lynne at (613) 562 - 5449.

Should you have questions about your pregnancy, or would like more information about HIV screening, please contact your health care provider. You may also choose to call the HIV Healthline and Network at 1-888-246-5840. This hotline is run by the Children's Hospital in Toronto and is especially for pregnant women. There is no charge for this call.

The above information has been reviewed with the participant.

Participant has indicated her understanding of the information and has given her verbal consent to participate in the study.

Signature of person obtaining consent Date of interview

(Valid until June 13, 2002)

APPENDIX 7

INTERVIEW GUIDE

MAIN THEME AREAS

1. Pregnancy
2. Prenatal care
3. Prenatal screening
4. Offer of HIV test – Pre-test counselling
5. Decision not to test
6. Decision to test
7. Attitudes to prenatal HIV testing
8. Waiting for and receiving test results
9. Risks and benefits, barriers and facilitators of future testing
10. Best practices in antenatal HIV counselling and testing – policy
11. Best practices in antenatal HIV counselling and testing – programme content
12. Personal questions

INTRODUCTION: ALL PREGNANT WOMEN

Objective: Establish experience of pregnancy

1. Let's start off by talking a little about your pregnancy.

- How are you feeling?
- How did you feel when you found out you were pregnant?

Objective: Establish nature of woman's prenatal care

2. Who are you seeing for your care during your pregnancy?

For each health care professional

- How is that working out for you?
- What are some of the good things about looking after you in your pregnancy?
- What are some of the disadvantages?

COUNSELLING: ALL PREGNANT WOMEN

Objective: What information was given and was it helpful?
Was voluntary nature of test explicit, was consent sought?

---

3. **Can you tell me about any blood tests that you have had in this pregnancy?**
(Elicit understanding of what the tests were and why they were done.)

    - What were you told about these tests?
    (Elicit understanding of confidentiality and the subsequent use of the test results.)

4. **During this pregnancy, has anyone talked to you about being tested for HIV?**
(IF NO, CONTINUE FROM SECTION 8)
(Establish timing of discussion, position of person offering the test and the appropriateness of that person relative to others involved in her care.)

    - What were you told about being tested for HIV in pregnancy?
    (Elicit perception of: mother to child transmission risk
    pros and cons of test for mother and baby
    use of positive results – reporting, testing options
    anything else?)
    - How did you feel about what you were being told?
    (Elicit perception of personal HIV risk.)
    - What was your impression of what your (doctor/nurse practitioner/midwife) wanted you to do?
    (Elicit understanding of voluntary consent and was this requested and given.)
    - What was it like to talk about HIV testing in your pregnancy?
    (Elicit details of nature of, and reasons for, previous tests.)
    - Had you thought about being tested in pregnancy?

NON-TESTERS: ONLY FOR WOMEN WHO DECLINED TESTING
Objective: What factors constituted decision not to test?

5. So you decided not to go ahead and get tested for HIV. Let's talk a little about that.

- What made you decide NOT to get tested?
- What were your concerns?
- What happened when you told your doctor?
- Would anything have made a difference?

TESTING: ONLY FOR PREGNANT WOMEN WHO HAVE BEEN TESTED

Objective: *What factors constituted decision to test?*
Risks and benefits of testing
Barriers and facilitators

---

6. **So you decided to go ahead and have an HIV test. Let's talk a little about that. What helped you decide on testing?**

7. **Let's talk now about the actual test, what happened?**

   - What did you think about that?
   - How do you feel about that now?
   - What would have been useful for you to know about the testing before it happened? ***(Gaps in Pre-test counselling)***
   - Do you think there were any benefits for you in going for a HIV test?
   - Did you have any worries in agreeing?
   - What would have helped you with these worries?
   - How was it waiting for the results?
     (Elicit disclosure of self-identified risk.)

POST-TEST COUNSELLING: ONLY FOR PREGNANT WOMEN WHO HAVE RECEIVED THEIR RESULTS

Objective: *Was post-test counselling utilised and perceived as opportunity to address future preventive behaviour?*

---

8. Let's talk about how you got your results.
(Elicit content of post-test counselling.)

- What do you think about that?
- How did you feel about that now?
- What would have made getting your results easier for you?
- Do you think, as a result of this experience, that you will change anything you do now for yourself?

FUTURE TESTING: ONLY FOR PREGNANT WOMEN WHO HAVE NOT BEEN OFFERED TESTING

9. Are there any good things for you personally in going for HIV testing in your pregnancy?

- Are there any things that you would be worried about if you went for testing?
- What would help you with these worries?
- Are there any other things that you need to know to help you make up your mind?
- Where would you like to go to have the test?
- Can you tell me why you would like to go there?
- For you, who would be the best person to give you the test and your results?
- Can you tell me why would be the best person?

PERCEPTION OF BEST PRACTICES: ALL PREGNANT WOMEN

10. Do you think it's a good idea for every pregnant woman to be offered testing for HIV during her pregnancy?

- What would be the ideal way to counsel and test pregnant women for HIV, based on your own personal experience? *(Elicit perception of when, who should do it, and what it should consist of.)*
- Based on your own personal experience, would you prefer to have the HIV test offered to you and then you have to agree to go ahead, or would you prefer to have it done as matter of routine and you would need to state that you didn't want to be tested for HIV?
- Do you think every pregnant woman should have to get tested for HIV?
  (IF YES) How could that be done?

11. Based on your own personal experiences, what would you want other pregnant women to know about HIV counselling and testing in pregnancy? For example:

- What sort of information should pregnant women be given and how?
- If you were asked to suggest to doctors and other health care providers what they should be telling women about HIV in pregnancy – what would you suggest?
- If you were asked to suggest to doctors and other health care providers how they should be testing pregnant women for HIV in their pregnancy – what would you suggest?
  (Elicit attitudes towards opt-in, opt-out, mandatory, only if at risk.)
- If you were asked to suggest to doctors and other health care providers how they should be talking to pregnant women about the results of their HIV test – what would you suggest?

Is there anything else that you would like to say to me about HIV counselling and HIV testing in pregnancy?

CONCLUSION OF INTERVIEW: ALL PREGNANT WOMEN

Objective: Obtain basic positioning information

12. I would like to ask you now a few personal questions. As before, you can decide whether you want to answer each question.

- How old are you?
- In what country were you born?
- How long have you been living in Canada?
- What language is spoken in your home?
- To which ethnic group do you feel you belong?
- What is the highest level of education you have completed?
- Do you work outside the home?
- Approximately, what was the level of your family income this year?
- What was the main source of that income?
- How many months pregnant are you?
- Do you have someone who is providing support to you in this pregnancy? *(Marital status)*
- How many previous pregnancies have you had?
- What are the ages of any children living with you?
- Do you plan to have another child?

APPENDIX 8

ETHICS APPROVAL LETTERS: OTTAWA HOSPITAL RESEARCH ETHICS BOARD

APPENDIX 9

ETHICS APPROVAL LETTER: OTTAWA-CARLETON HEALTH DEPARTMENT

APPENDIX 10

PREGNANT WOMEN PARTICIPATING IN THE STUDY

Pregnant Women Participating in the Study

Name	Description
"Amanda"	A 25 year-old single ex-IDU Aboriginal woman in her third trimester
"Angelica"	A 26 year-old visible minority "lower-risk" woman in her third trimester living with her partner
"Betty"	A 34 year-old "higher-risk" single woman from an HIV-endemic country in her second trimester
"Beverly"	A 33 year-old "lower-risk" married woman in her second trimester
"Bobbie"	A 30 year-old visible minority "lower-risk" married woman in her third trimester
"Bridge"	An Aboriginal 17 year-old single street-involved injection drug user
"Carole"	A 35 year-old separated ex-IDU Aboriginal woman in her second trimester
"Caroline"	An 18 year-old visible minority "lower-risk" woman in her first trimester living with her partner
"China"	A 24 year-old "lower-risk" single woman in first trimester
"Christie"	A 21 year-old "lower-risk" single woman in her third trimester
"Christine"	A 31 year-old "lower-risk" married woman from an HIV-endemic country in her third trimester
"Claire"	A 16 year-old visible minority "lower-risk" single woman in her third trimester
"Claudine"	A 19 year-old visible minority "lower-risk" single woman in her second trimester
"Connie"	A 23 year-old "higher-risk" single woman in her first trimester
"Dana"	A 38 year-old visible minority "lower-risk" married woman in her second trimester
"Deborah"	A 16 year-old single "lower-risk" Aboriginal woman in her first trimester
"Desiree"	A 21 year-old single "higher-risk" Aboriginal woman in her third trimester
"Eglamtina"	A 21-year old "lower-risk" married woman in her third trimester
"Eliza"	A 35 year-old woman with a history of injection drug use in her first trimester and living with the baby's father
"Elizabeth"	A "higher-risk" single teenager in her third trimester (age not known)
"Emily"	A "higher-risk" woman in her third trimester (age not known)
"Fatimah"	A 26 year-old visible minority "lower-risk" married woman in her third trimester

Pregnant Women Participating in the Study

Name	Description
"Gillian"	A 34 year-old visible minority "lower-risk" married woman in her second trimester
"Grace"	A 17 year-old visible minority "lower-risk" woman in her third trimester living with her partner
"Helen"	A 28 year-old visible minority "lower-risk" married woman in her second trimester
"Isabelle"	An married injection drug user and sex trade worker who is one week post-partum (age not known)
"Jacquie"	A 23 year-old single woman from an HIV-endemic country in her second trimester
"Jennifer"	A 28 year-old "higher-risk" married woman from an HIV-endemic country in her third trimester
"Jessica"	A 28 year-old "lower-risk" married woman in her second trimester
"Karyne"	A 17 year-old "lower-risk" engaged woman in her third trimester
"Kathy"	A 17 year-old single woman with a history of injection drug use in her second trimester
"Kedesha"	A 21 year-old visible minority "higher-risk" single woman in her first trimester
"Kristina"	A 16-year old "higher-risk" single woman in her first trimester
"Leanne"	A 23 year-old "higher-risk" single woman in her third trimester
"Leslie"	A 23 year-old "higher-risk" single woman in her second trimester
"Linda"	A 25 year-old "lower-risk" single woman in her second trimester
"Lisa"	A 19 year-old "higher-risk" single woman in her third trimester
"LisaLee"	A 18 year-old "higher-risk" single woman in her second trimester
"Lual"	A 26 year-old "lower-risk" engaged woman from an HIV-endemic country in her second trimester
"Mariah"	A 17 year-old "higher risk" single Aboriginal woman in her third trimester
"Marion"	A 33 year-old "lower-risk" married woman in her third trimester
"Mary"	A 24 year-old "higher-risk" separated woman in her first trimester
"Morning Star"	An 18 year-old "lower-risk" Aboriginal woman in her first trimester living with her partner
"Nancy"	A 22 year-old "higher-risk" married woman in her second trimester
"Natasha"	A 32 year-old visible minority "lower-risk" married woman in her third trimester
"Pebbles"	A 35 year-old "higher-risk" engaged Aboriginal woman with a history of injection drug use in her third trimester
"Polly"	A 29 year-old "lower-risk" woman from an HIV-endemic country in her third trimester living with her partner
"Rachael"	A 34 year-old single woman from an HIV-endemic country in her third trimester

Pregnant Women Participating in the Study

Name	Description
"Sally"	A 17 year-old "higher-risk" single woman living in her first trimester
"Sandra"	A 34 year-old "higher-risk" woman in her second trimester living with her partner
"Sarah"	A 41 year-old "higher-risk" single women who injects drugs and is in her first trimester
"Seiko"	A "lower-risk" single woman in her thirties in her first trimester
"Suzanne"	A 26 year-old "lower-risk" married woman in her third trimester
"Tammy"	A 17 year-old "higher-risk" single woman from an HIV-endemic country in her third trimester
"Vivianne"	A 25 year-old single woman from an HIV-endemic country in her third trimester
"Yvonne"	A 30 year-old visible minority "lower-risk" married woman in her second trimester
"Zenny"	A 17 year-old "low risk" single woman in her third trimester

APPENDIX 11

DESCRIPTIVE PROFILE OF THE PREGNANT WOMEN

Descriptive Profile of the Pregnant Women

Characteristics		Total (N=57) N (%)
Age (years) [a]	Mean	25.0 ± 6.8
	Range	16 – 41
By Group:	Under 20	16 (29.6)
	20 – 29	23 (42.6)
	30 – 39	15 (27.8)
Trimester		
	First	12 (21.0)
	Second	17 (29.8)
	Third	27 (47.4)
	Post-partum	1 (1.8)
Marital Status [b]		
	Married	16 (28.6)
	Unmarried	28 (50.0)
	Cohabiting	8 (14.3)
	Engaged	3 (5.3)
	Separated	1 (1.8)

[a] Data missing for 3 women
[b] Data missing for 1 woman

...continued

Characteristics	Total (N=57) N (%)
Country of birth [c]	
Canada	28 (53.8)
Africa	4 (7.8)
Asia	4 (7.8)
Caribbean	6 (11.5)
Central or South America	3 (5.8)
Europe	2 (3.8)
Mexico	2 (3.8)
Middle East	1 (1.9)
U.S.	2 (3.8)
Years in Canada [c]	
1 year or less	3 (5.8)
2 – 5	8 (15.4)
6 – 10	7 (13.5)
11 – 20	5 (9.6)
21 – 35	2 (3.8)
Lifetime	27 (51.9)
Language spoken at home [c]	
English	30 (57.7)
French	1 (1.9)
English and French	4 (7.7)
Bengali	2 (3.8)
Spanish	3 (5.8)
Middle Eastern	1 (1.9)
Other European	3 (5.8)
One or more various	8 (15.4)

[c] Data missing for 5 women

...continued

Characteristics	Total (N=57) N (%)
Ethnicity [d]	
Canadian	4 (8.0)
Aboriginal	5 (10.0)
African	3 (6.0)
Albanian	1 (2.0)
American	1 (2.0)
Bangladeshi	2 (4.0)
Black	4 (8.0)
African-Canadian	1 (2.0)
British-Canadian	2 (4.0)
Dutch-Canadian	1 (2.0)
French-Canadian	2 (4.0)
French-Aboriginal	2 (4.0)
German-Canadian	1 (2.0)
Greek	1 (2.0)
Indian	1 (2.0)
Lebanese	1 (2.0)
Mexican	2 (4.0)
Scottish	1 (2.0)
Spanish	2 (4.0)
White	1 (2.0)
Mixed race	4 (8.0)
Unsure	8 (16.0)

[d] Data missing for 7 women

...continued

Characteristics	Total (N=57) N (%)
Highest level of education [e]	
Some high school	14 (26.9)
Currently in high school	7 (13.5)
High school	13 (25.0)
Some college or university	8 (15.4)
College or university	10 (19.2)
Currently employed [f]	
Yes	20 (39.2)
No	25 (49.0)
Student	6 (11.8)
Level of 1999 Income [g]	
< $12,000	6 (12.0)
$12,000 - $19,999	8 (16.0)
$20,000 - $34,000	5 (10.0)
$35,000 - $59,000	4 (8.0)
≥ $60,000	7 (14.0)
Unsure	20 (40.0)
Source of 1999 income (all sources) [f]	
Welfare/social assistance/disability	18 (35.3)
Partner	14 (27.5)
Parents	7 (13.7)
Self	18 (35.3)

[e] Data missing for 5 women
[f] Data missing for 6 women
[g] Data missing for 7 women

...continued

Characteristics	Total (N=57) N (%)
Source of support (all sources) [h]	
Husband/Partner/Baby's father	32 (61.5)
Family	24 (46.2)
Doctor/Midwife	9 (17.3)
Friends	10 (19.2)
Social programmes	6 (11.5)
None	1 (1.9)
Number of previous pregnancies [i]	
0	20 (36.3)
1	21 (38.2)
2	9 (16.4)
3	2 (3.6)
≥4	3 (5.5)
Number of children at home [j]	
0	37 (68.5)
1	13 (24.1)
2	4 (7.4)
Plans to have other children [h]	
Yes	11 (20.8)
No	23 (43.4)
Undecided	19 (35.8)

[h] Data missing for 4 women
[i] Data missing for 2 women
[j] Data missing for 3 women

APPENDIX 12

RECOMMENDATIONS FOR WOMEN'S BROCHURE

TABLE OF CONTENTS

1.0 Utility of Written Text 309

1.1 Written text endorsed as component of pre-test discussion 309
1.2 Format of written text as both brochure and poster 310

2.0 Design / Layout of Brochure 310

2.1 Design of front cover 310
2.2 Personalised narratives 310
2.3 Language level/Scientific language 311
2.4 Tailored language requirements 312

3.0 Content of Brochures 312

3.1 Generalised content 312
3.2 Synthesised content – Information essential to include 313
3.3 Tailored content is essential 314
3.3.1 Information for teens 314
3.3.2 Information for immigrant women 314
3.3.3 Information for low risk women 314
3.3.4 Information for street youth 315

4.0 Distribution of Brochures 315

4.1 Distribution by health care provider at point of discussion 315
4.2 Public display of brochures 316

5.0 Other Dissemination Strategies 316

5.1 Television commercials, public service announcements as effective strategies 316
5.2 Newspaper coverage 317
5.3 Pharmacies as point of dissemination of advertisements 317

The researcher engaged the pregnant women in a discussion around their perceptions of the utility, design, content and dissemination strategies of a brochure for pregnant women explaining Ontario's prenatal HIV testing programme.

The discussion led to recommendations of other strategies for information dissemination including TV programmes, TV commercials and media coverage.

1.0 UTILITY OF WRITTEN TEXT

1.1 Written Text Endorsed as Component of Pre-test Discussion

Most women had wanted far more information than they received at the time of the offer of their HIV test. A brochure by itself was seen to have limited information value:

> *Yeah, every brochure just sits in the doctor's office. It's not the same as speaking to your doctor or seeing somebody to talk about it.*
>
> *It's really hard in a brochure, 'cause it's not everybody that's gonna take it and read it. They're probably gonna put it in their purse and forget it's there, or put it in the garbage or...*

However, many women emphasised the importance of written information ***alongside*** the discussion with their health care provider:

> *I think a pamphlet would be sufficient. Yeah. I think a pamphlet would be sufficient,* ***with the offer to discuss the material.*** *Something simple that could allow me to quantify the risk a little bit better.*

Written material enables the pregnant women to process the information at their own pace:

> *I think it would be a good idea, coupled with the counselling. Um, maybe just to uh, reassure the women that, you know, depending on what the poster says or the pamphlet says, um,* ***when they're away from the doctor they can read that, and maybe process that on their own.*** *You know, uh, making them a little more comfortable with the test. So I think that they're important.*

1.2 Format of Written Text as Both Brochure and Poster

While the attraction of a brochure was that it could be read and discussed outside the health care provider's office, some women took the information from the poster and not the brochure:

> *Yes, I saw the posters. There were pamphlets; I just didn't read them. But I saw the posters - so I thought, "same thing." Yeah, like the thing was, I saw the poster, so seeing the pamphlet I was thinking, "I've already read the poster; it's probably the same thing."*

Whereas, this woman emphasises the need for both:

> *I'm not the type of person who looks at posters. I look at them and ignore them completely. Posters, to me, are not...but certainly I work in some rural areas back home, and they work really well. The posters, especially if you are targeting uneducated groups. They have all these pictures and they work really well. But it really depends. Me personally, I don't even look at posters.*

2.0 DESIGN / LAYOUT OF BROCHURE

Recommendations to entice pregnant women to read the brochure included:

2.1 Design of Front Cover (i.e., judging the book by the cover):

> *Yeah, well, from the fact that I'm pregnant, anything that has a pregnant woman on it, I'm going to look at it. As soon as I see that I'm like, "Hey, what's that!"*

> *The colours and the designs and, you know, some of the things, the wordings, they [need to be] large, they're right there, they stand out. If I was personally designing one for HIV, it wouldn't be a picture like this. More my design – see I'd make them as real as possible. So more my design would be a needle and somebody you can test HIV, somebody saying you can get HIV, well, I would write sex there, 'cause you don't draw a picture of that, but like needles and stuff like that.*

2.2 Personalised Narratives

Several women explained that they needed to see themselves in the brochure in order for it to retain their interest and ensure continued reading. The brochure needed to speak to the women individually, to be relevant to their individual life circumstances. One woman offered a concrete suggestion as to how this could be achieved by presenting the information as vignettes of realistic life stories of pregnant women and their thoughts and experiences around HIV testing:

Graphics make a big difference. Um, maybe what would catch my eye, if you put it to me in a story form. For example, this I would find to be most interesting. If you give me four versions: this lady is into drugs, this lady is into, this lady is into nothing and just use the issue of her partner or her husband. And you use real names, that would attract me more than a list. Little cases. You try to make them as close to the reality as possible, and it depends on your issue, information or a push to have the test? Put one into telling the woman like me. You give her that loophole, and that's why she does the test, and it's positive, and this is what we can do. That to me would stick in more.

Many women endorsed this narrative approach over more straightforward and bland risk factor or statistical information:

Those are the way the pamphlets are, these are the list of the risk factors, those drugs, and I just look at it and throw it away... Yes, if it was presented in a way that would not assume anything about me ...We all know the way things are presented makes a big difference. But I wouldn't read any statistics or stuff like that.

2.3 Language Level / Scientific Language

Issues around the reading level of the language to be used and the inclusion of scientific and medical terms were discussed by many women. This younger woman speaks directly to the challenge of attracting teens with the appropriate reading level and use of terms:

So if there's a word they use that's huge and scientific and if they don't think someone will understand it, in brackets they put something that a teenager would understand, the slang word for it. A lot of these kids don't have an education; they can't read. It's really hard for them. And they look at words that are 12-letters long. They're not even going to read it, right? ***But when someone sees it where it's something we can understand, like slang words, then they'll read it because they know, "Oh I'll read this; why not."*** *Yeah, because the way they look, people look at them quicker, you know, and read them. It's a lot easier for teenagers in the street to read it when it looks like that, bright, in sort of a comic style, and using street language.*

2.4 Tailored Language Requirements

For women for whom English was not their mother tongue, the necessity of translating any information into their own language was paramount:

> *I didn't find it in Spanish, just English. All of them is in English. But if you find that in English, that's hard because so many people is difficult to read it, right? Because they don't go to the school, and some of them go, and is difficult too. But if more people doesn't go to school, where can they find it? They can't read it in English.* ***But if is in their language, maybe they can try to read.***

Unilingual brochures deter pregnant women from accessing the information they need:

> *Unfortunately for the Spanish community today, so many people don't speak English, or even if they do speak English they are too lazy. It's just like, I find out, some Portuguese or Italians, they are here for so many years, and they don't try to speak the English.* ***If they see some brochures in English, they won't try to take one.***

3.0 CONTENT OF BROCHURES

3.1 Generalised Content

> ***Why*** *it's being offered;* ***when*** *it's going to be offered - I think there should be maybe a standard practice when it's offered. It should not be offered at the maternal screening time. Timelines for expecting results; pros and cons to the testing; types of testing that are available - what's available from the physician; and then phone numbers to call to find out other places to go. What else - um, certainly what happens if it's positive; what is the impact on the foetus, on the mother. What are the next steps; emotional support; impact on family; testing for partners, that kind of stuff. It would have to be a 10-page sheet!*

> *I think I would first and foremost want to say, up-front, HIV, the choice is yours, you know. This is your choice to make. These are some of the facts. Here's the risk factors. Here's the prevalence, or incidence, or whatever. Here's how many women, here's how many pregnant women. Those kinds of things, you know. Why during pregnancy? Why should you take the test during pregnancy? Because, you know, we can think about your health issues. How it affects your baby, um and. So, think about in those terms. Here are places that you can go to get HIV testing, if you should decide. And, if you get a positive result, here's what's happened. Here's the people you can talk to, your health care provider. You can talk to these people. You can phone all these places, you that, sort of, like you're not alone. But again something very non-judgemental.*

That it doesn't hurt and if you go to the right person you can be completely comfortable about it and that it's a really good thing because you know what to do to protect your baby. I would put that it's a free test, and that you are not obligated to take it and that it's done in confidentiality and that they can't tell anybody and that you will talk to a counsellor before you have the test and that if you need to, you can talk to a counsellor after you get the results and that it will be done as quickly as possible, the results will come in as quickly as possible and that it's totally their decision. I would tell them that they would know if they had HIV or not and that it could help them take better care for themselves and their baby. And that what the risk factors are, and if they were at risk, what they should do. That just because you test negative for HIV, doesn't mean that you will test negative for other things and that the tests that they give you are really important. And that even though they're optional that you should take them.

3.2 Synthesised Content – Information Essential to Include

Many topics were cited as important to include in the brochure to allow women to make informed decisions about the tests. The subjects listed included:

- the nature of the test – what's involved, timing, range of testing options, no fee for test, window period;
- the reasons for taking it – early diagnosis and treatment for the mother, prophylaxis for reduction of risk to foetus and child;
- the consequences of a positive result;
- assistance with disclosing positive result to partner, family and friends;
- choices following a positive result;
- effects on the women's health – disease and treatments;
- effects on the health of the infant – disease and treatments;
- treatment available for themselves;
- treatment/interventions available to reduce the risk of their unborn child contracting the virus;
- treatment for the child after birth if it contracts the virus;
- social and financial supports available; and
- the reporting and handling of the test results.

3.3 Tailored Content is Essential

The information on HIV counselling and testing needs to be tailored to the specific individual needs of pregnant women. This concept relates directly to the earlier suggestion of individual case histories for the conceptual framework of the brochure.

3.3.1 Information for Teens

That it's not the end of the world; that they have to get an HIV test. That every adult, eventually, probably has one because of some circumstance in their life and it's not – it's not a disease that's discriminatory. It could happen to anybody, whether you're white, black, purple with polka dots, straight, gay you know – it doesn't choose who it's going to attack and that if you feel that you're at risk, it's very important thing to get a test because you could be putting other people at risk without realising it. That it doesn't have to be a scary thing and that there are people out there who will support you regardless what your decision is. But I think that you should get the test so that you know once and for all and that you protect yourself. Because you have to look out for you. I find that on some level when they direct things to teens, not really directing it to teens, they're directing it to children and they use like small words and they explain things over and over and over and they think that we don't listen and we have to read something like five times in order for it to sink in. So, they're not really based on us.

3.3.2 Information for Immigrant Women

[Interpreter speaking] *She says that there should be more information for women who immigrate to this country because in her country there is not a lot of information about this HIV positive. And then, some women, they get offended when their doctor try to talk about this disease. You not get this disease just by having sex. Some women they don't know this. Like say from transfusion... She says that it would be very interesting to have more programmes for people who are new immigrants to know more about this disease... It [a brochure] should be in other languages so it could be help to all the women.*

3.3.3 Information for Low Risk Women

Maybe review some of the risk factors, so they can sit there and say, "Wow, I didn't realise what that was," or that kind of thing. Because generally pregnant women in not-high risk groups, there's not a lot of information geared towards them. Like if you go into an HIV clinic or a walk-in clinic somewhere, you're going to see information there. You're going to see brochures and pamphlets. But if you're a married woman in your 30's you're not going to be exposed to the same kind of information.

3.3.4 Information for Street Youth

Yeah, but you need to get it out to mostly street youth, also who are getting targeted, you know. And where are they going to watch TV? You could just do like a newsletter, basically for street youth or something. Like you could talk about anything, but make sure you have something on HIV in pregnancy. And you can't be all medical or professional about it. You have to be straight out, blunt, use whatever words you want just to get the message out. Because if you use all these huge words, they're going to be like "whatever" and throw the paper away. But if you're like HIV, blah, blah, blah, they're like, "Shit, okay" and it gets through to them. Well, um I can't remember if [name of city] has it, I think they do, but here in [name of city] they have on Cable 13 messages like, "Are you abused? Go to Interval House" and their number. So maybe have one thing on there every six minutes about pregnancy and HIV testing. Um, posters, brochures, newsletters to street youth, even if you have to put it on the buses. Like, they have ads for Viagra on the bus, so why not have something a little bit more important than Viagra - like HIV testing up there.

4.0 DISTRIBUTION OF BROCHURES

The pregnant women had different needs concerning accessing the brochures emphasising the need for a range of distribution strategies.

4.1 Distribution by Health Care Provider at Point of Discussion

Brochures should be given to the woman by her health care provider at the time of discussing the offer to test for HIV:

I don't know, because I don't even check out the flyers in the doctor's waiting room. But I'll take what he hands me in his office. Because you're right in front of it; it's what you're looking at, what you're thinking about. When I kind of see them off the wall, I don't really. So if my doctor offers me something in his office, a pamphlet, I tend to take it and read it.

The only brochure I ever had was the one she gave me. I never really stopped and looked at the brochures [in her office].

This strategy would remove some of the problems perceived to exist if the brochures are on public view, and would help time-challenged women:

> *...because something like that, when it's sitting in the doctor's office, no, everyone's too embarrassed to go and pick it up anyways. And that's – and you can see it. People will walk by and look at it and keep walking and look at something else and you know. People are very scared about HIV.*

> *It depends on how long the wait is, or that kind of thing. With him, it's pretty much you're in and you're out, so there's not a lot of time to sit and look around and read or whatever. You're pretty much in and out of there. And half the time you go to the magazines before you go to the brochures. Because they always tend to have like, Parenting magazines or whatever. Usually it's on your lunch, or whatever you're doing, you just want to sit and vegetate or flip through. Yeah, I don't usually read the brochures.*

4.2 Public Display of Brochures

However, brochures should also be displayed in the waiting room, washrooms or other public areas of the health care providers' offices to remove problems in personally accessing information:

> *They should have more brochures and pamphlets in doctors' offices. Like sometimes, you know, women could be too shy to ask for the information. They should have it so if they are too shy, they can just take it. Same with the uh, the planned parent places. They should have, I don't know if they have it there. I don't see why not.*

> *It's like, when you see pamphlets, like me, you have to read them – you see a lot of people reading about this and that. When you're in there, people don't feel ashamed, I guess. It's just a pamphlet. People don't think you have it. It's not hard to read them. I sit there and read them all the time, and I may just fold over the front page so people can't see what I'm reading. But lots of people in there read it. They have no problem with it.*

5.0 OTHER DISSEMINATION STRATEGIES

On the basis that pregnant women "don't go to a doctor's office every day to read their stuff", the women interviewed recommended other dissemination strategies:

5.1 Television Commercials, Public Service Announcements as Effective Strategies

> *Some people don't read anything. You can put things up but they won't really; they're not interested. TV, everybody watches TV.*

Television. I think television is the biggest thing. Pamphlets are very good while they're there, but they don't really catch your attention, you know what I mean? You're not going to walk in a doctor's office and look around for it. I think that television is the best place, because everybody watches TV. I don't care who you are. Everybody at least at some time in their day watches television – I think yeah!, I think if they put it on TV more, I figure if they have a pregnant woman speaking about it, and a real-life experience, basically, that they should have a program on it is what they should have. And I know in [name of city], my God, they have the money up there. So, you know, there is funding out there that can do that.

Maybe ads on TV. It's not everybody who picks up the newspaper every day. Maybe in the women's magazines or in those Expecting magazines. Probably a catchy commercial, like all the drinking and driving commercials are very catchy, they're very in-your-face kind of commercials. Something of that would make it stick in your head, and then the next time you go [to the doctor's], chances are you'd remember to say something. I think that would probably be the approach that would be most effective, for myself or my friends, that would probably be the one that would get through.

5.2 Newspaper Coverage

If you go and put in the newspaper about HIV and that's also another way to get it out, 'cause a lot of adults read it. Announcements on radio shows would be good too. See I'm like, anything you can [do to] get it out. You want to put it in commercials. Put it in commercials because people watch commercials. Anything that will catch people's eye, because these [brochures] are good, but people don't always follow them.

5.3 Pharmacies as Point of Dissemination of Advertisements

It's like there should be ads everywhere, like in Shoppers Drug Mart, that say to take 4 with aspirin before you're pregnant, or whatever - like more of a campaign like that. In pharmacies, because that's generally where they go to pick up the pregnancy test, like in that aisle - maybe some brochure hanging there. Something like that, because that's generally first where people find out, because they do a home testing first. Or an insert, if you can get the pharmaceutical companies to put an insert in the box saying, "Test for HIV." Because whenever I go to Shoppers Drug Mart, they have flyers on everything in there. So they could have one available for that, in the box or even in that aisle. Maybe if there were ads in the subway, or on something that you do every day – watch TV, use the subway, or read magazines.

APPENDIX 13

RECOMMENDATIONS FOR HEALTH CARE PROVIDER'S HIV COUNSELLING AND TESTING CHECKLIST

TABLE OF CONTENTS

1.0 Policy Recommendations 320

1.1 Offer to test should be introduced to all women outside of pregnancy ... 320
1.2 Discussion of HIV test should take place over several early prenatal visits 321
1.3 Discussion of HIV test should not be integrated with discussion of other prenatal tests 321

2.0 Programme Recommendations: Principles of HIV Counselling and Testing 322

2.1 Voluntary nature of the HIV test must be upheld 322
2.2 The decision to test remains the woman's choice 323
2.3 Requirement for informed consent must be upheld 323
2.4 Pre-test counselling: Required components 324
2.4.1 The offer to test should be normalised, its importance and universality explained 324
2.4.2 Health care providers need to reassure pregnant women that standard of care will remain the same whether or not they are tested 325
2.4.3 Equal emphasis should be placed on a discussion of the advantages and disadvantages of HIV testing and of treatment options for both mother and child 326
2.5 Communicating test results 326
2.5.1 Test results must be given in person 326
2.5.2 Test results must be given promptly 327

1.0 POLICY RECOMMENDATIONS

1.1 Offer to Test Should Be Introduced to All Women Outside of Pregnancy

The Ontario policy states that the Ministry of Health will make voluntary HIV antibody testing available for all pregnant women and women planning a pregnancy. It would appear that the last sentiment needs to be pursued more actively as the general consensus was that pregnancy was not the appropriate time to raise with women the issue of HIV infection or to offer testing:

> *But, is best if you talk to someone before she's pregnant. And just try to explain everything. Because, it is very difficult. You are pregnant. You see that now I have HIV, what I supposed to do? I have to keep my baby, not to keep my baby. What? That is a stress, eh? You know it's going to be a great big stress. I don't think if I can handle that. So I not sure about this test right now in my thinking.*

Several women explained that had they had a greater awareness of HIV in general, and perinatal transmission in particular, they would have chosen to have been tested prior to pregnancy as knowledge of their status would have been a factor in their decision to become pregnant:

> *At least I would have gotten it done beforehand, that's if I had known about it. Because then you can make a more informed choice of about whether or not you want to get pregnant or not.*

> *No, I think before is better. Because if you have that risk, you can prevent bringing a child, right? But if, for me it was better they do it before, because I prevent if I have that infection. Maybe I don't try to bring a child. Sure they have a little risk, but they have it, right? But I think is better before...*

The Guidelines suggest that HIV testing should be offered routinely at visits for pap tests and consultations about contraception or STDs. Clearly, pre-conception testing maximises a woman's choice and prevents having to make life-altering decisions after the fact, as we have heard other women describe:

> *To explain to people, it is better to do that before. Because when you do that before, you can say, "Now I know." If both, if we have HIV, we have this disease and we decide we're going to have a baby and we know we are responsible for that.*

1.2 Discussion of HIV Test Should Take Place Over Several Early Prenatal Visits

The Ontario policy, as outlined in the Counselling Checklist, requires counselling to be done during the women's first visit and that women must be given the option of being tested at that first visit or at a subsequent prenatal visit. However, it is clear that this directive is acting against some women accepting the test. The policy as stated in the guidelines that counselling should be carried out over a series of prenatal visits should perhaps be considered.

> *I wasn't expecting to be asked. So my husband and I hadn't actually discussed it beforehand. So we said no. I think it would have been more helpful to actually know that that was one of the things I was going to be asked about at my next visit. I hadn't even thought about it.*

1.3 Discussion of HIV Test Should Not Be Integrated With Discussion of Other Prenatal Tests

If health care providers did discuss the range of prenatal tests available, many women were surprised to hear a test for HIV included in the list. Aware of and expecting the "usual" tests, women did not feel comfortable questioning the inclusion of the HIV test and agreed to be tested rather than initiate a discussion with their health care provider:

> *Because it was presented in such a nonchalant way, I think I would have been a little hesitant to say, "Oh no, I don't think I want to do that." I could have probably passed it off as, "No, I know a better way to be tested – it's called anonymous."[LAUGHS] And she might not have taken too much from that. But I think it would have been a little difficult for me to say no to it.*

In consequence, many women wanted more attention paid to this "new" test and in particular suggested that it should be discussed separately from the maternal serum screening:

> *I was kind of curious why she waited four months. I thought, that's the other thing. When I went for my pregnancy test, it was a urine test, I thought they might have offered me some testing at that time. Why did they wait? Why was it lumped in to the maternal [serum] screening time? And is it just because it's easy just to take all the blood at once? But I think it could have been offered a lot earlier. Especially with what I know about medication and the benefits of it – why did I not get tested sooner? Then it could have been separate from the maternal [serum] screening, because the maternal [serum] screening is way too important. As a pregnant woman, that's the test you want to know about. Do it much earlier than four months, not the day you get the pregnancy results, that's not the time to do the test, but maybe it's the next obstetrical check which is about a month later.* ***I think HIV testing should be a focus of the discussion. I***

think that should be separated from the maternal [serum] screening or anything else. Because it needs to have much more importance than it does. *For me, the biggest thing would be what happens to my results, and what does that mean for my health and the baby's health – that kind of stuff. I think because you see the physician so many times when you're pregnant, there's enough opportunity to, say, the first visit your pregnancy test comes back and she talks about the process – well then in that process - then the next visit you'll talk about the HIV testing that's offered. So at the second visit you talk about the testing, then maybe at the third visit you actually do the test. So it gives people a bit of time to talk about it, or even think about it.*

2.0 PROGRAMME RECOMMENDATIONS: PRINCIPLES OF HIV COUNSELLING AND TESTING

Authoritative guidelines for physicians in Canada, emanating from a range of professional organisations and licensing bodies, have clarified the underlying principles in testing for HIV.

2.1 Voluntary Nature of the HIV Test Must Be Upheld

The first underlying principle in testing for HIV referred to in the Guidelines is that,

> *Testing for HIV should always be voluntary...*

This principle is reflected in the Ontario Minister of Health's letter to Ontario physicians announcing the Prenatal HIV Testing Programme,

> *The Ministry of Health will make voluntary HIV testing available.*

The voluntary nature of the test is not however emphasised in the Counselling Checklist and this omission needs to be addressed. The concern exists that HIV testing may become so well integrated in the practice of routine prenatal care that pregnant women may have, or believe they have, no meaningful choice to make. For example, when very high rates of acceptance are reported by individual physicians or specific health units, one obvious concern is that the consent process may not have been adequate and that women may not have realised that they could refuse, i.e., that prenatal HIV testing in Ontario is voluntary. In this study, many of the women felt that they did not have the option to voluntarily participate in testing:

> *I probably could have said, "No, I don't really want to." But I kind of felt that it was just part of the whole package and I didn't think I had a choice.*

2.2 The Decision to Test Remains the Woman's Choice

Health care providers appear to have the potential to unduly influence patients' decisions and thus render the opportunity of testing as less than a voluntary experience. Some of the women, who thought that testing was not part of the whole package but rather was at the discretion of the woman herself, shared their perceptions of their health care provider's influence on their decision making:

> *Dr [name of doctor] says she recommend it and she make me feel it is very important to have this test. And I couldn't say no.*

This study does suggest, however, that it is possible to achieve at least a minimal threshold of voluntariness in a clinical setting, providing health care providers are sufficiently committed to communicating to pregnant women their respect for patient choice:

> *She provides you with the information you need. And it's your decision to make of what you want done. And she gives the options you have in terms of that. But she didn't push me one way or the other. To have it done was my choice.*

2.3 Requirement for Informed Consent Must Be Upheld

A major emphasis in the Ontario Counselling Checklist is the concept that while all pregnant women should be offered HIV antibody testing as part of routine prenatal care, the pregnant women needs to consent to the test before it can be actually be administered,

> *The test will not be done without informed consent.*

Similarly, in addition to stipulating that testing for HIV should always be voluntary, the Guidelines state categorically that testing for HIV should always be carried out only after the patient has given informed consent,

> *Testing for HIV should always be voluntary and carried out only after the patient has given informed consent.*

Based on the narratives shared by the women with whom testing for HIV had been raised in their pregnancy, most of the women were very clear that they had not, in fact, given their consent to be tested:

> *It wasn't consent really. It was more like, this is the way it's going to be.*

> *I thought it was mandatory, so I didn't question it. It was more like, "This is what you are getting tested for today."*

> *I didn't really consent. No. Not at all. I felt that it was a part of the test and I just went along with it.*

The Ontario Counselling Checklist states,

> *The purpose of counselling women about HIV antibody testing is to give women the information they need to understand the benefits and risks of the test. Only when women understand the benefits and risks are they able to give their informed consent for the test.*

This concept of the necessity of information before informed consent can be given is well described by one woman who addressed the necessary requirement for adequate information before informed consent can be given or indeed accepted:

> *Well, I went along with it. She didn't really come out and ask for a consent the way I know consent should be asked for. Because there was no discussion about the test, because there was no information given about the test, I certainly couldn't – I did not give* ***informed*** *consent. I gave my agreement. I gave consent to do it – but she gave me no information. So how can that be informed consent?*

In explaining her need for more information. This woman introduces the necessity for pre-test counselling which is considered next:

> *He should have explained it more. And explain the consequences – and all the things that could happen. He didn't even explain anything. He should have explained. He should have told me more about it – and he should have just explained like if somebody had it, the different things that they could do. And if there is any programmes or anything. It wouldn't be good if the results were positive then I wouldn't know about anything you know.*

2.4 Pre-test Counselling: Required Components

The pregnant women interviewed had many suggestions regarding the topics to be discussed with their health care provider before accepting the offer to test. These topics were mostly those absent from their own discussions and which, on refection, they felt they would have liked to have known about before accepting or declining the offer to test. The following itemised components are additional to those listed in the section on the content of the women's brochure.

2.4.1 The Offer to Test Should Be Normalised, Its Importance and Universality Explained

> *I do think it should be offered to everybody. But I think it has to be explained, and unfortunately for me it has to be explained that, that it's not anonymous. If they could find a way, like I said, I said that before I think, but if they could find a way to guarantee anonymous testing in the doctor's office then I think that would be perfect. But I still think it should be offered. Yes, and I think it should be made clear to them that everyone is offered the test, um, so that people don't feel*

stigmatised and they don't feel because again, people, friends of mine who have had children four or five years ago who were offered the test sort of would take them aback and say, "Well, do I look like I need the test?" Like, "Well, why would you be asking me?" kind of thing. So if you're not informed, I assume people, a lot of people, would react like that. So, I think it should be made clear to people, that everyone's offered the test. "And this is why we are doing it, and here are the risks, and here's -" Even give stats on HIV and say, "You know, you may not think that you might be at risk but, you know."

2.4.2 Health Care Providers Need to Reassure Pregnant Women that Standard of Care Will Remain the Same Whether or Not They are Tested

Many women alluded to future implications for their prenatal care if they declined the offer to test. For some women the concern was the interpretation of their reasons for refusal while for others the concern was for the continuance of their prenatal care if they did not take up their health care provider's suggestion to test for HIV in their pregnancy. These perceptions of the consequences of declining the test could be dispelled by the health care provider at the time the offer to test is made:

I guess because I didn't want to cause any problems. I didn't want to like, fight her on it and you know, if she though it was very important, I didn't want to say, "No, I'm not having it. I refuse on moral grounds." I didn't know what to say, other than say, "I don't want to have the test." But I knew that I was negative, so I was saying, "What's the big deal? I'm gonna have it." I guess somehow in my mind I'm thinking, just by having the test, I'm confirming that there could be a risk that I have it. But then I thought, but if I don't have the test, she's gonna wonder the whole time, why didn't she have the test and they're gonna, you know, think about why didn't I want to have the test. So I just decided to have it.

It very clearly wasn't a huge deal for her. She was sort of doing it because she felt like she was supposed to and because after I turned her down she said, "Well you know, I don't feel – some doctors feel that everyone should be tested, but I don't see that as all that necessary." And so after I had sort of [LAUGHS] blown my top, she very much put me at ease with that and she really made it clear to me that this wasn't going to affect how she was going to treat me, or that she was going to worry around me or anything like that...I sometimes worry that if you turn doctors down for stuff that they feel is very important they, you know, I mean I want her to trust my judgement as well. I mean, I trust her judgement but she has to know that somewhere inside me I must have whatever brain I had before I was pregnant so.

2.4.3 Equal Emphasis Should Be Placed on a Discussion of the Advantages and Disadvantages of HIV Testing and of Treatment Options for Both Mother and Child

An emerging theme from this study is apparent evidence of an imbalance between concerns for potential future infection compared with possible current infection. An emphasis on fetal benefits – on reducing the risk of HIV infection to the child – and a neglect of the needs of the possibly positive mother.

> *It wasn't presented in a way that was saying, uh, we want to get HIV testing so that* ***you*** *can be aware if you're HIV positive, and so we can be aware that you are, it was so that the* ***baby*** *is safe. So that, you know, your care can be assessed so that we can understand what's happening with the baby so that you know. Because I think that she was saying that there's new things that they can do to reduce the risk of transferring HIV to the baby through the delivery. So she was saying that's important for us to know, you know, so we have that. I don't think it was really presented in a way that was um, so that* ***you*** *can be aware of it and that type of thing. Uh, I guess that as a physician, as an obstetrician,* ***the doctor should have I think, a two-pronged focus – on the mother and on the child.*** *And I think that um, you know, I think maybe there could have been more of a focus on the mother, like, as in, so that* ***you're*** *aware of that, and we can get* ***you*** *care. Um, nothing was said to* ***me*** *about uh, you know, if I did have this disease, what kind of care* ***I*** *would get, what kind of treatments or what kinds of, you know, what was the course of action for me, even after this baby, nothing like that.*

2.5 Communicating Test Results

2.5.1 Test Results Must Be Given in Person

The Counselling Checklist stipulates that all test results should be given in person, not over the phone. This directive was heavily endorsed by the women in the study:

> *I think the results have to be done on a one-to-one basis with the doctor, someone that they trust. And provided in a very caring and sensitive way. With all the options laid out of what they can do, what their options are – during the pregnancy, after the pregnancy, etc. and what the risks are for the foetus.*

> *I think it's best to tell the person face-to-face in person rather than over the phone so you could see their facial expressions so that he can calm you down if you're crying or anything. Cause if you're at home, especially if you're alone too, you could go crazy, anything could happen. You could take the anger all on your shoulder and a family member or anything but if you're at the hospital or the doctor in person he can calm you down, he can help you.*

2.5.2 Test Results Must Be Given Promptly

Most women were very clear that when visiting their health care providers for the return of their HIV results, these should be given promptly with minimum introductory preamble in order to reduce the stress to the pregnant women:

> *And when I went into have the results, she didn't tell me right away. She sat me down and she goes "I'm going to read your results and I want to make sure that you're okay with this, and that you understand that this is a test, and it's accurate and that's why it's taken so long," right? And just the way she said it made me think that, "Oh no, she's going to tell me I'm positive," right, so I was so nervous, but then she told me that I was okay. Well, I think if she'd just come into the room and said that it was negative, that would have been easier instead of explaining to me that the test was accurate and – if she'd had said – just come out and said it, I think it would have been easier. 'Cause the way she put it made me think that, "Oh no, it's bad news."*

The consequences of not conforming to this recommendation can be devastating for the pregnant women:

> *When I went to get the [HIV] test results, I remember, I was sitting in the doctor's office for an hour in the room itself. For an hour all by myself in a gown, waiting for them to come and do – they were going to do a pap test. I was sitting there. I was emotional because I was pregnant. I was just looking at the clock and then, 45 minutes passed by and I started crying. I'm sitting here all alone and they're scaring me. I was waiting for the results. So it was like, okay something's wrong because they're taking so long. But then, the doctor came in finally an hour and maybe 10 minutes later and told me my results and said he was sorry they took so long. He told me my results – they were negative. And I was sitting there in like a hospital gown type thing, and just being emotional, being alone, making me wait an hour, I just felt like they didn't care, nobody cared. Well, they could have come in and said they'll be a few minutes and to hold tight, or just to let me know, reassure me that they know I'm here. Like, I thought they just totally forgot about me. And I was too nervous to walk out the door to say, "Hey, I'm still in here." I'm not a very outspoken person in that way. But I sat down alone and cried, and looked at the walls – what about me, I'm still here.*