

**Prevention of Vertical HIV Transmission and the HIV Response  
for Women in Latin America**

**by**

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**A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF**

**DOCTOR OF PHILOSOPHY**

**in**

**The College of Graduate Studies  
(Interdisciplinary Studies)**

**THE UNIVERSITY OF BRITISH COLUMBIA  
(Okanagan)**

**November 2012**

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## **Abstract**

This study uses mixed methods to explore the barriers to implementation of prevention of vertical (mother-to-child) HIV transmission in Latin America generally, and Mexico specifically. In 2001, at the United Nations General Assembly on HIV and AIDS, States made a commitment to achieve 80% coverage of this highly effective medical intervention among pregnant women by 2010. Yet, in 2009, just slightly over half of pregnant women with HIV globally could access medications to prevent transmission of the virus to their child, and in Mexico less than ten per cent of pregnant women with HIV had this opportunity. I identify the regional and national political context and institutional practices as contributors to sluggish scale-up; however, these are undergirded by cultural constructs of who is at risk of HIV infection and gendered sexual norms and discrimination which increase women's vulnerability to HIV. My qualitative and quantitative analysis both identify that women are primarily exposed to HIV within stable relationships. The failure to recognize HIV and AIDS as a significant public health issue for women in the region and to provide women with an opportune HIV diagnosis results in mortality and morbidity among women and their family members. To improve the HIV response for women in the region, the following actions must be taken: greater meaningful participation of women with HIV in both the women's reproductive health and HIV movements; universal offer of HIV-testing during prenatal care; conceptual and functional integration of HIV with reproductive health and gender-violence services; adaptation of evidence-based HIV prevention interventions for women in stable relationships; and the implementation of existing legislation which protects women's rights and institutionalization of gender transformative programs that can contribute to reducing women's vulnerability to HIV.

## **Preface**

A version of chapter 2 has been published. Tamil Kendall and Eugenia Lopez Uribe. (2010). Improving the HIV Response for Women in Latin America: Barriers to Integrated Advocacy for Sexual and Reproductive Health and Rights. *Global Health Governance* 4(1) [www.hghj.org](http://www.hghj.org). I was responsible for the study design and instruments, conducted the interviews with the Mexican policy-makers and activists, completed the literature review and analysis, and wrote and edited the manuscript. My co-author conducted interviews with decision-makers, advocates, and health-care providers in the other seven countries and provided critical input on the initial draft of the manuscript.

Chapter 3 is based on work conducted with Dr. Estela Rivero of the *Colegio de México*. I developed the research hypothesis and conducted the literature review. With my input, Dr. Rivero took the lead on designing the statistical analysis and ran the models. I wrote the manuscript, with the exception of the section that describes the data analysis; this section was drafted by Dr. Rivero in Spanish and I then translated it into English.

Ethics approval for this research was granted by the University of British Columbia Okanagan Behavioural Research Ethics Board (H09-00738). Ethics approval was also granted by the Mexican National AIDS Program (CENSIDA) Ethics Committee (CE-09-04-02 for the qualitative research and CE-09-02-01 for the quantitative analysis).

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## Glossary of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
CAUSES	<i>Catalogo Universal de Servicios de Salud</i> (Universal Catalogue of Health Services)
CDC	Centres for Disease Control
CENSIDA	<i>Centro Nacional para la Prevención y el Control del VIH/SIDA</i> (National Centre for the Prevention and Control of HIV/AIDS)
EIA	Enzyme Immunoassay
ELISA	Enzyme-linked Immunosorbent Assay
GIPA	Greater Involvement of People Living with HIV and AIDS
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV/AIDS
IDU	Injection Drug User
LGBT	Lesbian, Gay, Bisexual, Transgender
MDG	Millennium Development Goal
MSM	Men who have sex with men
NOM	<i>Norma Oficial Mexicana</i> (Official Mexican Standard)
PEPFAR	President's Emergency Plan for AIDS Relief
PMTCT	Prevention of Mother-to-Child Transmission
SRH	Sexual and Reproductive Health
SW	Sex worker
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session on HIV and AIDS
VDRL	Venereal Disease Research Laboratory (test to detect syphilis)
WB	Western Blot
WHO	World Health Organization

## **Acknowledgements**

I would like to express my appreciation of my doctoral supervisor, Dr. Naomi McPherson, and my committee members, Dr. Hugo De Burgos and Dr. Joan Bassett-Smith. They provided good natured, insightful, and timely feedback throughout my doctoral program and on the dissertation.

I received a Pierre Elliott Trudeau Doctoral Scholarship (2009-2012) and a Social Sciences and Humanities Research Council Vanier Canada Graduate Scholarship (2009-2012) which supported my doctoral program and research. I also received a University of British Columbia (Okanagan) Entrance Scholarship (2008-2009) and Graduate Fellowships (2010 and 2011). I was also awarded a Social Sciences and Humanities Research Council Michael Smith Foreign Study Supplement which funded my work with Dr. Estela Rivero at the *Colegio de México* in 2010.

Much of my doctoral research and the dissemination and advocacy activities based on the evidence presented in this dissertation were conducted in collaboration with a Mexican non-governmental organization, *Balance. Promoción para el desarrollo y juventud*. As well as being grateful to the entire staff of the organization for providing me a “home” in Mexico and supporting the synergy between research and action, I specifically want to thank Eugenia López Uribe and Gabriela Garcia Patiño for their help with the regional interviews and content analysis. This collaboration was supported by grants from: UNIFEM (now UNWOMEN) sub-regional office for Mexico, Central America, Cuba and the Dominican Republic; UNFPA’s Regional Office for Latin America and the Caribbean; and the Ford Foundation office responsible for Mexico and Central America.

I also thank all of those who shared generously of their time and knowledge to participate in my research, particularly the women with HIV who shared their stories.

**Dedication**

*All my relations*

## **Chapter 1. Introduction**

### **1.1 Research Objectives and Chapter Overview**

According to the Joint United Nations Program on HIV/AIDS (UNAIDS), in 2009 there were an estimated 34 million people living with the Human Immunodeficiency Virus (HIV) and 1.8 million deaths related to the Acquired Immune Deficiency Syndrome (AIDS), which is provoked by HIV's destruction of the immune system (UNAIDS 2010a). Of those living with HIV slightly more than half (52%) are women (UNAIDS 2010a). In 2008, 430,000 children younger than 15 became infected with HIV, 90% of them acquiring the virus during gestation, birth or breastfeeding, and 270,000 children died because of AIDS (UNAIDS 2008: 32-38). The vast majority of these deaths could have been avoided through prevention of mother-to-child transmission (PMTCT) of HIV<sup>1</sup>. PMTCT has three possible components: antiretroviral treatment during pregnancy, labour and post-partum; caesarean section or, if the woman's HIV is well-controlled, vaginal birth; and formula feeding post-partum. The feasibility and desirability of each of these components is dependent on the cultural and material context in which the woman lives, as well as her health status and the health-care delivery infrastructure. Nevertheless, PMTCT is an effective public and individual health promotion intervention which, under optimal circumstances, can reduce mother-to-child HIV transmission from 25-45% to 1-2% (DeCock et al. 2000; Read et al. 2007; Volmink et al. 2007). In order to access PMTCT, women must learn their HIV status before or during pregnancy. As well as being the gateway for PMTCT, HIV testing during pregnancy can be an important opportunity to inform pregnant women and their partners about HIV. If one or both of them is HIV-negative, counselling and testing can increase their capacity to prevent transmission of HIV. If one or both of them is HIV-positive, counselling and testing offers

the opportunity to reduce the probability of transmission to their child, promote their own health through early access to treatment and care, and plan their sexual and reproductive lives with the knowledge of their HIV-status, contributing to preventing new HIV-infections and re-infections. In other words, PMTCT should be the poster child for the effectiveness of antiretroviral treatment for the prevention of HIV transmission and is a golden opportunity to offer HIV-testing to women, allowing them and their families' timely access to treatment.

At the historic Special Session on HIV and AIDS (UNGASS) in June 2001, the United Nations member states committed to reaching 80% of pregnant women and their children with the essential interventions to prevent mother-to-child transmission of HIV, reducing the proportion of infants infected by 50% by 2010 (United Nations 2001). Yet, in 2007 when I began preparing for my doctoral research just 33% of HIV-positive pregnant women in low and middle-income countries, where 90% of people with HIV live, received antiretroviral medications for PMTCT (UNAIDS 2008: 124). By 2009, this number had increased to 53% but was still significantly below the 80% envisioned by the United Nations General Assembly when they met in June 2001. Latin America achieved the global average of 53% by 2009 but this regional average was still below that of the Caribbean (59% coverage), Europe and Central Asia (93% coverage) and Sub Saharan Africa (54% coverage); only the countries of East, South and Southeast Asia had been even slower to scale-up access to PMTCT, reaching only 32% coverage by 2009 (WHO 2010b: 87). When I examined international and regional rates of implementation of PMTCT, it became clear that the response in Mexico, the country where I had lived and worked as an HIV researcher and advocate for women with HIV from 2001 to 2007, was woefully inadequate. In 2007, UNAIDS reported that a mere 3% to 7% of pregnant Mexican women received antiretroviral medications to prevent vertical transmission of HIV; by 2009 when I began my research the

estimate for coverage had risen marginally to 3 to 9% (UNAIDS 2008: 14; UNAIDS 2010a: 271). My knowledge of Mexico's HIV response and the efforts being made towards provision of universal health care services made the fact that more than 90% of pregnant women with HIV were being denied an opportunity to prevent HIV transmission to their child and to learn their HIV status in timely manner shocking to me. This realization and my interest in generating evidence about why this was occurring and how the situation could be improved was the inspiration for my doctoral research.

Mexico is an upper middle-income country that has offered antiretrovirals for PMTCT since 1998 and free access to antiretroviral treatment to the population without health insurance since 2003 (Saavedra-Lopez and Bravo-Garcia 2006). The offer of HIV-testing to all pregnant women who attend prenatal care and reduction of new paediatric HIV infections by 75% through providing PMTCT services has been part of Mexico's official plan of action on HIV/AIDS since 2001 (Secretaria de Salud 2002c: 36). Medical guidelines include highly active antiretroviral therapy, programmed caesarean section or vaginal delivery for women with well-controlled HIV, and formula feeding (CENSIDA 2007). That is to say, at first glance the normative frameworks and needed antiretroviral medications for PMTCT seem to have been in place in Mexico since, at the very latest, 2003 when universal access to antiretrovirals for the population without employer-based health insurance was established. Nor can the failure to implement PMTCT in Mexico be attributed to low prenatal coverage or a high number of home births. Since 2006, 97.7% of Mexican women have attended at least one prenatal visit, 88.3% of women attend four or more prenatal visits, and 93.4% of births are attended by a skilled birth attendant, usually a physician (United Nations Statistics Division 2011). Yet, of the estimated 1800 to 3200 HIV-positive

Mexican women who give birth annually, in 2009 less than 10% of them received antiretroviral treatment (UNAIDS 2010a: 271; Uribe-Zuniga et al. 2008: 77).

My doctoral dissertation elucidates culturally mediated political, institutional, and individual barriers to the implementation of PMTCT over the past decade in the Latin American region, with a specific focus on Mexico in the period from 2001 to 2010. I also document the consequences of the omission of HIV testing during prenatal care for women with HIV and their families. The first chapter places the Mexican experience in regional context by providing a comparative analysis of the existing policy context for PMTCT and progress made in eight Latin American countries: Bolivia, Colombia, Guatemala, Honduras, Mexico, Nicaragua, Paraguay, and Peru. The chapter focuses on determinants of political priority to understand why these countries have not advanced towards implementing PMTCT as quickly as might be possible given existing health care delivery infrastructure. Specifically, I ask why the HIV and women's health movements in Latin America have not developed a coherent and persuasive discourse and a joint advocacy agenda focused on achieving the United Nations Declaration of Commitment on HIV and AIDS and the health-focused Millennium Development Goals: reducing child mortality (MDG4); reducing maternal mortality and achieving universal access to reproductive health (MDG5); and halting and beginning to reverse the spread of HIV and AIDS (MDG6). Chapter Two analyzes Mexico's normative framework and identifies institutional and cultural barriers to the implementation of PMTCT from the perspective of Mexican HIV activists, decision-makers, and health-care providers. I argue that one of the main barriers to the implementation of PMTCT in Mexico has been how cultural constructions of women's risk for HIV acquisition are encoded in normative frameworks. The third chapter of the dissertation uses quantitative methods to analyze a large national sample which documents pregnant women's reported HIV risk behaviours, their

perceptions of their male partner's risk behaviours for HIV acquisition, and the relationship between these behaviours and pregnant women having a reactive rapid HIV antibody test. The fourth chapter explicates the gaps between women's lack of HIV risk perception, and their knowledge of HIV transmission routes and their male partner's risk behaviours. To do so, I explore social constructions of HIV risk groups from the perspective of women now living with HIV and gendered sexual norms for relationship formation and maintenance. Finally, in the fifth chapter, I circle back to the cultural construction of HIV risk expressed in health system failures which delay women's and children's HIV diagnosis and the consequences of these delays for women and their families. Drawing on multiple data sources, analyzed using different methods, I seek to explain the poor progress towards implementation of PMTCT in the region by examining eight Latin American countries and conducting an in-depth case study of Mexico. Finally, I conclude by making policy and program recommendations.

## **1.2 Theoretical orientation and objectives**

The objective of this research has been to understand barriers to implementation of PMTCT and to generate evidence useful for advocacy in favour of the scale-up of PMCTC, HIV prevention for women in Mexico and other Latin American countries, and the health and rights of women with HIV and their families. With this aim, this research is inscribed within the tradition of critical ethnography which not only elicits the participant's point of view and describes the norms and practices of culture sharing groups, but also advocates for the emancipation of marginalized groups and proposes actions. Thomas (1993: 4) states that while "conventional ethnographers study culture for the purpose of describing it; critical ethnographers do so to change it". I begin from the premise that cultural forces shape and disadvantage some groups more than others. Ideas,

social norms and ideologies provide the underlying meanings for constructing social subjects and concepts like gender and race which “typify the invisible realms of meanings ... stratify people and distribute power and resources in subtle ways” (Thomas 1993: 34). Critical medical anthropology is complementary to critical ethnography in that it attends to the vertical linkages between the social group of interest and larger groupings of human society, and how these social relationships pattern behaviours, beliefs, attitudes and emotions, with a specific focus on how dominant cultural constructions of health and the functioning of health systems both express and reinforce social inequalities (Farmer 2005; Singer and Baer 2007: 33; Trostle 2005). Medical anthropologist Nancy Scheper-Hughes (1992: 171) states that “all variants of modern critical theory work at the essential task of stripping away the surface forms of reality to expose concealed and buried truths. Their aim then, is to ‘speak truth’ to power and domination, in individuals and in submerged social groups or classes”. The aim of this research has been to understand, from multiple perspectives, the barriers to the implementation of PMTCT in order to make recommendations that can improve maternal health care and promote the health and reproductive rights of low-income Mexican women, especially those who are living with HIV.

### **1.3 Preventing vertical HIV transmission: health systems, technical efficacy and perceptions of risk and HIV vulnerability among women.**

In the following section I provide background information drawn from the literature on perinatal HIV prevention. I first discuss the efficacy of and access to antiretroviral treatment for PMTCT internationally, access to HIV testing during prenatal care, and then briefly review anthropological critiques of the concepts of HIV risk and risk groups.

### *1.3.1 Access to and effectiveness of antiretroviral treatment for PMTCT*

The existing literature suggests that health system factors such as timely HIV testing and provision of antiretrovirals by health-care providers, the type of antiretroviral regimen provided, accessibility of the hospital or clinic, and where women give birth (at home, in a primary care clinic, in a second or third-level hospital) are more important for determining whether women successfully complete antiretroviral treatment for PMTCT than women's individual sociodemographic characteristics or attitudes (Albrecht et al. 2006; Colvin et al. 2007; Le et al. 2008; Manzi, et al. 2005; Nguyen et al. 2008; Nkonki et al. 2007). Taking antiretrovirals correctly is important because the biological function of antiretrovirals for PMTCT is to reduce transmission by lowering the mother's viral load (amount of HIV virus in her blood); through pre-exposure prophylaxis of the infant by crossing the placenta; and by providing post-exposure prophylaxis to newborns exposed to HIV. Highly active antiretroviral therapy (HAART-three or more antiretroviral drugs) which effectively lowers the mother's viral load can reduce vertical transmission rates to between one and two percent (Volmink et al. 2007). In rich countries, the standard of care for PMTCT is generally the provision of HAART to pregnant women with HIV from the second trimester onwards (Burdge et al. 2003; Clumeck et al. 2008; Jameison et al. 2007; Panel on the Treatment of HIV-Infected Pregnant Women and Prevention of Perinatal Transmission 2010). Even when HAART isn't introduced until the third trimester of pregnancy, studies from low and middle income countries have demonstrated that rates of PMTCT can be reduced to between two and four percent (WHO 2006: 28). Unfortunately, most of the 53% of pregnant women with HIV in low and middle income countries who received some antiretroviral treatment in 2009 were provided with less costly and less effective regimens than HAART (UNAIDS 2010a:78). In 2007, the distribution of ARV regimens reported to WHO/UNAIDS by

country governments was: single dose-nevirapine 49%; dual prophylaxis antiretroviral therapy 26%; triple prophylaxis antiretroviral therapy 8%; unknown 17% (Lo 2008). As of June 2010, the World Health Organization made a definitive statement that single dose nevirapine was not adequate for PMTCT and that at minimum all women with HIV should either receive four or more weeks of AZT or triple therapy during labour and delivery (WHO 2010a: 8-9).

The eight Latin American countries included in this research (Bolivia, Colombia, Guatemala, Honduras, Mexico, Nicaragua, Paraguay and Peru) all provide HAART for perinatal HIV prevention.<sup>2</sup> A regional multi-center study and reports from Mexico's *Instituto Nacional de Perinatología* (National Perinatology Institute) have demonstrated that mother-to-child transmission rates can be reduced to between 1%-2% in these country contexts (D'Ippolito et al. 2007; Uribe-Zuniga et al. 2008). But, despite existing technical guidelines and successes in reducing vertical transmission in some hospital contexts, in 2007 all eight of these countries reported higher rates of antiretroviral coverage for persons with HIV who needed antiretroviral treatment for their own health than they did for pregnant women who needed antiretroviral treatment for PMTCT (Kendall and Lopez-Uribe 2010:15). And in Mexico, five years of putatively universal access to antiretroviral medications (2003-2008) did not result in a reduction of the number of perinatal AIDS cases reported (Uribe-Zuniga et al. 2008: 77). Thus, the question arises whether access to HIV testing during prenatal care is a significant barrier to accessing PMTCT in these countries.

### *1.3.2 HIV testing during prenatal care*

Most pregnant women in low and middle-income countries accept HIV testing when it is offered during antenatal care. One large international study with 13 sites found an average acceptance rate of 92% (range 53-99%) (Cartoux et al. 1998). More recent studies analyzing

acceptance of rapid HIV tests among pregnant women attending prenatal care have estimated uptake at between 83% and 97% (Pai et al. 2007: 168). Mexican studies have found that 85% to 90% of Mexican women accept HIV antibody tests when they are offered during pregnancy (Romero-Gutierrez et al. 2007; Vera Gamboa et al. 2005). On all continents, pregnant women say they accept HIV testing to promote the health of their baby (Okonkwo et al. 2007; Oosterhoff et al. 2008; Romero-Gutierrez et al. 2007; Vera Gamboa et al. 2005). Different studies have found that a minority of women refuse prenatal HIV-testing (3%-30%) because they don't have their male partner's permission, they fear the test or the social consequences of a positive test result, or they do not consider themselves at risk for HIV (Campbell and Bernhardt 2003; Gruskin et al. 2008: 26-27; Romero-Gutierrez et al. 2007; Vera Gamboa et al. 2005). However, the most common reason that pregnant women are not tested for HIV during prenatal care is because the test is not offered (Nkonki et al. 2007; Perez et al. 2006; Sinha et al. 2008). Reflecting on the omission of HIV testing during prenatal care in Mexico, Uribe Zuniga et al. (2008: 81) state that the underlying reason "is the idea of medical personnel at both the supervisory and operational level that these are 'unnecessary efforts' because in the majority of cases the outcome will be 'normal'". That is to say, in the Mexican social imaginary "normal" pregnant women don't have HIV. The invocation of what is "normal" for pregnant women demands consideration of cultural constructions of HIV risk and vulnerability.

### *1.3.3 Conceptions of HIV risk and vulnerability: some anthropological considerations*

Anthropologists have made valuable contributions to the analysis of health and disease broadly, and HIV and AIDS specifically, through their critiques of epidemiological notions of risk and vulnerability. Anthropologists have questioned the tendency within epidemiology and some schools of public health to focus on individual as opposed to social responsibility for sickness

(Nguyen and Peschard 2003; Trostle and Sommerfeld 1996: 254-253). I would like to highlight two of these critiques related to the conceptualization of HIV risk and risk groups. The first critique addresses conceptions of cause and effect, and indeed, culpability for disease: by focusing in on the individual, the conceptualization of “high risk behaviour” implicitly “blames the victim” for HIV infection and assumes that what is needed for HIV prevention is knowledge about HIV transmission routes and prevention technologies. The second critique arises from the epidemiological construction of “risk groups” and reification of the “culture” of these purported risk groups, which simultaneously impedes those who have risk behaviour but don’t consider themselves as part of those groups from considering themselves “at risk” for HIV and obliterates emic social identities.

The social construction of “high risk groups” increases stigma and apports blame for engaging in behaviour which leads to HIV infection. One response to these critiques has been to focus HIV prevention education on “risk behaviours” (unprotected sex and sharing needles) which are portrayed as morally neutral and objective (Owczarzak 2009). Yet, while potentially less stigmatizing, the discourse of reducing risk behaviours continues to focus on the individual while omitting local and personal constructions and understandings of what we are doing when we have sex or use drugs. Our interpretations of the meaning of our behaviours and perception of what is “risky” goes beyond the insertion of the latex sheathed or unsheathed penis into bodily orifices or sharing a needle. The focus on “the facts” of HIV transmission and demand for “rational” responses to such scientifically proven risk through self-reflection and decision making—which is expected to result in actions which eliminate or mitigate risk—does not escape from the culture-blind, atomizing focus on the individual (Owczarzak 2009: 419-420; Pigg 2005). Focusing on individual behaviour without recognizing that this behaviour, and its meaning, is culturally

mediated and enmeshed in a web of social relations contributes to individualistic models for education and behaviour change as a response to the HIV epidemic—as if sexual and reproductive behaviour or any other behaviour was purely “market-like rational free choice” (Frankenberg 1994: 1333). Nowhere are the deficiencies of HIV information and education that ignore the cultural meanings and social contexts of behaviour and multiple constraints on behaviour change more evident than in the gaps between people’s knowledge of HIV transmission routes and their behaviour (Bronfman et al. 2002). Nguyen and Peschard (2003:447) argue that it is important to avoid

the pitfalls of methodological individualism, assumed universalism, and unidirectional causation. Rather, affliction must be understood as the embodiment of social hierarchy, a form of violence that for modern bodies is increasingly sublimated into differential disease rates and can be measured in terms of variances in morbidity and mortality between social groups.

In the field of HIV, understanding the cultural constructions of behaviour and the social relationships that increase vulnerability to HIV infection and disease progression has led to calls for interventions to modify the social, legal and economic contexts for HIV-risk behaviours rather than focusing on individual risk behaviours and transmission routes (Blankenship et al. 2006; Gupta et al. 2008; Parker and Aggleton 2003). I align myself with those who call for structural interventions to respond to “HIV vulnerability”. Ethnography linking HIV vulnerability and human rights abuses, including violations of economic and social rights, has been especially prevalent in Latin America (Bronfman et al. 2002; Buchalla and Paiva 2002; De Oliveira Santos and Paiva 2007; Edmundo et al. 2007; Hernandez-Rosete et al. 2008). My analysis focuses on social constructions of gender and uses the concept of “HIV vulnerability” to consider the social contexts in which women become infected with HIV, transmit the disease to others, and become ill

with AIDS, thus highlighting constraints on individual choice and identifying normative, institutional, and structural changes needed to improve people's capacity to effectively promote their health and well-being (UNAIDS 1998: 12-13).

Another critique that anthropologists and other social scientists have made of the epidemiological construction of "risk groups" and the concomitant tendency to construct these groups as having distinct "cultures" is that

reification of social categories as "risk groups," and the tendency to distance these groups from the 'general population,' have contributed to the complacency and denial of the reality of risk of infection among members of this "general population," even those whose geographical location and (heterosexual) behaviour places them at elevated risk (Schiller et al. 1994: 1344).

In addition to obscuring that all people who have unprotected sex or share needles can become infected with HIV, there is ample research demonstrating that individuals who would be placed in a "high risk group" for HIV from an etic perspective based on their behaviour; for example, men who have sex with other men or men who sell sex to other men, do not identify with the cultural umbrella of being "gay" or "homosexual" (Herdt 2001: 453-455; Kendall et al. 2007; Parker 2006; Prieur 1998: 137-138). Thus, HIV prevention efforts that call on these identities are doomed to overlook and fail individuals who do not claim these identities. Parker and Ehrhardt (2001: 108) state that anthropology has made an important contribution to HIV/AIDS research in describing and problematizing the identification, labelling and sexual cultures of so-called at-risk groups.

In this dissertation, I focus on the behaviour and perceptions of a culturally conceived "not-at-risk group"—women—who now represent half of those living with HIV internationally and about a third of those with the virus in Latin America (UNAIDS 2010a). Within the context of implementation of PMTCT in Mexico, I describe how cultural constructions of women's HIV risk

are encoded in policy priorities and normative frameworks and how women's own perceptions of HIV and capacities to implement HIV prevention are shaped by dominant norms for gendered sexuality and gender discrimination.

#### **1.4 Research Methodology: Mixed Methods**

Increasingly, public health practitioners and researchers are arguing for the use of complementary quantitative and qualitative methods to compensate for the relative biases and weaknesses of different methodologies and to combine their strengths in order to explain the complex determinants of health and illness (Baum 1995; Carey 1993; Dixon-Woods et al. 2004: 2-5; Trostle 2005: 85-91, 135-140). Multiple methods generate rich and multilayered understandings. Flick argues that “the combination of multiple methods, empirical materials, perspectives and observers in a single study is best understood, then, as a strategy that adds rigor, breadth, and depth to any investigation” (Fine et al. 2000: 2). Speaking specifically in favour of anthropologists and epidemiologists working together to understand and respond to public health issues and single researchers using both anthropological and epidemiological methodologies, Trostle (2005:172) argues for “thinking about disciplinary boundaries as semi-permeable membranes rather than defended borders”. In and of itself, ethnography is a research tradition that combines multiple methods such as documentary review, direct observation, informal interviews, and in-depth interviews (Singer and Baer 2007: 52-54). Further, as Parker and Ehrhardt (2001: 108) take great pains to emphasize, ethnography has historically drawn on both quantitative and qualitative methods.

Following the tradition of applied anthropology, my primary interest is to generate knowledge that will contribute to improving public policy and service delivery for women with

HIV in Mexico and other Latin American countries and preventing new HIV infections. I have taken the arguments of advocates of mixed methods to heart and engaged in policy analysis, quantitative methods and in-depth interviews to generate evidence to achieve the aforementioned goal.

While my research emphasises women's perspectives and experiences, I also aim to describe institutional ideologies, practices and relationships that shape women's experiences in their interactions with the health-care system, but are "beyond her view" (Smith 2006: 3). Thus, despite privileging the experiences of women with HIV, I am also interested in the beliefs and practices of health-care providers and decision-makers. The perspectives provided by health-care providers, policymakers and HIV activists are crucial for describing the historical evolution and context of PMTCT in Latin America and in Mexico, for understanding cultural, political and operational constraints, and for identifying points for intervention. In Laura Nader's famous phrase, I "study up" or at least "study across", interviewing health care providers and health care decision-makers who have similar educational and material privileges to me (Nader, 1972; Newton and Stacey 1995: 296). My professional and personal privilege and history in Mexico permitted me to access these groups of influential individuals. I have worked extensively in HIV policy and public health in Mexico with prestigious international research organizations and the United Nations system, and am a well-known advocate for women with HIV. I began by collaborating as a researcher with the *Red Mexicana de Personas con VIH/sida* (Mexican Network of People with HIV/AIDS) in 2001 and have continued to carry out research and advocacy with women with HIV, particularly the International Community of Women with HIV and AIDS (ICW) at the national and regional level, up until the present.

#### *1.4.1 Regional policy analysis and expert interviews*

The content analysis and interview guides were constructed around the four prongs of the WHO/UNFPA Glion consultation on strengthening linkages between reproductive health and HIV to respond to HIV among women and children: primary prevention of HIV infection in women; prevention of unintended pregnancies in women living with HIV; prevention of transmission from women living with HIV to their infants; and provision of care, treatment and support for women living with HIV and their families (UNFPA/UNAIDS 2004; WHO/UNFPA 2006). The policy analysis was guided by Shiffman and Smith's (2007) framework for analyzing the political priority accorded to health issues which considers: 1) political context and opportunities; 2) issue characteristics; 3) the power of the ideas used to portray the issue; and 4) the strength of the actors involved.

I reviewed reporting on the United Nations General Assembly Special Session on HIV and AIDS (UNGASS) and the Millennium Development Goals to assess operational progress towards meeting country commitments to prevent vertical HIV transmission and provide reproductive and HIV health care services in eight Latin American countries. To explore reasons for poor progress towards PMTCT in 2007, given high levels of prenatal care coverage and relatively widespread access to antiretrovirals, I also undertook a content analysis of the current National HIV and Reproductive Health plans to describe the policy context. Where specific technical guidelines for prevention of perinatal HIV transmission or HIV legislation existed, these were also analyzed.<sup>3</sup>

Health policymakers and administrators, health-care providers, HIV activists and feminists active in the area of sexual and reproductive rights were all interviewed. The regional sample includes 19 interviews from Central America (Guatemala, Honduras, and Nicaragua) and 27 interviews from South America (Bolivia, Colombia, Paraguay, and Peru) conducted between

September 2009 and June 2010. The Mexican sample includes 60 interviews, with state and federal policymakers and administrators, decision-makers, health-care providers working in HIV and reproductive health, and HIV and sexual and reproductive health activists conducted between July 2009 and January 2011. These interviews gathered perceptions about political, administrative, and cultural barriers to the implementation and scale-up of the PMTCT program. The interviews also explored the political context for SRH/HIV integration, identified institutions and individuals that had promoted or impeded PMTCT implementation, and documented the relationships between women with HIV and HIV and feminist reproductive health organizations. Interviews ranged in length from 30 to 90 minutes. Interviews were transcribed and analyzed with support of the qualitative data analysis software Atlas ti 6.0. Findings about preventing PMTCT and availability of sexual and reproductive health services for women with HIV were validated with 81 activists in national meetings with women leaders with HIV in Guatemala (n=12), Nicaragua (n=18), and Mexico (n=42) and at a forum with activists from all sub-regions (n=19).

#### *1.4.2 Perspectives of Mexican women*

In the Mexican case, my analysis focuses on women who access health services for the “open population”. The Mexican Health System has three major components: 1) private health insurance and providers; 2) legally mandated health insurance for individuals employed in the private sector or in the public sector (which includes separate clinic and hospital systems for private sector workers, public sector workers, the Armed Forces and employees of the national petroleum company, PEMEX; 3) and the Ministry of Health (SSA), which provides health services for the uninsured or “open” population (self-employed, informally employed, unemployed). Prior to the health reform described below, the uninsured population was estimated at 50 million

Mexicans (about half of the population) (Secretaria de Salud 2007: 50-51). Thus, the Ministry of Health serves the most economically, and often socially, vulnerable segment of the population.

In 2003, modifications were made to the General Health Law which allowed the establishment of the *Sistema de Protección Social en Salud* (System for Social Health Protection) with the aim of extending publicly funded health insurance to the uninsured (King et al. 2007: 480). As of June 2011, 48.5 million Mexicans (more than 90% of those who didn't previously have health insurance) had become affiliated with the *Seguro Popular* (Popular Health Insurance) (Secretaria de Salud 2011: 4-5). The System for Social Health Protection, including the Popular Health Insurance, is supposed to guarantee access to a comprehensive package of primary health care services, including ambulatory HIV care and has provided the financing mechanism for scaling up access to antiretroviral treatment in Mexico (Secretaria de Salud 2011). The Ministry of Health is also the segment of the health-care system that has been most active in scaling up access to HIV testing during prenatal care (CONASIDA 2009: 3-5).

#### *1.4.2.1 Questionnaire*

Between October 2006 and December 2009, health care providers (physician or nurse) administered a questionnaire to pregnant Mexican women who attended clinics and hospitals administered by the Ministry of Health and who accepted a rapid HIV antibody test as part of their prenatal care. The questionnaire collected sociodemographic information: age, number of live births, civil status, and ethnicity (as measured by speaking an Indigenous language). The questionnaire also sought information about women's risk behaviours for HIV acquisition and their perceptions of their sexual partner's risk behaviours for HIV acquisition over the past 12 months. These questions were asked before women received the results of the rapid HIV antibody test. The questionnaire asked women whether, during the past twelve months, they or their sexual

partner had had multiple sexual partners, engaged in sex work, injected drugs, been incarcerated, migrated to the United States, or if the male partner had had sex with other men. The data from the questionnaires were entered into a database by Mexico's National HIV Prevention and Control Program (CENSIDA).

The initial database consisted of 436,994 pregnant women who completed a rapid HIV antibody test between October 2006 and December 2009 and for whom a test result was recorded. Women from all 31 Mexican States and the Federal District (Mexico City) were included in the sample. Of the 9,506 health-care delivery sites which participated in the study, only 541 reported at least one woman who was reactive to the HIV antibody test. The analysis presented in the dissertation is limited to women who completed their rapid HIV antibody test at one of these 541 health-care delivery sites, reducing the sample from 436,994 women to 78,557 women. I then constructed a retrospective, quasi experimental case-control study to control for women's sociodemographic characteristics, geographic location, possible differences in health-care provider practices for offering HIV testing during prenatal care and other unobserved differences. Data were analyzed using the Stata Data Analysis and Statistical Software package (version 11).

#### *1.4.2.2 In-depth interviews with women with HIV*

My in-depth interviews with women with HIV took place in the South-Central region of Mexico. This region is comprised of Mexico City (population 8,720, 916), Mexico State (population 14, 161,000) and Morelos (population 1,605,000). Mexico State circles Mexico City on the West, North, and East and Morelos lies to the South of Mexico City. The Greater Mexico City Metropolitan Area which includes Mexico City (the Federal District) and part of Mexico State is the world's third largest urban agglomeration, with a population of 19, 231,821 (INEGI 2005). The geographical region is characterized by stark contrasts: a huge urban center located

within a few hours of small villages; the conspicuous consumption of the very few, visible at the high-end boutiques and crowded restaurants of fashionable neighbourhoods, while the many are just barely scraping together the minimum for a place to live and enough to eat. And the existence of diametrically opposed cultural currents; perhaps the most glaring are the legalization of gay marriage and abortion on-demand up until 12 weeks gestation in Mexico City, while the city's Cardinal, Norberto Rivera, condemns same-sex unions and has stated publicly that anyone involved in abortion is automatically excommunicated (La Jornada 2011; Zaragoza 2009).

In Morelos, I invited women with HIV and health-care providers from the HIV clinics in the State capital, Cuernavaca, and Anenecuilco, a rural town, to participate in interviews. In Mexico State, I conducted research in collaboration with four HIV clinics: Toluca (the state capital) and Cuatitlan, both industrial and agricultural centers that also serve rural populations from adjacent villages; as well as the municipalities of Ecatepec and Nezahuacoyotl, which are part of the urban sprawl which extends outwards from Mexico City proper. In Mexico City, I interviewed health-care workers and women with HIV from two of the National Institutes of Health: the *Instituto Nacional de Perinatologia* (National Institute of Perinatology) or INPER and the *Instituto Nacional de Enfermedades Respiratorias* (National Respiratory Disease Institute) or INER. The INPER and the INER are both third level, specialized reference hospitals with a mandate for teaching and research. The INPER hosts Mexico's pioneering PMTCT program and is the national perinatology reference hospital. The INER has one the largest client populations of any HIV clinic in Mexico City.

Interviews with women with HIV took place between August 2009 and May 2010. The criteria for women's inclusion in the study were living with HIV, speaking Spanish, being of reproductive age (18-49 years of age), and having had a pregnancy since 2001 when HIV testing

during prenatal care was included in the Mexican National AIDS Plan for the first time. Interviews ranged from one to two hours in length and included questions about the woman's family context, economic situation, education and work history, circumstances of the HIV diagnosis, interactions with the health-care system and health-care providers, experiences of gender violence, and sexual and reproductive practices and desires before and after the HIV diagnosis. The sample was purposeful and oriented towards maximum variation on two axes: 1) women who had been diagnosed with HIV during pregnancy as well as women who had not, and 2) women who were in relationship at the time of the interview (with both HIV-positive and HIV-negative male partners) and single, separated or widowed women (Creswell 2007: 125-127). Sample size was determined by the principle of saturation; saturation refers to the point at which additional interviews do not provide novel information about the issues of interest (Charmaz 2005: 527).

### **1.5 Sociodemographic characteristics of the women with HIV**

My analysis includes 55 interviews with women with HIV who received HIV care through ambulatory clinics run by the Ministry of Health: 11 women resided in Morelos, 7 in Mexico City, and 37 in Mexico State. The age range of these women with HIV of reproductive age was 19 to 41, with a median age of 27 years and an average age of 28 years. In terms of religious affiliation, 46 women (83.65%) identified themselves as Catholics, eight (14.55%) said they were “Christian”—that is members of a Protestant Church (usually from an evangelical denomination), and one (1.90%) didn't report any religious affiliation.

#### *1.5.1 Family network and living situation*

As illustrated in Table 1.1, the majority of the women (72.72%) were in a stable relationship at the time of the interview. Seven of the women had separated from the previous

partner. Six women were widows; in each of these cases the previous male partner had died of AIDS. Two women reported being single at the time of the interview.

<b>Table 1.1 Civil status of women with HIV who participated in the research</b>		
Civil Status	Number of women: 55	Percentage
Married (11)/Common Law (29)	40	72.73%
Separated	7	12.72%
Widowed	6	10.91%
Single	2	3.64%

In terms of family composition, all of the women had living children and/or were pregnant at the time of the interview. The number of living children ranged from one to five, with a median number of 2 children per women and an average of 2.1 children, similar to the fertility rate of 2.4 children per woman in Mexico (World Bank 2011a). About half of the women lived in nuclear families (consisting of herself and her children and possibly a male partner) while the other half lived in multigenerational family groupings. Karen’s description of her living situation was typical of the women in this sample. She said that “we have our house where my Dad lent us a room. Only my husband, my daughter, and I live there. But my parents and my two brothers live next door”. Whether they lived in multigenerational family groups or not, women’s access to property was generally provided through family networks and thus conditioned by family relationships, rather than outright ownership.

<b>Table 1.2 Family composition and living situation of the women with HIV who participated in the research</b>		
Living situation	Number of women: 53	Percentage
Nuclear family: spouse and children	17	32.07%
Nuclear family: woman and her children	6	11.32%
Extended family: spouse, children and other family members	15	28.30%
Extended family: multigenerational without spouse	11	20.75%
Other	4	7.54%

Women's living situations were fluid, and frequently precarious, because they had little money and depended on the goodwill of male partners and family members. Maritza said she was living with her mother after the birth of her child because "I don't have tile [on the floor] in my room, and lots of cold comes in. Where I live it's cold. So since the baby was born in the cold season, we are staying with her. Her house is tiled, and it is a little warmer". Thelma was one of the women who lived alone with her four daughters. Her previous male partner died of AIDS. A former boyfriend had wanted her to move to Acapulco with him, but didn't want to take her daughters; as a consequence she broke off the relationship. Thelma chose not to live with her parents because of the physical and psychological violence that she had experienced as a child, and which her father continued to exercise against her mother and other family members. She explained the economically difficult decision not to live with her parents saying, "with my parents there was always a lot of violence. And it continues, even though now it isn't beatings, it's verbal. But they still live like that. And that's why I decided to take my daughters and leave: I don't want what happened to me to happen to my daughters". After paying the rent for a single room for her and her daughters, she has very little money left over for food. She said that her parents have helped her economically since she started to rent. For example, if she doesn't have any money "for tortillas, they send me tortillas or they say: 'Come, come and eat here.' In that way, I receive a lot of support from both of them". The cost of housing had a dramatic impact on the family economy of the women with HIV who participated in my research. For example, because they don't pay rent, Daniela and her husband live comfortably on a single salary. Daniela stopped working as a receptionist when she went to live with her husband. Subsequently she worked for another year, and then stopped when her baby was born. Daniela, her husband and their child live with her husband's grandmother in the grandmother's apartment. Not having to pay rent makes Daniela feel

stable and secure. She explained that “economically, maybe we don’t have a super house, and it isn’t ours, but I feel like we get along well with his grandmother. We have enough to eat, we are healthy. We even have a TV so that my daughter can amuse herself. I mean, we have everything we need. Certainly no luxuries, but we are fine”.

### *1.5.2 Family income*

Reported monthly family incomes ranged from a mere 200 pesos (CAD 16)<sup>4</sup> to 10,000 pesos (CAD 800) per month, with a median family income of 3000 pesos per month (240 CAD) and an average of 3500 pesos per month (CAD 280). All of the women reported monthly household incomes below the Mexican national average of CAD 930<sup>5</sup> a month (INEGI 2009). This means that even without considering the cost of rent, about two-thirds of the women faced food insufficiency at the household level. In 2008, the cost of the most basic monthly food basket was estimated at CAD 90 per capita a month in urban areas (CONEVAL 2011). If we assume a household of two adults and two children, with children consuming half as many calories as adults, the minimum household income required to meet basic food needs in 2008 was CAD 270 per month. Only a third of the women in my sample (18 of 49, 36.73%) reported an income of CAD 270 a month or greater.

### *1.5.3 Occupation*

At the time of the interview, most of the women defined their occupation as “housewife” (37, 67.27%). Only three of the women were professionals: one was a dentist, another worked as an administrative assistant, and the third had been a teacher before she became pregnant (5.45% of the sample). Three more women either had worked or continued to work in the service industry as employees (5.45% of the sample). One had worked as a cashier, another had worked in a bar, and

the third had worked as a baker. Six of the women worked for themselves as petty merchants, selling juices or sandwiches or running a food stall (10.9% of the sample). Six more women worked as domestic servants (10.9% of the sample).

Frequently, women worked several jobs in order to make ends meet. Sandra explained her routine six-days a week saying,

I go to the medical office at eight: hurry up to do the cleaning. I finish the cleaning at about ten. At ten, I run home, and make lunch for my partner (because now I have a partner) and for my boy—who is about to turn two. At eleven—out to sell—I am a merchant. And that’s how it is all day long, until four, four or five at the latest. And then home again, to prepare supper again. We are running all day long. We don’t have time to say ‘let’s rest’.

Yet, despite her hard work, the family’s economic situation was precarious. Sandra earned 50 pesos a day at her cleaning job which was equivalent to their daily food costs. She said that “almost every day we spend 50 pesos on food, because we buy something that goes a long way, something nutritious. And also, here [at the HIV clinic], they give us groceries. So now we have beans, cooking oil, rice, soup. And that helps us a bit more. Now we don’t have to be worrying about the cooking oil”. In addition to her cleaning job, she and her partner rent a market stand where they re-sell vegetables. In this job, “there is no fixed salary, sometimes we sell and sometimes we don’t”. But they must generate a minimum of 750 pesos extra every month to pay the rent for their single room.

Like Sandra and her male partner, both Itzel and her husband contribute to the household economy. Itzel works as a live-in domestic servant and sees her husband every 15 days, if he isn’t travelling for his work as a labourer. Their “home” is a small house in the country, built on land which belongs to his mother. Itzel earns slightly more than double her husband’s income (2500

pesos every two weeks as oppose to 1200), and makes a greater contribution to their common expenses because her living expenses are absorbed as part of her job. She says:

He is earning 1200 pesos a week but with the meals—they have to eat. At least for us [live-in domestics], since we work in a house our salary is free and clear because we eat there, we bathe there, we do everything there. So, he contributes 300, 400, [pesos every two weeks] because his costs are about 600 [pesos]. And it is worse when he rents—you know that every month you have to pay rent—and then it is very little.

While in some families women worked and made a significant economic contribution to the family economy, in others women were economic dependents. This is understandable given that many of these women with HIV were currently pregnant, had been recently pregnant, or had young children. Consequently, many were working in the home. Women described a pattern of entering and leaving the labour market with their pregnancies. Maura had been the administrative assistant to the owner of a real estate company before her daughter was born. She decided to quit when she found out she was pregnant because

the job demanded all of my time. That is to say—there was no opportunity to rest. I didn't have a set time to come in or to leave. I also worked as an administrator, going to the municipality or wherever I had to go to get the paperwork in order. When [my boss] found out that I was pregnant, it was like she said: 'Now I won't be able to use you like I used you before.' And there were some conflicts. So I stopped working, for my own good and the good of the baby.

Fabiola described her economic dependence bluntly saying “my husband buys the diapers, and he is the one who clothes us, puts shoes on our feet, and feeds us”. Some women were not even aware of how much their male partner earned, only receiving a “household allowance”. For example, when asked about the household income, Yolotzin said “no, I don't know [how much my husband earns]. He just gives me 50-60 [pesos] a day”.

The social vulnerability implicit in women’s economic dependence was brought into sharp focus if their male partners became ill with AIDS. Carmen’s husband was the primary breadwinner even though her brothers and mother worked to contribute to the household economy. When he became ill, she says that she felt “worried about the kids, school, and everything. Food, everything for school, everything that was being asked for—maybe it was very stressful for him because he maintains the household and he might be saying to himself: how am I going to do it?”

Pamela said her greatest fear was her husband getting

sick again, right now he is in bed, and he can’t do almost anything .... He won’t be able to work until I don’t know when. We rely on my father-in-law. And it’s not the same as before. Before, my husband gave me my money, and I could buy what I wanted—things for my daughter. And now it is very different. We are dependent on my father-in-law, and with him it’s only food, and hospital bills.

Nor is Pamela well-equipped to support herself and her two children. She completed middle school but didn’t study any further because she met her husband and started working. She related that in the past her level of education had been a barrier to finding work.

#### 1.5.4 Education

<b>Table 1.3 The formal educational attainment of the women with HIV who participated in the research</b>		
Education	Number of women: 55	Percentage
None	2	3.64%
Primary school (partial or complete)	16	29.09%
Middle school (partial or complete)	20	36.36%
High school (partial or complete)	13	23.64%
University or technical training (partial or complete)	4	7.27%

When asked about their education history and aspirations, most of the women with HIV told me that they would have liked to have continued to study, but were not able to because of lack of economic options or lack of family support (often related to their gender). Only two of the women

didn't receive any formal education. Sofia had an accident as a child which left her vision impaired. When she began primary school, her teacher and mother decided that she wouldn't study because of her disability. Elodia had had to care for her younger siblings from a very young age to allow her mother to work. She explained that "sometimes my Dad worked, and sometimes he didn't. My mom worked all day long, and she had little kids, and she didn't have anyone to take care of them. So, I did the housework and looked after my little brothers". Other women left school of their own volition. Itzel, who completed primary school, said: "I didn't want to keep studying. ... No, there was no [economic reason], it was my decision, because one of my sisters would have supported me, but I didn't want to keep studying". She preferred to leave school, and six months later migrated from the country to the capital city of her state and began working as a live-in domestic worker. Pamela completed middle school, and then studied high school "in the open system—I got to the sixth semester but I didn't graduate. I needed ten materials to complete and I didn't go. I got together with my husband, common-law. And I stopped studying". However, in most cases, women didn't leave school of their own volition but because economic hardship (frequently exacerbated by the death or illness of a family member) or gender-based discrimination made it impossible or difficult for them to continue to study.

In terms of leaving school because the family could not or would not support the girl or young woman to study, there were notable differences between women raised in rural and urban areas. In rural settings, women left primary school to work, whereas in urban areas they tended to complete middle school and didn't necessarily begin to work immediately afterwards. Anel describes how she left school in the third grade because her parents "sent me to work or to do other things, in the house. And since they went to the fields to plant, I went to the fields to bring them food, to bring wood and all of that". It was the same for all of the children in her family

without gender differences, except for one brother who “wouldn’t obey them and leave [school]. Even when they beat him, he went, and he finished primary school. And we didn’t, they sent us to wash other people’s laundry to be able to eat eggs or beans”. Amparo was from the same State as Anel but grew up in an urban area. Like Anel, Amparo left school because of lack of economic resources but unlike Anel she was able to complete middle school. She related that “my parents didn’t have money to send me to *prepa* (high school). They enrolled me in the open *prepa*, but the teacher stole the money for the books and they didn’t give us any books”. Just like that, her high school education was over. She then took a series of courses but her parents wouldn’t let her work: “They told me that they didn’t want to see me in the street. They didn’t want to see me hanging out with any boys, no way”.

Accidents or illness of family members that put stress on the family economy were another reason that women left school. Sandra’s case is dramatic but emblematic of various women in the sample who left school when their parent or guardian became ill, had an accident which prevented them from working, or died. Sandra came from a rural area. She left school in 1985 at age eight “because my mom started to get sick, and we just couldn’t pay for the medicines. So, I left school. I left and went and asked for any work on offer, even washing dishes, anything. I went to harvest tomatoes, chiles, green tomatoes, fava beans. In the fields, they paid us ten pesos a bag”. Sandra says that she made the decision to leave school on her own, against her mother’s wishes. She related that “my mom really didn’t want me to leave school. But seeing the situation that we were in, that we didn’t have enough for her medicines, I said: “I would rather that my mom is well, that she is here with us, than go to school””.

Beginning a stable relationship with a man was another reason that women stopped studying. However, when I analyzed women’s reasons for entering into the relationship or for

leaving school as a consequence of the relationship, I frequently found that gender-discrimination and violence lurked in the background. Carmen explained that her father refused his economic support for her to continue her education beyond middle school. Rather than allowing her to go to high school and date her boyfriend, because he feared that she would get pregnant and drop out as her sister had done, her father preferred to “transfer her guardianship” to another man. When her father met her boyfriend (now her husband) for the first time he said, ““You know what, go with her now, take her away because I don’t want her to turn out like her sister”. Lilia also left school and lived with her boyfriend. When I asked her to explain why she had taken this decision, she said it was a strategy to escape the violence she experienced at home. In her words, “they hit me, they insulted me. And my parent’s way of hitting—well, my Dad, when he hit me, he didn’t hit me with a belt but with his fists, right? ‘I’ll give you a beating, or kick you about’. And my mom didn’t hit with a belt but with a cable”. When she began to experience some academic challenges during middle school, specifically learning English, Lilia decided to drop out of school and go to live with her boyfriend. She said:

I wanted my own life, right? I wanted to leave my family because I didn’t feel good with my parents, I didn’t feel good with my family because my father mistreated my mother, and because of the stress and all of that, I didn’t want to be with them. I wanted to go, to avoid so many problems, and to live on my own.

Sometimes the violence that motivated women to seek a relationship that allowed her to leave her family, and often to leave school as well, wasn’t directed at her but at other family members.

Lucrecia was fifteen when she decided to leave home to escape her stepfather’s violence against her mother. She explained that “he hit my mother ... Sometimes he threw her out of the house, he insulted her terribly. So, the day came when I said, I don’t want to go home, I don’t want to know

anything about it. So I went with my boyfriend. And in the end, the result was worse [because she became infected with HIV]”.

Women also said that they had left school because of an unplanned pregnancy. Thelma says “I only had a little bit more to do to graduate from high school, when I got pregnant with my first daughter”. Another woman, Jimena, was told by her physician that she had to leave school because her pregnancy was high risk and that “with all of the bouncing around in the bus, the baby was going to come [miscarry]. And that’s why they forbid me to go to school, and I didn’t go”. Instead, she went to live with the father of her child and the man who transmitted HIV to her. After the birth of her first child, Jimena wanted to continue her education, but her male partner refused. She says that he didn’t like her studying because

... he had the idea that [I should be] in the house, in the house, in the house. I told him: ‘Let me finish my high school and then we can see what we will do.’ But he didn’t like the idea. He was a very jealous man, excessively so, and he got jealous about anything. And that’s when the beatings started. But I was completely blind. I didn’t know whether to *echarme por atras* (leave) or to stay. And I decided to stay, that he could do what he wanted with me. And that was my mistake.

### *1.5.5 Sociodemographics and Social Vulnerability*

The sociodemographic profile of the women with HIV who participated in my research highlights why gender discrimination and related HIV vulnerability anchor my analysis. The women with HIV who participated in the research lived in poor conditions, often precariously housed, and were either self-employed or employed in the informal sector. With few exceptions, these women were relatively under-educated and not able to attain well-paid administrative or professional jobs. In seeking to understand why so many women left school, the precarious economic situation of their families and gender discrimination related to relationship formation, pregnancy and gender violence come to the fore. In other words, these women with HIV were

socially vulnerable, both before and after the HIV diagnosis, because of economic and gender inequality. Recognizing women's social vulnerability provides crucial context for the following chapters, which consider, among other issues, the relative influence of women with HIV in regional social movements, women's risk behaviour for acquiring HIV, and their perceptions of their male partner's risk behaviours from both a quantitative and qualitative perspective, as well as the trajectories of women through the health system before they received their diagnosis with HIV or AIDS.

## **Chapter 2. The Regional Political Context for Prevention of Mother-to-Child HIV**

### **Transmission and Provision of Integrated Reproductive Health Services to Women with HIV**

The objective of this chapter is to locate Mexico's challenges in scaling up prevention of mother-to-child HIV transmission within the regional context. Based on the analysis of documents and interviews with decision-makers and advocates from the women's health and HIV movements in eight countries (Colombia, Bolivia, Guatemala, Honduras, Mexico, Nicaragua, Paraguay and Peru), I identify ideological barriers to the implementation of PMTCT and explain the low priority accorded to women and children in the HIV response. I also examine how tensions and fissures within civil society represent a barrier to increasing the political priority accorded to PMTCT as well as to recognizing and meeting the sexual and reproductive health needs of women living with HIV. I am particularly interested in how the epidemiological context of HIV in Latin America and the position of women living with HIV within networks of people with HIV and vis-à-vis the broader women's health movement have impacted on the priority accorded to PMTCT and SRH/HIV integration.

Civil society is increasingly influential in setting global and national health policy (Loewenson 2003; WHO 2001). Two areas of global health where civil society actors in both the global north and the global south have been especially active and successful at generating both international and domestic awareness and political will, have been HIV and sexual and reproductive health (Bernstein 2005; Crossette 2007; Heywood 2008; Nelson and Dorsey 2007; Parker 2009; Tantivess and Walt 2008). In Latin America, activism for access to treatment by networks of people living with HIV and in favour of reproductive rights by the women's movement is ongoing, as these aspects of the right to health are not effectively guaranteed despite

international agreements (Amachastegui et al 2010; Asociación Agua Buena 2007; Faundes et al. 2007; Kampwirth 2006; Lopez 2010; Shepard 2000; Stern 2005). The prevention of vertical HIV transmission and the sexual and reproductive health and rights of people with HIV would seem to be a strategic issue for joint advocacy and collaborative action between these two influential civil society movements. Therefore one must ask why the HIV and women's health movements in Latin America haven't developed a coherent and persuasive discourse and a joint advocacy agenda focused on achieving the United Nations Declaration of Commitment on HIV and AIDS and the health-focused Millennium Development Goals: reducing child mortality (MDG4); reducing maternal mortality and achieving universal access to reproductive health (MDG5); and, halting and beginning to reverse the spread of HIV and AIDS (MDG6).

## **2.1 Normative and Operational Integration of Reproductive Health and HIV Services in Eight Latin American Countries**

The synergistic benefits of linking sexual and reproductive health (SRH) and HIV have been recognized and promoted by the United Nations System for over a decade (IPPF/UNPFA/UNAIDS/GNP+/ICW/Young Positives 2009; UNFPA/UNAIDS 2004; WHO/UNFPA 2006). Yet, global monitoring demonstrates insufficient progress. In 2008, a mere 21% of pregnant women giving birth in low- and middle-income countries were tested for HIV and only 45% of pregnant women living with HIV received antiretroviral treatment to prevent vertical HIV transmission (WHO 2010: 8-9). Significant numbers of women with HIV continue to report an unmet need for contraception and high rates of unintended pregnancies, as well as other sexual and reproductive rights violations (Adair 2009; Bell et al. 2007; deBruyn 2006; Desgrees-Du-Lou et al. 2002; Kendall 2009b; Nakayiwa et al. 2006). In 2001, the member states of the United Nations committed to reaching 80% of pregnant women with interventions to reduce

PMTCT of HIV by 2010 (UNAIDS 2008). Table 2.1 shows that while the eight Latin American countries analyzed have included preventing PMTCT in national HIV and reproductive health plans, operational progress has been insufficient. In 2007, only two countries (Nicaragua and Peru) were halfway towards meeting the target and most countries reported less than 10% coverage. This failure cannot be explained by the absence of needed health-care infrastructure. All of the countries report antenatal care coverage and access to antiretrovirals disproportionately higher than the estimated number of pregnant women living with HIV who actually received treatment.

<b>Table 2.1 Policy and operational progress on PMTCT and SRH/HIV Integration in eight Latin American countries<sup>6</sup></b>									
Country	Bolivia <sup>a</sup>	Colombia <sup>b</sup>	Guatemala <sup>c</sup>	Honduras <sup>d</sup>	Mexico <sup>c</sup>	Nicaragua <sup>f</sup>	Paraguay <sup>g</sup>	Peru <sup>h</sup>	
<i>Epidemiology of HIV among women<sup>1</sup></i>									
HIV prevalence adults 15-49 (2008)	0.20%	0.60%	0.80%	0.70%	0.30%	0.20%	0.60%	0.5%	All <1%
Women with HIV	2,200	47,000	52,000	7,400	57,000	2,100	5,800	21,000	Total 194,500
<i>Policy: Integration of HIV and reproductive health services</i>									
Preventing mother-to-child HIV transmission in the HIV Plan	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100%
Reproductive health of women with HIV mentioned in HIV Plan	No	Yes	Yes	No	No	Yes	No	No	37.5%
Preventing MTCT in Reproductive Health Plan	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	87.5%

<b>Table 2.1 Policy and operational progress on PMTCT and SRH/HIV Integration in eight Latin American countries (cont.)</b>									
<i>Health-care system capacity: Access to prenatal care, safe delivery, and antiretrovirals<sup>j</sup></i>									
Country	Bolivia <sup>a</sup>	Colombia <sup>b</sup>	Guatemala <sup>c</sup>	Honduras <sup>d</sup>	Mexico <sup>e</sup>	Nicaragua <sup>f</sup>	Paraguay <sup>g</sup>	Peru <sup>h</sup>	Average
1 prenatal visit	77.2% (2008)	93.5% (2005)	84.3% (2002)	91.7% (2007)	86.1% (1995)	90.2% (2007)	94.2% (2004)	91.0% (2006)	88.5%
4 prenatal visits	57.9% (2003)	83.1% (2005)	No data	80.8% (2006)	No data	77.8% (2006)	78.8% (2004)	87.4% (2006)	77.63%
Skilled birth attendant	65.8% (2008)	96.4% (2005)	41.4% (2002)	66.9% (2006)	93.4% (2006)	73.7% (2006)	77.1% (2004)	71.0% (2006)	73.2%
% of people who with advanced HIV disease receiving antiretrovirals (2007)	22%	38%	37%	47%	57%	30%	22%	48%	37.6%
<i>Progress towards preventing vertical HIV transmission<sup>k</sup></i>									
% of pregnant women with HIV who received antiretrovirals to prevent PMTCT (2007)	No data	6%	7%	34%	5%	No data	No data	39%	18%

Interviews with HIV activists and decision-makers in the eight countries confirmed that, once diagnosed, the vast majority of women with HIV receive antiretroviral treatment to prevent PMTCT. This suggests that a key stumbling block for implementation of PMTCT in Latin America is the failure to integrate HIV into maternal-child health by offering HIV testing during antenatal care. The reproductive health needs of people living with HIV remain invisible in national HIV plans. Less than half of the eight countries studied mention reproductive health in their national HIV plans. The 81 HIV activists from across the region (mostly women leaders with HIV) consulted during the validation process corroborated that even when family planning for women living with HIV is mentioned in the National Reproductive Health or HIV plan, the sexual and reproductive health care counselling in HIV care is generally limited to promotion of the male

condom; in no setting were other contraceptives routinely provided in HIV clinics (see also Campero et al. 2010b; de Bruyn 2006a; Gogna et al 2009; Rosales nd). The integration agenda is far from being realized in the countries studied. However, the capacity of these health-care systems to deliver antenatal care, family planning services, and antiretroviral treatment means that advocacy which increases the priority given to SRH/HIV integration can pay huge dividends towards achieving MDGs 4, 5, and 6. What barriers must be overcome for this to occur?

## **2.2 The Political Context: International Impetus and Local Inertia**

At the supranational level, the impetus to link HIV and SRH to achieve the Millennium Development Goals is gaining momentum. Major HIV funding mechanisms such as the Global Fund for AIDS, Tuberculosis and Malaria and the US Global Health Initiative with PEPFAR2 are explicitly soliciting investments in HIV/SRH integrated service delivery, as are some bilateral donors (Dickinson et al. 2009; Global Fund to Fight AIDS, Tuberculosis and Malaria 2010). Since his appointment in 2009, the Executive Director of UNAIDS, Michel Sidibé, has made SRH/HIV integration a policy priority (Sidibé 2010). HIV was explicitly recognized as a driver of maternal mortality during the 54<sup>th</sup> Commission on the Status of Women (United Nations Economic and Social Council 2010). Despite tensions provoked by donors not meeting or scaling back prior commitments for HIV treatment, there appears to be an international consensus among the UN system, donors, and global civil society on the need to integrate SRH and HIV to achieve the MDGs (ICASO 2010; Lewis 2010). In Latin America, country members of the Pan-American Health Organization have committed to a plan for eliminating mother-to-child transmission of HIV and syphilis by 2015 (PAHO 2010).

Does the political impetus exist at the country level where implementation will take place? While it seems curmudgeonly, it is important to remember that when the original targets for

preventing PMTCT and providing HIV and reproductive health services were established in the MDGs and UNGASS more than a decade ago, the political context also seemed promising. To generate strategies for moving forward in Latin America it is important to identify past political barriers to progress.

### **2.3 Issue Characteristics: Women and Children in Concentrated HIV Epidemics**

Shiffman and Smith (2007) identify a series of issue characteristics which facilitate a health issue attracting political priority. These include the existence of effective interventions — the extent to which avenues for addressing the problem are clearly explained, cost-effective, backed by scientific evidence, simple to implement and inexpensive; the availability of credible evidence and indicators to measure the problem; and perceived severity. PMTCT has a strong evidence base for clinical efficacy and the cost-benefit of universal voluntary screening is clear for countries with high HIV prevalence, as well as in low prevalence HIV epidemics where HAART is the standard of care, as in these Latin American countries (Gomez 2008; Graves et al. 2004; Patrick et al. 1998; Volmink et al. 2007). Evidence which shows that the provision of reproductive health services to women with HIV (especially contraceptives) and SRH/HIV integration improves coverage, quality of service delivery, and can be cost-beneficial in generalized HIV epidemics is accumulating (Wilcher et al. 2008; WHO/UNFPA/IPPF/UNAIDS/UCSF 2009; WHO Maximizing Positive Synergies Collaborative Group 2009). Since 2004, multilateral organizations have recognized that in addition to being necessary for preventing vertical HIV transmission, prenatal HIV-testing has multiple benefits (UNFPA/UNAIDS 2004; WHO/UNFPA 2006). Offering HIV-testing during prenatal care is a unique opportunity for HIV education with HIV-negative women and permits timely access to health-care for women with HIV. Testing may also allow early diagnosis for the women's partner(s) and other children. Yet, only 19 of 72 of my research

participants identified one or more of these additional benefits of prenatal HIV testing. Likewise, in response to questions about optimal contraceptive methods and priority SRH issues, most of the decision-makers and activists consulted reduced the SRH needs of women with HIV to condom access. These responses suggest that while the United Nations System has articulated the benefits of strengthened linkages between HIV and SRH and the integration of services, these arguments are not necessarily known or accepted by government and civil society actors in the countries studied.

According to Shiffman and Smith (2007), the second group of issue characteristics which impact political priority involve measurement: does credible evidence exist to show the problem is serious? One of the important findings of my research is that insufficient epidemiological data on HIV prevalence and incidence among women and children, and related maternal and infant mortality, negatively impacts the priority given to PMTCT and SRH/HIV integration. A feminist active in reproductive health from the Andean region said:

We are part of the working group on safe birth and motherhood, and HIV isn't part of the agenda. Because we don't have sufficient data, and it doesn't seem that the incidence is significant. ... For those working on HIV, the issue of pregnant women living with HIV is supposedly miniscule. That it is a part of the agenda that is trying to take funds away, or diminish the importance of HIV in risk groups. So, for neither of the two sides is this issue relevant.

In the countries studied, estimated HIV prevalence in the general population is low (<1%) but UNAIDS estimated that in 2007 there were 194,500 women with HIV representing 35% of the total population of people with HIV in the eight countries studied (Table 2.1). However, only a minority of both men and women in these countries know their HIV status or are on treatment. The lag in recognizing HIV infection in the absence of widespread access to testing, contributes to perpetuating the idea that HIV is not a women's issue. A decision-maker from the United Nations

working in Mesoamerica stated that “concretely in HIV there is a cultural barrier: in this country they still think that it is a problem of men who have sex with men; and that there is a low incidence in women; and until the contrary is demonstrated, public policy is going to prioritize men who have sex with men”.

The failure to implement HIV testing during prenatal care because women are perceived as “low risk” creates a feedback loop in which heterosexual women of reproductive age from the “general population” living with HIV are not diagnosed. The failure to capitalize on the opportunity offered by prenatal care to allow women to access a timely diagnosis means that in the short-term, existing infections among women remain invisible to health-care providers and national decision-makers. This undermines arguments for prevention and care programmes for women with National AIDS Programmes, and in the decision-making mechanisms of international donors, such as the Country Coordinating Mechanisms of the Global Fund for AIDS, Malaria and Tuberculosis (Lamb Guevara 2010: 37). The failure to diagnose women is also an impediment to involving the broader women’s movement. A feminist from the Andean region noted that “in our own feminist organizations, we have not effectively incorporated the issue of HIV in the agenda—because of our assumption that it is an issue for gay groups”. A second and related issue characteristic is the underreporting of AIDS-related maternal and infant deaths in the region. A feminist ally of women living with HIV from the Southern Cone said bluntly that “maternal mortality is just that. If it is with HIV or without, no one is interested—they don’t record it, they don’t measure it”. AIDS-related morbidity and mortality among infants and children are also underreported. A feminist from Mesoamerica who has been working with women with HIV at the local level for several years reported that in 2007, she was told by the physician charged with buying HIV medications for her state medical system that “we don’t have any [HIV medications

for children], because there are no HIV-positive children”. However, she and I know women with HIV from the State who have HIV positive children; the invisibility of children with HIV and failure to purchase paediatric HIV medications is extremely worrisome. Not implementing PMTCT creates a vicious cycle where failure to diagnose HIV among women and children perpetuates the perception that the issue is unimportant and justifies the omission. In contrast, scale-up of prenatal HIV testing makes the impact of HIV on women and children visible and can engender a virtuous cycle. A United Nations system decision-maker from the Southern Cone stated that because rapid testing has been made “available in most, not all, of the maternal-child hospitals, a large number of pregnant women with HIV have been diagnosed. Based on this activity, you can see the feminization of HIV”. Further, government decision-makers from both Mesoamerica and South America reported that nationally generated epidemiological reports showing increased numbers of HIV diagnoses among women spurred them to develop policies and implement programmes.

According to Shiffman and Smith’s framework, PMTCT and the integration of SRH and HIV services have characteristics such as clinical efficacy and cost-benefit that could motivate political priority. However, the synergistic benefits of SRH/HIV integration were not readily articulated by the majority of the experts interviewed. Further, failure to identify HIV cases among women and children contributes to the perception that PMTCT and SRH/HIV integration are relatively unimportant health issues for the countries studied.

## **2.4 The Power of Ideas**

The power of ideas refers to the importance of framing a resonant and coherent argument for both internal and external audiences. To be most convincing, the argument or “collective action frame” should build consensus about what the problem is and then mobilize for action (Benford

and Snow 2000). SRH/HIV integration to achieve the health-related MDGs comes up against two divisive frames: the perception that the implementation of PMTCT privileges infant health over women's rights and, an issue at the core of the vertical vs. horizontal health care delivery debate—funding.

#### *2.4.1 PMTCT and Constructing “Women as Vectors”*

Some feminists and women living with HIV in Latin America objected to focusing on PMTCT as an advocacy priority in the field of women and HIV on the grounds that the intervention is implemented in a way that treats women as vectors of HIV transmission. A woman leader with HIV from Mesoamerica said that PMTCT offers the “advantage of reducing mother-child transmission, but one disadvantage is that only the child is considered important, they keep conceiving of and treating women like machines”. The understanding of PMTCT prioritizing the baby's health over the woman's rights excludes the intervention as a rallying point for feminists. A Mesoamerican feminist explained her lack of interest in PMTCT because “they don't think about the woman's life, or her health, but about the child. ... Personally, as a feminist, I would focus on other areas, not that one”.

#### *2.4.2 Funding: HIV vs. Reproductive Health*

Competition for funding was cited by some members of women's groups as a reason for not becoming involved in HIV. For example, a feminist from South America said that “there is a network of organizations that work on HIV, and they have asked us to join. But we, no, no, no. Because it is a world of men, where people are frequently fighting over money”. Feminists reported being accused by gay colleagues of being interested in women and HIV for mercenary motives. Some women with HIV expressed caution about collaborating with other movements out

of fear that they would “use HIV for their own benefit”. With specific reference to SRH/HIV integration to achieve the Millennium Development Goals, the perennial argument that HIV captures the lion’s share of available resources was articulated as a barrier. A feminist from Mesomerica articulated this argument clearly saying,

Conceptually, I agree with it [integration]. Since Cairo in 1994, we have talked about a focus on reproductive health, and that is the way it should be. That should be the model, which hasn’t happened and I don’t know if it is going to happen. But there is another issue—there is a worldwide struggle for resources. Maternal mortality is the MDG with the fewest resources internationally. And if now you want to include HIV, HIV will take away more of the already scarce resources for maternal mortality. And HIV has its own MDG, isn’t that right? And its own resources, and its own actions.

#### *2.4.3 Framing an Integrating Discourse: Women’s Rights and the Right to Health*

A promising avenue for overcoming divisive framing was identified in the rights-based discourse articulated by women with HIV and based on their lived experience. Increasing the capacity of women with HIV to link their experiences to the content and objectives of the international conferences would support them to enunciate a “frame bridge” between the master narratives of the HIV movement—the rights to health and non-discrimination, and the master narrative of the women’s movement—women’s rights and combating gender oppression (Benford and Snow 2000).

Women living with HIV have experienced the consequences of fragmented HIV and reproductive health-care delivery. Some of these consequences include: losing a child to AIDS (MDG4); raising children with HIV (MDG 6); not finding out about their HIV diagnosis until they or their partner became ill because of AIDS (MDG 6); or experiencing unintended or unwanted pregnancies because dual protection (condom plus another contraceptive method) is not promoted in HIV care (MDG 5). Women living with HIV asserted their right to health services

independent of their HIV status. For example, this regional leader with HIV stated that “part of the right to health is comprehensive care—from availability of services like the HIV test, exams, ultrasounds, all of that and prenatal care that should be evaluated by health professionals—all of this has to be a human right of every woman, independent of her [HIV] status”. Other women leaders with HIV reflected on how gendered power differentials had negatively affected their sexual and reproductive health, and emphasized the importance of skills-building and access to services which would allow them to take “autonomous decisions about our bodies”. However, minimal or no participation in sexual and reproductive health advocacy or exposure to the women’s movement prior to their HIV diagnosis also means that many women living with HIV don’t speak the language of the Cairo and Beijing conferences or frame their demands and priorities in the language of the MDGs (Field Notes March 3, 2010; April 14 2010; April 18 and 19 2010.) Emblematically, a new woman leader with HIV from Mesoamerica said:

I haven’t worked [with the feminist movement] but now that I am coordinating the network [of women with HIV], I am just starting a process of information gathering, education, absorbing everything that’s related to gender and HIV, women, AIDS, to have a discourse on these issues; right now, my discourse on these issues is poor.

The discourse enunciated by women with HIV based on their felt needs and lived experiences echoes framing used by the broader HIV movement in their struggle for the right to health and non-discrimination and also resonates with the discourse of the feminist women’s health movement on women’s right to autonomy and the ill-health caused by gender oppression.

Currently, the limited ability of many women leaders living with HIV to speak the language of the international conferences and frame their demands in these terms, makes it difficult for them to communicate the need for integration of SRH and HIV services as a common agenda and be recognized as champions for women’s health and rights.

## **2.5 Strength of Actors: Women with HIV Face Barriers Within the Broader HIV and Women's Health Movements**

Shiffman and Smith (2007) identify four components of “actor strength” that contribute to the priority accorded to a health issue: the existence of guiding institutions; leadership; cohesion of the policy community; and civil society mobilization. While the United Nations system has provided policy guidance, PMTCT and SRH among women living with HIV is not the remit of a single United Nations agency, and joint responsibility can lead to inaction. Commenting on the lack of action on PMTCT and the integration of SRH and HIV services driven by the UNAIDS Theme Group, one United Nations official commented: I don't think we are taking sufficient advantage of our differentiated capacities. And at times, despite striving for inter-agency collaboration, we are falling into vertical execution”. A feminist from South America noted,

there is a monopoly of the LGBT [Lesbian, Gay, Bisexual, Transgendered] population that has received a lot of support from the international agencies. UNAIDS has indicated that this is the population that you have to work with, as has UNFPA. The only voice that has spoken up for the issue of pregnant women and the importance of vertical HIV transmission has been, notoriously, UNICEF.

While the United Nations pronounced itself in favour of SRH/HIV integration and the implementation of PMTCT at the global level, this has not translated into strong and cohesive leadership at the national level in the countries studied.

Another aspect identified by Shiffman and Smith as important for generating political priority is civil society mobilization. Again, mobilization has been stronger and more effective at the global level than nationally or locally. At the supranational level, advocacy by the International Community of Women Living with HIV/AIDS (ICW) for the sexual and reproductive rights of women with HIV, has garnered recognition from the United Nations and support from feminist,

reproductive rights organizations (deBruyn 2006a; United Nations 2009). However, at the country and community level, most Latin American women leaders with HIV continue to be fairly isolated and lack institutional support from either the broader HIV movement or the women's health movement. In the words of one woman leader with HIV from Mesoamerica who has worked as a "trainer of trainers" with her peers: "It doesn't work to do ten trainings in the capital, bringing a woman from each state, if you leave her all alone *pariendo chayotes* (shitting bricks)<sup>7</sup> in her state, or in her community". The most common organizational alternative for women with HIV is to participate in local mixed gender HIV organizations, which tend to be led by gay men. In these spaces, women living with HIV struggle to get their issues on the agenda. In the words of a woman leader with HIV from the Andean Region, "discrimination is present there too. It is as if they say 'this group is different, they are not like us', and they push us aside". Reflecting on the absence of reproductive rights from a manifesto on the rights of people living with HIV, which proclaims sexual rights (CONASIDA/GIS-SIDA 1992; CENSIDA 2007: 13-14), an HIV activist from Mexico noted that "the vision is clearly macho, from a masculine perspective, and furthermore a gay perspective. So, you see how we can eliminate certain issues or agendas or things, just because they aren't inside you. They aren't internalized". While mutual support between people living with HIV exists, in the experience of this Mesoamerican woman leader with HIV "solidarity has limits. Everyone has their own agenda, and they have to fight for their agenda".

With respect to the broader women's movement, the continued perception that HIV is not a women's issue, HIV-related stigma and discrimination, and class differences are barriers to coalition building. When feminists express surprise, shock, distaste or fear when HIV is mentioned, as in this account by a woman leader living with HIV from Colombia, the idea that

HIV is not a women's issue is perpetuated. She explained that she “once went to a training with feminists, with lesbians, and when I started talking, speaking about HIV, they were terrified: ‘Omigod, we never thought HIV could happen to us’ —it really surprised me”. HIV-related stigma was identified as another barrier to collaboration. This feminist from Mesoamerica said that collaborations between women with HIV and feminists won't prosper until “we share and dialogue as peers, I think that is when there will be better results. Because there are still people in the feminist movement that, if they know the *compañeras* (women) have HIV, they put up a big wall. And they don't want to work with them, and they stay away from them”.

Both feminists and women living with HIV reported instances when members of the women's movement avoided physical contact and spatial proximity with women with HIV and with feminist colleagues known to work with HIV-positive women. For example, a member of the Mesoamerican women's movement asked a woman leader with HIV to co-present with her on the sexual and reproductive rights of women with HIV at a meeting of a feminist, professional organization. For the first time, her feminist peers “never sat at the table with me [sic]. I felt discriminated against, I felt stigmatized—just for working on the issue”.

Class differences also make coalition building between women with HIV and feminists difficult. Latin American feminism is a heterogeneous movement but most leaders are educated professionals with excellent contacts inside governments and multilateral organizations (Alvarez 2009; Phillips and Cole 2009). In contrast, most women living with HIV in the region come from situations of social disadvantage. While detailed sociodemographic information on women with HIV is scarce, my experience working with women with HIV in the region over the past ten years, the current study, and what can be gleaned from published studies from different countries, suggests that women with HIV tend to have low to medium education levels (primary and middle

school), work at home or as unskilled labourers, and are living at or below the poverty line (Aracena et al. 2005; Donoso et al. 2002: 36-45; Kendall and Perez-Vazquez 2004:45-46). Discussing a meeting with government officials and feminist leaders in Mesoamerica, women living with HIV spoke about struggling to gain respect for their proposals because they lack university degrees, but also disparaged feminists as *chalinitas* [little shawls] because they appropriate the shawls traditionally worn as adornment by Indigenous women (Fieldnotes April 13, 2010). Perhaps as a consequence of these social hierarchies, the leadership of women living with HIV tends not to be recognized by the broader women's movement: none of the international and regional champions for the integration agenda identified by feminists who participated in the research were HIV-positive women.

My research also identified feminist organizations that were working “on HIV” without working with women living with HIV. This dialogue with the director of a feminist organization that works on sexual and reproductive health in Mesoamerica clearly demonstrates the failure to recognize women with HIV as colleagues or even potential beneficiaries of capacity building programs.

**Gabriela Soto:** The idea of [the NGO] is precisely to train new leaders, so that new voices are heard. We have Indigenous voices, we have union leaders, we have a bit of everything.

**Researcher:** And has the organization ever considered women with HIV as a possible public for inclusion in your networks?

**Gabriela Soto:** We work on HIV. These leaders have a menu of ten key issues that they have to discuss with civil servants, or health promoters, or in workshops, etc. And one of the issues is HIV and STIs.

The Greater Involvement of People with HIV (GIPA) principle is important because it can improve the relevance, acceptability and effectiveness of programs, in this case by bringing the need for and benefits of multiple linkages between SRH and HIV to the forefront. GIPA also

destroys the stigmatizing assumption that the “experts” or “service providers” are HIV negative, while the “beneficiaries” are people with HIV (UNAIDS 2007). The inclusion of HIV in the agenda of feminist SRH organizations without the corresponding inclusion of women with HIV and their perspectives is one reason that feminists who are engaging with HIV-positive women told me that there “is no articulated response yet” between the two movements.

In general, the level of collaboration reported by feminists and women living with HIV did not go beyond attending public marches or rallies to support the other movement. There are, however, some promising trends. In 2009, women living with HIV were included for the first time in the monitoring and evaluation of the International Conference on Population and Development carried out by regional feminist networks and the United Nations; in 2012, the regional network of women with HIV again participated in this preparatory meeting. In 2009, an organized contingent of women living with HIV attended the regional *Encuentro Feminista* (Feminist Encounter)—an important event for feminist organizing in the region—for the first time. In 2011, the regional leadership of the International Community of Women Living with HIV and AIDS (ICW) attended the 30<sup>th</sup> Anniversary of the *Encuentro Feminista* held in Bogota, Colombia. Women leaders with HIV participated actively during the dialogue sessions (which are the main activities during the *Encuentro*) and were specifically mentioned in the concluding remarks on sexual and reproductive, as well as economic, social, and cultural rights; in addition, the Regional Secretary of ICW made a political declaration which asserted the common agenda of women with HIV and feminists in the area of sexual and reproductive rights and gender violence (Fieldnotes November 23-26, 2011).

My research also identified instances of initially superficial involvement, such as attending the same marches, developing into more committed relationships. In one country, marches

progressed to joint lobbying of legislators and then to women living with HIV challenging feminists to include them in their SRH agenda, by saying: “If you, as feminists, as a women’s movement, are proclaiming the sexual and reproductive rights of women, where are we?” In this instance, a coalition of women’s groups rose to the challenge which opened the door to provide technical support in gender analysis to women living with HIV. This support was perceived as valuable by women leaders with HIV and contributed to them developing a feminist analysis. A woman leader with HIV who participated in this process recounted that

it has been years of women [with HIV] without any training. It is only now that we are learning that it is because we are women that we live in these conditions, and that it is related to questions of patriarchal power. We are also recognizing how institutions have created violence against women, unemployment, stigma and discrimination.

Another avenue for coalition-building between women with HIV and the women’s movement that was identified in this research is the potential of relationships between women with HIV and lesbian feminists for building bridges. In the words of a lesbian feminist from South America, “HIV is very close to LGBT, so when we L [lesbians] are there, we are the ones from the feminist movement who get together with the women with HIV”.

In summary, the leadership and a cohesive policy framework for SRH/HIV integration generated at the global level in the United Nations system has not translated into strong guiding institutions at the country level in the eight Latin American countries studied. Nor has the integration agenda been prioritized by civil society organizations led by gay men or feminists. Women with HIV interact with both movements, but at the national and local level are relatively weak actors.

## **2.6. Discussion**

At the international level, there is a strong impetus and global consensus on the importance of integrating SRH and HIV services, including PMTCT, to achieve the MDGs. Commitment by members of Panamerican Health Organization to eliminate vertical transmission of syphilis and HIV by 2015 can be a focus for regional advocacy. A window of political opportunity is open.

Issue characteristics identified as barriers to the emergence of a cohesive policy community must be addressed in order to move forward. These include the perception that HIV among women and children is an insignificant public health issue, lack of awareness among stakeholders of the multiple benefits of implementing PMTCT, and reductive conceptions of the SRH needs of women living with HIV. Greater awareness of existing evidence for the value of SRH/HIV integration in concentrated HIV epidemics and the public health costs of inaction, could lower some of these barriers. Findings that show the cost-benefit of universal voluntary HIV screening for pregnant women even in very low-prevalence HIV epidemics in high- and middle-income countries where HAART is the standard of care need to be widely shared. Also, stakeholders need to be sensitized to the fact that HIV and AIDS related maternal mortality made a significant contribution to overall maternal mortality rates in Guatemala, Nicaragua and Paraguay between 1990 and 2008 (Hogan et al. 2010). And, a slow but steady rise in AIDS-related maternal deaths while other causes of maternal mortality have decreased has also been documented in other countries, such as Mexico (Uribe-Zuniga et al. 2008:77). Further, my analysis suggests that implementation of PMTCT can transform perceptions of the HIV epidemic among national decision-makers, inciting a virtuous cycle of action on HIV for women and children to replace the vicious cycle of omission.

I found that the multiple benefits of implementing PMTCT and a comprehensive conception of the sexual and reproductive health needs and rights of women with HIV are marginalized discourses. The narrow and divisive framing of PMTCT as infant health vs. women's rights rather than promoting the health of women, children, and the community, and tensions over funding between SRH and HIV civil society, government programmes and UN agencies are significant impediments to the SRH/HIV integration agenda. International reviews have vindicated the generally positive effects of investments in HIV for health systems and demonstrated positive results of strengthening linkages between SRH and HIV for the quality of service delivery and some initial cost-benefit analyses (IPPF/UCSF/UNAIDS/UNFPA/WHO 2009). To generate a cohesive policy community for SRH/HIV integration in Latin America, these findings must be widely disseminated and more operational research on SRH/HIV integration must be conducted in concentrated HIV epidemics. Moreover, based on their lived experience, women living with HIV perceive SRH/HIV integration as a priority but have faced challenges in attracting institutional support and political priority from the HIV and women's health movements. Within networks of people living with HIV, different perceived needs and priorities from the predominantly gay male membership are barriers to prioritizing PMTCT prevention and SRH/HIV integration. While feminists, including the author, are working with women living with HIV at the country and regional level, generally speaking these are recent collaborations that haven't yet generated an articulated advocacy agenda between national networks of women living with HIV and the women's movement. Research and evidence-based dialogue may be a particularly effective platform for coalition-building. In other highly politicized settings, researchers have successfully brought together fragmented actors and provided technical support for coalition-building around women's health without being seen as competitors for scarce resources (McGovern 2007).

The following chapters of my dissertation go some way towards providing an evidence base that could catalyze coalition-building and evidence-based policy-making in one of the countries included in this regional analysis: Mexico. The selection of Mexico comes from both personal interest and analytical criteria. At the personal and professional level, it is the Latin American country where I have done most of my research and have the strongest relationships with civil society organizations, the United Nations, and government decision-makers. Further, the decade that I spent as an advocate in the area of women and HIV in Mexico engendered feelings of personal responsibility and desire to address Mexico's abysmal record on PMTCT. Over and above my personal affinity for the country and feeling of responsibility, there is a compelling technical reason for selecting Mexico as the focus country for my in-depth case study of the failure to implement PMTCT. Of the eight countries, Mexico reports the highest per capita income, the highest coverage of antiretrovirals among people with advanced HIV disease who need these medications (57%)—and yet, also reports the lowest rate of coverage for providing antiretroviral treatment to pregnant women to prevent PMTCT in 2007 (5%), and the smallest change in increased coverage between 2007 and 2009 (from 3% to 7% coverage to 3% to 9% coverage) (UNAIDS 2008, 2010a; World Bank 2011b). In the next chapter, I explore perspectives of decision-makers and health-care providers on cultural constructions of "risk groups" and the administrative and normative framework for PMTCT within the context of Mexico's political transition and health-care system in order to understand in greater depth why Mexico has made such poor progress towards the implementation of PMTCT.

### **Chapter 3. Preventing Vertical HIV Transmission in Mexico: Political, Institutional, and Normative Barriers**

Why—despite high rates of prenatal care coverage, access to antiretrovirals, and national and international policy commitments to prevent mother-to-child transmission of HIV—has Mexico made such minimal progress towards implementing this extremely effective medical intervention over the past decade? Following from the regional analysis presented in the previous chapter, I identify five significant political and cultural barriers to the implementation of PMTCT in Mexico. First, I look at the prevailing conceptualization of how best to respond to Mexico's concentrated HIV epidemic and how competing priorities have impacted on the political priority given to PMTCT. Second, I consider how the context of political democratization and health-care reform in Mexico has influenced implementation of PMTCT. Third, I analyze how the respective powers and responsibilities and vertical organization of the National HIV and Reproductive Health Programs leave PMTCT in a programmatic no man's land. Fourth, building on this analysis, I examine the evolution of the normative framework for each of these programs vis-à-vis perinatal HIV prevention. And finally, I consider how the sexual stigma associated with HIV simultaneously makes pregnant women invisible as subjects who could be HIV-positive and absolves individual health-care providers and institutions of any moral responsibility for vertical HIV transmission. I then use the scale-up of HIV testing of pregnant women which took place during 2007-2008 as a case study to consider how these factors influenced implementation of vertical HIV transmission during that period and how they are impacting on the continued expansion and sustainability of the program.

For this analysis I draw on 60 semi-structured in-depth interviews conducted with past and current national and state-level decision-makers from HIV and Reproductive Health, as well as representatives of the United Nations system in Mexico (n=16), HIV health-care providers from Mexico City, Mexico State and Morelos (n=27), and HIV activists, feminists and HIV experts from across the Republic (n=17).<sup>8</sup>

### **3.1 Mexico's epidemiological context, the evidence-base for PMTCT and political priority**

As I discussed in the previous chapter, Shiffman and Smith (2007) identify the existence of credible evidence that the health problem is serious and the existence of a well-documented and cost-effective means to respond to the health problem as crucial factors for determining the political priority of a health issue. As in the other countries of the region, the low estimate of HIV prevalence among Mexican women as compared with other groups, specifically men who have sex with men, causes HIV among women to be perceived as a marginal public health problem. While PMTCT is highly effective, competition for resources and an international HIV prevention dogma of “focused prevention” reduces the priority given to diagnosing HIV among pregnant women. “Focused prevention” is the idea that resources can be optimized by investing in HIV prevention and diagnosis among populations with higher HIV prevalence and greater probability of becoming infected with or transmitting HIV because they have greater numbers of new and/or concurrent sex or drug using partners than other populations (Over and Piot, 1996). Focused HIV prevention seeks to control the virus among so-called “high-risk” populations, thus diminishing “epidemiological bridges” and the expansion of the HIV epidemic to the general population (Over and Piot 1996; Thomas and Tucker 1996). That individuals who do not belong to these “high risk groups” become infected with HIV, and that

frequently those who are categorized as belonging to these “high risk groups” don’t consider themselves members, are important critiques of this prevention paradigm (Parker 2006; Parker and Ehrhardt 2001: 108; Schiller et al. 1994). Nevertheless, this theoretical framework can be considered hegemonic internationally, and has been promoted by the National AIDS Program in Mexico during the period under study, especially from 2004 until the present (Das 2008; Kendall forthcoming). In the Mexican context, this panorama has been further complicated by an economic modelling exercise which found that universal HIV testing among pregnant women was not cost-effective (Rely et al. 2003).

### *3.1.1 Mexico’s HIV epidemic and prioritizing populations for prevention*

UNAIDS classifies HIV epidemics as being generalized or concentrated. In generalized epidemics, HIV is well established and the sexual networks of the general population are considered sufficient to sustain the epidemic. The numerical proxy for a generalized HIV epidemic is that HIV prevalence is consistently 1% or more among pregnant women. Concentrated epidemics are those in which HIV is well-established among certain vulnerable or “most at risk populations,” such as men who have sex with men (MSM), injection drug users (IDU), and sex workers (SW). The numerical proxy for concentrated epidemics is HIV prevalence of 5% or greater among certain sub-populations, but less than 1% among pregnant women in urban areas (UNAIDS/WHO 2000: 24).

Mexico’s HIV epidemic remains concentrated with a general population prevalence estimated at 0.3% (3 people with HIV for every thousand inhabitants) (UNAIDS 2010a). The total estimated number of people living with HIV is 220,000 of whom 59,000 are women (UNAIDS 2010a). The estimates of HIV prevalence (the percentage) of people living with HIV by population group indicates that male sex workers (15%) and men who have sex with men (11%)

are the most affected, followed by people who use injection drugs (5%), female sex workers (2%), those who are incarcerated (1%), clients of sex workers (0.6%), heterosexual men (0.5%), and heterosexual women (0.2%) (CENSIDA 2010: 10). This epidemiological panorama in conjunction with a reigning ideology of HIV prevention that focuses on “most at risk populations” has presented serious challenges to the political priority given to PMTCT.

On one hand, it is easy to understand the priority given to men who have sex with men in the Mexican HIV epidemic, as they are clearly the population most affected. During our interview, a State HIV decision-maker told me that “on World AIDS Day we can do 300 tests in a public plaza, and get one reactive [result]. But if I go outside a gay disco with 100 tests, I’ll come back with 7 or 8 reactive tests. So, obviously, epidemiologically, that is telling me where to follow HIV. Nevertheless, I think that we can’t neglect women”. With specific reference to perinatal HIV prevention, another HIV decision-maker articulated the theory of “epidemiological bridges” during our conversation, contending that

providing preventative care for this population [MSM] will allow you to stop transmission networks. If you care for pregnant women, you’re not going to stop transmission networks—other than perinatal. I mean, you are only going to avoid, you won’t avoid the epidemic—you’ll avoid children getting infected. And it seems to me that avoiding infections among children is reason enough, right? But I don’t think that you have to choose between one and the other.

While these State decision-makers put emphasis on the importance of not neglecting women despite their low HIV prevalence or ignoring prevention of vertical HIV transmission because it won’t bring the expansion of the HIV epidemic under control, the evidence suggests that low HIV prevalence among women has caused prevention of vertical HIV transmission to be considered a marginal issue by both of the programs with related mandates: reproductive health and HIV. In

October 2009, Alejandra Cruz, a federal decision-maker with more than fifteen years experience working in HIV explained to me that the

problem is earmarking resources specifically for HIV testing in pregnant women. It's not so much [money], but it is a resource problem because when it comes down to it you say: where are those resources going to come from? So, if you say: it's reproductive health's responsibility. And according to me it should be, because it is maternal and newborn health. Nevertheless, when you put everything that belongs to maternal health together in a big bag and it's time to choose priorities that are real problems, HIV comes last because it's not a serious problem when you talk about maternal and perinatal health in Mexico—it's not like Africa. ... And when you talk about the resources for HIV, preventing perinatal HIV transmission isn't the number one priority. Why? Because UNAIDS and the economists say: if you have few resources, put them where the impact will be greater. So, where should we spend prevention resources if they are limited? On MSM, because that's where you'll get the biggest impact.

An HIV physician who has played an important role in promoting prevention of vertical HIV transmission in the country reflected on the priorities of the National AIDS Program (CENSIDA) from 2004-2008, saying that “during that period it [policy] focused on MSM, so they spent the money on MSM,” adding in a sarcastic tone that the attitude of CENSIDA was “perinatal [cases] are so few—as long as we give them treatment!”

In truth, Mexican perinatal AIDS cases are not as few as appear in official statistics. To illustrate this fact, I will use the most recent publicly available estimates. In 2009, UNAIDS estimated that based on fertility rate and HIV prevalence among women, there were 1500 to 4500 pregnant Mexican women with HIV who needed antiretroviral treatment in 2009; only 124 of them received it (UNAIDS 2010a: 270-271). If we assume the low end of the 25-45% perinatal transmission rate without treatment estimated by De Cock et al. (2000) and 100% success of prevention among those women who did receive treatment, between 250 and 1000 Mexican infants were born with HIV in 2009. Yet the official number of perinatal AIDS cases

reported in Mexico in that year was 101 (CONASIDA 2009: 7). As I have argued for the region in Chapter 1, the failure to implement the perinatal HIV prevention program in Mexico results in the invisibility of HIV among women and children, lowering the political priority of the program, and creating a vicious cycle of omission.

### *3.1.2 The “evidence” for PMTCT, cost effectiveness, and political priority*

Shiffman and Smith (2007) state that in addition to evidence that shows the problem is serious, the existence of a simple, cost-effective intervention for which there is substantial evidence of effectiveness contributes to political priority for health issues. The medical intervention to prevent mother-to-child HIV transmission is 98-99% effective (Volmink et al. 2007). The case of perinatal HIV prevention in Mexico is curious in this regard, because while the strong scientific base of the intervention caused it to be adopted early on a small scale, there has been considerable confusion and debate about the cost-effectiveness of the intervention in the context of Mexico’s HIV epidemic. The latter factor has limited scale-up.

In historical perspective, the federal HIV program responded quite quickly to clinical evidence that providing antiretroviral treatment to pregnant women could reduce transmission to their offspring. The first scientific article that showed antiretroviral treatment (monotherapy with AZT) reduced mother-to-child HIV transmission was published in 1994 (Connor et al. 1994), though preliminary results had been shared at the International AIDS Conference held in Amsterdam in 1993. Alejandra Cruz, who participated in the discussions about prevention of perinatal HIV transmission since the very beginning, said that by 1993 the National AIDS Program was discussing how to implement PMTCT and what it would cost. In 1996-1997, the National AIDS Program created a special fund to offer antiretroviral treatment to women and children from the “open population”. At this time, adults from the general population without

health insurance did not have access to antiretroviral treatment. Alejandra Cruz's explanation of how the decision to start to implement PMTCT was taken confirms the importance of both scientific evidence and resource rationing in the policy and program process. She said that, "first, we were really interested in starting to implement something [prevention of perinatal transmission] that had been proven effective. Second, we wanted to gradually start increasing [treatment] access because at that time the resources weren't available". Yet, despite this early attention to prevention of vertical HIV transmission, as of 2009 little progress had been made towards effective coverage (UNAIDS 2010a: 271).

The gap between the early provision of antiretroviral treatment for prevention of mother-to-child HIV transmission and limited scale-up in the intervening years comes down to access to HIV testing for pregnant women. While the National AIDS Program estimated how much medication was needed to prevent perinatal HIV transmission in 1996, "the truth is that the medication didn't get used. And that's how we know that it's not enough to have the medication, you need a *whole strategy* to ensure that pregnant women receive services in an opportune fashion, something that we still have problems with" (Alejandra Cruz, federal decision-maker). During her interview with me in October 2009, Dalia Antunez, a State decision-maker who has worked in HIV since the mid-nineties explained that

something very complicated is happening in Mexico: there are certain public policies that aren't linked to actions and the existing access to services. From my point of view, that is the case with prevention of mother-child transmission. ... In the beginning the policy was: the person who asks for medication, get's it. That was the policy, and it still is. And that's the problem. Every pregnant woman who asks for medication will receive it. And they'll give her information about it, but a policy of access to testing was never defined.

As in the other countries in the region discussed in the previous chapter, the lack of access to testing has been the Achilles heel of the implementation of prevention of vertical HIV transmission in Mexico.

I want to propose that the perception of cost-effectiveness of offering HIV testing to pregnant women in Mexico has been a significant political barrier to prioritizing scale-up of prevention of vertical HIV transmission. In 2003, a mathematical modelling study which evaluated the cost-effectiveness of the universal offer of HIV testing to pregnant women in Mexico stated that even the most cost-effective scenario was “at best only marginally cost-effective compared to other interventions to reduce infant/child mortality, suggesting that the SSA [MOH] should question whether to implement a detection programme at all” (Rely et al. 2003: 297). I specifically asked health-care providers and decision-makers about the impact of this study and of arguments about cost-effectiveness and cost-benefit in decision-making vis-à-vis the implementation of PMTCT in Mexico. The people I interviewed knew of the study by Rely et al. (2003) and the findings had been used in the arguments made by representatives of the National AIDS Program at the federal and state level. In general, my interviewees considered the study to have had an impact, even if they didn’t all agree that the cost-effectiveness argument was foremost in decision-makers minds. For example, Roberto Newton, an HIV clinician, clearly remembered having a conversation in 2005 during which “an [HIV] program coordinator from the Southeast was talking about that data—studies from Mexico that say you shouldn’t systematically test pregnant women because the prevalence is really low”. Another HIV physician, Dalia Tagle thought that “if you prevent even one case [of perinatal HIV], I think it was worth it. All of it is a cost-benefit. But health policies are always based in budgets, and the money available. So if someone says [referring to Rely et al.] this isn’t a good time to offer the test—it definitely has a big influence”.

Eduardo Sanchez, a decision-maker responsible for prevention and health promotion in his state (which oversees both reproductive health and HIV) told me the following:

If you save a life with a health intervention, well, for me the cost-benefit is justified, and even more so when it is a baby born without AIDS...personally, I feel it's been well spent. Nevertheless, health policies aren't concerned with the specific, but with the universal. ... Magnitude, significance, and vulnerability all play a fundamental role in determining the priorities for the budget: there is never enough money. So sometimes there are painful decisions.

In other words, if he was making decisions based on his personal feelings, he would support all health interventions, including prevention of perinatal HIV transmission; but, in actual fact, he is called upon to prioritize within budget constraints. And as he admitted freely, frequently these decisions are made on the basis of political criteria rather than public health criteria because "*el que tiene más saliva, traga más pinole*" (the squeaky wheel gets the grease)<sup>9</sup>.

### 3.1.3 Interrogating cost-effectiveness as a reason for not implementing PMTCT

Many of the health-care providers and decision-makers I interviewed responded to my questions about the impact of the cost-effectiveness argument on the implementation of PMTCT by arguing against this perspective. A review of these arguments is relevant because they suggest where research is needed and the kinds of arguments that may be most effective for promoting implementation of prevention of vertical HIV transmission in the Mexican context. Two types of arguments were made. First, respondents made technical arguments about why PMTCT is cost-effective. Second, they made moral or ethical arguments about the responsibility of the health system to provide access to HIV testing for pregnant women.

In terms of technical arguments, several respondents criticized Mexico's epidemiological surveillance and specifically the HIV and AIDS prevalence data on which the cost-effectiveness modelling and subsequent public policy decisions had been made. They argued that HIV is more

widespread among women than reflected in the estimates published by the National AIDS Program, especially in certain geographic areas. They mentioned that under-reporting and late reporting of AIDS cases skews epidemiological surveillance and cited alternative sources of data that show higher general population HIV prevalence, such as the national blood survey and prevalence from clinics that offer voluntary counselling and testing. In addition, they frequently cited a study from Tijuana which found an HIV prevalence of 1% among pregnant women (Viani et al. 2006). Second, many of the people I interviewed argued that universal testing of pregnant women to prevent vertical HIV transmission is cost-effective because the cost of long-term treatment for infected children is very high.<sup>10</sup> Therefore, they asserted, “if you detect even a very few cases of children who don’t get infected, with very few cases, you pay for all of the tests” (Dalia Antunez). This argument is in line with studies that show universal HIV testing of pregnant women is cost-effective, even in very low prevalence epidemics, in countries that provide free antiretroviral treatment to the population (Gomez 2008; Graves et al. 2004; Patrick et al. 1998). Finally, respondents pointed out that the costs of HIV tests had diminished dramatically in recent years, changing the parameters on which Rely et al.’s (2003) study were based, and increasing the cost-effectiveness and cost-benefit of offering universal HIV testing to pregnant women.

The other type of argument stated that the use of cost-effectiveness as the sole criteria for public health policy is not moral. Many of these arguments called upon the way things should be, rather than the way that they actually are, much like the difference between Eduardo Sanchez’s position as a private citizen and what, as a health administrator, he calls “painful decisions”. A physician, who cares for people with HIV in Mexico City and Mexico State, Ivonne Guemes, said “I wouldn’t have the courage to choose—ethically, finances shouldn’t come into it, it’s about adequate care for the patient”. Given her lack of valour for those kinds of decisions, she is

fortunate that as a health-care provider, she doesn't actually participate in the budgeting process but only practices in the context created by the decisions made by others. A federal decision-maker said: "it's not valid in public health to have competing—well, sometimes they do compete—but with perinatal transmission, I see it as a responsibility that the Mexican government can't delegate". The phrasing used by this decision-maker demonstrates the tension between ideals and practice: health issues get prioritized but in this case, the decision-maker doesn't want to be the one who placed a low priority on perinatal HIV transmission.

Three types of moral critiques were made about the failure to implement perinatal HIV transmission: one argued for scale-up as a basic human right, another focused on women's reproductive role and the well-being of children, and a third critiqued the political and health system by questioning the morality of decision-makers. Jorge Claro, a United Nations representative typified the human rights arguments, when he said:

From my point of view, when taking policy decisions, you can't ignore the right that women have, in this case pregnant women, to access the test for prevention. ... It seems to me that we can't keep sitting there in this country, taking decisions as if the epidemic is concentrated in groups of MSM, sex workers, and that the rest of the population doesn't deserve to have access to prevention because they have only a few cases. It would be like saying: we are only buying and promoting the use of condoms in this country for the highest risk groups—because that's where the epidemic is concentrated, and no one else is going to have any kind of problem. It seems to me that way of thinking feeds absurd decision-making in our health system. So, from my point of view, we need to *guarantee* universal access to testing.

Hilda Francis, an HIV clinician, said she understood the cost-effectiveness argument, in that most pregnant women would test negative and thus many tests would be used to identify only a few HIV-positive women, but said that "since I am a mom, it is hard for me to accept that the woman doesn't have the option of doing the test, and then both of them are infected and not one". Finally, a few people who I interviewed attacked the morality of the motivations of health-care

administrators and policymakers. For example, Dalia Antunez pointed to both the perception of the seriousness of the problem and the existing legal framework saying that decision-makers “don’t want to divert health personnel to it [perinatal prevention] because they think that it isn’t a priority problem, it’s not a massive issue, and on top of it, they can’t be sued. Sorry, but that is how ugly it is. They are worried about [safe] blood, because they can be sued, but not with mother-child”. Here, this policy-maker argues that one of the reasons health-care institutions and administrators don’t prioritize PMTCT as much as ensuring a safe blood supply—despite the fact that prevalence in the general population and thus the risk of transmission is relatively low in both cases—is that they are legally liable if someone becomes infected with HIV through blood products or blood transfusion but not liable in cases of vertical transmission.

Following Cook et al. (2010: 255-256), I have argued elsewhere that it is strategic to ground arguments for the extension of HIV prevention and care services in Mexico in women’s right not to suffer the consequences of sexism and gender discrimination in the delivery of health services (Kendall forthcoming). Following from this, and as discussed in more detail in the first chapter, arguments for the implementation of perinatal HIV prevention based solely on women’s reproductive role are not strategic. Such arguments reinforce the traditional and stigmatizing construction of women as vectors of disease and fail to recognize the multiple benefits of perinatal HIV prevention for the woman as well as for the child. Child-focused arguments also alienate potential allies from the broader women’s movement. For Mexico it is important to disseminate information about the multiple benefits of opportune HIV diagnosis in the context of prenatal care for women’s health, children’s and families’ health and as a public health intervention. Up-to-date costing studies to demonstrate the cost-effectiveness of prevention of vertical HIV transmission using Mexican data are needed to demonstrate that, as well as being ethical, the implementation of

this program is an effective use of scarce resources in a concentrated HIV epidemic in which there are competing priorities. Finally, it is necessary to address the administrative responsibility of institutions, introducing consequences and sanctions for the failure to implement PMTCT. However, this will not be possible until an adequate governance framework is in place.

### **3.2 Health-care governance and implementation of prevention of perinatal HIV transmission**

In my journey to understand the failure to implement prevention of perinatal HIV transmission in Mexico, three issues related to governance and the structure of the Mexican health-care system became evident. The first relates to health-care delivery in a decentralized federation that has experienced significant changes to its political system during the past fifteen years. The second relates to the vertical organization of health-care programs, specifically the reproductive health and HIV programs. Prevention of perinatal HIV transmission must occur at the intersection of these programs, and thus vertical funding, priority setting, and indicators for evaluation represent significant barriers to implementation. The third and final governance barrier is the evolution of the normative framework for PMTCT in Mexico, a process which has yet to be satisfactorily completed.

#### *3.2.1 Decentralization, democratization and health-care reform*

A very brief overview of recent Mexican political history is necessary to understand how the current governance and organization of the health system presents problems for program implementation. For seventy years until the year 2000, the *Partido Revolucionario Institucional* (Institutional Revolutionary Party) or PRI governed Mexico. Under this regime, the authority embodied in the figure of the President was supreme during his six years in office and he named his successor by selecting him as the presidential candidate for the PRI. This system provided both

a mechanism for resolving disputes among political elites represented by different factions within the one-party system and solved the problem of succession (Lawson 2000: 270-271). This ostensibly democratic process led some to call this authoritarian regime the “perfect dictatorship” (Vargas Llosa 1991).

The movement towards multiparty political representation in Mexico began to bubble at the end of the 1980s, in part because the economic crisis and demographic growth meant there wasn't enough political patronage to go around, and also because increased literacy and urbanization created an electorate that was not part of the traditional corporatist apparatus of the PRI and were thus less willing to turn a blind eye to electoral fraud and pork-barrelling (Lawson 2000). The political transition picked up steam with the first popular election of the Mexico City mayor (previously selected by the president) and the PRI losing control of the lower house of congress in 1997, and culminated in the election of Vicente Fox, the presidential candidate for the *Partido Acción Nacional* (National Action Party) or PAN in 2000 (Lawson 2000: 271-275; Napolitano and Leyva Solano 1998: 2).

The period leading up to the PRI's loss of power was accompanied by important political and fiscal reorganization during the Zedillo presidency (1994-2000) which was called “the new federalism”. The fiscal reform completed in 1997 gave legislators the power to increase the federal budget, removing this power from the remit of the Executive Branch (Puente 2012). Many interpret the decentralization of budgets to the States as “political insurance” for the PRI because it moved economic power to State governors, where the PRI would continue to hold sway in many States. Politicians from the centre-right and centre-left have all claimed that the version of federalism implemented by Zedillo has strengthened the power of regional political bosses in comparison to the national government, raising crucial issues about the shifting relationship

between centralized and decentralized power (Gledhill 1998: 11). Legislatively, financially and symbolically, the figure of the all powerful president, and thus his ability to discipline officials and politicians, has been seriously eroded through the process of democratization (Lawson 2000: 286). Yet, well-established institutions and institutional cultures of transparency and fiscal and programmatic accountability do not yet exist, particularly at the State and municipal levels where funds are supposed to be spent and programs implemented (Auditoria Superior de la Federación 2012; Fuentes 2012; Castillo 2012).

At the same time, Mexico has gone through several health-care reforms. These health-care reforms have only been implemented in services for the “open population” run by the Ministry of Health because the unions and administration of the Mexican Social Security Institute have mobilized to block reforms (Homedes and Ugalde 2009: 1; Vargas Bustamante 2010: 927). After the debt crisis of 1982, the federal government promoted the decentralization of health-care as a condition of loans from the World Bank and International Monetary Fund (with only 14 of 32 States accepting decentralization by 1987) (Homedes and Ugalde 2009: 2). From 1988 to 1994, the Salinas administration retreated from decentralization and introduced a large, federally financed poverty alleviation program called *Solidaridad* (Solidarity)—now *Oportunidades* (Opportunities). President Zedillo then moved towards decentralization of the health system for the “open population,” giving the States full responsibility and economic control, a scheme which all of the States had agreed by 1999 (Homedes and Ugalde 2009: 3; Vargas Bustamante 2010: 927). In 2003, after the PAN took power, the Popular Health Insurance was introduced to provide health insurance for the “open population”—the half of the population which didn’t have employer-based health insurance. The Popular Health Insurance can be seen as a centralizing reform, in that it establishes a list of illnesses to be treated and States must agree to treat these as a condition of

receiving funds. The period between 2003 and 2012 has been a period of increased government spending on healthcare services, financed through the System for Social Health Protection (primarily the Popular Health Insurance). This program aims to achieve “universal health-care coverage” ensuring all Mexicans with a basic package of health-care services called the CAUSES by the end of 2012. The CAUSES (Catalogue of Health Services) defines the diagnosis, treatment (including medicines and other medical supplies), medical attention and follow-up for 100% of primary care interventions and about 90% of the reasons for which people seek hospital care (Chertorivski-Woldenberg 2011: 492). Special programs financed through the System for Social Health Protection have had a strong focus on maternal health, including free prenatal and obstetric care and achieving a political agreement to allow portability of emergency obstetric care, which in theory allows women to access emergency obstetric care at any of the three major institutions (IMSS, ISSSTE, SSA) which constitute Mexico’s fragmented health system. The Social System for Health Protection is also the mechanism through which universal access to antiretroviral treatment has been financed. The efforts to implement the System for Social Health Protection is the backdrop against which we need to understand prevention of perinatal HIV transmission in the period under study.

### *3.2.2 Democratization, decentralization and health-care governance*

Research participants cited the changing political context as contributing to difficulties in implementing health policy generally and PMTCT specifically. A representative of a United Nations Agency explained that Mexico’s size and federal political structure makes it

much more complicated than in other countries where you have a national policy, and that national policy governs the whole territory. I think that is the first significant barrier in the case of Mexico. And it also has to do with, shall we say, a complex political practice which has become more *acute* in recent years. The country was used to having a [federal] government that defined everything, for all of the States.

And then you began to have a government that is a different political stripe than the governor, and different from the mayor. So it starts to become three times as complicated to follow a proposal that was made by the President, for example. So, the Ministry of Health can dictate norms that are very clear, that are in agreement with international instruments. And the Minister of Health from any state can accept them, or not accept them.

A federal decision-maker, Daniel Burgos, explained that the erosion of the authority of the president in the context of health-care decentralization has complicated implementation of policy at the State level. In his words, during the PRI regime:

Even the governors paid attention to the President. The State Ministers of Health had to listen to the Federal Minister of Health. Well, obviously, in terms of democracy, that wasn't a democracy. Afterwards the [political] transition occurred; and it has been a bit chaotic because it depends on persuasion. It isn't only the norm as a guideline, but also convincing the State health services to do their part. Because many state health services decide what is the priority for their state.

In the specific case of prevention of vertical HIV transmission, state level decision-makers explained how multiparty representation and health system decentralization posed challenges to the implementation and sustainability of the effort to increase coverage of HIV testing among pregnant women which began in 2007. Gabriela Diaz, an HIV decision-maker at the State level told me that:

The tests were all used up in 2008 and in 2009 detection drops again because it's not part of the program. It was a federal program, and the federation hasn't sent more tests for use in women. And obviously, the State isn't interested in testing women. On the one hand, I think it has to do with the country's politics. The political decisions are made by the political parties. So, in a federation, if the federal government is from the PAN and there are other political parties governing in other states, well, it gets to be a political confrontation. And that political confrontation is reflected in the fact that the programs aren't continued. And a program as important as early detection in pregnant women is gone because if the federation doesn't send more tests, the State won't buy [them]".

This presents a conundrum. The States receive the budget for and are responsible for the provision of health services. The role of the federal programs is to establish technical and normative frameworks and to supervise program implementation. In this respect, the contract between the States and the Social System for Health Protection for the provision of a basic package of services (the Popular Health Insurance) is a centralizing reform and a potential lever for scaling up implementation of vertical HIV prevention. Esther Cordera, a federal decision-maker, described the problem of resource distribution and responsibility for HIV testing and argued that the Popular Health Insurance would scale-up HIV testing for pregnant women. She said that prenatal HIV testing is included in the CAUSES of the Popular Health Insurance<sup>11</sup>, and “so the States should buy the test and they should offer it. The federal government is not responsible for or obliged to send medical supplies that they don’t buy in the State. The State has the money. Often we do it to meet shortfalls, but it isn’t our role”. However, in practice, at least in sexual and reproductive health, unless there are earmarked resources provided by the federation,

the States have so many other priorities to pay attention to, you find that the response is random. As a consequence, women’s treatment is very unequal, and we even enter into questions of respecting human rights. ... First of all, the interpretation of national legislation is not the same at the State level. And then the interpretation in terms of implementation of the health services, and what is important, and what isn’t important—I think there is too much leeway, too much flexibility in decision-making, without a sufficiently developed system of accountability (United Nations Representative).

In the context of democratization and health-care decentralization, developing systems for oversight of program implementation is an incredible challenge and a priority for responding to important social problems such as health. There have been some interesting and innovative responses by civil society to the lack of oversight and accountability, including establishment of

citizen observatories for priority health issues such as maternal mortality ([www.omm.org](http://www.omm.org)) and the use of freedom of information requests for fiscal monitoring ([www.fundar.org](http://www.fundar.org)). For perinatal HIV prevention, it has been difficult to identify who is accountable and how they may be held responsible because, despite the fact that Mexico has signed international agreements and set targets for prevention of perinatal HIV transmission in National AIDS Plans since 2001, the vertical organization of health-care and current normative frameworks have consigned the issue to an administrative abyss.

### **3.3 HIV and Reproductive Health: Vertical Programs**

While the heads of the National Center for Reproductive Health and Gender Equity and the National AIDS Program report to the Deputy Minister of Prevention and Health Promotion, the programmes are organized vertically with independent reporting hierarchies, different mandates, and different indicators to evaluate success. Jorge Claro, a UN official, explained that:

In all of the [subsystems] there is a marked difference between HIV/AIDS programs and Reproductive Health programs. Each of these programs has their own infrastructure, their own personnel, and their specific regulations. And they are managed parallel to and completely isolated from each other. So even though there can be political will, and legal instruments signed by the country, because HIV and reproductive health are managed separately and isolated from each other, it really limits the possibility for interaction.

This isolation is expressed in how the programs are organized and how they are funded.

Commenting on the need for structural change, Dalia Antunez, a state-level HIV decision-maker, stated that reproductive health and HIV “are programs that receive different funds. It isn’t money per patient, it is money by program”. A portion of health-care funding transferred from the Federal government to the States is calculated using historical budgets, which were established on the basis of existing health-care infrastructure (hospitals and medical personnel). This formula unfairly

benefits the more developed states. Another portion is assigned through programmatic budgets for “special programs” like reduction of maternal mortality or family planning. The financing of the Popular Health Insurance moves towards addressing some of these structural issues and inequalities. It ties health financing to the person (rather than the program) and the per capita formula adjusts for the inequities stemming from historical budgets, providing the same amount per capita to each State (Chertorivski-Woldenberg 2011: 493). However, additional funding provided to the States by federal programs is provided programmatically and prioritized programmatically. A federal decision-maker with responsibilities in the area of reproductive health stated the following.

I have to reinforce tests to detect preeclampsia and eclampsia—other things that are more linked with my target—which is maternal mortality. I have to prioritize, and because of the [global financial] crisis, resources are now limited. So, I have to make links. The internal administrative controls demand that I channel my resources according to *my targets*, and diminishing perinatal [HIV] transmission isn’t one of my targets. I am not the owner of that target. CENSIDA [National AIDS Program] is the owner of that target. So it is more justified for CENSIDA to assign resources to HIV testing for pregnant women than for me to assign resources.

These restrictions and vertical organization also impact on the actions that are prioritized by health-care workers. Explaining why some health centers in her State weren’t applying HIV tests to pregnant women despite having rapid tests in stock, Cecilia Ubaldi, a physician working in an HIV clinic said that:

In the end the MOH has too many programs, too much paperwork, and it takes up time, so they [health-care personnel] can develop the habit of offering testing to all of the pregnant women, or not. ... All of this is managed through programs. And each program demands targets, demands a specific form. Reproductive Health has very specific guidelines for prenatal care. However, detection of STIs during pregnancy is not one of the parameters prioritized by reproductive health. So we’ve seen that they always fall by the wayside. They don’t offer testing of HIV or VDRL [syphilis] or any other STI. They fill out the specific forms for prenatal care.

Until the forms for prenatal care include HIV and syphilis testing, health-care providers are unlikely to offer the tests. And, these tests are unlikely to be added to the form until they are one of the targets assigned to the reproductive health program.

An additional problem with the assignment of prevention of perinatal HIV transmission to the HIV Program is that the health-care providers who work in HIV have no contact with pregnant women, unless a pregnant woman perceives herself at risk of HIV and seeks out voluntary testing and counselling at an HIV clinic. A State HIV decision-maker put it succinctly saying that assigning the responsibility for offering HIV-testing to the AIDS programs is “like assigning the application of the tetanus shot to infectious disease specialists [which is part of prenatal care in Mexico]: insufficient, impossible. How can the tiny infectious disease services reach all those pregnant women?” Health-care and administrative personnel working in HIV not only lack any point of contact with pregnant women through the health system, but HIV clinics and programs also tend to be very small and have a limited number of staff. Daniel Burgos, a federal HIV decision-maker, indicated that the relative sizes of reproductive and HIV services had been a barrier to the implementation of PMTCT because the “National AIDS Program doesn’t have the capacity, the human resources, to train each and every one of the nurses, at least not the nurses that work in maternal-child health. It is a much bigger program than HIV/AIDS, with thousands and thousands of personnel”. In contrast, in many States, the National AIDS Program is represented by a single person, who is of relatively low rank within the State epidemiology program and who is often charged with several other thematic programs as well as HIV. The number of free-standing HIV clinics run by the State Ministries of Health has increased in recent years. However, HIV programs are Lilliputian when compared to the size of primary-care clinics and hospitals serving pregnant women. To give an idea about the difference in the size of the programs and people

employed we need only to contrast the 32,468 people with HIV who received antiretroviral treatment (and are enrolled in ambulatory care at an HIV clinic) with the approximately million and a half women who received prenatal care in institutions run by the Ministry of Health in 2009 (CONASIDA 2009: 4, 20). In this context, Diana Castro, an HIV decision-maker working at the State level asks: “when a woman goes to a health clinic in the second month of her pregnancy, and she isn’t tested—who is responsible? How can you tell me that it is the AIDS program? It’s the responsibility of the person who was responsible for her prenatal care”. Yet, in terms of the assignation of programmatic responsibilities and normative frameworks, from 2001 up until the present, HIV testing of pregnant women has not been incorporated into the normative framework governing prenatal care. Thus, in policy and practice, HIV testing of pregnant women remains the responsibility of the National AIDS Program.

### **3.4 Mexico’s Normative Framework for PMTCT**

Mexico’s normative frameworks for delivering health-care are expressed in legal and technical instruments. The legal instruments have greater hierarchy. The overarching framework is provided by the General Health Law and specific laws for different health issues. Below the laws are the *Normas Oficiales Mexicanas* (Official Mexican Standards), commonly known as NOMs. NOMs are developed by expert committees, go through a period of public consultation, are approved by the committee and become official when they are signed off by the responsible Minister or Deputy Minister and published in the *Diario de la Federación* (Federal Daily Gazette). Alongside the laws and NOMS are programmatic plans that are prepared every six years with the election of a new president of the republic. The central plan is expressed in the National Development Plan. Plans are then developed for each sector (for example health) and each

program (for example HIV) to complement the National Development Plan. The two NOMs which have direct bearing on prevention of vertical HIV transmission are the NOM on medical care during the prenatal period, labour and delivery, and the puerperal period (NOM-007) and the HIV NOM (NOM-010). The sectoral plan which is relevant is of course the National Health Plan, and the two programmatic plans are those of the National AIDS Program and the National Centre for Gender Equity and Reproductive Health.

#### *3.4.1 The evolution of PMTCT in the HIV NOM*

During the time period that concerns us (2001-2012), the HIV NOM has been revised three times. The first HIV NOM was published in 1993, and it recommended that health-care personnel advise women with HIV to avoid pregnancy, informing them about the risk of perinatal transmission and to avoid breastfeeding (Secretaria de Salud, 1993b). In 2000, the NOM was revised and, though it still recommended that women with HIV not become pregnant, it was updated to include the scientific knowledge that mother-to-child transmission of HIV could be reduced and instructed health-care workers to provide antiretroviral treatment in accordance with the applicable clinical guidelines (Secretaria de Salud, 2000). The revision published in November 2010 was a huge leap forward in terms of preventing perinatal HIV transmission and promoting the reproductive rights of women with HIV. The 2010 NOM states that both public and private health services are *obliged* to offer free and voluntary HIV testing to all pregnant women. In addition, rather than focusing on advising women with HIV to avoid pregnancy, the NOM now states the following:

Health care providers must provide scientific information about perinatal HIV transmission to women with HIV in order to allow them to exercise their right to decide about the number and spacing of their children, in accordance with the 4<sup>th</sup> Article of the Constitution of the United Mexican States, the General Health Law and the NOM 005-SSA2-1993 on family planning. If pregnancy is desired, undertake

appropriate medical follow-up on general health and antiretroviral regimen from before pregnancy, prenatal care, etc. described in the Guidelines for Antiretroviral Management for People with HIV in order to reduce the probability of vertical transmission. The right of women to decide about their reproductive life must be respected (Secretaria de Salud 2010, Article 5.6.5).

### *3.4.2 Incorporating HIV and other STIs into prenatal care: NOM-007 and the Reproductive Health Program*

In 2001, for the first time, prenatal HIV testing was mentioned in the National HIV and AIDS Plan. The objective was to incorporate perinatal prevention of HIV and other sexually transmitted infections in all of the institutions that are part of the health sector, eliminating congenital syphilis and reducing new perinatal HIV cases by 75% (Secretaria de Salud 2002c: 36). The HIV NOM was not under revision at this time, but the NOM legislating the prevention and control of sexually transmitted infections was. To establish a normative framework which included HIV testing for pregnant women, the modification of the NOM linked HIV testing to syphilis testing which was already included as a routine part of prenatal care: any pregnant woman who was positive to syphilis was to be offered HIV testing as well (Secretaria de Salud 2002a). This change in the NOM was then translated into an operational document which included HIV testing of all pregnant women positive for syphilis as part of the Safe Pregnancy component of the Equal Start in Life program run by the National Centre for Reproductive Health and Gender Equity in 2002 (Secretaria de Salud 2002b: 26). There are also other operational technical documents that include HIV testing for women. The CAUSES, the catalogue of basic health interventions to be provided as part of the Popular Health Insurance, published in 2009 states that prenatal care should include “hepatic function, bloodwork, urine test, VDRL, blood type, and for high risk women, HIV-testing” (Secretaria de Salud 2009a: CAUSES 86). And the National Women’s Health

booklet recommends prevention of HIV and other sexually transmitted diseases, including HIV testing among women 20-40 years of age who are “at high risk” (*Cartilla Nacional de la Salud de La Mujer*-Women’s National Health Card).

The repeated references to HIV-testing for “high risk” women in these documents derive directly from the NOM which governs prenatal care, labour and delivery and care of the infant in the post-partum period (NOM-007). In contrast to the HIV NOM, NOM-007 has not been updated since 1993. Currently the NOM states that during pregnancy HIV testing should only be offered to “high risk women—those who have received blood transfusions, drug addicts, and prostitutes” (Secretaria de Salud, 1993a, Article 5.1.6). There was universal agreement among the 60 health care providers who worked in HIV, decision-makers from both Reproductive Health and HIV, and HIV activists that I interviewed, that the description of “high-risk women” in the guidelines for pregnancy, labour and delivery does *not* correspond to the profile of women with HIV in Mexico. Dalia Antunez, a state decision-maker, said that only offering prenatal HIV testing to “high risk women” “was always my argument with them. I told them that this way we won’t stop [perinatal transmission]. In the two years that we ran this other [prenatal HIV screening] program in the State, *none* of the positive women had those characteristics, *none*”. Another State decision-maker working in HIV, Gabriela Diaz said that “Epidemiologically there is no reason why the NOM should be like that. The women [with HIV] are engaged in diverse activities, and the *least common* is sex work”. Among the people that I interviewed, consensus exists on the desirability of including HIV testing for all women in the new version of NOM-007, and it has been included in the draft version of the NOM. The decision-maker responsible for NOM-007 stated that “what we are proposing is that it is obligatory to offer it [the HIV test] to every woman, not that it is done,

but that it is offered. ... We are already working at the operational level, we are insisting, we are promoting [testing]. But we also have to adjust the legislation”.

A barrier to the publication of the new version of the NOM-007, which is not related to HIV, has been wrangling over the normative framework for access to emergency contraception and pregnancy termination. The Chair of the National Pro Life Committee in Mexico (PROVIDA) participates as a civil society member in the expert committee in charge of reviewing NOM-007. In 2009, an HIV health-care decision-maker told me that they had been at a meeting where “*we all* voted that it [NOM-007] was ready for publication, and he didn’t agree. We had to make an agreement that a new group would be formed to review some issues that had already been reviewed. And the members of that group were designated, and we weren’t included”. As of June 2012, the modification of NOM-007 still hasn’t been published.

### **3.5 NOMS and Healthcare Practice**

In addition to tracking the historical evolution of the NOMs, I sought to discover what health-care providers and decision-makers actually knew about the NOMs governing PMTCT to understand how the normative framework impacts on decision-making and service delivery. At the time when most of the interviews took place (July 2009-April 2010) neither the HIV nor Reproductive Health NOM recommended HIV testing for all pregnant women. Thus, I was surprised to find that a large number of health-care providers and decision-makers believed that the NOMs incorporated HIV testing of all pregnant women. This belief was especially common among physicians working in State HIV clinics (as opposed to the federal research and teaching hospitals) and universal among the HIV psychologists and social workers that I interviewed. The following dialogue was typical of the responses to my questions about NOM-007.

**Researcher:** What do you know about what the NOM for prenatal care, birth and the puerperal period says—should HIV testing be offered to all women or not?

**HIV Social worker:** Yes.

**Researcher:** No! It says that the test should be offered to women who are drug addicts, have had a transfusion, or prostitutes, only.

**HIV Social worker:** Well, that's really wrong.

**Researcher:** It's from '93, it hasn't been updated...and that profile, with those types of risks, are those the women that you see here?

**HIV Social worker:** No, in general the most affected are housewives.

During the interviews it became evident that just as health programs are organized vertically, knowledge of the NOMs tends to be vertical in that each program follows the NOM that governs it, and health workers and decision makers don't necessarily consult the regulatory frameworks of related programs. When asked whether HIV testing of pregnant women was included in the reproductive health NOM, one state decision-maker with a decade of experience in HIV said, "I don't know". Another State decision-maker working in HIV, Adriana Guerrero, responded to my questions by saying, "no, I don't understand the question, [we don't implement PMTCT] based on what the reproductive health NOM says...We do it because in the HIV program we are seeking to [reduce] vertical transmission". Likewise, health-care workers follow the guidelines for their program. Paty Conde, an HIV physician described the NOMs as "divorced," saying that "the reproductive health NOM doesn't mention HIV; where [HIV] care for pregnant women is explained is in the [HIV] manual. So, there is a need to unify the two NOMS because we are still a bit divorced. ... And lots of doctors don't know the HIV manual, only those of us who work in HIV".

The lack of knowledge of the NOMs among the people I interviewed along with the common belief that HIV testing of pregnant women was already included, led me to question how much the failure to update the NOMs was actually impacting on the implementation of prevention

of mother-to-child transmission of HIV. My growing scepticism about the utility of the NOMs was compounded by the description of a “*cultura de apariencia*” (culture of appearance) by those that I interviewed and their deep cynicism about the discrepancy between what is written on paper and reality. One Representative of a United Nations Agency insisted that “*entre el dicho y el hecho, hay un trecho*” (actions speak louder than words)<sup>12</sup>. Another UN Representative told me that in comparison with other Latin American countries,

Mexico is the country that always signs [international conventions]. So what can be done? We have to disseminate what has been signed, and find a way to get the people to make demands. I think that one of Mexico’s problems, compared to other Latin American countries, is that *there isn’t a culture of demanding that the authorities fulfill their responsibilities*.

Acceptance of the failure to comply with health-care legislation and guidelines was commonplace. For example, a senior HIV physician who I interviewed before the HIV NOM was updated to include the offer of HIV testing to all pregnant women told me that “the legislation says that it [prenatal HIV-testing] is obligatory. But sometimes the guidelines aren’t upheld. We don’t follow the guidelines. We aren’t educated to follow the guidelines, and nobody follows the guidelines”. A young clinician who had recently completed his practicum and begun working in HIV swore up and down that both NOM 007 and the manual for prenatal care included HIV testing. His cynicism about the gaps between health policy and the reality lived in public health clinics is evident in his explanation that he knew (wrongly) that HIV testing of pregnant women was included because he “read the NOMs at night, to see what lies they told”. Another United Nations official, Jorge Claro, explained that “there are many dead letter laws because there hasn’t been a parallel effort to gather the necessary resources to implement. The laws are forgotten and they are only executed in an almost *ad hoc* manner, only for those who demand it, and it isn’t given *a priori* by the institution”.

Clearly, the change in NOM-007 isn't enough to guarantee the implementation of perinatal HIV transmission just as the inclusion of the goal of reaching 100% of pregnant women with HIV testing in the 2001 National AIDS Plan in 2001 wasn't enough to achieve substantive change in the implementation of PMTCT (Secretaria de Salud 2002c: 36).

Yet, decision-makers and health-care providers saw the NOMs as useful expressions of political will and as a crucial instrument for resource allocation. The NOM can be a tool to communicate political will and the absence of HIV testing from the NOM governing prenatal care communicates a clear message. Zaria Tagle, a senior HIV doctor working in a State clinic said that “one of the greatest problems is that there is no legislation, the decision hasn't been taken to implement an ELISA [HIV test] as an obligatory test during pregnancy. ... I don't think that the political decision has been taken to say: Ok, every pregnant woman should receive the offer...should take the test”. A federal decision-maker underlined the utility of the NOM as a governance tool that can bring about changes in a decentralized health system saying “to offer the test, we have to pass the legislation. If it is in the NOM, it is a better way to compel them [the State health services]. And if it is in the indicators to evaluate the performance of the States, that's another way to compel them”. Discussing the failure of the semi-autonomous Mexican Social Security Institute that provides health-care for private sector to implement HIV-testing for pregnant women, this research participant added that “they hide behind the fact that there aren't norms and that the norms that are in force say [you need to offer] syphilis testing to pregnant women—but it doesn't say HIV testing, and the HIV NOM still says that you don't have to offer it to all women”. A state decision-maker with a long history of working in the State reproductive health program with a focus on prenatal care echoed the importance of having an up-to-date

NOM-007. In her comments, she explored the relationship between policy and practice in the implementation of PMTCT, stating:

As an administrator, I need the NOM to be up-to-date, because the more arguments you can make—it's an official NOM, programs, guidelines—the more backup you have with the operational level. But since HIV is a global disease, the health personnel don't question it, right? I mean, if the [NOM] says it or doesn't say it, I don't think it is very relevant. But as civil servants, we need the paperwork as the foundation for our actions. ... Because of course when it is written down—official norms and guidelines—it gets done. But the NOM can be updated, and we can lack the medical material for the operational level. The important thing is to have the tests, to apply them, and to have official support.

The internal contradictions in this health-care decision-maker's comments reveal tensions within institutions and the gap between the ideal and the reality in health-care practice. Much in the same way as the policymaker who told me that health priorities shouldn't compete—but they do, the decision-maker cited above tells us that if something gets included in the NOM “it get's done” and then immediately contradicts herself by saying that unless the medical material is available, the program won't be implemented. Thus, I conclude from these interviews that an up-to-date NOM-007 and sustained access to the materials to offer HIV-testing to pregnant women are both necessary but not in themselves sufficient to ensure the scale-up of the HIV-testing.

The relationship between policy and purchasing can be a virtuous or a vicious circle, as the NOMs are also an integral part of the process of resource allocation. The high-level federal Reproductive Health decision-maker made the relationship between budgets and policy clear when stating that it was not possible for the program to sustain access to HIV tests in prenatal care because their mandate is reduction of maternal mortality. Likewise, a state HIV decision-maker, who had been very proactive about establishing a prenatal HIV testing program in her State, explained how linking reactive syphilis test results to access to HIV testing for pregnant women in

the 2002 NOM on prevention and control of sexually transmitted infections became a barrier to the universal offer of HIV-testing. She recalled arguing with employees of the National AIDS Program about her operational plan, which would receive federal funds, because “they told me ‘you can’t include so many tests, you have to calculate based on your syphilis prevalence.’ No, I’m sorry, but I’m not going to only test women who are positive to syphilis. I am going to offer the test to all of the women. So, my calculation is based on all of the pregnant women that we care for, period”. Just like NOM-007 which only recommends HIV testing for “high risk women,” linking HIV testing to a positive syphilis test in the STI NOM perpetuated the underlying assumption that some pregnant women are more at risk of HIV than others.

### **3.6 The Reproductive Health NOM and cultural constructions of women’s HIV risk**

My analysis has led me to conclude that deconstructing the normative and cultural construction of women “at-risk” of HIV is the cornerstone for scaling up perinatal HIV prevention. Despite decision-makers, health-care providers and HIV activists rejecting the accuracy of describing Mexican women with HIV as “drug addicts, women who have received blood transfusions and prostitutes,” this stigmatizing cultural construction persists in both health-care legislation and in practice, providing an administrative and moral mechanism to ration health-care resources by not providing HIV testing to all pregnant women. The idea that health-care providers can somehow identify which pregnant women are at risk for HIV is deeply rooted in institutional cultures. One HIV decision-maker insisted that “you can identify [HIV risk], if and only if, you have lots of time with a woman who is coming for periodic check ups during her pregnancy”. His opinion was that since prenatal care does not frequently occur in that way, HIV testing of pregnant women should be routine. But, it is important to note that he held the belief that given the

opportunity, health-care providers can identify women who are more at risk of HIV infection than others. Other HIV health-care providers manifested that in their institutions, pregnant women were only offered HIV testing if they

have some risk, some history, some situation that could be suspicious, then you give them very direct information. [To identify possible risk] you ask questions. For example, when you examine the woman you might see tattoos. In their history, if they have had other pregnancies, did they receive a blood transfusion? Have they had one partner, many partners, and were their partners people with other risk factors: if they have had other partners, or if they have unprotected sex, or other risk behaviours” (Vicente Guzman, State HIV health-care provider).

Some participants, such as the physician cited above, were correct in understanding that such screening for risk factors was in line with the current norm for prenatal care. Others believed that “the norm is to offer it one hundred-percent to every woman, but lamentably because of budgets we have had to screen in order to apply HIV tests” (Martin Cortes, State HIV physician).

The cultural construction of “at risk” women functions effectively as a reason for rationing access to HIV testing because it resonates with dominant beliefs that associate HIV with stigmatized sexual behaviour, and automatically exclude pregnant women as subjects of risk.

Felipe Castillo, an HIV physician, argued that one of the major barriers to the expansion of HIV testing, especially among pregnant women, has been that

health personnel are part of Mexican society, occidental society, and I think most of the world, in the sense that HIV is related with sexuality. And sexuality, in general in the world, is still something that is secret, silent, forbidden. There are nations that are more advanced than others, but in general it is still secret, silent, forbidden, sinful, and perverse.

At the beginning of the HIV epidemic the most affected populations in the United States and other rich countries were socially marginalized and stigmatized: gay men, sex workers, drug users, and immigrant people of colour—the infamous four Hs—homosexuals, hookers, heroin users, and

Haitians. This historical occurrence bequeathed a social imaginary to the world and contributed to making HIV invisible among women and children in the United States until relatively late in the epidemic (Treichler 2004). The social imaginary which links HIV to marginalized and stigmatized sexualities continues to be encoded in health-care legislation that targets “at-risk” women for HIV-testing and is extremely common among Mexican health-care providers. Hilda Francis, an HIV physician, told me that

In general, physicians think that only homosexuals, or certain classes [become infected with HIV], so they don't think of it as something routine, like someone who works in this area and sees it all the time does. ... For example, when I got pregnant two years ago, my doctor never asked me to take an HIV test. So I asked him, 'aren't you going to ask me to take an HIV test?' 'You don't have risk factors.' ... 'And how do you know?'

In Mexico, the high prevalence among men who have sex with men and the stigmatization of sexualities that are different from the monogamous heteronormative model described by the Catholic Church are barriers to the re-evaluation of the Mexican HIV epidemic and the perception that women in stable relationships can be exposed to HIV. Zaria Tagle, a senior HIV physician, said that “in Mexico, we have always held the idea that pregnant women are protected from everything. As if pregnancy is preventative—which is really absurd. And there is fear of HIV testing with a pregnant woman. I think that has been another factor: how can I tell a pregnant woman to do an HIV test?” She went on to explain that the cultural taboo against asking a pregnant woman to do an HIV test is related to not revealing how sexual behaviour varies from the ideals put forward by the Catholic Church. She said,

in theory, in our Catholic society only monogamous couples should exist. So, all good Catholics who go to church are assumed, in theory, to be monogamous, when we know that doesn't exist, that it isn't real. So, if that's the theory, how can you take a political decision that says that there is going to be prevention or that I am going to apply an HIV test to a pregnant woman? Because if do, then I am saying that maybe

her first sexual relationship wasn't with her husband, maybe she had other partners. It means accepting something that the Mexican society still doesn't accept very easily. It has a lot to do with the Catholic influence. The Church has really limited the public policies needed to be able to respond strongly [to HIV], especially among pregnant women.

It is interesting that this health-care decision-maker places emphasis on the sexual history of the pregnant woman rather than her male partner; as I will discuss in more detail in subsequent chapters, while in contemporary Mexican society women may have more than one lifetime sexual partner, it is normative that men will do so. Thus, offering the HIV test to pregnant women simultaneously threatens to reveal the gap between Catholic doctrine and Mexican sexual practice and the sexual double standard which simultaneously idealizes monogamy and includes multiple sexual partners as a central part of the construction of masculinity. Other health-care providers said offering HIV testing to pregnant women is potentially explosive because it “call's into question the fidelity of my partner” (HIV physician) and could “reveal my husband's faults” (HIV psychologist).

### *3.6.1 Sexual stigma and responsibility for vertical HIV transmission*

The sexual stigma associated with HIV also means that the moral responsibility for vertical transmission does not fall on the institutions or individual health-care providers that deny women the opportunity to prevent HIV vertical transmission by offering testing, but rather on the woman and her male partner. Esther Cordera, a high level federal official working in Reproductive Health, passionately asserted her belief that “cases of congenital syphilis, like cases of polio, like cases of measles, are now *unacceptable* in our country. I think that it should be established that a case of congenital syphilis is at the same level, we should scream bloody murder. A pediatric HIV case, we should say: That can't be! What happened?” Her impassioned plea to increase moral outrage about a case of vertical transmission of a sexually transmitted infection, like HIV or syphilis, to

the same level as childhood cases of polio or measles, is an eloquent testimony to the fact that they are not considered equal. Esther Cordera's reference to both syphilis and HIV reveals the relationship between sexuality and the moral condemnation of the family rather than the institution that failed to prevent vertical transmission. She says that "we should scream bloody murder" in a context where those affected remain silent out of shame, and the common-sense understanding is that perinatal transmission of HIV or other sexually transmitted infections is the woman's fault. Moving from the institutional level to health-care providers, the sexual stigma related to HIV is understood to absolve physicians of responsibility for vertical HIV transmission in the eyes of their peers. Roberto Newton, an HIV physician, explained.

Among gynaecologists there are things that you shouldn't overlook, and which cause a lot of ridicule. For example, a premature birth, a malformation in the infant—those are things that physicians as a group really punish, it's highly penalized among gynaecologists. How is it possible that you provided the prenatal care, and look at the complication the child has. But not HIV, because, what our fellow physicians say is that 'it's her fault,' 'it's that the husband...' So the blame isn't placed on the gynaecologist, but rather on the intimacy [sexual relationship] of the woman, or her partner—that the partner infected her and that's that. So I think that they perceive that other things are more punished by their peers, but [perinatal transmission of] HIV isn't something that they are penalized or criticized for.

The health legislation which recommends HIV testing during pregnancy only for "at risk" pregnant women perpetuates a social imaginary which associates HIV with stigmatized sexualities. In terms of administrative responsibility, this legislation provides justification for rationing of health-care resources and protects institutions and individual health-care providers from legal sanctions for perinatal HIV transmission of HIV. The legislation also codifies cultural ideas about sexuality and HIV, absolving health-care institutions and providers of moral responsibility for vertical HIV transmission. Further, HIV testing of pregnant women has the potential to simultaneously reveal the variance between sexual practice and Catholic

doctrine on monogamy and bear witness to individual men’s sexual infidelity—showing the hypocrisies inherent in the dominant religious and sex-gender order with a single blood test. From this perspective it is hardly surprising that, despite the conviction of individual health-care decision-makers and providers that HIV in Mexico doesn’t primarily affect “at risk” women, implementation of prevention of vertical HIV transmission has advanced by fits and starts.

### 3.7 Scaling up HIV testing during prenatal care (2007-2010)

The first step towards preventing vertical HIV transmission is providing women with an opportunity to know their diagnosis. Table 3.1 demonstrates that the coverage of HIV tests administered to pregnant women attending prenatal care in health services administered by the Ministry of Health (MOH) jumped dramatically between 2006 when it was only 10% to over 50% by the end of 2009, but then dropping again to 44% in 2010. This period provides a case study for the implementation of prevention of vertical HIV transmission in Mexico. The experience illustrates the relationship between political will, and administrative instruments and practice. I show that vertical program organization, lack of adequate normative frameworks, and competing priorities for scarce resources— expressed through the lack of an up-dated NOM and budget assignation—are important barriers to the scale-up and sustainability of perinatal HIV prevention in Mexico.

<b>Institution</b>	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
<b>MOH</b>	ND	ND	ND	5.5%	8.8%	10.2%	20.9%	43.0%	53.3%	44.0%
<b>IMSS</b>	ND	ND	3.3%	3.9%	0.4%	0.9%	1.5%	6.4%	9.6%	15.6%
<b>ISSSTE</b>	ND	ND	7.0%	3.3%	3.2%	0.5%	0.6%	0.6%	0.6%	0.8%
<b>SEDENA</b>	19.4%	24.9%	23.7%	36.1 %	45.7%	26.9%	28.5%	36.0%	36.7%	45.7%
<b>PEMEX</b>	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

<b>Total</b>	0.4%	0.4%	1.4%	5.4%	6.7%	7.3%	13.1%	31.4%	39.0%	34.6%
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### 3.7.1 Political opportunity, progress, and problems with PMTCT

In February 2007, the National AIDS Program announced that during that year all pregnant women attending prenatal care in services administered by the Ministry of Health would have access to rapid HIV tests thanks to the purchase of 869,550 rapid tests for use in this population by the National Centre for Reproductive Health and Gender Equity (Godinez Leal 2007). Esther Cordera explained that the purchase came about when the federal reproductive health program “had an opportunity because the legislative branch increased our resources. And looking at the strategic actions that we could take, based on our powers, something that we are responsible for improving is prenatal care”. The importance of mandate and the barrier represented by vertical programs is clear in this health decision-maker’s description of the rationale for purchasing rapid HIV tests. At this juncture, with additional resources that must be spent rapidly, she includes HIV tests for prenatal care within her remit, but when resources are scarce, the Reproductive Health Program prioritizes medical materials, tests and programmes that are more tightly linked to the indicators for evaluation which actually “belong” to reproductive health, like the number of maternal deaths. Alejandra Cruz, a federal decision-maker working in HIV, commented that

from a programmatic or strategic planning perspective, or if an economist looked at it, they’d say, ‘Maybe before buying those thousands of tests and sending them, it would have been good to have a well-defined medium and long-term plan. And to consider in what type of activities you should spend the money on, to expand afterwards.’ Nevertheless, unfortunately, that is not how things get decided in the public service. I can tell you that when the decision was taken to buy those tests, it was money that had to be spent quickly. Don’t ask me why, because initially it wasn’t from our budget. But I imagine it was for the same reasons that we have, year after year. It’s a budget that has to be spent quickly or it’s gone. You can’t make changes in that moment—you can’t say, ‘no, no, no, it would be better to spend this much on tests and we should do a strategy and a campaign.’ Often in practice you can’t do it that way. And that’s why the decision was made [to buy the tests]. And believe it or not, having those tests gave us the justification, because it wasn’t a

pretext, the justification to go into reproductive health services and insist on coordination between the programs providing medical prenatal care and all of the rest.

The allocation of the additional funds which were spent on the rapid HIV tests was made by the legislative branch, a consequence of the 1997 fiscal reform mentioned above which took authority over the budgeting process away from the Executive and put it in the hands of the legislature. To spend the resources, the reproductive health program purchased a large number of rapid tests. The tests were then distributed to the States with a memo instructing health-care providers to offer HIV testing to every pregnant woman who attended prenatal care. The tests were accompanied by a form which was to be filled out and signed by the health-care providers, and then sent from the health care site to the local health department who would then send them to the State Representative for Reproductive Health who would then forward them onwards to the National Centre for Gender Equity and Reproductive Health which in turn would forward the questionnaires to the National AIDS Program for analysis.<sup>14</sup> The winding road that each questionnaire had to take shows us the complex relationship between HIV and Reproductive Health in the states and at the federal level and suggests why implementation of programs that demand integration—like prevention of vertical HIV transmission—are institutionally challenging. While the National AIDS Program and the National Centre for Reproductive Health and Gender Equity collaborated at the federal level to design the questionnaire that accompanied the tests, at the beginning of the roll-out of the program communication and collaboration did not occur at the State level. One consequence was the lack of a specific training programme or communication campaign to educate health-care providers or pregnant women about HIV-testing during prenatal care and prevention of perinatal HIV transmission prior to the national distribution of the rapid

tests. Initially, this lack of communication was a barrier to the adequate use of the rapid HIV tests.

Gabriela Diaz, a decision-maker in a State HIV programme explained that

the order didn't come to the HIV program. The national order [to apply the tests] was for FP, Family Planning. So, well, FP doesn't know how to apply the antibody test, but in the end, where do the pregnant women go for medical care? The FP program, not the HIV program. Who has direct contact with pregnant women? The primary care clinics. And those primary care clinics are the ones that see all the women, so, it's logical for them to take care of the testing. But they got the tests without training, without knowing how to counsel, without knowing how to offer the test. And the women got really frightened when they [health-care providers] said that they were going to do an HIV test. They got scared because they thought something bad was happening.

Initial problems with testing and counselling included women refusing testing because the benefits of the test hadn't been explained to them; or, if they had a reactive test, believing that they had AIDS and were going to die before their test result had been confirmed. However, the delivery of the rapid tests to primary care clinics provided the impetus for HIV to start working with reproductive health. During 2008-2009, the National AIDS Program and Centre for Gender Equity and Reproductive Health convened regional meetings to bring together the State representatives of reproductive health and HIV and the relevant hospital directors to train them on prevention of perinatal transmission, to make agreements as to how to train primary care providers in HIV counselling and to establish protocols for referral and follow-up between the two programmes.

Some of the tensions between the federal government and the states and the barriers to implementation in decentralized health systems are also evidenced by the administrative and bureaucratic delays in the delivery of the rapid HIV tests and their use in 2007 and 2008. Dalia Antunez, an HIV decision-maker from one of the States, pointed out that:

The tests arrived in the States three months before the expiry date. Obviously, eight hundred thousand tests to apply in three months—it's absurd. ... But, by then, the States can't

negotiate. They [the federal government] give you the whole lot with those expiry dates, and you lose. And if you don't use them, it's your problem because you can be sued by the comptroller's office. Because the tests were in your possession when they expired.

State-level HIV health-care decision makers and HIV activists reported that rapid tests had been used for populations other than pregnant women because they were going to expire, and that many tests expired without being used or were used after their expiry date. The failure to use the tests for pregnant women points to the lack of coordination between reproductive health and HIV, but also to the sexual stigma which marginalizes HIV within the health system. Martina, a woman leader with HIV, said that the Ministry of Health in her State must have received lots of tests because

they were giving them away. But, you have to understand that the tests expired in December. So in November, on the 15<sup>th</sup> of November, they went to the civil society organizations to give us the tests so that we would help them, because they were going to expire. And even with all of that, so many of those tests expired. I mean, it's like they realised when they were about to expire, then they said: 'Oops, we've needed to do this all year.' And it was shocking how many tests expired. And it didn't only happen in [my state]. It happened all over the country.

Evaluating the process, Esther Cordera from the federal Reproductive Health program recognized that there were difficulties in the program scale-up. She said that:

The tests weren't applied to every woman otherwise we would have had practically 100% coverage in one year. The tests took a long time; in every process where there are changes in how things function, it takes a long time. There are 32 different state bureaucracies. But it improved. From an average of 5%, which was the HIV coverage, to the last reports where you obviously have 30-40% increase in a year, which will make a difference.

### *3.7.2 Creating momentum for integration to support PMTCT*

While imperfect in its execution, the delivery of more than 800,000 rapid tests to primary care clinics for use in prenatal care was a significant step forward in terms of scale-up

of testing between 2006 and 2009 and increased awareness of perinatal HIV prevention among the health-care workers and administrators who have contact with pregnant women. Gloria Vergara, a State decision-maker from Reproductive Health explained that

in years past, the HIV/AIDS program had screened pregnant women to detect HIV. But from 2006 approximately, when they told us that we should offer the rapid HIV test to every pregnant woman, systematically, it became much more active. They, the pregnant women, voluntarily accepted whether or not they were going to take the test. So, from the time that the Equal Start in Life Program implements HIV testing in pregnant women it became more widespread.

Before the delivery of the rapid tests, HIV testing of pregnant women was something that happened very rarely. Ignacio Flores, an HIV administrator who had worked for many years as an HIV doctor in the same State as Gloria Vergara, said that the provision of rapid tests to primary care clinics had transformed access to HIV testing during prenatal care. In the past “at least here in [State], in my professional environment: Negative. Negative. Unfortunately, there were no rapid tests for pregnant women. Maybe about 10% of the family doctors sent the *mujercitas* (little women) to do an ELISA [HIV test]. ... Pregnant women, I had three pregnant women in twelve years [of clinical practice]”. Distributing rapid tests to the primary care clinics overcame one of the key barriers related to the vertical organization of the HIV and Reproductive Health programs by putting the tests in the hands of the health-care personnel who actually have contact with pregnant women.

The delivery of rapid tests to primary care clinics also increased awareness of the existence and effectiveness of prevention of mother-to-child transmission and provided the grounds for increased collaboration between reproductive health and HIV. This was implemented through different strategies in different states, and basically depended on the interest and capacity of the head of the State HIV program. In Mexico City, the director of the HIV program secured support

from UNICEF for a meeting “headed by the Minister of Health and the directors of public health and hospitals ... we are going to try to do it top-down, rather than bottom up”. In Mexico State, the director took a bottom up approach focused on training the health-care providers working in primary care to apply HIV tests. A colleague from the Reproductive Health Program said that

the results of the program are due to her good work. It hasn't been us or anybody else: it has been her and her department, and her way of getting people to fall in love with opportune diagnosis. ... The first [reaction] was more paper—more activities that are going to dissolve into the sea of activities that we do, but when they started to learn about the program, the truth is we've had a really good response from all of the physicians, well not all of them, but the vast majority.

Health-care providers and women with HIV recounted that at least some providers became really interested in the PMTCT program and were willing to go the extra mile to prevent perinatal HIV transmission. Some examples are health-care workers taking the time to advise women when HIV tests were delivered after there had been a stock-out at the clinic and accompanying women with reactive test results to the HIV clinic for confirmatory testing instead of just referring them. Yet, despite a favourable response from the health-care providers who received training, the program still hadn't reached full coverage by 2009. An HIV physician, Felipe Castillo explained that

One or two people were trained per health clinic. When, depending on the clinic, there are 30-200 people working in each health centre. So the people who have the knowledge—to put it that way—to offer the test are those one or two people, who are going to get lost within the health centre. So, the offer doesn't exist because the majority don't even *know* that they have to offer it. Continued training of the people who were aware and who had the *opportunity* was lacking. This [training] needed to be founded on a normative framework, and at the same time, all of the workers in the health care sector needed to be trained. And there should be posters in every health center offering the test, and in the *cartilla* (booklet) for prenatal care that every woman gets it should be included: did you ask for the test? So it [the HIV test] isn't offered because they don't know about it, because they don't want to get involved, because they see it as extra workload.

The initiative to scale-up HIV testing of pregnant women was an important advance because it finally put the HIV tests in the hands of the health-care providers who care for pregnant women. However, the relative size of the HIV program as opposed to the reproductive health program, the vertical organization of the HIV and reproductive health programs, and the absence of HIV testing for all women from the prenatal care NOM continue to be barriers to full coverage and sustainability. Gabriela Diaz, a state HIV decision-maker, said “we think that possibly it was a pilot, what was done with testing in 2007 and 2008. And if it was a pilot, it was a success. And since we can see that offering the test to pregnant women is a success, we should follow-up by strengthening this program”.

### *3.7.3 Barriers to scale-up and sustainability*

A key factor for program strengthening and sustainability is the purchase of HIV tests by the States. When I interviewed different stakeholders in 2009 and 2010, they expressed different perspectives on the extent to which the prenatal HIV testing program continued to be implemented. In general, administrators from reproductive health assured me that the State had assumed responsibility for the continuation of the program and that they were purchasing HIV tests and distributing them. In contrast, HIV health-care workers perceived that the implementation of the program was limited by access to tests. This variance provokes doubt about the level of scale-up and sustainability of the PMTCT program in the States. For example, in July 2009, one higher level health administrator told me that in his State

there is continuity in the policy and I am sure that there is commitment. Above all because everyone has realized that there is no going back. Rather than curing, we have to prevent, so they clearly understand the concept of prevention. And we have a good number of tests, from CENSIDA [National AIDS Program] and Equity and Gender [Reproductive Health] and thank goodness, we can meet the demand from pregnant women in the State.

In contrast by March 2010, the state HIV program coordinator said

I don't know what is going to happen with that target [of reaching 100% of women in prenatal care with HIV testing]. Effectively, [the 5000 tests the HIV program will have] aren't exclusively for use in pregnant women. Last year, [reproductive health] bought rapid tests, but it seems that this year they aren't going to, they aren't obliged to buy them. That's what they told us at the budget review.

But six months later, in September 2010, an administrator familiar with the relevant reproductive health program in the State said that though there were problems in the supply chain because “the administrative process is slow, we are buying about twenty thousand tests”.

So while it is clear that the purchase and distribution of rapid tests to the States for use with pregnant women in 2007-2008 has established PMTCT as an issue to be considered, the lack of clarity about who is responsible for ensuring the continuity of this program—HIV or reproductive health—continues to be a barrier for the sustained assignment of the resources necessary to bring the program to scale. Lack of resources necessarily raises the issue of competing priorities from the perspective of HIV decision-makers. In the words of another HIV program coordinator, who I interviewed in December 2010,

the State program has a certain budget, and out of that budget, if I work with pregnant women, I am not going to reduce incidence, new cases of transmission. ... so because of resources, maybe I am not going to have the forty-five thousand [tests] guaranteed only for pregnant women, because if I did, I would also need to have equity in being able to guarantee the other thousands of tests that I need for key populations.

Similarly, in another state, the head of the reproductive health program responsible for prenatal care said that, starting in 2009, they had purchased sufficient tests for pregnant women. However, HIV health-care providers and administrators from the State indicated that there had been variations in the flow of pregnant women with reactive test results seeking confirmatory testing from the HIV clinics, suggesting that the supply chain was not guaranteeing continuous access to

the necessary medical material. Interviews with women with HIV confirmed that there had been stock-outs of HIV tests in the primary care clinics. In August 2009, a director of an HIV clinic in the State said,

Public policy is something that tells you what you have to do, and what actually get's done is something else. Remember, we agree that it [HIV testing of pregnant women] implies a budget. And the budgets aren't sufficient to do what they want to do. I mean, it's only on paper, in writing. But one thing is them telling you 'it's written down' and another is them giving you the resources to do it. They don't give us sufficient resources for those tests and we don't receive enough of those tests. The prevention department is asking me for tests: Lend me ten tests, fifteen tests, because they used them all up. There aren't enough medical supplies to have an impact. Programs aren't sustained.

Another HIV care provider who had run a perinatal HIV prevention program also attributed budget cuts and consequent inability to sustain the program to changing institutional priorities. He recounted that a new hospital director cut the budget for HIV tests for pregnant women in half in 2009, "even though the money was available. And now they are just going to spend it on something else that they think is important. That's the problem: political will. If the person responsible is interested in the program, they spend on it, and if they're not interested, they take away money and divert it to influenza, because right now influenza is trendy". As long as perinatal HIV prevention remains a discretionary program rather than a program that is budgeted for as a regular part of operations and monitored and evaluated against the priorities and budgets that are provided to the States and health-care institutions by the federal government, the program will be subject to the whims of politicians and hospital administrators. At the macro level, we can perceive the consequences of this situation in the drop in coverage of HIV testing among pregnant women attending prenatal care at the Ministry of Health in 2010 (Table 3.1).

My analysis of decision-makers and health-care providers perspectives on the implementation of PMTCT in Mexico over the past decade, and of the distribution of 800,000

rapid tests to primary care clinics between 2007 and 2008 as a case study for program scale-up, has allowed me to identify important political, cultural, and institutional barriers to increasing effective coverage and sustaining the PMTCT program. Multiparty representation in the Mexican political system and decentralization of responsibility for health-care delivery without the development of adequate systems of fiscal and programmatic conditionality and accountability complicates the implementation of health programs. In the case of PMTCT, the vertical organization of Reproductive Health and HIV and relative program capacities and mandates has left this program in an administrative abyss. Until an adequate normative framework is promulgated, through the inclusion of the obligatory offer of HIV-testing to all pregnant women as part of prenatal care in NOM-007 (which governs prenatal care, labour and delivery, and the post-partum period) lines of responsibility will continue to be unclear. Despite an extraordinary effort on the part of the Ministry of Health in 2007-2008 to scale-up coverage of HIV testing during prenatal care, this intervention continues to be optional. As my case study shows, the discretionary rather than obligatory nature of the program has directly impacted on resource allocation and program sustainability.

Moreover, I have sought to demonstrate that the cultural construction of women's risk for HIV, which is encoded in the indication to offer HIV testing only to "high risk" pregnant women during prenatal care, is an accurate representation of the social imaginary which continues to reign. In this respect it is crucial to recognize that identification of HIV among pregnant women uncovers two central hypocrisies in the Mexican sex-gender system: it reveals the inexistence of marital sexual monogamy prescribed by the Catholic Church and provides convincing evidence of the "*doble moral*" (sexual double standard) that idealizes sexual monogamy, demands it from women, and expects men to have multiple sexual partners. While HIV health-care providers and

decision-makers reject the characterization of women with HIV as “high risk” based on their experience, they also state that among their peers from the general health-care system, the idea that HIV only affects “the other”—gay men, promiscuous women, sex workers—persists. In the following two chapters, I will explore the reports of pregnant women and of women with HIV of their risk behaviour for HIV acquisition and perceptions of HIV vulnerability before the diagnosis using quantitative and qualitative analysis. The quantitative analysis allows me to describe the relationship between pregnant women’s HIV risk behaviour, their reports of their male partner’s risk behaviours, and the woman having a reactive HIV antibody test. The qualitative analysis allows me to analyze women’s HIV risk perception in the context of gendered sexual norms. Drawing on both sources of information allows me to demonstrate how the social imaginary of the concentrated HIV epidemic—where HIV only affects social and sexual deviants—plays out at the individual level, and the negative consequences for women’s health.

## **Chapter 4. Mexican Women's Risk Behaviours for HIV Transmission: A Quantitative Analysis<sup>15</sup>**

The ratio of women to men with AIDS in Mexico has increased dramatically over the past twenty-five years and women now make up about a quarter of those living with HIV (UNAIDS 2010a). The first female Mexican AIDS case was notified in 1985 (Uribe-Zuniga and Panebianco 1997). At that time the ratio of male to female AIDS cases was 10.8 men for every woman; by 2009 this number was 3.9 male AIDS cases for every female AIDS case (CENSIDA 2010: 11). We know that Mexican women become infected with HIV almost exclusively through sexual contact and 99% of female HIV and AIDS cases registered in 2010 identified heterosexual transmission as the HIV exposure category (CENSIDA 2010:15). Relatively high HIV prevalence among men as compared to women, especially men who have sex with other men, has led various authors to propose that Mexican women are vulnerable to HIV infection because of the risk behaviour for HIV acquisition of their male partners (CENSIDA 2010: 15; Kendall 2009; Magis-Rodríguez et al. 2002). Yet other than being able to identify that women become infected almost exclusively through heterosexual contact and that women who engage in sex work, have been incarcerated, and/or use injection drugs have higher HIV prevalence than women in the general population, we know little about Mexican women's risk behaviour for HIV acquisition. Furthermore, there is a dearth of information from large, national samples that describes and analyzes the relationship between women's risk behaviours for HIV acquisition, those of their male partners, and HIV status. To design strategies to reduce women's risk for HIV infection, it is necessary to know about their behavioural risk for HIV infection, as well as their perceptions of the male partners' risk behaviours. In a context where the national health-care legislation which

governs the offer of HIV-testing during prenatal care recommends the offer of HIV testing to “high risk women—those who have received blood transfusions, drug addicts, and prostitutes” and where coverage with antiretroviral treatment to prevent vertical transmission is estimated to reach less than 10% of the women who need it, characterization of pregnant women’s risk behaviours, their male partners’ behaviour, and relationship with HIV status are urgently needed as input for decision-making.

This chapter aims to fill the existing information gap by analyzing the relationships between pregnant women’s self-reported risk behaviour for HIV acquisition, their reports of their male partner’s risk behaviours, and women’s reactive results to the rapid HIV antibody test. The research analyses the reported risk behaviours and rapid antibody test results from a large sample (n=78,557) of pregnant women who received prenatal and/or labour and delivery care at clinics and hospitals administered by the Mexican Ministry of Health between October 2006 and December 2009. The women included in the sample were offered and accepted a rapid HIV antibody test. Health-care providers filled out a short questionnaire for each woman as part of the counselling and informed consent process (before she received the results of the rapid HIV antibody test). The questionnaire collected their age, number of pregnancies, number of live births, civil status, and ethnicity (as measured by speaking an Indigenous language) and asked women about some of their risk behaviours for HIV acquisition, as well as perceptions of their sexual partner’s risk behaviours. The questionnaire asked women whether during the past twelve months they or their sexual partner had had multiple sexual partners (woman and male partner); engaged in sex work (woman and male partner); injected drugs (woman and male partner); been deprived of their liberty (woman and male partner); migrated to the United States (woman and male partner); and engaged in bisexual behaviour (male partner).<sup>16</sup>

## **4.1 Mexican research on HIV acquisition risk behaviours**

### *4.1.1 Multiple and concurrent sexual partners*

Ethnographic research suggests that while expectations of male sexual fidelity are changing among younger generations of Mexican men and women, male sexual infidelity has been, and in many instances remains, a common feature of stable relationships (Hirsch 2003; Gayet et al. 2008; Guttman 2007:130-132). A proportion of women and men construct male sexual infidelity as acceptable, as long as the man shows “respect” for his wife or main female partner by exercising discretion (not being seen in public with another woman, not inviting other sexual partners into the home) and not diverting economic resources from the main household to support another sexual partner and household (Hirsch et al. 2002; Hirsch et al. 2007; LeVine et al. 1986). In 1992, a representative household survey in greater Mexico City found that 15% of married and cohabiting men reported extra-relational sex; in this study condom use with primary partners was negligible and under 25% with secondary partners (Pulerwitz et al. 2001:1651). Another study found that men’s extra-relational sexual activity increases during women’s pregnancies, particularly in rural areas (Gayet et al. 2008).

Little is known about extra-relational sex among Mexican women. Guttman (2007:132) suggests that women having sexual relationships outside of their main relationship had become more common in Mexico City early in the new millennium. Survey research with Mexican college students found that a proportion of young women have concurrent sexual partners, but that this practice is less common among young women (11%) than among young men (23%) (Sanchez-Aleman et al. 2008:431).

#### *4.1.2 Sex work*

From the early days of the HIV response in Mexico, female sex workers have been a priority population for prevention. During the mid and late nineties, prevention projects implemented by the National AIDS Program included training of peer educators, HIV education, and promotion of the male and female condom in Mexico City and on Mexico's southern border (Kendall and Perez-Vazquez 2004:52-53, 60). During the early 1990s, HIV prevalence among female sex workers in Mexico City varied between 0.4% and 0.6% (Uribe-Salas et al. 1997: 1013). National prevalence estimates remained between 0.3% and 0.6% up until the end of the 1990s (UNAIDS/WHO 2008). A study conducted in 2005-2006 found an HIV prevalence of 1% among female sex workers; the relatively low rate of infection found in this study may be related to the fact that injection drug use among this population was only reported by 2% of the research participants (Gayet et al. 2007: 20-26).

The same study found an average HIV prevalence of 15.1% among male sex workers; prevalence in the three cities included in the sample varied from a low of 3.1% in Acapulco, a tourist destination on the Pacific coast, 12% in Nezahuacoyotl, a large city in the urban sprawl adjacent to Mexico City, to a high of 25.5% HIV prevalence in Monterrey, an economic and industrial centre in Northern Mexico (Gayet et al. 2007: 20). In Acapulco and Monterrey 7% of respondents stated they had ever injected drugs and 13% of these had shared needles; while in Nezahuacoyotl the use of injected drugs and needle sharing was insignificant. In all sites, clients of male sex workers were predominantly men; however, some male sex workers reported sexual contact with women; in Acapulco and Monterrey 30% of the male sex workers interviewed said they had had sex with a woman during the past week, while in Nezahuacoyotl only 3% did so (Gayet et al. 2007: 22-24). The study of male sex workers in Acapulco, Monterrey and

Nezahuacoyotl did not characterize the sexual and gender identities of male sex workers, but a qualitative study in Mexico City identified men who have sex with men, men who have sex with women, transvestite and transgender women all engaging in sex work (Infante et al. 2009).

#### *4.1.3 Injection Drug Use*

Men are the majority of injection drug users in Mexico, but women injection drug users have been found to have higher HIV prevalence than their male counterparts (10.2% vs. 3.5%,  $p=.001$ ) (Strathdee et al. 2008a). Qualitative research on gender and drug use in the Northern border cities of Ciudad Juarez and Tijuana suggests that women injection drug users are more vulnerable to HIV infection than their male peers because the gendered hierarchy of drug use dictates that women inject after their male partner, and at times other injecting partners (Firestone-Cruz et al. 2007). In Tijuana and Ciudad Juarez, there is overlap between women engaging in sex work and using injection drugs, with significantly higher HIV prevalence among women sex workers who inject drugs as compared to those who don't report injecting (12% vs. 6%) (Strathdee et al. 2008b). It is important to note that a study with pregnant women at the Tijuana General Hospital also found an association between using injection drugs and living with HIV. The study found an overall HIV prevalence among pregnant women of 1%, significantly higher than the national estimate of 0.09%; among pregnant women who reported using drugs, HIV prevalence was 6% (Viani et al 2006).

#### *4.1.4 Bisexual behaviour (men who have sex with men and women)*

HIV prevalence among Mexican men who have sex with other men is estimated at 11% (CENSIDA 2010: 10). Both in terms of the routes of transmission for HIV infection reported by men historically (1983-2011) and for new HIV infections identified among men in 2011, about a

third of cases (33%) are attributed to homosexual transmission, a fifth (20%) to bisexual transmission, and just under half (47%) to heterosexual transmission (CENSIDA 2011). When considering male bisexual practices and their possible implications for HIV transmission to women in the Mexican context, it is important to note that unlike in North America and Europe, where sexual identity has been framed in terms of object choice, in Mexico and much of the rest of Latin America sexual gender identity flows from the act of penetration (Caceres 1996: 138). These cultural constructions of gendered sexuality facilitate male bisexual behaviour and allow masculine-looking and acting men who have sex with other men to consider themselves and be considered by others as “normal” (heterosexual) men as opposed to homosexuals (Carrillo 2002: 57; Kendall et al. 2007; Prieur 1998: 137-138). Existing Mexican research suggests that a significant proportion of men who have sex with men also have sex with women, indicating that men’s bisexual behaviour could make a contribution to the HIV epidemic among women who have sex with men. A recent study of men who have sex with men from four Mexican cities found that 42% had had sex with a woman in their lifetime and 19% had had sex with a woman in the six months prior to the interview (Gayet et al. 2007:20). In terms of the contribution that men’s bisexual behaviour makes to HIV infection among women, a retrospective study with 150 HIV positive Mexican men who had a stable female partner found that 92% had engaged in anal intercourse with another man during their lifetime and 70% had had unprotected sex (oral or anal) with another man during the three years prior to the HIV diagnosis. Only 2 out of 150 female partners of these men had considered the possibility that their partner engaged in sex with other men, and none had considered condom use necessary, except occasionally for pregnancy prevention (Mireles-Vieyra et al. 2002). Qualitative research with Mexican women with HIV suggests bisexual behaviour by the male partner is unrecognized prior to the diagnosis, and

remains an extremely stigmatized and emotionally difficult issue post-diagnosis (Kendall & Perez-Vazquez 2004: 129-130).

#### *4.1.5 Incarceration*

Globally, HIV prevalence among incarcerated populations tends to be significantly higher than among the general population; Argentina and Brazil report prevalence rates of over 10% among people deprived of their liberty (Dolan et al. 2007). In the Mexican context information about HIV infection among people deprived of their liberty is scarce. One small study from Durango (n=181) identified one HIV positive prisoner, for a prevalence of 0.6%; the same HIV prevalence as reported among Mexican blood donors (Alvarado-Esquivel et al. 2005: 683). Another study in a prison in Tijuana (n=205) and a prison in Ciudad Juarez (n=296) found HIV prevalence of 2.53% and 1.29% respectively; all of the HIV-positive men identified were injection drug users (Magis-Rodriguez et al. 2000). The most recent research carried out with 20,000 men and 2,000 women deprived of their liberty in Mexico City prisons found an HIV prevalence of 0.9% among men (almost double the 0.5% estimated for heterosexual men in the general population) and 1% among women (five times the rate of 0.2% estimated for heterosexual women in the general population) (Sanchez 2011).

#### *4.1.6 Migration to the United States*

Around the world, the rupture and reformation of social networks and behaviour change associated with migration and other forms of population mobility have been linked to the expansion of the HIV epidemic in a range of geographic and social contexts (Decosas et al. 1995). A growing body of literature describes the HIV vulnerability of international migrants transiting Mexico and of Mexican migrants in the United States. These studies suggest that human rights

abuses, economic insecurity, freedom from the social controls of the home community, and feelings of loneliness and isolation in transit and host communities, contribute to HIV-risk behaviours among migrants. Such risk factors include increased numbers of sexual partners for male and female international migrants, increased contact with commercial sex workers for men, entry into sex work and sexual coercion for women and sometimes men, increased sexual contact between men, increased drug and alcohol use, sex with partners who use injection drugs, and needle-sharing for injection of recreational and medicinal drugs (Apostolopoulos et al. 2006; Bronfman et al. 2002; Bronfman and Minello 1999; Caballero et al. 2002; Magis-Rodriguez et al. 2004; Munoz-Laboy et al. 2009; Organista et al. 2004). A third of Mexican AIDS cases are concentrated in States with a long history of labour migration to the USA (Shedlin et al. 2005). When Mexico collected information about migration history as part of the classification of AIDS cases, a quarter of people with AIDS had spent long periods of time in the USA (Carrillo and DeCarlo 2003: 1). And a recent study found an HIV prevalence of 1.15% among Mexican migrants deported through Tijuana, significantly higher than the 0.03% prevalence estimated for the general Mexican populations (Rangel et al. forthcoming).

#### *4.1.7 Pregnant women's risk factors for HIV infection*

Existing Latin American research associates pregnant women's risk behaviour, particularly a larger number of lifetime sexual partners, with HIV infection. However, these studies have also suggested that the risk behaviours reported by women for their male partners are an even more important predictor of women's HIV infection than their own behaviour. A study of 4620 pregnant Guatemalan women from Guatemala City found that HIV-positive status was predicted by the number of women's lifetime sexual partners, and three male partner risk factors: being HIV-positive, being a migrant worker, or the woman suspecting that the male partner had extra-

relational sex (Johri et al 2010). An older study from Vitoria in Southern Brazil found that pregnant women attending prenatal care at public clinics who reported using injection drugs and engaging in sex work, or who had a partner who used injection drugs, or had been incarcerated had significantly higher odds of being infected with HIV (Miranda et al. 2001). A study with pregnant women from Peru looked specifically at the impact of sexual networks on HIV infection among pregnant women. Women who had had more lifetime sexual partners were more likely to be HIV-positive, but the majority of HIV positive pregnant women (50 of 75) had no risk factors whatsoever other than unprotected sex with the stable male partner. Pregnant women's seropositivity was most strongly associated with the sexual behaviour of the male partner (sex with female sex workers, sex with other men, and sex for money or gifts) and the size of the woman's sexual network which resulted from her male partners behaviour (Johnson et al. 2003). Similar relationships between the HIV risk behaviour of pregnant women and that of their stable male partner have been identified in other countries with concentrated HIV epidemics, such as Thailand (Siriwasin et al. 1998).

Three single-site studies of the risk factors of HIV-positive pregnant Mexican women are available. One study among pregnant women attending a hospital in central Mexico only recruited women who reported HIV acquisition risk factors additional to the unprotected sex that resulted in pregnancy (n=2257). The two HIV-positive pregnant women who were identified reported chronic sexually transmitted infections and risk factors for their male partners (migration, tattoos and multiple partners) (Romero-Gutierrez et al. 2009). In the Yucatan, a study of 310 pregnant women tested for HIV between January 2000 and March 2001, did not identify any HIV-positive women; 15% of women reported having had more than one lifetime sexual partner and 38% said their stable male partner worked outside of the locality where she lived (Vera Gamboa et al. 2005). On

Mexico's northern border, pregnant women attending the Tijuana General Hospital (n=2721) were significantly more likely to be HIV-positive if they had not received prenatal care, reported that they or their partner used drugs (injected or other drugs), and reported a higher number of sexual partners (Viani et al. 2006). In a follow-up study at Tijuana General Hospital with 62 HIV-positive pregnant women, Viani and colleagues found that HIV prevalence was higher among women who presented in labour as compared to those who were enrolled in prenatal care, and that those women were more likely to report drug use, more sexual partners, commercial sex, incarceration and homelessness (Viani et al. 2010: 83-84).

## **4.2 Definition of the variables used in the analysis**

### *4.2.1 Sociodemographic characteristics*

We categorized women's sociodemographic characteristics according to age (12-20 years, 21-30 years, older than 30 years); number of live births (0, 1, 2, 3 or more), civil status (married, common-law, and other, e.g. single or divorced); and whether or not the respondent spoke an Indigenous language, which is used as a proxy for ethnicity (Indigenous vs. non-Indigenous).

### *4.2.2 Rapid HIV antibody test results*

The most common way of diagnosing HIV infection is by detecting antibodies to HIV. There are two types of blood tests for detecting HIV antibodies: screening assays and confirmatory assays. The first screening assays to be developed and the most widely used are enzyme immunoassays (often referred to as EIAs or ELISAs). The other types of screening assay are known as "rapid tests". Rapid tests have the advantage of not requiring laboratory infrastructure. The specimen (which can be blood or tissue from the inside of the mouth) is mixed with a reagent and the results are usually available in less than 20 minutes (WHO 2009:3).

When a single screening assay is used in a population with a low HIV prevalence, such as women in Mexico, the probability that a person is actually infected when they have a reactive test result (i.e. the positive predictive value) is low. That is to say, a proportion of the people who have a reactive result to an ELISA or a rapid HIV test are not actually infected with HIV. Mexico's National AIDS Program estimates that the HIV prevalence among heterosexual women is 0.2% (CENSIDA 2010: 10). The Centres for Disease Control estimate that the positive predictive value of rapid HIV antibody tests is 50% in a population with this prevalence. In other words, there will be two true positives and two false positives for every 1000 people tested. However, because we limited our analysis to the 5.69% of healthcare sites that had at least one reactive test result, we estimate that the prevalence among our sample of 78,557 women is higher than the estimated national average. Even if we use the very conservative prevalence of 0.2%, 389 women out of 78,557 who tested at these healthcare delivery sites would be true positives, for a population prevalence of 0.5% and a positive predictive value of the test would be 71%--5 true positives and 2 false positives for every 1000 women tested (rather than 50%) (CDC 2007). It is important to note that the negative predictive value—that is negative test results—is almost 100% irrespective of the HIV prevalence in the population. “False positives” can be a problem, but “false negatives” are not.

The accuracy of positive test results can be improved if a second test is used to retest all those people found reactive using the first screening assay. People who are positive or reactive to the screening assay (ELISA or rapid test) are referred for confirmatory testing. The most commonly used confirmatory assay is the Western Blot (WB), and this is the standard of care in Mexico. However, the WB is very expensive and studies have shown that a combination of ELISAs and/or a combination of two or three rapid tests can provide results as reliable as the WB

at a much lower cost. Therefore, since 2002, WHO and UNAIDS have recommended that countries implement HIV testing strategies which use a combination of ELISAs and/or rapid tests rather than ELISA/WB (WHO 2009:3).

The database analysed did not include the results of confirmatory testing for the pregnant women, therefore a proportion of the women classified as “reactive” in this analysis would be found to be HIV-negative upon confirmatory testing. Probably the rate of women wrongly categorized as “reactive” when they were HIV-negative is lower in our analysis than the 2 out of 1000 predicted by the CDC because we estimate prevalence in our sample to be higher than the estimated national average and there was more than one test result available for 39% of the women, as per the WHO/UNAIDS guidelines for confirming HIV test results without using the Western Blot. It must be noted however, that the WHO/UNAIDS guidelines require using different brands of rapid tests for the confirmation algorithm. My ethnographic research indicates that in some clinics health-care providers did have a stock of another brand of HIV rapid test to confirm a positive HIV diagnosis, but we cannot affirm that this was the case for all of the clinics and hospitals that provided data used in this quantitative analysis. The lack of confirmatory testing is a limitation of the database. For this reason, we refer to the pregnant women who took a rapid HIV antibody test as being “reactive” or “non-reactive” rather than HIV-positive or HIV-negative, as we cannot be certain of their HIV status.

For the analysis, women were categorized as being “reactive” to the rapid HIV antibody test, if they had at least one reactive rapid test result and no non-reactive test results. The first rapid HIV test administered during prenatal care could have a reactive, invalid, or negative result. In some cases, a second rapid test was administered to corroborate the results of the first test; a proportion of women with reactive, invalid or inconclusive, or non-reactive test results from the

first test completed a second rapid HIV antibody test during prenatal care. Finally, another group of women who had either a reactive or invalid test result for the first or second rapid HIV antibody test were re-tested during labour and delivery. To categorize a woman as “reactive” or “non reactive” for this analysis, the following criteria based on results of the three possible tests were used: women with two reactive test results are considered reactive (reactive result for the first test as well as a second or third test); and women with a reactive result to the first rapid test, who did not have a result for any subsequent test or who had invalid or inconclusive test results were also considered reactive. Any woman who had a non-reactive test result, independent of whether she had a reactive or inconclusive test result on file, is classified as non-reactive.

#### *4.2.3 Risk behaviours*

We focus the univariate analysis of women’s reported risk behaviours and the reported risk behaviours for their sexual partners on women who *do not* report risk behaviours. The rationale for this choice is twofold. First, we want to highlight that most women responded in the negative to questions about HIV acquisition risk-behaviours: reporting these risk behaviours was uncommon. Second, when answering questions about the sexual partners risk behaviours, possible responses included “yes,” “no,” and “don’t know”. Few women affirmed categorically that their male partner engaged in HIV risk behaviours. The likelihood of women answering “yes” as opposed to “I don’t know” or not answering the question seems to be related to the social stigma associated with the risk behaviour. In the Mexican cultural context, if a woman has suspicions about her sexual partner’s behaviour or is aware of risk behaviour but finds sharing this knowledge socially embarrassing, answering “I don’t know” provides a means of cooperating with the interviewer while avoiding a direct lie or a difficult admission. Cloaking a range of taboo or socially difficult sexual subjects such as sexual infidelity, the sexual activity of young people, or homosexuality in

silence has been identified as a common Mexican strategy to promote group harmony and minimize conflict or embarrassment for all of the parties involved (Carrillo 2002: 139-140; Hirsch 2003: 103). The table below uses the 1496 women included in the case-control sample to exemplify the relationship between yes, don't know, and missing data in response to questions about the sexual partner's HIV risk behaviour. It is noteworthy that when asked about highly stigmatized behaviours like male sex work, injection drug use, and bisexual behaviour, the proportion of women who answered "yes" is significantly smaller than the proportion of women who answered "I don't know". It is also worth mentioning that the absolute smallest proportion of women (less than 1%, n=3), reported that their sexual partner had sex with other men, and that this question had almost double the non-response rate of the other questions (10% as opposed to 5% to 6%); this may indicate health-care providers discomfort with asking the question as much as women's discomfort in answering it.

	Yes	Don't know	Total (yes and don't know)	No data
Sex work	1.40%	9.20%	10.6%	5.35%
Multiple sexual partners	19.65%	28.61%	48.26%	5.21%
Injection drug use	4.21%	12.03%	16.24%	5.08%
Incarcerated/ Deprived of liberty	5.61%	6.28%	11.89%	5.41%
Migration to the USA	18.65%	6.02%	24.67%	6.15%
Bisexual behavior	0.20% (3)	10.70%	10.9%	9.76%

Faced with these ambiguities in women's responses about their male partner's risk behaviours, we focused the univariate analysis on women who stated clearly that their sexual partner did not engage in the identified risk behaviour.

### 4.3. Data Analysis

We analyzed the data using the Stata Data Analysis and Statistical Software package (STATA version 11). The first stage of analysis compares the reported risk behaviours of pregnant women who were reactive and non-reactive to the rapid HIV antibody test. We then conducted a logistic regression analysis to describe differences in sociodemographic characteristics between reactive and non-reactive women with the sample of 78,557 women. We conducted univariate and multivariate logistic regressions where the dependent variable was the risk behaviour of interest (for example, in the first model, if the woman reports multiple sexual partners, in the second model, if she reports sex work, etc.), and the independent variable was her rapid HIV test result (reactive or non-reactive). This analysis tells us if reactive women varied from non-reactive women in terms of their reported risk behaviours and their perceptions of their sexual partner's risk behaviours. We ran 24 models. The first twelve were univariate models that considered the rapid HIV test result as the only explanatory variable. The following twelve statistical models analyzed whether or not the effects found in the univariate models were maintained if we controlled for women's sociodemographic characteristics. In these multivariate logistic regressions we included the control variables (age, number of live births, ethnicity, and marital status) as well as the result of the rapid HIV antibody test (reactive or non-reactive). All of the adjusted models control for potential correlations of observations within health-care delivery sites and are adjusted for standard errors.

In the third step of data analysis, we analyzed the differences between the reported risk behaviours of reactive and non-reactive women from the case-control sample using univariate and multivariate logistic regressions (n=1496). All of the models run with the case-control sample are fixed effect models at the level of the health-care delivery site. The fixed effect models have the

advantage of controlling for unobserved differences arising from the geographic context and possible selectivity bias in the offer of HIV testing to pregnant women that could exist at the level of the health-care delivery site or by individual health-care providers. The differences between the results of the models using the total sample and the ones using the case-control sample permit us to observe and compare the effects of women's sociodemographic characteristics, reported risk behaviours, risk behaviours reported for the male partner, and the geographic and health-care delivery context in which a woman was offered HIV testing on the outcome of interest: a reactive or non-reactive rapid HIV antibody test result. Finally, using the case-control sample, we calculated the proportion of women who did not report any risk behaviours for themselves or for their male partners and compare the results of reactive and non-reactive women.

#### **4.4 Pregnant women's reported risk behaviours and HIV antibody test results (total sample)**

Of the 78,557 women from the 541 health-care delivery sites included in the analysis 77,780 (99.01%) were not reactive to the rapid HIV antibody test and 777 (0.99%) were reactive. When we analyzed the sociodemographic characteristics of reactive and non-reactive women from the total sample (n=78,667), we found that reactive women are significantly more likely to be older (age > 21 years old) ( $p < .001$ ), have more children (2 or more) ( $p < .001$ ), to be married (formally or common law) than to be single or divorced ( $p < .001$ ), and to speak an Indigenous language ( $p < .005$ ) than non-reactive women (see Table 4.2). With respect to reporting risk behaviours for themselves and their male partners, pregnant women reactive to the rapid HIV antibody test were significantly less likely to say that they and their sexual partner did not engage in risk behaviours for HIV acquisition than were non-reactive women in all possible risk behaviour categories (Table 4.3).

**Table 4.2 Sociodemographic characteristics of pregnant Mexican women with reactive and non-reactive rapid HIV antibody test results<sup>17</sup>**

Variable	Non-reactive women (n=77890)	Reactive women (n=777)	Total (n=78,557)
<b>Age</b>			
12-20 yrs	36.67%	26.25%***	37.55%
21-30 yrs	46.76%	53.54%***	46.83%
<31 yrs	15.35%	20.21%***	15.40%
<b>Number of live births</b>			
0	44.74%	31.66%***	44.61%
1	25.93%	25.35%***	25.92%
2	16.31%	22.27%***	16.37%
3 or more	13.02%	20.72%***	13.10%
<b>Ethnicity</b>			
Non-Indigenous	79.55%	75.68%**	79.52%
Indigenous	20.45%	24.32%**	20.48%
<b>Marital status</b>			
Married	40.77%	45.05%***	40.81%
Common-law	44.25%	44.27%	44.25%
Other	14.97%	10.68%***	14.93%

\*\*\* p<0.001 \*\*p<0.005 \*p<0.05

**Table 4.3 Comparison of risk behaviours reported for themselves and their male sexual partners by pregnant Mexican women with reactive and non-reactive rapid HIV antibody test results**

	Reactive women (n=777)	Non-reactive (n=77890)	Complete Sample (n=78,557)	p value
<b>Do <u>not</u> report this risk behaviour during the past 12 months</b>				
Sex work	96.14%	98.34%	98.32%	0.001
Multiple sexual partners	79.54%	85.56%	85.5%	0.001
Injection drug use	97.04%	98.34%	98.33%	0.005
Deprived of her liberty	96.40%	98.03%	98.01%	0.002
Migration to the United States	93.31%	95.62%	95.59%	0.002
<b>Do <u>not</u> report this risk behaviour for their sexual partner during the past twelve months</b>				
Sex work	81.60%	87.70%	87.64%	0.001
Multiple sexual partners	44.14%	52.85%	52.77%	0.001
Injection drug use	75.80%	81.88%	81.82%	0.001
Deprived of liberty	80.44%	85.46%	85.41%	0.001
Migration to the USA	68.98%	76.10%	76.03%	0.001
Bisexual behaviour	76.84%	84.05%	83.98%	0.001

A larger proportion of non-reactive than reactive women did not report risk behaviours for themselves, for their male partners, or for either ( $p < .001$ ) (Table 4.4). Yet, if we focus our attention on the reactive women, it is notable that three-quarters of the reactive women did not report any risk behaviours for themselves, about a third did not report any risk behaviour for their male partners, and more than a quarter did not report any risk behaviour whatsoever. Reactive women were statistically less likely than non-reactive women to state that their male partner did not have multiple sexual partners. Nevertheless, it is striking that nearly half of the pregnant women in this sample knew or suspected that their male partner had had multiple sexual partners during the past twelve months (Table 4.3).

	<b>Reactive women (n=777)</b>	<b>Non-reactive (n=77890)</b>	<b>Complete Sample (78,557)</b>	<b>p value</b>
<b>Does not report risk behaviour for herself</b>	75.16%	82.07%	82.00%	0.001
<b>Does not report risk behaviour for her sexual partner</b>	30.89%	40.93%	40.83%	0.001
<b>Does not report any risk behaviour (either for herself or for her male partner)</b>	28.96%	38.82%	38.72%	0.001

We ran logistic regressions to calculate whether or not reactive women had greater odds of reporting risk behaviours for HIV-acquisition during the past 12 months than did non-reactive women (Table 4.5: Unadjusted Odds Ratios). We then conducted multivariate logistic regression to control for the statistically significant sociodemographic differences observed between reactive and non-reactive women, adjusting for age, number of live births, civil status and ethnicity (Table

4.5: Adjusted Odds Ratios). The control of sociodemographic characteristics in the multivariate logistic regression with the complete sample differs from the analysis of the case-control sample presented subsequently because it controls for sociodemographic characteristics without controlling for the health-care delivery site and the women are not matched 1:1 for their sociodemographic characteristics as they are in the case-control sample.

<b>Woman’s risk behaviours during the past 12 months</b>	<b>Unadjusted Odds Ratio (S.D.)</b>	<b>Adjusted Odds Ratio (S.D.)</b>
<b>Sex work</b>	2.383*** (0.449)	2.270*** (0.465)
<b>Multiple sexual partners</b>	1.525*** (0.136)	1.542*** (0.156)
<b>Injection drug use</b>	1.809** (0.386)	1.796** (0.407)
<b>Deprived of her liberty</b>	1.857** (0.361)	1.762** (0.387)
<b>International migration</b>	1.564** (0.226)	1.459* (0.233)
*** p<0.001 ** p<0.005 * p<0.05		
Note: Odds ratios presented, non-reactive women vs. reactive women. Results of control variables not presented.		

Even after adjusting for sociodemographic characteristics using a multivariate logistic regression, reactive women were more likely to report all of the risk behaviours for HIV acquisition than were non-reactive women. When comparing reactive and non-reactive women of the same age, number of live births, civil status, and ethnicity, reactive women had greater odds of reporting sex work, multiple sexual partners, injection drug use, having been deprived of their liberty, and migrating to the United States. Likewise, pregnant women reactive to the HIV antibody test women were significantly more likely to report HIV risk behaviours for their sexual partners than non-reactive women, even after controlling for sociodemographic characteristics (Table 4.6). Reactive pregnant women had greater odds of reporting that their male sexual partner engaged in sex work, had

multiple sexual partners, used injection drugs, had been incarcerated, had migrated to the United States, and had engaged in bisexual behaviour.

<b>Table 4.6 Estimate of the association between risk behaviours reported for the male partner and pregnant women’s reactive HIV antibody test results, using a fixed-effects multivariate logistic regression, complete sample (n=78,557).</b>		
<b>Sexual partners risk behaviours during the past 12 months</b>	<b>Unadjusted Odds Ratio (S.D.)</b>	<b>Adjusted Odds Ratio (S.D.)</b>
<b>Sex work</b>	1.608*** (0.150)	1.689*** (0.208)
<b>Multiple sex partners</b>	1.419*** (0.103)	1.469*** (0.129)
<b>Injection drug use</b>	1.442*** (0.121)	1.543*** (0.154)
<b>Deprived of liberty</b>	1.429*** (0.130)	1.481*** (0.165)
<b>International migration</b>	1.432*** (0.112)	1.389*** (0.133)
<b>Bisexual behaviour</b>	1.589*** (0.136)	1.613*** (0.184)
*** p<0.001 ** p<0.005 * p<0.05		
Note: Odds ratios presented, non-reactive women vs. reactive women. Results of control variables not presented		

#### **4.5 Pregnant women’s reported risk behaviours and HIV antibody test results (case-control sample)**

One of the objectives of our study was to analyze the relationship between the HIV acquisition risk behaviours that women reported for themselves and for their male partners and a reactive rapid HIV antibody test result. In the case-control study we sought to control for the influence of the health-care delivery site on women’s reactive test results, in order to isolate the association between women’s behaviours and their report of their male partner’s risk behaviours and a reactive or non-reactive test result. *Where* women took their HIV test could have a variety of impacts on reactive or non-reactive test results. First, different health-care providers and health-care institutions could have different practices for offering HIV-testing to pregnant women. For example, as documented in the previous chapter, some of the sites could limit the offer of testing

to women who were perceived to have risk factors whereas others could offer HIV testing universally to all pregnant women. Second, the location of the health-care delivery site reflects the stage and type of HIV epidemic occurring in the community. There are significant regional variations in the evolution of the HIV epidemic in Mexico, differences between the proportion of women affected as compared to men in rural and urban areas and in different regions of the country, as well as differences in the geographic distribution of some of the risk behaviours measured in the questionnaire, such as injection drug use and migration to the United States (Gayet et al. 2007; Magis-Rodriguez and Hernandez-Avila 2008; Strathdee and Magis-Rodriguez 2008; CENSIDA 2011). To control for these and other unobserved differences associated with where the pregnant woman received her prenatal care, we constructed a retrospective case-control study by matching each reactive woman with a non-reactive woman with the same sociodemographic characteristics who completed a rapid HIV antibody test during prenatal care at the same health-care delivery site. In the case-control sample there were no significant sociodemographic differences between the non-reactive and reactive women. In the case-control sample, the only risk behaviour reported by women which remained significant was that reactive women were less likely to report not having multiple sexual partners during the previous twelve months than non-reactive women (79.28% vs. 85.83%,  $p < .0001$ ). However, significant differences persisted with respect to women's reports of their male partner's risk behaviour. Reactive women were significantly less likely to say that their sexual partners had not engaged in sex work, injected drugs, or had sex with other men than were non-reactive women ( $p < 0.05$ ). Differences in reporting that the sexual partner had multiple sexual partners or migrated to the United States were no longer statistically significant in the case-control sample.

<b>Table 4.7 Comparison of pregnant Mexican women with reactive and non-reactive rapid HIV antibody tests who do not report any risk behaviours for the male partner, case-control sample (n=1496).</b>		
<b>Does not report risk behaviour for the sexual partner</b>	<b>Reactive women (n=748)</b>	<b>Non-reactive women (n=748)</b>
<b>Sex work</b>	81.55%*	86.50%
<b>Multiple sex partners</b>	44.12%	48.93%
<b>Injection drug use</b>	75.80*	81.55%
<b>Deprived of liberty</b>	80.48*	84.89%
<b>Migration to the USA</b>	69.12	69.25%
<b>Bisexual behaviour</b>	77.01*	81.68%
* p<0.05		

We then conducted a multivariate regression analysis with the case-control sample, using a fixed effects model to control for the women's sociodemographic characteristics, the geographic context and possible selection bias in the offer of HIV testing during prenatal care by controlling for the health-care delivery sites where the women were tested and interviewed, and other unobserved differences between the women and the health-care delivery sites. Reactive women's greater odds of reporting multiple sexual partners remained even after adjusting for the sociodemographic control variables (AOR 1.506, p<.005), but none of the other risk-behaviours reported by the women for themselves were statistically significant (Table 4.8).

<b>Table 4.8 Estimate of the association between pregnant women's own risk behaviours and a reactive HIV antibody test result, using a fixed-effects multivariate logistic regression, case-control sample (n=1496).</b>		
<b>Woman's risk behaviours during the past 12 months</b>	<b>Unadjusted Odds Ratios (S.D.)</b>	<b>Adjusted Odds Ratios (S.D.)</b>
<b>Sex work (n=148)</b>	1.481 (0.351)	1.505 (0.443)
<b>Multiple sexual partners (n=610)</b>	1.690*** (0.252)	1.506** (0.238)
<b>Injection drug use (n=136)</b>	1.252 (0.421)	1.331 (0.488)
<b>Deprived of her liberty (n=140)</b>	1.532 (0.479)	1.476 (0.463)
<b>Migration to USA (n=286)</b>	1.385 (0.325)	1.374 (0.326)
*** p<0.001 ** p<0.005 * p<0.05		
Note: Odds ratios presented, non-reactive women vs. reactive women. Results of control variables not presented		

The relationship between pregnant women being reactive to the rapid HIV antibody test and reporting risk behaviours for themselves changed dramatically in the case-control sample as compared to the complete sample. However, the relationship between women having a reactive rapid HIV antibody test result and greater odds of reporting HIV risk behaviours for their sexual partners remained similar to the total sample, with reactive women in the case-control sample having greater odds of reporting that their male partners engaged in risk behaviours for HIV-acquisition.

<b>Table 4.9 Estimate of the association between reporting risk behaviours reported for the male partner and pregnant women’s reactive HIV antibody test results, using a fixed-effects multivariate logistic regression, case-control sample (n=1496).</b>		
<b>Sexual partners risk behaviours during the past 12 months</b>	<b>Unadjusted Odds Ratio (S.D.)</b>	<b>Adjusted Odds Ratio (S.D.)</b>
<b>Sex work (n=504)</b>	1.566** (0.247)	1.609** (0.264)
<b>Multiple sex partners (n=900)</b>	1.263* (0.144)	1.240 (0.144)
<b>Injection drug use (n=654)</b>	1.497** (0.207)	1.492** (0.214)
<b>Deprived of liberty (n=564)</b>	1.442* (0.217)	1.430* (0.219)
<b>Migration to the USA (n=818)</b>	1.007 (0.121)	0.992 (0.121)
<b>Bisexual behaviour (n=634)</b>	1.407* (0.198)	1.42*** (0.202)
*** p<0.001 ** p<0.005 * p<0.05		
<b>Note:</b> Odds ratios presented, non-reactive women vs. reactive women. Results of control variables not presented		

## 4.6 Discussion

The sociodemographic characteristics of pregnant women reactive to the rapid HIV antibody test differed significantly from those of non-reactive women. Reactive women were more likely to be older, to be married, to have more children, and to report an Indigenous ethnicity than non-reactive women. The association between Indigenous ethnicity and reactive rapid HIV antibody tests results agrees with the indirect estimate by De Luca and colleagues (2010: 49) that women make up a greater proportion of AIDS cases among Indigenous as compared to non-

Indigenous populations in Mexico (20.7% vs. 16.5%). These findings underscore the need for more research and action on HIV prevention and care for Indigenous groups in Mexico, with emphasis on meeting the needs of Indigenous women. The other sociodemographic characteristics associated with reactive test results among pregnant women—being older, having higher parity, and being married—suggest that the longer period of time that a woman is sexually active, *even within a stable relationship*, the greater the possibility of exposure to HIV infection. This finding agrees with international research indicating that in both concentrated and generalized HIV epidemics, women’s HIV exposure tends to occur in stable relationships. In Asia, women are predominantly infected with HIV by their husband or stable male partner; in India, for example, 90% of women became infected with HIV within a long-term relationship (UNAIDS 2010a: 132). Indeed, several studies from Africa have shown that married women are at greater risk of HIV infection than their single counterparts (Hageman et al. 2010: 113).

Our analysis consistently found that the report of risk behaviours for themselves and the male partner was associated with a reactive rapid HIV antibody test among pregnant women. Nevertheless, it would be a mistake to overlook two findings salient for HIV prevention among women in Mexico: 1) a significant proportion of reactive women did not report any risk behaviours for themselves or their male partners; and 2) the most common risk behaviour reported by both reactive and non-reactive women was the male partner having multiple sexual partners during the past twelve months.

The majority of pregnant women in our study who were reactive to the HIV antibody test did not report any risk behaviours for themselves (75.16%), an important proportion did not report any risk behaviour for their male sexual partner (30.89%), and more than a quarter (28.96%) did not report any risk behaviours for either themselves or their male partner. This finding coincides

with Viani's (2010: 84) single-hospital study in Tijuana which found that 24% of the 68 HIV-positive women had no identifiable risk factors. Observational research from the United States of America has estimated that between 8 and 57 per cent of HIV-positive pregnant women have identifiable risk factors (Chou et al 2005: 40). Selective offer of HIV-testing based on perceived or reported risk factors during prenatal care may miss a significant proportion of pregnant Mexican women with HIV and deny them and their children access to timely health-care. This finding emphatically counters the current Mexican normative framework for prenatal care which suggests HIV testing during pregnancy only for "high risk women".

Second, far and away the most common risk behaviour reported by both reactive and non-reactive women in this study was that the male partner had had multiple sexual partners during the previous twelve months. Just slightly more than half (52.77%) of the 77,890 pregnant women included in the total sample said that their sexual partner did not have other sexual partners. In the total sample, the difference between reactive and non-reactive women's reports of their male partner having other sexual partners was statistically significant ( $p < 0.05$ ) but in the case-control sample where only 44.12% of reactive women and 48.93% of non-reactive women asserted that their sexual partner did not have other sexual partners, this difference was no longer statistically significant. The ubiquity of pregnant women knowing or suspecting that their sexual partner has other sexual partners is critical for thinking about HIV prevention among Mexican women.

When we compared reactive and non-reactive women with the same sociodemographic characteristics who received prenatal care at the same health-care delivery site, the only statistically significant difference in women's own risk behaviour was that reactive women were more likely to report multiple sexual partners. The fact that women's risk behaviours, with the exception of multiple sexual partners, are no longer significant after we control for

sociodemographic characteristics and the health-care delivery site, suggests that women's individual risk behaviours are a less important determinant of their vulnerability to HIV infection than the state of the epidemic at the community level and their male partners HIV risk behaviour.

In stark contrast to what we observe with respect to the association between women's own risk behaviours and a reactive rapid HIV antibody test during pregnancy, the risk behaviours women report for their male sexual partners remain significant in all of the logistic regressions with both the complete sample and the case-control sample. In the case-control, fixed effects model, women with a reactive HIV antibody test had much higher odds of reporting that their male sexual partner engaged in sex work, used injection drugs, had a history of incarceration, or had sex with other men. Our analysis makes a significant contribution to the literature by associating women's perceptions of their male partner's risk behaviours for HIV acquisition with reactive HIV antibody tests in a large, national convenience sample of pregnant women attending prenatal care in health-care facilities administered by the Mexican Ministry of Health. This finding lends credence to the proposition that focused HIV prevention with men who trade sex, use drugs, have sex with other men, or are incarcerated *can* contribute to HIV prevention among women (Over and Piot, 1996; Thomas and Tucker 1996; Das 2008: 283).

Empirical evidence demonstrating that HIV prevention with "high risk" or key populations reduces HIV infection among pregnant women, or other groups of women from the general population is not plentiful. However, research from India indicates that extensive and intensive HIV prevention efforts focused on female sex workers has contributed to a decline in HIV prevalence among young women attending prenatal care in the geographic areas where the interventions took place (Kumar et al. 2011; Moses, Ramesh, et al. 2008). Mexico is currently receiving support from the Global Fund for AIDS, Tuberculosis, and Malaria to strengthen HIV

prevention and harm reduction interventions with men who have sex with men, male sex workers, and drug users (including those already living with HIV) (FUNSALUD, 2011). Our findings suggest that if coverage is sufficient, these focused HIV prevention interventions with men who engage in risk behaviour could eventually contribute to reducing HIV prevalence among pregnant women. Unfortunately, my fieldwork has documented concerns among both grassroots HIV activists and policy-makers that inadequate training methodologies, limited resources for community capacity building, and narrow conceptualizations of the range of gender and socio-cultural identities of men who have sex with men are resulting in lack of coverage and insufficient impact to reach the desired HIV prevention goals of the Global Fund project (Fieldnotes August 21 and 22, 2011; Fieldnotes January 21, 2012).

Our findings should not be taken as support for continuation of public policy and health-care practice which limits Mexican women's access to HIV prevention information, education, and HIV testing (Kendall forthcoming). Rather, it signifies the need to focus on reducing women's risk for HIV infection within stable, long-term relationships. This analysis associated women reporting that their male partner had risk behaviour with them having a reactive HIV antibody test. To complement these findings, the following chapter provides a detailed analysis of HIV knowledge and risk perception among women with HIV before their diagnosis. Both analyses highlight that normative behaviour for Mexican men, such as having multiple sexual partners, is an important source of HIV vulnerability for women.

## **Chapter 5. Mexican women's risk behaviour for HIV Transmission: A Qualitative Analysis**

Drawing on the experiences of Mexican women with HIV, in this chapter I argue that the dominant constructions of gendered sexuality and a patriarchal socioeconomic system which idealizes marriage as women's *raison d'être* and justifies men's domination of women within stable relationships are important drivers of the HIV epidemic. Specifically, I seek to show that the association of HIV with stigmatized sexualities and cultural expectations for men's and women's sexual expression and couple formation and maintenance, are powerful incentives for women to overlook their male partners HIV risk behaviour and to ignore their own vulnerability to HIV infection.

### **5.1 Gendered sexual norms in Mexico**

Traditional Mexican gender norms prescribe male dominance and female submission (cf. Ortner 1972). Related cultural constructions of sexuality encourage male risk-taking (including having multiple sexual partners) while dictating female monogamy and sexual passivity (Herrera and Campero 2002; Kendall, 2009). Social and economic gender relations in Mexico are being transformed through processes of social and economic change, including declining birth rates, increased entry of women into higher education and the formal economy, globalized media consumption, and international migration. However, many studies suggest that dominant conceptions of gendered sexuality continue to hold sway, are changing more slowly than other aspects of the gendered social structure, and remain significant for HIV-prevention and care in the Mexican context (Allen-Leigh and Torres-Pereda 2008; Carrillo 2002; Hirsch 2003; Kendall and Perez-Vazquez 2004; Leyva and Caballero 2009; Melhuus 1998; Sanchez-Bringas 2003: 16-19,

44-45; Szasz 1998: 78). In *Sexual Meanings*, Ortner and Whitehead (1981:7-9) assert that the same cultural axes and symbolism that organize gender also cut across gender categories and are used to stratify groups of men and women and other social groups. In Mexico, a central symbol for the definition of gender and the exercise of power is the act of penetration—open vs. closed and active vs. passive are important cultural dichotomies, and the act of sexual penetration (“chingar”) is used as an analogy for the exercise of power and the establishment of domination/subordination in a variety of social contexts (Paz 1985: 29-40, 75-88). Melhuus (1998: 356) argues that Mexican sexual identities “hinge on and gain their meanings from the act of penetration: the virgin, never penetrated, and the prostitute, ever penetrated; the true man penetrates, the homosexual is penetrated”. Referring to Mary Douglas’ concept of pollution as a guardian of social boundaries, Priour (1998: 258-259) argues that in the Mexican context, the penetrating agent is not seen as polluting. Rather, it is being penetrated in a way that transgress social norms and moral boundaries—outside of marriage, for non-procreative ends (women) or becoming a “not-man,” losing male honour by being penetrated (homosexuals)—that pollutes the penetrated. This concept of pollution through penetration has historical roots and contemporary expressions in Brazil, Spain and other Mediterranean cultures (Berco 2008; Parker 1996; Schneider 1971: 20-22).

Mexican men face a cultural imperative to prove their heteronormative masculinity, including the need to demonstrate that they are not homosexuals, through risk-taking which ultimately can have deleterious effects on their health (de Keijzer 2005:184, 193-195). In the field of sexuality, these dominant patterns can express themselves through having multiple sexual partners (including other men), having unprotected sex, and combining sex with the use of drugs and alcohol (Kendall and Perez-Vazquez 2004: 23; Liguouri, Gonzalez-Block and Aggleton, 1996). Gendered sexual expectations include Mexican men initiating sexual relations—taking the

active role in courtship, establishing the conditions for sexual intercourse—the when, where and how—and being the penetrating or “active partner” (Carrillo 2002:184; Rodriguez and de Keijzer 2002: 110, 227-232). While both men’s and women’s capacity to experience sexual desire is recognized, men’s sexual desire is considered stronger and less controllable—a biological need, if you will—and men’s expression of and actions driven by desire are considered “natural” (Carrillo 2002: 42; Castro 2001: 154; Kendall et al. 2007: 466). In contrast, expressions of sexual desire may ruin a woman’s reputation (Herrera and Campero 2002). Mexican men continue to express their preference for a “modest,” sexually inexperienced, and preferably virginal woman for marriage; if she is not a virgin, she must give the appearance of being a virgin. Men may enjoy sexual adventures with sexually experienced women (sex workers and *gringas* or *chicanas* in the United States), but they still want to marry a virgin from the *pueblo* (village) (Carrillo 2002: 43-49, 186-189; Hirsch 2003: 142-143; Sanchez-Bringas 2003). The attitudes expressed about the difference between women for “fun” and women for marriage at the end of the last millennium by men in Jalisco and Mexico City were not very different from those expressed by Manuel, in Oscar Lewis’s (1963:41) classic ethnography *The Children of Sanchez*, in the 1950s:

Well, when we got to the room, I began to kiss her on the neck and on the arms, and she returned my caresses. I took off her shoes and stockings...that is the most exciting thing for me...the one who struggles a little, who shows a little shyness, excites me more. ... As a matter of fact, she was an expert and taught me a lot...different positions and how to hold back. That’s when I learned that women enjoy it too. But she wasn’t for me because I wasn’t the one who had dishonoured her. Women who have screwed others were not to my liking.

Manuel recognizes that women get as well as give pleasure from their sexuality, but also articulates how expressing sexual desire and pleasure can have negative social repercussions for women—in this account not being considered for a serious relationship. Carrillo (2002: 43) notes

that gendered expectations about the performance of sexuality have changed even less than other aspects of gendered relationships, such as decision-making about money or performance of domestic labour. Partially as a consequence of these constructions of male sexuality, men are permitted more sexual exploration and also feel entitled to pursue casual sex with women whom they don't consider potential spouses (Carillo 2002: 42, 184-186; Gutmann 2007: 130). Hirsch et al. (2007:986) argue that it is important to recognize "that extramarital sex, though typically portrayed (in Mexico and elsewhere) as a breach of social norms, is a fundamental if tacit dimension of gendered social organization rather than the product of individual moral failings or a breakdown in social rules".

The sexual double standard contrasts tacit acceptance of men's "bad behaviour," such as having multiple sexual partners or drinking alcohol as part of their demonstration of their masculinity, and the negative effects on women's sexual reputation and social possibilities if she expresses her sexual desires outside of the bounds of a stable relationship (Herrera and Caballero; Sanchez-Bringas, Melhuus 1998). As one might expect, given the importance of penetration as a central symbolic axis for the creation of gendered sexual identity in Mexico, virginity holds a special place in female constructions of sexuality and women are basically divided into two types—"good women" and "bad women" (Melhuus 1998; Szasz 1998). Good women are virgins at marriage or at least at the moment of engagement; in the middle and upper-social classes the engagement is longer in part to demonstrate that a pregnancy out of wedlock was not the motivation for the union. Further, while it is understood that both men and women have sexual needs, good women do not express sexual desire or actively seek to meet their own sexual needs, but rather respond to masculine sexual demands in order to marry, procreate, and keep their husband satisfied so that he won't seek sexual "relief" elsewhere. This "traditional" discourse

fuses women's sexuality with reproduction: the first serious affective/romantic relationship leads to a stable union and children (Hirsch 2003: 116; Sanchez-Bringas 2002; Szasz 1998: 85). In many respects, reproduction within marriage and the status of being a "respectable mother" continues to be culturally constructed as the *raison d'être* of women's lives.

Sexually active women who express and seek to satisfy their own sexual desires are classified as "bad women". These women are not considered culturally adequate for marriage or deserving of respect—they exist in the social imaginary, and often in practice, to be used by men, and discarded. Neither her family nor the man will protect a girl or woman who "goes too far," even if she was forced. While there is a greater margin for women to express sexual desire within marriage than was present in previous generations, women still walk a fine line between being categorized as a "woman of the street, *una mujer de la calle* (a prostitute) and the symbolic opposite of *la mujer de la casa* (the wife)" (Hirsch 2003: 99). Mexican women are not completely without agency in the face of these restrictive constructions of their sexuality, but they are certainly limited by them. Even today, women show sexual modesty [shame] as a gambit to protect themselves from negative treatment:

*Verguenza* is a quality that all well-brought-up girls should know enough to display; showing shame in early marriage is a deliberate performance of being a good girl. ...There was a tension in this part of the conversation, between their desires to satisfy their husbands and their fear of crossing a line and acting like a woman of the *calle* as opposed to one of the *casa*. As one woman said, discussing her reluctance to have anal sex with her husband, "*somos de amor, no somos de pago*" (we are the ones [who do it for] love, we are not [those who do it] for money" (Hirsch 2003: 214-215).

A common contemporary strategy is to maintain the façade of sexual shame and passivity and to make sure the man feels that he is in control of the sexual act and sexual expression, for example

by making a show of resistance or pain, even if in actual fact a woman is experiencing pleasure (Carrillo 2002: 103; Marston 2003).

Underlying the dichotomy of the “virgin” and the “whore” is a patriarchal culture in which men own women’s bodies. In small villages and the huge, sprawling metropolis of the Greater Metropolitan Area of Mexico City, for all but a tiny minority of the best educated and wealthiest women, a woman belongs to her family, and the responsibility for preserving her virginity and the family’s honour rests with the males of the family, until such moment as she “gives herself” to a man (Sanchez-Bringas 2003: 125-127, 152). In many parts of rural Mexico, this rite of passage continues to be enacted through “bride robbing,” which can be consensual or forced (Hernandez-Rosete et al. 2008; Kendall and Pelcastre-Villafuerte 2010: 519; Rodriguez and de Keijzer 2002: 111-125). Rodriguez and de Keijzer (2002: 227-228) relate that:

Crossing the doorway is a transition from one *status* to another, crossing the threshold starts an irreversible transition. Women and the community recognize the act as the loss of virginity, which is manifested in their testimonies as an irreversible physical change about which the bride says, ‘*Oh God, what have I done?*’ The social signification is that she instantaneously stops being a *senorita* (young lady) and becomes *la senora de* (the woman of or Mrs. Jones)... independent of the wedding and sexual consummation, which usually occurs later.

In both rural and urban areas, women traditionally passed from one house to another—moving from the status of *hija de familia* (the daughter of the family) to *senora de* (Mrs Jones). I want to emphasize the fact that there is no return from crossing the line between belonging to the family of origin and belonging to the husband. The cultural logic is that once a woman makes this choice—crosses the threshold by having sex with a man or being seen to have sex with a man (in small communities because it is known that she has passed a night unsupervised by her family of origin or in both rural and urban settings because she is seen to be pregnant)—she must live with the

consequences of that choice by establishing a stable union with that man and *aguantar* (endure), or face the ruin of her social reputation. One significant change is that at least in Mexico City and among the women in my sample, the “choice” of a male partner is usually made by women themselves rather than the family group. However, this also means that the women can’t count on the protection or intervention of the family group and community if after having sexual intercourse, the man doesn’t formalize a relationship, recognize offspring, or provide economic support (Sanchez Bringas 2003: 215-220; Szasz 1998: 95-97). In urban areas, a small minority of upper-middle and upper-class women are living independently while they engage in post-secondary education or work, but they still must maintain their reputations by not being seen to be pregnant outside of wedlock. During the decade (2002-2012) that I lived and worked in two large cities in Southern Central Mexico (Cuernavaca and Mexico City), I interacted socially with women of the educational elite—women with at least a bachelors degree, who had vacationed or studied in the United States or Europe, were employed and usually lived independently of their family of origin. They are the privileged few enjoying the fruits of increased education, economic opportunities and self-determination for women. My observation from group and individual discussions is that these women engaged in extramarital and casual sex as frequently as among a comparable Canadian group, say graduate students, and short-term sexual relationships were not stigmatized. However, in the only two cases of accidental pregnancy that I know of, one woman formed a stable relationship and went on to have more children and the other woman was stigmatized for choosing to continue a pregnancy where the father was not interested in establishing a serious relationship with her. Thus, even among these women, the strong link between pregnancy — the socially outward sign of sexual relations — and establishing a relationship, and the censure of women who are unable or unwilling to form that relationship with

the father of her child, continues. Single mothers and divorcées—women who have been unable to keep a man—are still called *fracasadas* (failed or fallen women) (Agoff et al. 2007: 1215; Lagarde 1990). These women belong to no one and thus are “public women”—women who are no longer protected by a male authority within the private sphere. There is some heterogeneity in the dichotomized cultural stereotypes of “good” and “bad” women and their consequences in different social groups and at different moments of the lifecycle, but patterns of behaviour are quite stable in diverse contexts (Szasz 1998: 85, 91-92). Women’s greater role in decision-making over their bodies, sexuality and reproduction, primarily due to access to contraceptives, hasn’t dramatically modified gendered sexual norms, the sexual double standard, or sexual and domestic violence against women (Szasz 1998: 86). Finally, it is important to note that even when men and women articulate discourses that are critical of these traditional dichotomies between “good” and “bad” women and the sexual double standard (including associating them with the older generation), their sexual and reproductive histories often testify to the continued relevance of these cultural constructions (Amuchastegui 1998: 111-112; Sanchez-Bringas 2003: 216-220). These dominant constructions of the appropriate sexual roles for men and women and their interactive dynamics are an important background for understanding the HIV epidemic among Mexican women and women’s risk-perception for HIV acquisition in the context of stable relationships.

My interviews, conducted with 55 women living with HIV of reproductive age from three States in Southern Central Mexico (Mexico City, Mexico State, and Morelos), allow me to contextualize the relationships between risk-behaviours for HIV acquisition, risk perception, and cultural constructions of gender and sexuality. These interviews permit more nuanced insight into women’s vulnerability to HIV infection. While the in-depth interviews and the quantitative analysis presented in the previous chapter tell a similar story in that they highlight the importance

of men's risk behaviours for women's HIV infection, the qualitative analysis provides a more complex view. The dominant story remains one of women in stable relationships being exposed to HIV through the risk-behaviour of their male partners. However, the qualitative interviews problematize the characterization of women as unaware victims of men's risk behaviour while simultaneously allowing us to appreciate the gendered constraints that women face in HIV-prevention and pointing to the need for structural interventions aimed at cultural transformation of gendered sexual norms.

## **5.2 “It never crossed my mind”: Women's knowledge of HIV transmission and risk-perception prior to HIV diagnosis**

When asked what they knew about how HIV was transmitted prior to being diagnosed with HIV, these women from South-Central Mexico accurately identified unprotected sexual intercourse and blood borne transmission, principally sharing needles; they did not, however, mention mother-to-child transmission of HIV and when specifically asked most women said that they had not been aware of vertical transmission before being diagnosed. Their information about HIV had been gathered from television and radio campaigns, and among the younger women, from school. Noemi's response when asked what she knew about HIV before her diagnosis is typical: “Well the truth is—nothing. Well, I knew that it was a disease caused by [sexual] transmission and that, well like that, but I never, ever imagined that I was going to get it. I didn't even know the symptoms or how you could realize that you had it”. It is important to underline that only a few women knew about the existence of antiretroviral treatment before being diagnosed, and that many had stigmatizing beliefs which associated HIV and AIDS with death,

and with sexually stigmatized populations, such as homosexuals and female sex workers. Sara says that she knew “nothing” about HIV before her diagnosis.

Pure and simple they treat it like, well, sometimes we are so *arraigados* (so stuck in our ways), so closed-minded, so ignorant that even if you think it is a disease—well yes, obviously it’s sexually transmitted—but what you have in mind, because that’s what’s emphasized, is that because it’s sexually transmitted this disease only affects people who are homosexuals, or people who are *sexoservidoras* (women who are prostitutes). And that’s the emphasis, well the focus that you, well, at least *I* had. And that they get it, and for better or worse, little by little they deteriorate and they die and that’s it.

The stigmatization of HIV through association with death and with “the other”—homosexuals and female sex workers—contributes to women saying repetitively that the possibility that they could become infected with HIV “*ni siquiera me paso por la mente*” (never crossed my mind). Women’s corollary response about why they didn’t use condoms was “*pues no creía que fuera necesario*” (well, I didn’t think it was necessary). Itzel says she had heard of HIV before being diagnosed, because of people who ask for donations

in the metro in Mexico [City]: ‘please help those who have HIV/AIDS.’ And then they give you a flyer, and when I saw that I said, ‘oh poor things, they are going through all of this, what kind of life is that.’ And I never imagined that I would also go through this ... I knew that it was through sexual transmission or blood transfusion. But I never thought that one of the two partners that I had had would transmit it to me, or something like that—I never thought about that.

Women said they hadn’t used condoms before the diagnosis because they had had few sexual partners and were generally having intercourse within what they perceived to be committed relationships. Patricia explains that she never used condoms before being diagnosed HIV-positive “because I only had two partners, well no, I never used anything”. Condoms could be included or excluded from a relationship depending on reproductive goals, but generally weren’t used for disease prevention after the first or second time that a couple had sex. Karla says that she used

condoms inconsistently “out of fear of getting pregnant, I never imagined HIV”. Manuela’s explanation of her condom use highlights the relationship between sexuality, reproduction, and stable relationships which are fused in traditional constructions of Mexican women’s sexual expression (Hirsch 2003: 116; Sanchez-Bringas 2002; Szasz 1998: 85).

**Researcher:** Before the diagnosis, did you use condoms?

**Manuela:** Never, because we wanted to have a baby.

**Researcher:** And with your first partner?

**Manuela:** Not with him either, because, well, we were a couple and he was my only partner, why would we use a condom?

Unprotected sex was the rule within stable relationships. Pamela explained that she had used condoms with the sexual partners she had before her husband, but she didn’t use condoms with him “because I was going to go and live with him. And with the others, they weren’t partners, they were friends”. Pamela construes entering into a stable relationship as eliminating sexual risk. Later in their relationship, Pamela’s husband engaged in extra-relational sex. During this period, he only came home to sleep and the frequency of their sexual contact was limited. But when he returned home and they resumed their sexual relationship, Pamela didn’t conceive of the need to test for sexually transmitted infections or practice protected sex.

**Pamela:** When we got back together, and I forgave him, yes [we had sex], but when he was with that woman, hardly at all.

**Researcher:** But when he came back did you use condoms?

**Pamela:** No.

**Researcher:** And did it occur to you that that could be risky?

**Pamela:** No.

Reconciliation seems to trump possible risk. Maritza expressed dual awareness about the existence of sexually transmitted infections and the exclusion of condom use from committed relationships when she recounted her history of condom use with her cocaine using, violent boyfriend. She said

that “the first times [we had sex], I said we could avoid risks, infections, from HIV, or AIDS, well, for that reason. But when my husband became an established partner, the person that I was going to live with, we didn’t want to do it. That’s it”. It is clear that in the social imaginary and everyday practice, condoms don’t belong in serious, stable relationships. Veronica said she knew that HIV could be transmitted by “needles, used razors or sexual transmission, but one never thinks of living, of being in the shoes of those people [with HIV]”. She and the male partner who transmitted HIV to her never used condoms

because we liked it natural, and I had always said that the day that I went to live with someone, it was going to be because I was going to be stable and happy with my partner, right. I have never liked having lots of boyfriends, so I felt like I was only with him and he [was only] with me, and we weren’t screwing anyone, so we said: why? So that’s why I didn’t use it.

Veronica’s comment reveals how having unprotected sex symbolically sanctified her relationship as the idealized, monogamous relationship which is “stable and happy” (see also Sobo 1995).

All of the women knew that HIV can be transmitted through unprotected sex but this knowledge didn’t translate into HIV risk-perception. Theresa said,

I had heard of the disease, but I never thought it could touch me. We are so ignorant, because I said that it only happens to girls who are having sex with whatever man or to homosexuals because they don’t take care of themselves, but one never knows whether their husband is cheating on them, and one doesn’t know what kind of diseases they pick up in the street.

She had never used condoms because she “didn’t think it was necessary”. In retrospect she says, “when you aren’t in the know, you aren’t interested in knowing. You’re blind, because you say, he’s my husband, why would I [use a condom], because of your ignorance, but now I think that even if he is your husband, you should take care of yourself for prevention”. The importance of unprotected sex for signalling that relationships are serious and committed, and the underlying

demand that sexuality is for reproductive ends within the larger Catholic context, is a barrier to women's HIV risk perception.

### **5.3 *Hijas de familia* (good girls) and *fracasadas* (fallen women) facing HIV**

While the social imaginary of “good” and “bad” women plays an important role in conditioning some women's HIV risk perception, this research forcefully demonstrates that these cultural categories are largely irrelevant for women's HIV infection, with both *hijas de familia* and *fracasadas* participating in the research. In fact, the sexual histories of women with HIV in both cultural categories undermine the cultural stereotype of Mexican women having a single lifetime sexual partner. The number of lifetime sexual partners reported by women ranged from one to twelve, with an average of 2.98 and a mean of three lifetime sexual partners. Of the forty women with HIV who shared how many lifetime sexual partners they had had<sup>18</sup>, only ten reported a single partner, the majority reported having between two and four lifetime sexual partners, and a mere five women reported that they had had five or more lifetime sexual partners.<sup>19</sup> Of the 55 women with HIV who participated in the research, forty-five became infected in the context of a stable relationship (marriage or common-law), two more became infected with their long-term lover, four became infected in the context of a casual or short-term sexual relationship, one became infected in the context of a relationship that she hoped would become long-term, and three became infected with HIV through blood-borne exposure.<sup>20</sup> I have examined in detail the histories of the seven women who became infected with HIV outside of relationships that seemed to conform to the cultural norm for long-term stable relationships. Though I would hasten to mention that the lines between “short-term” and “long-term” relationships quickly blur as some women hoped and expected that the short-term sexual relationship that resulted in their HIV-infection

would become a long-term relationship and others had long-term relationships with lovers. These seven women could be considered cultural stereotypes of *fracasadas* or fallen women given that they were single-mothers or divorcees and one had worked as a *dama de compania* (bar hostess), but their sexual histories are not that different from the other women in the sample. Finally, there is no particular pattern which distinguishes the sexual histories of these women relative to others except that they believed they became infected with HIV outside of the context of a stable relationship. Half of them reported having significantly more lifetime partners than the mean for the sample (more than five partners), but the other half didn't. I found that the cultural dichotomy between "good" and "bad" women and the stigmatizing associations of HIV with deviant sexuality increases women's vulnerability to HIV. Gender constructs lead those who classify themselves as "good women" to believe that if they follow gendered sexual rules they will be protected from HIV, while simultaneously increasing the social vulnerability, and consequently the HIV vulnerability, of "failed" women. One of the findings of this research is that both culturally determined categories of women become infected with HIV.

### 5.3.1 *Hijas de familia (good girls)*

Lucrecia's statement about her knowledge of HIV before she learned she was HIV-positive explicitly makes the link between being a "good woman," only having sex in the context of stable relationships, and believing herself to be protected from HIV. She said she had

heard on TV, you know they play lots of commercials. So, I had heard that HIV/AIDS was sexually transmitted, but did I pay attention to it, well no. The truth is that I was never—how could I put it—one of those bad girls, that have lots of boyfriends and lots of partners. My first boyfriend was the father of my son. And that was the one that I got married to, my first boyfriend and my first husband. And after that, I was alone for three years with my son. Well, not alone because I lived with my mom. You could say alone, without a partner. And after that I met my daughter's father.

Her sexual history is typical of the women in the sample: two or three sexual partners with whom they have had children. My research also suggests that the protective behaviours that families engage in to preserve their daughter's "innocence" (including their virginity), may actually contribute to women's vulnerability to HIV infection because it deprives them of knowledge about the wider world that could increase their HIV risk perception. Magaly's first sexual partner transmitted HIV to her. She said that

he was a drug addict, but I wasn't, well, when he was with me, I never saw him drugging himself. But afterwards I found out [at work] that he acted that way because he used drugs. And I was like 'ohhhh.' What happened was that with my family, even though I am twenty years old, and I went [to work] when I was nineteen, they had me in a glass box: 'don't do that,' 'don't go out,' don't.' So I really, really didn't know much, and when I got my freedom, I started disastrously and I got infected.

Magaly was a trained teacher with a university education. She knew how HIV was transmitted and used condoms at the beginning of her first sexual relationship. But when the relationship got more serious and they began living together, protected sex fell by the wayside. In Magaly's words, "he was my first partner. Before, I had had a boyfriend, but only handholding and stuff like that. And well, he didn't look sick, or anything. And well, no, it never occurred to me". Women also attributed a respectable social reputation with being "sexually safe" when evaluating potential male partners. Maura considered that she wasn't at risk of HIV because

I was a very calm girl. I liked parties and everything, but I was always responsible. I didn't drink, I didn't smoke, healthy. And I knew [about HIV] and my slogan was always: 'the best safe sex is not to have sex.' Until, supposedly, the right person came along. And the right person came along, and the right person that I went with was infected, without knowing that he was infected.

When asked whether she ever considered testing for HIV or other sexually transmitted infections before having unprotected sex, Maura said that she hadn't and referred to her impression of her husband's family. She said she hadn't thought about HIV because

I met him with all of his family. And it was a good family, I mean, really, really good. And I can say, well, everything happened really fast with him. I got together with him—when would it be—after a month. Because I met his family first, I didn't know him. And sometimes, one trusts in that, in knowing the family, and seeing that it is a good family. And I met him too, and he seemed very calm, very attentive. I really hardly knew any details about his life. All of the details started to come out after I knew him, and they started to say: 'Oh, he went out with this one and with that one' But since they were relationships before me, it didn't bother me. It was only later that it came out that he was a womanizer, that he was this and he was that. But still, no, it [STI testing] never occurred to me.

Lucrecia, Magaly and Maura exemplify the nexus of beliefs about women's sexual modesty, involvement in a stable relationship, and consequent exclusion of condoms for disease prevention.

### 5.3.2 *Mujeres Fracasadas (Fallen Women)*

Seven of the fifty-five women who participated in the research reported that they had become infected with HIV while engaging in short term, casual or concurrent sexual relationships. All of these women could be considered *fracasadas* in that they had not successfully parlayed their sexual exchange into a stable relationship—all were divorced or single mothers. Their stories highlight that women are unlikely to consign themselves to the “failed woman” category, but that the etic assignment of this category may have negative impacts on their treatment by male sexual partners. I have chosen to explore these women's HIV transmission histories in detail because they are exceptions that show the diversity of experiences.

Jacinta's second husband, and father of four of her six children, was abusive. When she turned eighteen and told him that she wanted to get her official identification, he said “animals don't have identification”. He made her walk with her eyes downcast and forbade her to greet

anyone on the street or to wear make-up. They had a tumultuous relationship, exacerbated by her mother-in-law's constant criticism and tattling to the husband about her supposed faults as a woman (being inept at cooking, cleaning, etc.). This alternated with her family coming to their home and bringing her back to Mexico City, sometimes without her consent. Jacinta's rebellion against familial control, for example, running away from home at sixteen and having her first affair, which put her in the failed woman category, is a counterpoint to her lack of physical autonomy: she was basically kidnapped and physically moved from one place to another both by family members and male partners. The definitive separation from her second husband came when

my Dad came to visit, and she [the mother-in-law] says: you know what, 'your daughter is this, she is so lazy, she is this and that!' —and she started with the whole litany to my Dad. She said 'now my son has another woman because she doesn't wash clothes properly' —and No! The things that she said to him. And my Dad, he said 'you know what, little girl, get your stuff and let's go, get your kids, and we are out of here.' And I was like 'not again.' I got my things, and my dad grabbed the kids, and we left. He said 'Well, if they don't want you here anymore, what are you doing there.' And four or five months later, he [her ex-husband] got married, and he got properly married because we were only living together but he got married in the Church and at the civil registry.

In some ways, Jacinta is the cultural stereotype of the "fallen woman". She had several children with her second husband, but he never formalized the relationship with her despite the fact that they lived together for eight years. Instead he got "properly" married to another woman shortly after they separated. When she and her children left and went to live with her father, they were sharing their living quarters with an old family friend and her son. The son sold drugs, used injection drugs, had been incarcerated, and had relationships with women for money. Jacinta began having a sexual relationship with him, and then wanted to stop. She said that initially, the relationship

was by mutual consent, but he had a girlfriend, and I said, no. Well after, I said ‘not anymore.’ But he came ... in my room and he pulled me by the legs ... saying ‘c’mon, c’mere.’ And I said, “uuufff”, even though I didn’t want to. And then he would say, ‘c’mon, come here right now!’ And he would pull me really hard. Until I reached my limit and I said: ‘you know what, leave me in peace or I am going to tell your girlfriend.’

Despite Jacinta’s threat to tell his girlfriend about their sexual relationship, her housemate kept on sexually harassing her until she challenged him to a physical fight, daring him to hit her. When I asked Jacinta why she didn’t cry out or try to run away when her housemate was forcing her to have sex, given that her father was in close physical proximity, she explained that “my Dad had a really close relationship with his mom, so, no. And also, my Dad is one of those people who goes to sleep and is lost to the world. So no, well I didn’t want to make a big problem since they had known each other for years, so I said: I’ll stop the problem, and that’s it. I decided to stop the problem, so as not to make a big deal”. As a sexually experienced woman who entered into the sexual relationship by mutual consent, Jacinta is not culturally protected from rape. She is also socially and economically vulnerable—making “a big deal” about being sexually coerced might not have only jeopardized her father’s friendship, but her and her children’s place to live.

The stories of Clara and Sandra blur the lines between casual and long-term sexual relationships and also underline how economic dependence, gender violence and stigmatizing stereotypes about HIV are constraints on women’s ability to reduce their HIV risk. Clara was infected by someone she met at the bar where she worked as a hostess. She explained the relationship in the following way:

I was alone, and the dad of my youngest son never took any responsibility. I was always a single mother with my youngest kids. I met him [at the bar], and I started to get to know him, and then we started to go out, and he rented me an apartment, a room, and then I started to buy my things and went to live there.

Her lover paid the bills and visited her several times a week. She never used condoms “because I was sterilized”. Clara said she initiated the sexual relationship, explaining that she “took the decision to be with him, because three months had gone by and he had never insinuated anything. I even thought that he was a pansy, and that he was with me to hide it. He never suggested that we have sex. I was the one who took the decision”. Her decision to consolidate their relationship through sex provides a key insight into the dominant sex gender system: the exchange of women’s bodies for social position and economic support (Szasz 1998). In retrospect, she thinks her lover knew that he was HIV-positive as he had symptoms of AIDS, talked to her about the existence of the specialized HIV clinic in Mexico City, and when he found out about her diagnosis said “ ‘*no hay que buscar culpables*’ (it’s no good trying to blame anyone)”. In Clara’s opinion, “another man, knowing that he was clean, would have killed me on the spot”. Neither Clara’s etic characterization as a *fracasada*—a single mother and a woman who works as a bar hostess (several steps in the hierarchy above a street-based sex worker but involved in the same profession)—nor her suspicion that her male partner may have sex with other men, caused her to perceive herself as vulnerable to HIV nor to take preventive action. The contribution of HIV stigma to her failure to perceive HIV as a possibility is suggested by her dichotomization of the “clean” (HIV-negative) with, implicitly, the “dirty” (HIV-positive).

Sandra could have been infected by either of her two previous sexual partners, both of whom had risk behaviour for HIV acquisition and with whom she had three-month long relationships. In both cases, she went to live with them, and in that way became somewhat economically dependent. One was a man she met in a discotheque and with whom she accidentally got pregnant. The importance of unprotected sex for establishing the conditions of a serious relationship and women’s consequent vulnerability are highlighted by her comment that “I had the

illusion of sharing my life with him, of becoming more than just boyfriend and girlfriend. I wanted to be with him. But it didn't work out and he left". She knew that he used drugs, suspected that he was sleeping with other women, and thought that "maybe he had it [HIV], he might have been infected because he took, I mean, I saw some boxes of medicine, but he never told me what they were for. Whenever I asked him, he didn't answer. I think that maybe he was infected or had another disease, and he never wanted to tell me". He also exercised sexual violence against her on a regular basis. She says that when she "didn't want to [have sex], when I wanted to go out, he wouldn't ever let me go out: first we had to have sex and then I could go where I wanted". When he found out she was pregnant, he left town without leaving a forwarding address.

She met her next partner while buying *tamales* (steamed corn dumplings) after mass. They started dating and he introduced Sandra to his family. Just as for Maura and other women who placed themselves in the "good girl" category, perception of and treatment by the man's family were important in Sandra's initial evaluation of her partner and her decision to live with him. She said that:

His family was really kind to me. They were very, very attentive, never an unkind word. And after two months, he asked me to come with him, to live with him. [He said] that he was alone, that his wife had died, he started to tell me a pack of lies, because they were lies, his wife was alive and had stayed on the other side [in the United States]. But like a dummy, I went with him to his house.

Sandra soon discovered that as well as being a return migrant with a wife "on the other side," her boyfriend was violent towards her, an alcoholic and had sex with sex workers. Sandra caught him with "two ladies dedicated to the, to the 'happy life' [sex work]. And when I found them like that, in bed, and that's when I became afraid, thinking that those women have sex with one man after another". Despite knowing about her partner's risk behaviour, her sister-in-law hinting that HIV was common in the United States, and being worried enough about HIV to go and do an HIV test,

Sandra never used a condom with this partner because “he didn’t like condoms. And we always did it without a condom. ... I spoke to him about it, but he told me that he didn’t like condoms. He said, ‘those damn things aren’t worth a damn.’ So we had [sexual] relations without condoms, and that’s when this happened to me”.

Some of the women also engaged in concurrent or casual sexual relationships. Camila was one of the youngest women to participate in the research and she reported having the highest number of sexual partners (twelve). She had been involved in long-term concurrent sexual relationships in the past and continued to do so at the time of the interview. She had her first sexual relationship at the age of thirteen and reported initially using condoms with most partners. She says “the first time, I did think, well he might have something, but it was only the first time, maybe the third time I said, ‘We’re fine, nothing is going to happen,’ and it was like ‘don’t put on a condom’”. Camila had shared her HIV status with both of her sexual partners, but neither of them had been tested at the time of the interview

Sofia became infected with HIV while having sex with a neighbour. She related that one day he said; ‘You have to have sex,’ because I wasn’t having sex. So, he said, ‘C’mon, let’s have sex.’ And I did. He was my friend’s husband, but my friend didn’t know. He was the one who infected me, because he coughed and coughed. I thought it was a cold. Now I imagine that it was this [AIDS], because he was always coughing and coughing and coughing. As the saying goes: curiosity killed the cat.

Stating that she slept with her neighbour because “I wanted to have sex,” Sofia boldly owns her sexual desire and curiosity. But her autonomy in choosing to have sex didn’t translate into protective behaviour. Even though she knew her casual lover was a thief, used injection drugs, and had been in jail, Sofia “never imagined he would have this damn disease. I mean, it never crossed my mind, that he could be infected. Maybe he knew, but he didn’t tell anybody”.

Manuela and Gisela both became infected having sex with a lover; Gisela with a long-term extra-relational partner and Manuela during a one-night stand away from home. Both Gisela and her lover were married, and they maintained a relationship for more than two years. After she had developed symptoms of AIDS, gone for testing, and was waiting for the results, she ran into her former lover who looked ill and asked him “‘what’s happening with you?’” And he said, ‘no, no, I don’t have anything.’ He said ‘my wife is sick and I am really worried’ and he told me a story ...It seemed strange to me because he said ‘*de algo nos vamos a morir*’ (we all have to die of something).’

Manuela described her sexual adventure as “revenge” for the multiple sexual betrayals that she had experienced with her ex-partner:

When my son was three years old, I separated from my kid’s father. My ex was a real womanizer and we fought about it constantly. He didn’t come home and stuff like that. So, during a trip that I went on to Guatemala, hurt and disappointed because of my ex, the only thing I wanted was vengeance. So I met a guy and had sex with him, and he is the one who infected me, I guess, because I had never had sex with anyone else.

Manuela’s idea that she can avenge herself for her ex-husband’s sexual infidelity by having sex with someone else implicitly calls on men’s ownership of women’s bodies. By “giving” her body to someone else through the act of sexual intercourse, she is taking from her ex-husband the exclusive sexual dominion over her body that had been his due within the context of the marriage. Drawing on the work of Corinne Kratz, Holly Wardlow has described “negative agency” whereby Huli women in Papua New Guinea refuse to fulfill designated gender roles for their kin networks and spouses. One of the forms that “negative agency” takes is women exercising their sexuality outside the confines of the bridewealth system, as revenge for mistreatment by spouses and failure to provide protection by male kin (Wardlow 2004). This is understood as a form of “theft” of

women's reproductive capacity from the family and the clan (Wardlow 2006: 14-16). What is poignant in Wardlow's accounts and those of Manuela, Gisela and other's is how women's negative agency can be expressed through self-harm or result in unfortunate consequences for women (Wardlow 2006: 15).

Even in relationships that might be considered "socially risky," in that they are occurring beyond the bounds of a sanctioned stable relationship and women might know about or suspect risk behaviour on the part of the male partner, this knowledge didn't translate into protective behaviour. In the case of these Mexican women, the "negative agency" exercised by sexual intercourse outside of marriage-like relationships (because of their own sexual desire or for their own material gain) is conditioned by compliance with other gender demands, such as male economic and sexual domination and unprotected sexual intercourse as the cultural norm. Social networks and stereotypes about HIV also discouraged the "positive agency" that women could have exercised by demanding condom use. With the exception of Manuela, who had a one-night sexual liaison in another country, all of these "fallen women" had sex with men who were part of their social networks (the neighbour, the son of a family friend) or with whom they had or hoped to have a long term relationship. As with, the "good girls" risk-perception was diminished by women's own stigmatizing stereotypes about HIV, and the capacity to implement protective behaviours were further constrained by economic dependence and gender-violence. There are also several suggestions, that these women's social categorization as "fallen women" may have resulted in men devaluing these women and their health, to the extent that they had unprotected sex with these women while knowing that they were HIV-positive or failed to advise their former sexual partners when they became aware of their HIV diagnosis.

## 5.4 Women’s report of their and their male partners HIV risk behaviours and contexts for HIV transmission

If unprotected sex in the context of a relationship is excluded as a risk-factor for HIV acquisition, women’s reports of their own risk-behaviours make it abundantly clear why they did not consider themselves to be at risk of HIV infection before receiving their HIV-positive diagnosis. Table 1 allows us to appreciate how uncommon risk behaviours for HIV-acquisition other than unprotected sex were among these women with HIV.

Risk behaviour (lifetime) <sup>a</sup>	Yes	No
Injection drug use (n=54)	0	100% (54)
Other drug use (n=54)	7.41% (4)	92.59% (50)
Sex work (n=54)	1.85% (1)	98.15% (53)
Migration (n=54) <sup>b</sup>	24.17% (13)	75.93% (41)
Deprived of liberty (n=48)	0	100% (48)

<sup>a</sup>Denominator for the proportion (%) of women who reported the risk-behaviour is the actual number of women who answered the question

<sup>b</sup> 10 of the respondents had migrated internally, 3 had migrated internationally (predominantly to the United States of America)

A very small proportion of these women with a confirmed HIV diagnosis reported engaging in sex work, none had used injection drugs, and the use of other drugs was uncommon. Almost a quarter of the women had migrated internally or internationally. Migration has been associated with increased vulnerability to HIV among Central American and Mexican women. Most women have sexual relationships during the migratory journey, often in situations of subordination where condom negotiation is not possible (including sexual violence), and new sexual and affective relationships established in the host community, increase the size of women’s sexual networks (Kendall and Pelcastre-Villafuerte 2010; Caballero et al. 2002). In the case of migration to the United States, sexual and drug use norms in the host community are also associated with increased

HIV-risk and there is an epidemiologically greater probability of being exposed to HIV because of higher population prevalence (Kendall and Langer 2006; Organista et al. 2004). In my sample, a few women did become infected with HIV during a period of migration to a region with a higher HIV prevalence, either within Mexico or internationally. However, these HIV infections occurred in the context of stable relationships.

While it makes sense that women might not consider themselves at risk of HIV prior to the diagnosis based on their own HIV-risk acquisition behaviour, it is not as clear why women overlooked the relationship between their male partners' risk behaviour and their own HIV risk. As in the national, quantitative sample presented in Chapter 4, among these 55 women with HIV, the male partners' risk behaviours for HIV-acquisition seem to be crucial for women's exposure to HIV. In responses to questions about the HIV-risk behaviour of the man who she believed transmitted HIV to her, a significant proportion of these 55 women with HIV retrospectively identified risk behaviours.

<b>Table 5.2 Risk behaviour reported for the male partner (n=55)</b>			
Risk behaviour <sup>a</sup> (lifetime)	Yes	Don't know	No
Sex with men (n=55)	16.36% (9)	20% (11)	63.64% (35)
Injection drug use (n=55)	21.82% (12)	3.63% (2)	74.55% (41)
Other drug use (n=55)	45.46% (25)	3.63% (2)	50.91% (28)
Sex with sex workers (n=53)	30.19% (16)	11.32% (6)	58.49% (31)
Engaged in sex work/compensated sex (n=54)	7.40% (4)	11.11% (6)	81.49% (44)
Migrant (n=54)	44.44% (24) <sup>b</sup>	1.85% (1)	53.71% (29)
Deprived of liberty (n=48)	16.67% (8) <sup>c</sup>	2.08% (1)	81.25% (39)
<sup>a</sup> Denominator for the proportion (%) of women who reported the risk-behaviour is the actual number of women who answered the question <sup>b</sup> Fourteen of the respondents reported that their male partners had migrated internally, ten had migrated internationally (predominantly to the United States of America) <sup>c</sup> Four were detained for very short sentences, from days to weeks, due to minor infractions like being drunk and disorderly. Four were incarcerated for longer terms, including one who was incarcerated in the United States.			

If we include both the women who affirmed categorically that the male partner engaged in the risk behaviour, and those who said that they didn't know and therefore could suspect that the male partner did engage in the risk behaviour, the number of women reporting risk behaviours for the male partner is relatively large: sex with other men 36.36%; injection drug use 25.45%; other drug use 49.09%; sex with sex workers 41.51%; engaged in sex work or compensated sex 18.51%; migration 46.29%; deprived of liberty 18.75%. These proportions of women are notably higher than the proportion of women reporting that their male partner could have engaged in risk behaviours from the large national sample of pregnant women presented in the previous chapter. This difference is especially marked for socially stigmatized behaviours such as having sex with other men and engaging in sex work or compensated sex. In this respect, it is important to note that in contrast with the quantitative sample of women who completed the questionnaire before being tested for HIV, the 55 women who answered these questions have a confirmed HIV diagnosis, and most knew that they had been living with HIV for at least several years before the interview. In the period between the diagnosis and the interview, women had often gone through a process of piecing together information about how they became infected—through discussions with the male partner, friends and family and remembering and reinterpreting past events—as part of the assimilation of the HIV-diagnosis. The process of women's increasing awareness and acceptance of the *import* of men's behaviour for HIV infection over time is clear in the interviews. Yet, even if we consider that women may not have known about their male partners risk behaviours or considered the impact of men's risk behaviours for their own health until after the HIV-diagnosis, there is still a striking disconnect between women's reports of men's risk behaviours and their failure to consider themselves vulnerable to HIV-infection before the diagnosis. This is the tragedy of how the social imaginary of the “concentrated epidemic,” which I have identified as a barrier

for the implementation of appropriate public policy for women in the field of HIV, is acted out at the individual level. The social imaginary which associates “not men” (homosexuals) and “bad women” (sex workers) with HIV obscures the heterosexual HIV epidemic occurring within stable relationships in Mexico.

#### *5.4.1 Infected by Her Husband/Stable Relationship*

More than 80% of the women with HIV who participated in the research were infected with HIV in the context of a stable long-term relationship. In general, the man whom they believe transmitted HIV to them was their first or second sexual partner, and they had had children together. One of the most important findings of this analysis is that about two-thirds of the women were aware that their stable male partner had multiple sexual partners including, in some cases, sex with other men or sex workers, that they used drugs or alcohol to excess, and/or that the male partner was physically, sexually or psychologically violent towards her, *prior to the diagnosis*. These behaviours typically overlapped, with the male partners who transmitted the virus exhibiting more than one of these behaviours. Consequently, even if a woman didn't know that her husband had sex with other men, she did suspect he had multiple sexual partners or knew he was physically and sexually violent. Despite knowing that HIV was transmitted through unprotected sex and blood, women did not perceive themselves as at risk of HIV-infection at the same time as they generally had some awareness of their male partner's risk-behaviour for HIV acquisition.

In what follows I document what women said about their male partners having multiple sexual partners, migrating, using drugs, and exercising gender violence to explore the idea that dominant cultural constructions of masculinity normalize these behaviours, contributing to women's acceptance of them as part of everyday life. Men's greater mobility—whether through migration, for their work, or because of the existence of homosocial spaces like bars and

cantinas—provides men with opportunities to have multiple sexual partners and use drugs and alcohol (Hirsch et al. 2007; Phinney 2008). Gender discrimination, gender violence, and the expectation that a woman will maintain a stable relationship at all costs—which are integral parts of the dominant gender paradigm—further constrain women’s ability to negotiate HIV risk reduction through behaviour change, condom use or leaving the relationship.

#### 5.4.2 *Multiple sexual partners*

Knowing or suspecting that their male partners had other sexual partners was common. For some women, that their male partners had multiple sexual partners seemed completely naturalized and taken-for-granted. For example, Silvia, a young woman from an Indigenous group in Oaxaca, was fifteen when she got pregnant. Her deceased husband had been her first and only sexual partner, but he had “had lots of women”. For Maura, the perception of being married to a “quiet” man from a “good family” only came unravelled after they had been married for several years. Other men had a more obvious risk profile of using drugs and being violent towards their partners as well as having multiple partners. The pattern of men having extra-relational sex during women’s pregnancy was also identified among these women. Women said that they knew their partners were having extra-relational sex when they stopped having intercourse with the same frequency as previously. Yolotzin was diagnosed during prenatal care with her third daughter. Her single lifetime sexual partner was her HIV-positive husband, who had migrated to the United States, had multiple sexual partners, and has been and continues to be violent towards her. She told me that she doesn’t leave him because she is economically dependent and has young children. Yolotzin’s experience is an excellent example of women’s socialization to *aguantar* (endure) in order to maintain their relationship and also provides insight into the gendered dynamics of sexual practice. She said that she knew her husband was having sex with someone else because

during all of my pregnancy, he didn't use me, I mean, we didn't have relations. If we had relations once, that was a lot. No, I'm lying. We had relations three times, and not more. And that's how I knew that he was screwing around. I never said anything. I didn't want to get angry, I was pregnant. Because he made me get angry. He was always fighting, looking for a fight. But I never said anything, I never tried to find out what was going on or catch him. I didn't know. I am not one of those people who are jealous. I was always innocent with a clean heart. ...I don't believe in fighting, I don't believe in fighting, but I was suspicious.

After giving birth, she spent the traditional forty days rest and seclusion at her mother's house.

When she returned home, her husband didn't initiate intercourse with her, until Yolotzin said that she

even began to feel rejected: 'now he isn't going to want to have sex with me'? Or he is going to go and have sex with someone else? And then he says to me, 'come.' Now he wanted to have sex with me, and that's when I saw, on his part [penis] he had bumps, like little, fresh, red bumps. And I said, 'ay why do you have those little bumps, noooo. Don't be a bastard—excuse me—don't be a bastard, you want to have sex with me like that and you have that—you'll infect me. But he, I mean, the machismo, pure machismo saying 'oh, it's nothing, it just got irritated because of urine, and it's nothing.' Always his ignorance and his arrogance, his machismo”.

On this occasion, Yolotzin successfully refused to have sexual intercourse, and went to her mother-in-law for help and advice. Her mother-in-law responded by giving Yolotzin antibiotics to treat her son's sexually transmitted infection. When Yolotzin gave her husband the medications, he made a big show of refusing to take them, but she later found the empty box. She assumed that he had taken them. His symptoms cleared up and they resumed having unprotected intercourse.

Yolotzin's story effectively illustrates some of the constraints women face to reducing their HIV risk within the context of a stable relationship. On the one hand, faced with a visible indication of her husband's sexual infidelity and her imminent exposure to an active sexually transmitted infection, she was able to refuse sexual intercourse. She also intervened in his treatment, with the support of her mother-in-law. But the “proof” of her husband's sexual

infidelity and Yolotzin's refusal to have sex on one occasion, didn't result in her confronting her husband or him admitting his extra-relational sexual activity or taking potentially protective behaviour like HIV-testing or condom use. Reflecting on the absence of condoms from her sexual relationship with her husband, Yolotzin emphasized her "innocence" and conformity with her assigned gender role: her devotion to her children, sexual modesty, sexual fidelity to her husband, even when he migrated to the United States for years at a time, and avoidance of conflict and confrontation within her marital relationship. In her words,

I never thought of using a condom, that is what being an *innocent* is. I lived in innocence, but innocence isn't reality. I was devoted to my children—completely innocent. I was innocent, and so I thought he was too. I never thought of using a condom. When he went to the United States, I did tell him, on the phone: 'Take care of yourself' because that is where this disease is, where it is *more abundant*. But, here in Mexico, I have also seen a lot, a lot of this disease. Ay! Today, there is a lot [of HIV] in Mexico, it has spread a lot, a lot. ... Even though I am ignorant, I have always been cautious. [I heard about HIV] on TV, be careful. I have always been really focused on being cautious about things. I have always been really prudent. During the time he was gone, if a man even came close to me: Ay I was afraid! [laughs]. I was afraid! I don't know what it was, really! I don't know what my idea was, but they made me feel really afraid. And look who came to infect me—my husband, my own husband. I took care of myself here, if they even came close to me [laughs], if they came to talk to me, and they wanted to flirt, oh, no, not me. Never. I didn't even look at them. I was always with my daughter—being respectable and taking *care of myself*. And that's how life is, the person that we least expect is the one who comes and infects us.

Unilateral monogamy is not a successful HIV prevention strategy for women. Yet, given the exclusion of the condom from stable relationships and the dominant gendered sexual norms prevalent in Mexico, women have few other options. The double discourse which simultaneously expects men to have multiple sexual partners and sanctifies the monogamous marriage as a condom free zone is a significant barrier to HIV prevention. In order for women to reconcile the behaviour expected of men with the ideals of the stable relationship in which they have been

socialized, they need to deny their HIV risk (Hirsch 2002; Sobo 1995). The difficult situation faced by women is portrayed in this joke about a new bride's three prayers on her wedding night: "Dear God, please make my husband faithful to me. Dear God, please keep me from finding out when he is unfaithful to me. Dear God, please keep me from caring when I find out he is unfaithful to me" (Hirsch et al. 2002: 1227). Women "not seeing" or taking seriously men's extra-relational sex and other forms of HIV risk behaviour is essential in order to maintain marriages in a society where men are expected to have multiple partners. Azucena, whose partner transmitted HIV to her knowing his HIV-positive status, put it this way:

Lots of people told me that he was [a womanizer]. He was a taxi driver, and people said: 'That guy who is your boyfriend, I saw him with this one, and I saw him with ...' Ah, I said, 'I don't believe it.' And they said: 'Oh yes, he has had lots of girlfriends.' But since he's a man, I just said 'really?' or, 'oh yeah.' But I never thought about it [HIV and using condoms]. It never even crossed my mind. And well, what had to happen, happened.

Azucena dismissed warnings about her boyfriend's extra-relational sexual behaviour because "he's a man". In other words, she expected him to have other sexual partners as part of his masculine identity. Consequently, community gossip about his behaviour didn't increase her risk perception for HIV-acquisition or prompt her to take preventive measures like condom use. And, even when the women who participated in the research raised extra-relational sex, sexually transmitted infections, or condom use—as Yolotzin did implicitly and non-confrontationally with her husband—men's bald-faced denials and the power imbalance in the sexual relationship frequently stymied preventive action. Luisa expressed women's impotence in the face of men's extra-relational sex when she said

I knew that he went with other girls, and after he died [of AIDS] they told me that he had screwed a ton of girls where he worked [in a municipality]. And even when I asked him in the hospital, he still told me no, that I was crazy, 'you're crazy, how can

you even think that I would do that to you.’ But many times I thought it. I felt that he was cheating on me. He was one of those people who likes to go with one and then another.

In Luisa’s case, the fact that her partner exercised sexual violence against her further reduced her ability to protect herself from HIV and other sexually transmitted infections. She explained that her former partner “hit me if I wouldn’t have sex. He hit me and said that I had slept with someone—that type of abuse. If I didn’t let him grab me, he took me by force”.

#### *5.4.3 Mobility and Multiple Sexual Partners*

Almost half of the women reported that their male partner had migrated, and several more had male partners who travelled for their work. The nexus of mobility, drug use, and multiple sexual partners was common. Narcisa’s partner had been an international migrant who used drugs and had multiple sexual partners, including engaging in acts that can increase probabilities of HIV transmission, like multiple men having sex with the same woman one after another. Narcisa knew that “most of the time that he was in California, he used drugs ... he told me that when he lived there, in the United States with his cousins, they would bring women and all of them fucked them”. Maria Jose had only had one lifetime sexual partner who was a long-distance truck-driver. She seemed resigned to him having multiple sexual partners, saying “on the highway there are a lot of women. Before he was with me, he had other partners, and along the highway he met more”. She had been in treatment for the human papillomavirus (HPV) for three years before being diagnosed with HIV. She knew HPV was “from sexual transmission, and I said that to him, and he said, ‘oh, no, it was in a bathroom,’ and I told him that it was only [transmitted] the other way. He also had warts on his genitals, but I didn’t know what that was about”. Even though she was in treatment for HPV, Maria Jose was not counselled by health-care personnel to use condoms consistently until after she was diagnosed HIV-positive. Men’s denial of the source and

signification of sexually transmitted infections and the failure of the health-care system to intervene by increasing women's knowledge of sexually transmitted infections, raising the issue of men's sexual infidelity, and promoting condom use, all contribute to maintaining women's HIV risk-denial.

#### *5.4.4 High risk partners: sex with sex workers and other men*

When men disclosed that they had had “high-risk” partners they identified those “high-risk” partners as female sex workers. In only a very few cases did men disclose that they had had sex with other men. For example, Karen and her husband had discussed their relative sexual histories early in their relationship. Initially, he disclosed having had sex with sex workers, but minimized the potential risks by claiming he had always used condoms. After the HIV diagnosis, he admitted that he had had unprotected sex with sex workers. However, he didn't disclose to his wife that one of the sex workers was a transvestite; this event was only shared with my male research assistant in the context of an in-depth interview. The stigma associated with having sex with other men resulted in men hiding these relationship before and after the HIV diagnosis, and frequently even after the relationship with the woman had ended. Several women suspected that their husband's might have had sex with other men because they had many gay friends, but their partners denied it. It was rare that women could confirm that their partner had had sex with other men, and when they did learn about bisexual activity it was through gossip or an unforeseen discovery. Rosa found out that her husband was engaging in extra-relational sex when they exchanged cellular telephones and she found messages sent by her husband to an unknown number arranging sexual dates in return for payment. After she and her husband were diagnosed and they separated, she received a message from the number saying “hey buddy, are you going to keep fucking, cuz if not I won't keep bugging you”. Yet it was not necessary for Rosa to know about

her husband selling sex to other men for her to perceive that she might be vulnerable to HIV through having unprotected sex with him. Rosa's ex-partner engaged in other behaviours associated with increased HIV-risk such as being sexually, physically and psychologically violent, and using marijuana and alcohol to excess.

#### *5.4.5 Drug use*

A fifth of the women said that their partners had used injection drugs, and almost half (45.64%) said that the male partner who they believed transmitted HIV to them had used other kinds of drugs, ranging from smoking marijuana and inhaling paint thinner to smoking crack and methamphetamine. In the quantitative analysis presented in the previous chapter, the questionnaire completed by pregnant women during the context of HIV antibody testing in prenatal care only asked about injection drug use. Yet the difference in reported rates of male partners' drug use between the two samples of women is dramatic—97.04% of 777 pregnant women reactive to the HIV antibody test said that their partner had not used injection drugs, as compared to only 74.55% in the qualitative sample. In representative national samples the reported rate of illegal drug use in Mexico is about 5%; if marijuana is excluded, the rate is well below 1% (CONADIC 2008: 41). The frequency of drug use reported by this sample of Mexican women with HIV for their male partners is truly striking, and perhaps indicative of the evolution of the HIV epidemic in Mexico.

Nellie thinks her first sexual partner and father of her child transmitted HIV to her. She met him at the age of eighteen, they started dating, began having sex, and when she got pregnant they started to live together, “but he wanted to keep on hanging out with his friends, using drugs—because the truth is he used drugs—so I left him”. Anel got infected with her second husband. She separated from her first husband because he was having an affair. Her second partner was a return migrant. He had left Mexico at the age of fourteen and came back at twenty-eight. He had been

involved in the drug trade in the United States, where he had been incarcerated, and had had sex with sex workers as well as engaged in compensated sex and sex with other men. Anel experienced vaginal infections after they started having sex, which were treated with suppositories without a physician or pharmacist recommending condom use or HIV testing. Anel knew that HIV was transmitted by having unprotected sexual intercourse or through sharing needles. But she wasn't concerned about having sex without a condom because

it was only with the father's of my children that I didn't [use a condom]. I wasn't having sex with this one and that one. And, well, if I had sex with someone that I liked or whatever, we used a condom. But supposedly in order not to get pregnant. And in all of that time, I didn't get pregnant, and I used condoms. And with the one that I didn't use a condom, I got infected and I even had a baby.

Despite her male partner's past behaviour and the fact that she had recurrent vaginal infections, HIV wasn't imaginable to her. She said she was "expecting another disease, like cancer or diabetes. But I never imagined, I never expected this disease". Among women whose male partners had a history of drug use, the socialization of denial encoded in the popular saying "*ojos que no ven, corazon que no siente*" (eyes that don't see, heart that doesn't feel) is particularly relevant; denial is necessary if women are to maintain relationships with men who are expected to engage in putatively "unacceptable" behaviour. Amparo clearly articulated the link between love and refusing to recognize the HIV risk behaviour of her male partner. She said that she met her first husband

in high school. And I was his girlfriend. We lasted for a year and three months. He was a freshman and I was a senior. I left high school, and he stayed. But he didn't finish, he dropped out. And I didn't know that he was a drug addict. They told me, but since I loved him—and he never did it in front of me—I said: 'no, no, I don't believe you.' And we went out for a year and three months, and after a year and three months, I went [to live] with him. I went with him, and after three months living together, I got pregnant with my first child. But, I didn't realize that I was infected until, like, seven years [later].

In the intervening seven years, she came to realize that her partner was addicted to drugs. When her child was born, he disappeared for a month. Later she found out that he had gone to Acapulco and engaged in compensated sex with men and women to support himself and his drug habit. When he was dying of AIDS, he taunted her by saying “‘have you gone to the doctor yet?’” but he didn’t disclose his status and she didn’t seek HIV-testing. Nellie and Amparo might seem to exemplify women’s “blindness” about men’s behaviour and subsequent ability to maintain their illusions and their relationships. But of the fifty-five women I interviewed, Thelma epitomizes the refusal to perceive her partner as representing a risk for HIV and accept that she herself might be infected. Thelma knew that HIV was transmitted through unprotected sexual intercourse and blood. But she didn’t know about mother-to-child HIV transmission and believed that “you died and there was no cure”. Her husband was a long-distance trucker, had lived in Tijuana where he had used injection drugs, and he continued to use methamphetamine and crack during his relationship with her. He was also physically and psychologically violent towards her when using drugs. She had a difficult relationship with her in-laws and believed they told her that her husband was having extra-relational sex to hurt her, rather than because it was true. When her husband began to get sick with AIDS, he abandoned her. In her efforts to track him down, she spoke to a friend who said he was sick. And then someone from her husband’s neighbourhood called her father and told him that her husband had HIV. Yet despite her father’s encouragement and the fact that she was attending prenatal care with her third daughter, Thelma chose not to be tested. When asked why, she said she “just didn’t accept that I could be sick, because of my husband. ... Later, when I learned that my husband had died, then, yes. Because I had said: ‘No, my husband is fine, and he is going to come for me.’ And I always held on to the idea that he was fine, and he was going to come”. In this sample of women with HIV, the refusal to associate their male partners’

HIV risk behaviour with their own vulnerability to HIV, sometimes even after having received substantive information about the existence of that risk behaviour or being told about a partner being diagnosed with HIV, was notable.

#### *5.4.6 Gender violence*

The women with HIV who participated in this research frequently experienced sexual, physical and psychological violence from the male partner who transmitted HIV to them. Several international studies have linked experiencing sexual and physical violence from a male partner with higher rates of HIV infection among women (Dunkle et al. 2004; Silverman et al. 2008). Direct links between sexual violence and vulnerability to HIV infection include the greater biological risk of HIV-infection during violent or forced sex and decreased ability to negotiate condom use among women who experience gender violence (Campbell et al 2008; Manfrin-Ledet and Porche 2003). There is also a growing body of literature indicating that men who perpetrate Intimate Partner Violence (IPV) have more sexist views about men's and women's respective roles and report higher rates of HIV-acquisition risk behaviors than their peers who do not engage in IPV (Campbell et al. 2008; Gonzalez-Guarda et al. 2008; Raj et al. 2006; Silverman et al. 2007).

The experiences of Mexican women with HIV who participated in my research indicate that the links between traditional masculine identities, gender violence, and increased HIV vulnerability are relevant in this context. Jimena's first partner was physically, psychologically and sexually violent. She had heard community gossip that he used drugs and "that he was excessively sexual ... with the dancers from the cabaret. But I didn't know about that until after, I found out about the gossip. And I said 'Oh my lord, what have I gotten myself into!' [laughs] ... I thought that alcohol was his only problem, and it wasn't true". Jimena sketched a picture of her ex-partner which conforms to that of the typical "macho". He was "excessively sexual," so much so that he

had sex with sex workers, and used substances to excess. He also exercised physical, psychological, and sexual violence against Jimena. In fact, it was the escalation of the physical violence that finally drove Jimena to flee and return to her family.

Jimena knew how HIV is transmitted, but mixed facts about transmission with moral judgements about sexual promiscuity that constructed HIV as a problem for “others” rather than for herself. She said that she “knew that you get infected if you didn’t use a condom, if you were with one partner after another, used other people’s needles, it’s also transmitted that way. Also if you have contact with another person that has the virus, and you have an open wound, it can also be transmitted like that”. She had used condoms occasionally with her former partner. But,

he didn’t use one when he forced me sexually. There were times when we had [sexual] relations because he forced me. Not because I wanted to. At those times, well, he did whatever he wanted. But—I’ll say it again—I didn’t do anything, I didn’t put up my hands, I didn’t say, ‘no, I don’t want to.’ Even when it hurt me, even when I didn’t like it, I allowed it. And that’s something that I don’t, even now I haven’t been able to understand why I did that. ... Even now, I think that he was the last man for me. I guess you could say that I didn’t want to be an old maid. That’s what I deduce, that’s what I have figured out. I was afraid of staying single. I saw everyone living together, getting married, having a good partner. So maybe that’s why I decided to put up with and endure everything that he did to me”.

Jimena clearly articulates her “endurance” of mistreatment by her ex-partner as the price she pays for a stable relationship. It seems a tragic irony to me that she explained her decision to stay with an abusive man as a way to avoid becoming “an old maid,” given that she was only twenty-two when I interviewed her, and had gotten pregnant with her first child at nineteen years of age.

Jimena takes responsibility for not resisting unwanted sex with her former partner, just as she blames herself for choosing him in the first place, having sex with him, and ultimately for becoming infected with HIV. This idea is reinforced by her family; for example, by her mother commenting on Jimena having a painful and invasive vaginal swab as part of her gynaecological

care at the specialized HIV clinic, saying “Oh, daughter! Well, thank your *principe azul* (prince charming)”. Even though in Jimena’s account her mother’s tone is affectionate, the statement is a reminder that Jimena “chose” the man who transmitted HIV to her. Jimena said she is at fault

for getting overexcited, for not having waited, for not letting things take their course. Why? Because the boyfriends that I had before, I had *la costumbre y la maña* (the habit and was really good at): Where do you live? Who is your Dad? Who is your Mom? What work do you do? What do you study? Are you going to study? Are you going to work? What are you going to do? What do you want to be when you grow up? I mean, I questioned them too much. And in the end, I failed myself. Because in the end, I didn’t know, I mean, I didn’t ask him anything. I gave myself just like that. And that was, that was my mistake.

Here I want to explore how the cultural construction in which women are responsible for choosing a good man and condemned to live with the consequences of making a poor choice impacts on HIV vulnerability. Jimena’s ex-partner expressed the idea that once a woman “gives” herself to a man—initially by having sexual intercourse, but more definitively by going to live with him—she must live with the consequences. He told her “you came with me, so now you have to *aguantar* (endure)”. Catalina’s husband gave a similar reason for confining her to the house while he went off to party, dramatically illustrating the differential levels of physical autonomy permitted to women and men. As well as being physically violent, Catalina’s husband caused her

a lot of psychological damage, because he said that I was really dumb. He insulted me and said ugly things to me. ...On the weekend, he went out, he went with his friends and he left me there. I asked him to give me permission [to go] or to take me to see my parents, but no. He said that no, that I had come [to live] with him, and that if I wanted to see my parents, then I should have stayed at home. I mean, he was really *machista* (sexist). So, I said, ‘but why do you want me here if *you are going out* anyways and you won’t be here with me—let me go home, I want to go home, I am not going to...’ But he said no, and he got up, and he left. And then, from what people told me, he had sex with other women, he was in the “*vida alegre* (happy life)” —as they say around here.

In Catalina’s account, the control that men exercise over their wives bodies and movements is clear. She must ask her husband for permission to leave the house; his refusal is embedded in the

cultural logic that she has moved from her being under the guardianship of her family to his tutelage—as he says, if she “wanted to see her parents, then [she] should have stayed at home”. There is no corresponding obligation for him to ask Catalina for permission to go where he wishes or for how he uses his body. As a man, he is free to go where he will and to behave as he wishes, including having sex with other women and using drugs and alcohol. Both Jimena and Catalina’s abusive husbands told them that they had chosen to come live with them, and now had to live with the consequences (*aguantar*). Once Mexican women have made the decision to be with a man, the expectation is that they will make the relationship work, by fulfilling their sexual and domestic “duties” and managing their husband’s behaviour without provoking confrontation (Carrillo 2002: 291-292; Hirsch 2003: 115-119, 125). If women make a bad choice or are not skilful at meeting their male partner’s expectations, consequences can include gender violence, which is culturally justified by her failure to properly fulfill her role (Agoff et al. 2006; Agoff et al. 2007).

Social justification of gender violence is compounded by a traditional cultural current in which women’s bodies belong to men in the context of a stable relationship (Hirsch 2003: 115-116). This cultural logic is expressed in the popular expression “he used me” to denote sexual intercourse (Castro 2001:155). Lourdes’ deceased husband responded to her objections to him violently raping her, saying ““That’s why you got married, and that’s why you’re my woman, you are going to want it [sex], forced or not. Kids, not anymore, but that you are going to give me what I want: yes. And if not, I am going to look for it elsewhere.”” Men’s physical and sexual domination of their female partners is a barrier to condom use. Jimena’s partner didn’t use condoms when he forced her to have sex. Lourdes ex-husband never used a condom. And when Catalina raised the issue of condoms because she feared she might be at risk of HIV and other sexually transmitted infections because of the rumours she had heard about her husband’s drug use

and sex with other women including sex workers, he said “no, that he didn’t like, that he didn’t like to use condoms. Because, as they say around here: he was a *macho*. He said no”. Catalina told me she couldn’t insist on condom use with her physically and psychologically violent husband “because that was the way he was. Yes, the truth is I went through so many things that I say: psss. I don’t know where I found the strength, only God knows, and he was the one who helped me to overcome everything that I went through”. When reflecting on what she had learned through the process of her diagnosis and what she would want to share with other women, Catalina said that she wanted to give her daughter a different kind of sexual education than she received from her mother, permitting a more open and factual exchange about sexuality. Catalina’s mother taught her to demand “respect” from men and to be careful of her sexual reputation but didn’t provide any practical information about disease or pregnancy prevention. Catalina explains that her mother had said

that when you had a boyfriend, if they really cared about you, then they should respect you, and shouldn’t go asking us to have sex or whatever. ... She said, lots of men are *muy canijos* (really insatiable) and the only thing they want is to get you into bed, and after that they’ll leave you—like they say—they’ll dump you and that’s it. And that they go around telling afterwards, and ignoring you.

Catalina’s mother’s version of sexual education is inscribed in the traditional dichotomy between good and bad women in which choosing the wrong man represents both sexual and social ruin. My interviewees demonstrate clearly that both “good” and “bad” women get HIV. Moreover, the gender ideology which elevates achieving and maintaining a stable relationship as the objective of women’s lives actually encourages women to naturalize and accept the HIV risk behaviour of male partners and to “endure” relationships which have negative impacts on their health, including HIV infection.

## 5.5 Discussion

The contrast between these women's knowledge of their male partners' risk behaviour for HIV acquisition and their very low risk perception for HIV infection prior to the diagnosis presents an apparent paradox, resolved through a deeper understanding of HIV-related stigma and gendered sexual norms. The paradox arises from 1) HIV-related stigma and discrimination which associates HIV with marginalized sexualities, namely homosexuals and "easy" women; 2) the centrality of risk-taking to dominant cultural constructions of masculinity, thereby normalizing men's risk behaviours and reducing women's HIV risk perception; and 3) the fetishisation of the "stable relationship" as offering protection from HIV infection. The substrate on which these cultural constructions rest, and which needs to be transformed in order to overcome women's "AIDS-risk denial" (Sobo 1995) and promote condom use, is continued gender inequality, including men's sexual ownership of women's bodies and gender violence.

My interviews with Mexican women with HIV clearly demonstrate that prior to the diagnosis this group of women continued to think about HIV as a disease which affected homosexuals and "bad women" (sex workers or women with multiple sexual partners). These categorizations were intimately linked with the fact that they repeatedly said that becoming infected with HIV "never crossed my mind". Women who could be categorized from the outside as "bad women" because of their sexual behaviour, didn't consider themselves as such, have greater risk perception for HIV-acquisition, or use condoms more or less than women who would be culturally categorized as "good women". Both groups of women became infected with HIV. The dichotomization of women into two categories based on their sexual reputation and association of HIV with "bad women," only misleads women about their risk and increases their vulnerability. Unequal gender relations (which encompass homophobia and the devaluation of

effeminate MSM), and the sexual double standard which prescribes women's ignorance or appearance of ignorance of all things sexual present significant barriers for HIV prevention, especially for condom use by Mexican women in stable relationships. The continued identification of HIV as a "gay disease" by the women with HIV who participated in my research, is also extremely worrisome (see also Kendall et al. 2007; Liguori et al. 1996; Prieur 1998: 90-91; Szasz 1998).

The interviews also demonstrate that Mexican cultural and social constructions of sexuality continue to promote a sexual double standard which expects and accepts men's extra-relational sexual activity and other risk-behaviours for HIV acquisition. There is an urgent need to denaturalize men's HIV risk behaviour, especially the tendency to have multiple sexual partners and to use alcohol and drugs to excess. Highlighting the relationship between men's HIV-risk behaviour and women's vulnerability to becoming infected with HIV in stable relationships is needed. Prior studies with Mexican women have identified a disjuncture between women's suspicion that their male partner may be sexually unfaithful and the perception, or perhaps more accurately, the wish that trust in a marriage or a stable relationship obviates the need for condom use (Kendall and Pelcastre-Villafuerte 2010; Hirsch et al. 2002; McQuiston and Gordon, 2000).

Carrillo (2002:268) states that

Within the circular logic of the [Mexican] cultural script (trust leads to love, love to sex, sex to more trust and love), it was difficult to insert the recommendations of existing HIV prevention messages because they all seemed to invert the cycle (safe sex and condoms indicate casualness about sex and a lack of love, and they can also create mistrust, which in turn reduces the ability to justify sex). Getting rid of condoms meant that trust was developing, that the sexual partners were falling in love, and that the relationship was becoming strong and intimate. Wanting protection against HIV meant the opposite: that love and trust were not developing and, by extension, that the relationship was threatened and the desire for sexual interaction was not fully justified.

In addition to the cultural logic which associates condoms with lack of trust, the accounts of these Mexican women with HIV indicate that they imbued marriage or the stable relationship with the ability to protect them from HIV infection, despite all evidence to the contrary (see also Martina 1992). This fetishisation of the “stable relationship” in conjunction with cultural construction of HIV-risk behaviours as normal male behaviour contributed to HIV risk-denial among my informants. Even as women recognized that male sexual infidelity and other risk behaviours were common in the community and knew or suspected that their male partners engage in HIV risk behaviour, they denied that they were at-risk, in part by having unprotected sex—the very act that resulted in their HIV infection (see also Hirsch, Higgins, Bentley et al. 2002; Sobo 1995).

Condom use remains uncommon among married Mexican women. In 2006, only 6.4% of married women aged 15-49 used condoms as a contraceptive (United Nations Statistics Division, 2011). The use of condoms at any age or in any conjugal union, put women at risk of being labelled an “easy woman” or a “prostitute,” with the implicit threat of remaining single or being abandoned (Szasz 1998: 85; Sánchez Bringas 2003: 216). Szasz (1998:85-86) states that

Virginity, and in general access to a woman’s body, acquires an exchange value that women give to receive something different: economic compensation or a promise of marriage, support, or affection. The use of contraceptives, and particularly condom use, breaks with these codes because it signifies a woman who desires the sexual relation for itself, instead of it being an offering of her body to satisfy the desire of others and who must consequently compensate this offering.

Szasz’s description of the exchange of women’s bodies for social status, economic support and/or love is part of a larger cultural context in which men—first the men of the family and then her husband—exercise dominion over women’s bodies, determining where they may go, who they may see, and with whom they may engage sexually. This paradigm of male ownership of women’s bodies was expressed most clearly in my research through male partners refusing to use condoms,

lying about the nature and origin of sexually transmitted infections (including HIV) while knowingly exposing their female partners, and exercising psychological, physical and sexual violence against the research participants. These are all actions which indicate a failure to recognize the woman as a human-being of equal value with the right to make informed decisions, exercise autonomy about the uses and movement of her body, and promote her own health. In women's accounts, male partners who exercised different forms of gender violence and domination invoked the fact that the women had lost their right to self-determination by coming to live with them, and now had to endure (*aguantar*). Further, there was significant overlap between the male partners' HIV risk-behaviours, such as having multiple partners and using alcohol and drugs excessively, and the exercise of gender-violence. As others have found in a variety of cultural contexts, my research suggests that dominant constructions of masculinity that legitimate violence are tied with other HIV risk behaviours, simultaneously increasing women's exposure to HIV infection and significantly constraining their ability to implement protective behaviours such as condom use (Campbell et al. 2008; Dunkle et al. 2004; Gonzalez-Guarda et al. 2008; Raj et al. 2006; Silverman et al. 2007; Silverman et al. 2008).

This analysis conclusively shows that women's knowledge of HIV transmission routes and indeed knowledge of their male partner's risk behaviour for HIV-acquisition is not sufficient to produce HIV prevention behaviour. Rather, the transformation of gender inequality, stigma and discrimination related to HIV, and prevailing sexual norms among women and men is needed. These social and cultural transformations are at once urgent and a long-term project. In the short-term, health-care systems can improve their performance in HIV education for women, promotion of HIV prevention, and offer of timely diagnosis. My research identified missed opportunities to heighten women's awareness of their HIV vulnerability when they came into contact with the

health-care system for their sexual and reproductive health—particularly diagnosis and treatment of other sexually transmitted infections. In relation to prevention of vertical HIV transmission, women’s lack of perception of themselves as vulnerable to HIV means that they are unlikely to seek out a specialized centre for voluntary HIV counselling and testing or to solicit an HIV test during pregnancy from their attending physician. In the following chapter, I analyze the context of women’s HIV diagnosis and map their trajectories through the health-care system, documenting good practices for the offer of HIV-testing and the consequences of late diagnosis for women and their families.

## **Chapter 6. Health seeking trajectories and system failures: Consequences for women, children, and families**

Around the world, prevention of vertical HIV transmission has been recognized as an important pillar to achieve the Millennium Development Goals, particularly the health-related goals of reducing child and maternal mortality (UNAIDS 2011: 9; WHO 2010b). In previous chapters, I have explored the regional and national social, political, policy, and health delivery contexts which present obstacles to achieving these goals. In this chapter, I document and critically analyze some of the consequences of Mexico's abysmal failure to rapidly scale up PMTCT by exploring the circumstances in which the 55 women who participated in this research received their HIV diagnosis. Specifically, I consider women who were diagnosed during prenatal care, women who were diagnosed as a consequence of the death or AIDS related illness of a child or a male-partner, and women who were diagnosed when they themselves progressed to AIDS. The objective of this chapter is to contrast the benefits of diagnosing HIV perinatally with the failure to do so in terms of lives lost, disease progression, and economic and emotional consequences. This qualitative analysis of women's trajectories through the health-care system allows us to appreciate some of the reasons why testing for HIV during prenatal care is an important opportunity to promote the health of women, children and other family members; identifies practices which can contribute to increasing prenatal testing coverage; and underlines the urgency of increasing awareness of symptoms of AIDS among children and women in order to hasten diagnosis of those who are infected.

## 6.1 HIV diagnosis during prenatal care

All of the women with HIV who participated in this research had had a pregnancy since 2001, when offer of HIV testing during prenatal care became a goal of the National AIDS Plan (Secretaria de Salud 2002c: 36). Furthermore *all* of the women in my sample attended prenatal care prior to being diagnosed with HIV. The number of visits during the pregnancy before learning of the HIV-diagnosis ranged from 1 to 11, with a mean of 7 and an average of 6.5 visits.<sup>21</sup> In other words, there were ample opportunities to offer HIV-testing to the women who participated in my research during prenatal care. This is typical in Mexico, where 88.3% of women attended four or more prenatal visits in 2006 (United Nations Statistics Division, 2011). Yet, only 22 of the 55 women interviewed were offered HIV testing as a part of their prenatal care. Diagnosis during prenatal care was more common in the period between 2007 and 2009 when the federal government distributed rapid HIV antibody tests for use by pregnant women attending primary care clinics run by the Ministry of Health.

Isela is one woman who benefited from the federal initiative to scale-up HIV testing during prenatal care, and her experience can be considered a “best case scenario” for the offer of testing and confirmation of test results. In March 2010, she told me that she learned her HIV diagnosis when she was “four months pregnant, because at the Neza health centre, they do an HIV test on all of the women. I didn’t want to do it, because I didn’t doubt my partner. I said: ‘No, why—and I didn’t need to either, because I had done it before. But they did the test there.’ In response to my questions about giving her informed consent she related that eventually she took the decision to take the HIV test

whatever the result. I was calm. I went and they told me to sign my consent and everything. And then they did the test. A nurse took care of me. And he told me that it was positive, that it had come out positive. When I heard that, I felt like the world

was ending and it was even worse because I was pregnant. I didn't know what to do. They told me not to worry, that they were going to send me to do a CD4<sup>22</sup> to find out if I really had it or not. And that I didn't need to worry that it [HIV] was going to hurt me, or hurt my baby, and all of that.

Isela hadn't perceived herself as being at risk for HIV infection. She and her male partner were unusual in the sample in that they had taken HIV tests previously, with negative results. She had been monogamous since being tested for HIV and believed that her husband had been as well. Her testimony highlights the importance of the HIV testing being a routine part of prenatal care, rather than an optional extra based on the woman's own risk perception. Isela's rapid HIV test was conducted with informed consent and the post-test counselling that she received emphasized the need for confirmatory testing and reassured her about the consequences of a positive diagnosis for her and her child. Isela chose to share the test results with her partner immediately and he came in for testing. They received couple counselling and testing, and he resulted positive. Isela was then referred to a specialized teaching and research institution for the rest of her pregnancy, and was able to participate in a program that provides both emotional and economic support to pregnant women with HIV. Her case is an example of optimal counselling, confirmation of test results, referral, and post-natal support for women with HIV and their families.

Of the twenty-two women who were offered HIV testing during prenatal care, two had negative test results which points to the potential benefits of offering women a second opportunity to test in the third trimester of pregnancy. In the United States, it is suggested that a woman be offered a second opportunity to test if she lives in an area with more than one AIDS case per thousand inhabitants or reports other risk factors for HIV-acquisition (Branson et al. 2006: 9). Neither of the women who tested negative during pregnancy reported traditional risk factors (concurrent partners, drug use or sex work) but both reported suspecting that the partner who

infected them had risk factors (contact with sex workers in one case and sex with men in another) and both had experienced physical or sexual violence in their lifetime. Further, both women came from States with an accumulated incidence over one case per thousand inhabitants—in fact only 11 of Mexico’s 32 States have lower accumulated AIDS incidence (CENSIDA 2011). That these two women who tested for HIV during pregnancy initially tested negative also underlines the importance of promoting condom use during pregnancy as part of post-test counselling for HIV, syphilis and other sexually transmitted infections. Preventing HIV transmission during pregnancy is particularly important because during seroconversion (the initial period of HIV infection) viral load is very high and this would increase the probability of transmission to the child.

Two other women who were offered HIV testing chose not to be tested. During her first pregnancy in 2007, Pamela attended prenatal care from the second month of gestation and went to a total of nine prenatal visits. Near the end of her first pregnancy, all of the pregnant women attending the clinic were informed as a group in the waiting room that HIV testing was available and that they were to request a test from the doctor. But, Pamela didn’t ask the physician for a test. Her reasons for not asking were multiple. She wasn’t given the piece of paper that had the “medical order” for the HIV test on it, an oversight she attributed to the fact that “we were many, many [pregnant women], and many didn’t do [the test] for the same reason”. But her more substantive reasons for not seeking out HIV testing included her erroneous beliefs about HIV, lack of knowledge about prevention of mother-to-child transmission of HIV, and her fear that she could be HIV-positive. At the time, her sum knowledge about HIV and AIDS was “only that it was transmitted through sexual relations, and before they thought that having AIDS meant dying quickly, and supposedly there were no medicines to treat it”. The information about HIV testing provided by the clinic as part of her prenatal care did not include any information about the

existence of mother-to-child transmission of HIV and the possibility of prevention if a woman was HIV-positive. So, from Pamela's point of view, there were no benefits to knowing her HIV status—she didn't know that HIV could be transmitted from mother to child, or that this transmission could be prevented, and she believed AIDS to be an untreatable, fatal disease that would lead to a rapid death. Finally, she was afraid of a positive result. She said she didn't ask for the test “because I was afraid that they would tell me that I had it [HIV]. My husband has tattoos, he has five, and I thought that if they did [the test] they were going to say: ‘yes, you have it’—that's why I didn't go”. Fortunately, Pamela's first child is HIV-negative. Unfortunately, Pamela's partner progressed to AIDS before he was diagnosed. At the time of the interview in August 2009, Pamela was pregnant with her second child and was receiving medical care to prevent vertical HIV transmission because her husband had become ill with AIDS and, as a consequence, she was diagnosed HIV-positive. If Pamela had tested positive during her first pregnancy and agreed to inform her partner, his disease progression could have been averted through access to antiretroviral treatment. Instead, he became so ill that he needed to be hospitalized and the family migrated to live with Pamela's in-laws. This case shows the benefits of opportune diagnosis not only to avoid vertical HIV transmission but also to promote the health and well-being of other family members.

Sandra was the other woman who was offered HIV-testing during her pregnancy in 2007 and declined to test. Sandra had been tested as part of her prenatal care during her first pregnancy in 2003 with a negative result. During her second pregnancy in 2007, she was offered an HIV test but the possibility of vertical HIV transmission was not explained. When I asked her why she decided not to test, she replied “because I thought that I didn't have anything, since the first [HIV test] was fine, I said ‘why bother, since I am probably okay’”. The health-care providers offered her HIV testing again after her son was born, but she refused. Sandra's son is HIV-positive, and by

the time Sandra was diagnosed approximately two years after his birth, both she and her son were experiencing extreme weight loss related to AIDS. In her words, by the time she was diagnosed, she “ate, at most, just one tortilla and then I didn’t want anymore. No, no, it didn’t taste like anything, food didn’t taste good to me ... I weighed 30 kilos (66 lbs), like 30 kilos, and now I weigh 56, 57 and a half (127 lbs)”.

Pamela and Sandra’s experiences suggest some important points to take into account for the offer of HIV-testing during prenatal care. First, pregnant women need to be informed of the existence of mother-to-child transmission of HIV and that if the test is positive there is a high probability (98-99%) that transmission can be prevented. In general, prior to their diagnosis, the women interviewed were not aware of the existence of mother-to-child transmission of HIV. Women’s knowledge of HIV transmission tended to be limited to sexual and blood borne transmission. Elodia’s response to questions about knowledge of HIV transmission before the HIV diagnosis is typical of the responses of the women with HIV that I interviewed.

**Researcher** : But you knew before how the virus was transmitted?

**Elodia**: Well, I had never gone to a talk about it, but I thought that through injections and all of that. But I really didn’t know about this disease.

**Researcher**: But you knew that it was transmitted through sexual intercourse?

**Elodia**: Yes.

**Researcher**: And you had heard that through injections?

**Elodia**: Yes.

**Researcher**: And did you know that it could be transmitted from the mother to the baby during labour or breastfeeding?

**Elodia**: Oh no, I didn’t know about that.

Lourdes, whose son died of AIDS in 2009 told me in October of that year that she knew little about HIV and nothing about vertical transmission of HIV before her son was diagnosed in 2002. She said she

knew that people had this [HIV], but I didn't even know how [it was transmitted]. And when I got pregnant, I didn't know. Because if I had known, I would have done everything possible for my son not to get infected. Or I wouldn't have gotten pregnant. I don't know. But I didn't know—it was only after my son was born, and they did [the HIV test] when he was a year and two months old, [that I found out about HIV].

Existing evidence suggests knowledge of PMTCT is minimal among women in Mexico. A study from the specialized paediatric AIDS clinic in Mexico City found that only 5% of these mothers of HIV positive children knew about the possibility of vertical HIV transmission prior to the diagnosis (Uribe-Zuniga et al. 2008: 77). Another survey found that among women with HIV, who have been living with the diagnosis for some time and are considered community leaders, a small proportion (12.5%) didn't know about the existence of vertical HIV transmission and 50% overestimated the probability of mother-to-child transmission with adequate medical care (Loggia 2010). Both my own research and these other studies suggest that knowledge of the existence of mother-to-child transmission and the possibility for prevention is low both among the general female population and community leaders with HIV.

Second, Sandra's idea that she didn't need to take an HIV test during this pregnancy because she had taken one in the past suggests the need to explain that because they have obviously had unprotected sex, pregnant women may have been exposed to HIV and other sexually transmitted infections. Third, Pamela's resistance to HIV testing because she feared a positive result indicates that the stigmatizing myth that HIV is the same as AIDS, and that AIDS leads to a speedy death needs to be dispelled and the potential benefits of an opportune diagnosis for women's own health explained. Fourth, and finally, even though the decisions that they took not to undergo HIV testing during pregnancy seem to have been decisions made without the benefit of the key information about the benefits of HIV testing, Sandra and Pamela's refusal of

testing underlines that a minority of pregnant women will choose not to be tested. The option to “opt-out” of prenatal HIV-testing is needed to respect women’s right to refuse medical interventions (Gruskin et al. 2008). Sandra and Pamela were able to refuse HIV testing, and this decision did not result in the withdrawal of care or undue pressure which could have caused them to avoid health services.

## **6.2 The context and health consequences of late HIV diagnosis for women and their families**

In the case of the other 33 women who participated in this study, despite having had a pregnancy since 2001 when the National AIDS Plan mandated prenatal HIV testing for pregnant women and having attended prenatal care, they were not offered HIV-testing during pregnancy. The most common routes to the HIV diagnosis among these 33 women were: a child becoming ill or dying of AIDS; the male partner becoming ill or dying of AIDS; or the woman herself becoming ill with AIDS. It is worthwhile mentioning the other routes by which seven of the 33 women were diagnosed with HIV: when they or their male partners were tested for HIV as a condition of employment (Amparo was working as a “hostess” in a bar and Araceli’s ex-husband was tested when he entered the police force); three women were tested for HIV prior to surgery (two gave informed consent and one did not); Manuela completed HIV-testing as part of a routine health check while living in the United States; and, Azucena was infected by a partner who knew his status and was in treatment but didn’t inform her until she became pregnant. With the exception of Azucena, whose male partner took her to the ambulatory HIV clinic when she became pregnant, all of these women were diagnosed through “provider-initiated testing and counselling” (an HIV test is suggested by the health-care provider) as opposed to traditional “voluntary testing and counselling” (an individual seeks out HIV-testing of their own volition)

(WHO/UNAIDS 2007:14-16). Indeed for four of the seven women, testing was not even voluntary as it was a condition of employment or access to health services.

For the remaining twenty-six women, diagnosis with HIV resulted from their children, their male partner, or themselves progressing to AIDS. Health-care providers in all of the study sites confirmed that while testing during pregnancy had increased in recent years, most commonly women found out about their diagnosis because of an AIDS-defining illness. Dr. Conde from Morelos explained that most women were diagnosed “during pregnancy, or some because the husband died and she was diagnosed, or because the children had it; I mean, some of the women were diagnosed because of the problem when it shows up in the kids, and that’s what we haven’t been able to prevent”. Among the women with HIV who participated in my research, the consequences of not having had access to timely HIV testing included late diagnosis, disease progression, and child deaths.

### *6.2.1 AIDS-related Morbidity and Mortality among Children*

Of the women in my sample, four had experienced the death of a child who had tested positive for HIV, three had lost a child who had symptoms that could be due to AIDS without a diagnosis, and ten had living HIV-positive children. Their children’s AIDS-related illness or death was a common trajectory for women to find out about their HIV diagnosis. One of the scenarios was learning the HIV-diagnosis as a result of the death of a child. What is particularly tragic about these cases is that invariably the parents had sought medical care for their children. Itzel and her husband went deeply into debt seeking medical care for their son. When her son died because of AIDS-related complications at two years of age in 2008, Itzel had also progressed to AIDS. She said:

Imagine what I went through with my little guy and it never occurred to them to test him [for HIV]. Analysis after analysis, they pricked him wherever they wanted and they never did this one, until the very last days when he had a convulsion and then, according to them, they wanted to do a more advanced test. By then we had gone through everything. Paediatricians and paediatricians, private ones, and the best—we spent so much money. I tell my husband: I wouldn't care about all of the money in the world if he was here and healthy... We took him to one [doctor] after another. In private [clinics], in Santa Fe [an exclusive neighbourhood in Mexico City], to what was supposedly the best hospital in Atacomulco, with the best paediatrician who has two professions—she was one of those head doctors, that study your noggin—what are they called?—neurologists, she was a neurologist-paediatrician. And she never told us anything. We went to her appointments like she told us to, and we paid money, and we bought medicines, and nothing. And we got deeply into debt. And for what? Nothing. Doctors and doctors and nothing. Why didn't it occur to them to think just for a minute about [HIV]? And we didn't either because, well, we never could have imagined it.

The odyssey of seeking medical treatment for their son without having an HIV test recommended suggests that HIV and AIDS remains an “unimaginable” diagnosis for women and children in the social imaginary of many health-care professionals. By the time of her son's death, Itzel had also progressed to AIDS, and both mother and child had the same clinical symptoms: extreme weight loss (wasting), vomiting, and diarrhoea. Itzel explained that it “seemed strange to me that I had the same symptoms as him, you understand? I had totally lost weight, a lot of diarrhoea, and everything that we ate, I threw up, and that was how he was”. Compounding the failure to recognize the symptoms of AIDS was the fact that Itzel and her husband would not have learned that their son died of AIDS if her husband had not tracked down and requested the test results from the physician who had ordered the HIV test for their son just before he died.

Karen went through a similar process of seeking health-care for her son and not receiving an HIV diagnosis until shortly before he died. Karen's son died of AIDS at three years of age, and her daughter is HIV-positive. The history of Karen's pregnancies and the AIDS-defining illnesses in her family offered multiple opportunities for diagnosis, and the prevention of her son's death

and her daughter's HIV infection. During her first pregnancy in 2004, she and her husband were both public sector employees with health insurance. Yet despite attending eight prenatal visits and doing "eight ultrasounds with my son, every month I did one," Karen was not offered HIV testing. Her son was born vaginally and she breastfed exclusively for three months after which time she fed him with formula and breast milk. Her son was a sickly child and was already being hospitalized regularly for infections and respiratory problems when she became pregnant with her daughter. Indeed, Karen said she "hadn't planned on getting pregnant because my son was always getting sick and he was starting to get more fragile. ... When I was nine months [pregnant with her], he was hospitalized, and I had to be with him". During her second pregnancy, Karen still had health insurance because her husband continued to work in the public sector. She attended six prenatal visits. Yet, she wasn't offered HIV testing either as a consequence of her son's repeated illnesses, her husband's manifestation of AIDS-defining illnesses, or as part of prenatal care when pregnant with her daughter in 2006. Karen told me that she sometimes feels "impotent about my son because we knew that my husband got sick a lot from this. He was hospitalized several times and they never, ever diagnosed anything". In fact, before the HIV diagnosis it seems that her husband had oesophageal candidiasis, an AIDS defining illness, and one of the most common manifestations of immune suppression in people with HIV. Karen stated that "they always said that my husband had herpes in his throat because he always had lots of *algodoncillo* (cotton wool)—as we say here—it was always white. He was always sick to his throat, he had ulcers, and sometimes he couldn't even eat because of the sores". Yet, an HIV test was never recommended. Just as her husband's symptoms didn't provoke suspicion of HIV, her son was also misdiagnosed. She related that "they told me that he had adenoiditis, and that was why he was always getting sick in his throat. So we finally got together enough money, and my father also lent us [money], so that

he could have an operation”. After the operation, Karen’s son became acutely ill and remained hospitalized. At the same time, his younger sister became ill and was hospitalized. It was only the hospitalization of the younger sister that alerted the attending physicians. Karen said that “when they saw the two little siblings hospitalized, they asked why. It seemed strange to them, and they started to do tests”. Finally, the whole family was diagnosed HIV-positive, but her son died. In other cases, physicians, particularly at the specialized paediatric AIDS clinic at the General Hospital in Mexico City, recognized symptoms of AIDS in toddlers before they reached death’s door. For example, Nellie related that “at exactly 1 year and 2 months he started to have temperatures and temperatures. They did the [HIV] test, and he was positive, and then they told me that I was also positive”.

My study also identified cases of potentially preventable AIDS-related mortality among children and presumptive cases of AIDS-related deaths that were not identified or registered as such. In the case of Karen’s son, she claims that “the doctors didn’t offer any hope. They told me that it was a miracle that he was still alive, and he still survived another twenty days. Until we had done all the tests, and started taking medicine, he died. I feel like he sacrificed himself so that we could live”. The question arises whether Karen’s son would have survived if he had received a more rapid confirmation of his HIV diagnosis and access to antiretroviral treatment during his hospitalization. The experiences of other women from the sample suggest that this may have been the case. For example, like Karen, Catalina was receiving health services for public sector employees in Mexico State but, unlike Karen, Catalina had the good fortune to meet a knowledgeable social worker who sent her to Mexico City to obtain antiretroviral treatment for her child. Again, like Karen, Catalina was told to give up hope because her son was going to die. She said that:

the doctors from the ISSSTE told them that there was no hope for my son—that it was in God’s hands. So, the social worker called Mexico [City] and that is how I was sent, they took me there from the ISSSTE. Because I said to the social worker: ‘I don’t know Mexico [City], I don’t know how to find my way around, how am I going to do it?’ She said: ‘I know it is going to be difficult, but you are going to learn, for your son’s sake. Because you see, here they are telling you that they don’t have the treatment, and there they are going to give your child the treatment he needs.’ When I got there, the doctors said: ‘bring the boy, they told me that he’s dying, let’s see him.’ And they said: ‘no, my girl, don’t pay them any mind, this child is more alive than the two of us put together, don’t worry, with Gods’ help he is going to be fine. We are going to give him the medicine he needs right away.’ And I said: ‘yes.’ And that’s how he started to get treatment, they did the tests they needed to do, and they started to give him treatment.

Catalina’s son recovered and at the time of the interview he was ten years old. Several other women had children who had died of symptoms that could be AIDS-related but who died without a diagnosis. For example, Lilia miscarried and then, “in 2005, I had another baby who died at twenty-seven days old. He got pneumonia in one of his little lungs”. Antonina’s daughter died, but “even now, three years later, I don’t know what killed her. She was sick to her throat. We took her to the doctor, but never found out what was wrong with her”. Between 2000 and 2006, Mexico reported about 200 cases of perinatal HIV transmission per year. Conservatively, this is about a 50% underreporting (Uribe-Zuniga et al. 2008: 77, 85). We cannot be sure that the cases of child mortality described by these women with HIV are due to AIDS but, given the symptoms reported and underreporting of perinatally acquired AIDS cases nationally, it seems reasonable to assume that these child deaths were missed opportunities to avert infections by implementing PMTCT or save the child’s life through antiretroviral treatment. Moreover, they were missed opportunities to provide women with a timely diagnosis for her own health, and to allow them to take informed decisions about subsequent reproduction and prevent vertical transmission of HIV to future children.

### 6.2.2 *Diagnosis of the male partner*

Another route to the HIV diagnosis for women was when a male partner became ill with AIDS. In Carmen's case, health-care services missed the opportunity to diagnose her in 2003 when she was pregnant, but when her husband got sick in 2009, both of them were diagnosed. Fortunately, although she was not diagnosed during any of her pregnancies, Carmen's three children are HIV-negative. For various women in the qualitative sample, their male-partner's diagnosis with AIDS coincided with their pregnancy. Lorena was three months pregnant when her husband was diagnosed.

They did a test on my husband because he was really thin. He couldn't even walk anymore, he had fever, diarrhoea. They did various tests and the HIV test came back positive. I was pregnant with him [her son]. The doctor told me that he had to do the test on me first for the baby. Then they sent me to the clinic. And they gave me treatment first. But I found out because of my husband.

Lorena was at the ideal point in her pregnancy to begin antiretroviral medication, and it is clear that her health care providers expedited her access to treatment to have the best possible probabilities of preventing vertical transmission. In other cases, male partners developed AIDS and were diagnosed very late during their female partner's pregnancy. Maritza was thirty-six weeks pregnant when her former partner and the father of her child was hospitalized; he died of AIDS within weeks. His illness led to her diagnosis. Maritza explained that

on Monday night, my mother-in-law called and told me that she needed to speak with me urgently. She said: 'Since I can't see you, I have to tell you on the phone.' I said, 'You know what, call me later because I am in the street and I can't hear you properly.' Half an hour later she called and said that they had done some HIV/AIDS tests on him [Maritza's male partner], and they were positive, and that probably I also had it, and the baby too. That right now the baby was okay because the baby was inside me. But that if the baby was born normally, not caesarean, the baby would get infected. So she told me that I had to talk with my doctor so they would do the tests and then we would see how everything came out.

Martiza's story is notable for several reasons. Maritza was receiving specialized prenatal care to manage a different health condition at the regional hospital. Despite affirmations made by the staff from the HIV clinic inside the hospital in December of 2009 that testing had been offered routinely to pregnant women for "two, possibly as many as four years" (Martin Cortes, HIV physician), Maritza had not been offered an HIV test during her prenatal care in 2009. Second, the level of detail about prevention of vertical transmission provided by the mother-in-law suggests that a health-care provider discussed this issue with her specifically. Health-care providers knew Maritza and the staff would have seen an extremely pregnant woman tending to an AIDS patient. This may have motivated them to share more detailed information with the mother-in-law in order to bring Maritza in for testing.

### *6.2.3 Women's Progression to AIDS*

The other common route to diagnosis was when a woman herself progressed to AIDS. However, this process was also fraught with misdiagnosis and delay. Over and over again, women related that they had sought health care for a variety of AIDS-related ailments without their physicians ever suggesting an HIV test. Paola's story exemplifies the difficulty that women have receiving an HIV diagnosis despite being symptomatic. She told me that

for almost a year I was doing tests. I was going to urologists and other specialists because it seemed that I had a urinary tract infection. I had pain that wouldn't go away. I went to several different physicians but none sent me to do the [HIV] test. It was only when I felt really sick, I had a lot of diarrhoea and fever, I went to a doctor who knows my father, a family doctor. And with him, with trust, based on the symptoms, the medicines, and that I hadn't gotten better, he sent me to do an ELISA.

Paola had progressed to third stage AIDS before she received her diagnosis. Research has shown a close relationship between gynaecological disorders and HIV among women, prompting expert clinicians to recommend testing if women have one of the following conditions: candidiasis;

cancer causing (oncogenic) strains of human papillomavirus or an abnormal papanicolaou smear as both are more likely among women with HIV; herpes simplex virus shedding; positive test for *treponema palidum*; and cytomegalovirus (Squires 2007: 295)<sup>23</sup>. Noemi had different symptoms than Paola, but she also experienced a long period of health-seeking and progressed to AIDS before she was diagnosed. She explains that the doctors she consulted before her diagnosis

prescribed medicines and the symptoms calmed down, but they came back, and I was like that for a long time. After that, plain and simple, it was chronic. I coughed a lot. They told me that it was pneumonia. They controlled it, I was okay, and then I got sick again. After that, they did tests but they never did one of these [HIV] tests. Because they didn't think that it could be this [AIDS]. They said that no, well it was just pneumonia, it was pneumonia, and they prescribed medicine, and I got better, and then again. Finally, a doctor sent me to do an [HIV] test and it came back positive. I was horrified because I was only nineteen when I was diagnosed, when I did the first test. And I had never had [sexual] partners, except my one and only boyfriend.

Recurrent pneumonia is an AIDS-defining condition. Noemi presented with recurrent pneumonia for years without an HIV test being suggested and was at death's door before she was diagnosed. She was so ill that the doctors told her parents to "take her to the hospital, if you take her home she might not see the dawn because she is really sick". Noemi said that her parents

took me to the General [Hospital] in Mexico [City]. And when I got to Emergency and they put me in intensive care because I had third grade dehydration, they said I arrived weighing thirty kilos (66 lbs). By then I had pneumonia, dehydration, I was in the third stage of HIV [sic]. And as well, I had genital herpes, and also in the mouth. I was at the end. In fact, they told my family to come and say goodbye because they couldn't do anything for me.

Over and over again, the women in my sample told me about getting very ill—losing weight, having fevers and diarrhoea, a chronic chest infection or pneumonia, or on-going gynaecological complications, and consulting a variety of physicians without receiving the recommendation of an HIV test.

It is not only physicians who are unlikely to perceive that a woman could be living with HIV or AIDS. Women themselves have little knowledge of HIV and AIDS, and as we discussed in the previous chapter, mistakenly they don't perceive themselves to be vulnerable to HIV-infection. Additionally, women's own beliefs about health, illness and HIV/AIDS can be barriers to health-care seeking and recognizing AIDS symptoms. Anel's experiences show how health system failures and individual perceptions and decisions can interact to delay an HIV diagnosis. Despite having symptoms of AIDS and seeking treatment from a series of doctors working in the private and public sector, she was not diagnosed. Delay caused by health care providers was exacerbated by Anel's beliefs about health and illness. On the Day of the Dead, when Mexican's believe the worlds of the living and the dead are close together, and they honour their dead ancestors, a fire started in the room where she and her family were sleeping. Anel was extremely frightened by the fire, and after it occurred she became even sicker. She diagnosed her illness as *susto*, or fright sickness. *Susto* is a culture-bound syndrome generally believed to be brought on by a startling occurrence that may cause the departure of the soul from the body. Symptoms include loss of appetite and weight, listlessness, and lack of motivation to carry out the activities of daily life (Baer and Bustillo 1993: 91). These symptoms are also commonly associated with AIDS. When Anel recovered somewhat from the *susto* several months later, she went to a doctor who encouraged her to take an HIV test. Anel told me that she

got sick in November, the very Day of the Dead, I got sick. There was nothing left of me but skin and bones. And we didn't know why. We didn't know why or what I had. Because I was getting paralyzed, my hair was falling out, I was really skinny. I was really sick but my family didn't know [what it was] and neither did I. Supposedly, my son's father didn't know either. Nobody knew about this disease that we have. And after that, they took us to lots of doctors. They took me because I was really sick. I got sick after I had the baby. I had the baby in October, and in November he was a month old.

The electricity went out that night. And we put a candle on the dresser. But it was made of—what is it called—sawdust [pressboard], one of those things made out of wood but that light on fire easily. And the candle burnt it. I was lying down with my baby. My other two kids were playing, and he [male partner] was too, and they went to sleep. And they didn't remember to put out the candle. At midnight, I got up and it was burning and I got really scared. We lived in just one room, so the bed was right here. And the baby had a mosquito net and those also burn quickly. Oh no! I was so scared! Things were exploding, something hit me here [she touches her face] and I still have the scar. And I was really scared because I thought: 'The baby—my children are going to burn!' I got scared, and that's when I got sick. ... I had already gone from doctor to doctor, with private [doctors], with the soldiers [the Military Hospital], the General Hospital, and we didn't know [about the diagnosis]. And I wanted to get better, right? [I had] a super strong diarrhoea. Ay, really ugly! And then when I got better, I went to the clinic. In January, I went to the clinic, and I told the doctor from *Oportunidades* (Opportunities): I have this [*susto*]. And she said: 'well go and do this [test] because it seems strange to me. And I think you have another illness, but let's make sure. I don't want to say anything until I am sure.' And I went. They did a rapid test, and with all the confidence in the world, I asked the nurse what they were doing. I said: 'I don't think so, I don't know, but do the test, I don't know.' And they did, and the result was positive. I started crying like a crazy woman right there. And then they gave me a piece of paper, and they sent me here [to the specialized HIV clinic]. And they took more blood and they said they would give me a result by such and such a day. And I came back, and they confirmed that yes [the HIV test was positive].

Anel began seeking a diagnosis in October and wasn't confirmed HIV-positive until February.

Anel's perception that her symptoms were due to *susto*, as well as the severity of her illness, resulted in a failure to seek out further opinions from health-care providers, delaying her diagnosis by at least three months. Her unfortunate interaction with the health system and her own failure to comprehend important information about her illness didn't end with her initial diagnosis. Usually, when a woman is diagnosed positive, the HIV clinic asks her to invite her male partner and children to be tested as well. Anel shared the diagnosis with her male partner, who initially resisted and then agreed to an HIV test. His test result was positive. But it doesn't seem that follow-up was carried out with her five month old child. Anel knew that HIV could be transmitted through

sexual intercourse or sharing needles, but she did not grasp the implications of her HIV-positive diagnosis for her children. Her infant became ill, but in our discussion she asserted that

I didn't take the baby [to the hospital] because of HIV; I took him to the Children's Hospital because he had a lot of diarrhoea and he had a rash. They did a lot of tests; they said that the case was complicated, and I didn't have any idea, I didn't know. I never imagined that he could be contaminated too. But because I breastfed him.... They never told me that this [HIV] is what he had. Not even when he died and they gave me the papers, never.

**Researcher:** What did it say in the papers [death certificate]?

**Anel:** No, they said it was dehydration, something like that. But not a serious illness, they didn't write that.

I have presented Anel's case in detail because it shows variability in the knowledge of women and AIDS among different health-care providers in the same city and because it suggests how women's own perceptions of their illness may be an obstacle to accessing timely and adequate care for themselves and for their children.

### **6.3 Economic and emotional consequences of the failure to diagnose and late diagnosis**

The failure to diagnose HIV in a timely fashion resulted in child deaths as well as deaths of male partners, and disease progression among men, women, and children. Disease progression compromises immune response and potentially quantity as well as quality of life. The illness process and futile health-care seeking—consultations with specialists who ordered every test under the sun except an HIV test, and recommended surgical interventions and medications that treated symptoms associated with AIDS without ever considering HIV—represented a significant economic cost for families. In many cases, the families simply could not afford their odyssey through the medical system, and became indebted to other family members to pay their bills. Itzel explains that when seeking a diagnosis for her son, “sometimes my husband said, or I said: ‘Well, now there is no money.’ And then he'd say: ‘well, we'll get it from wherever we can, as long as

he's okay, and healthy'". As men and women progressed to AIDS, they also became unable to work, digging their families into an ever deeper economic hole. Death, illness or abandonment by the male partner also left women and children in difficult economic situations. For example, Anel's HIV-positive partner left them to migrate back to the United States, but previous criminal charges against him for involvement in drugs resulted in him being apprehended and imprisoned on the Northern border. At the time of the interview in March 2010, she was the only economic support for her family. She described being the sole breadwinner and the primacy of her job as a burden and a barrier to her HIV treatment: "I arrive too early for my appointments, and I apologize a million times, because I can't, at work they don't give me time off. And if I lose [my job] how do I eat? It is the only thing I have to support my kids".

The emotional costs of the failure to prevent vertical HIV transmission were also high, both for those women whose children died of AIDS and for those who had children living with HIV. Julia, a psychologist working in an ambulatory HIV clinic, called the HIV infection of children a "double grief" for their mothers.

I am speaking about part of the Mexican culture in which the value of maternity is channelled into moral questions, questions of values, of virtues, right? A good woman is a good mother, a good mother gives everything for her child, and a good mother who gives everything for her child would not forgive herself for an irresponsible act or let herself be, let herself be, let herself be—I don't know how I can express this—to not provide protection to avoid that the child be born infected. Based on my work experience, this is how I could sum it up: when children are born infected because they didn't realize in time, the mothers experience a double grief and they have to work doubly hard to accept [the diagnosis]. First, to accept that they are the ones who are alive. And afterwards to work out the guilt that they were the ones who infected their children.

Karen, who was inconsolable about the AIDS-related death of her son and wept for most of the two hours that we spent together, confirmed Julia's analysis of women's assumption of blame for

HIV transmission to a child, or worse, a child's death. Karen said that "it hurts me because he was a child and he wasn't guilty of anything. I feel that I am [guilty] because I didn't take care of myself, and I never realized that he was sick [with AIDS]". Karen never suspected she could be HIV-positive, did everything possible to discover the cause of her son's illness, and yet, is plagued by guilt because of his death. Lourdes experienced the same process of taking her sick son to "doctors and doctors and nothing, nothing at all". In her testimony, the assignation of blame to a mother for a child's illness is externalized in the comments of health-care providers. Embarking on yet another journey to find out why her son wasn't responding to the medications he had been prescribed, Lourdes went to the regional hospital. She told me that she

had a bag of medicines and prescriptions and I don't know what all. And even then the doctors who were there hit me with everything they had. They said, 'What an irresponsible mother. How is it possible that she is just letting this child die? Can you believe it?' 'No Miss, [she said], I am not letting him die. Here are all of his prescriptions, all of his medicines, everything that I am giving him, and he just doesn't get better.' 'Why?' Well, I also wanted to know what was wrong with my child.

Lourdes didn't know about the possibility of vertical HIV transmission prior to her son's death and had an HIV-positive daughter after her diagnosis when she became accidentally pregnant, unsuccessfully tried to induce an abortion, and was given sub-standard antiretroviral treatment by the religious charitable organization where she received her care. With respect to her knowledge of HIV and AIDS before she was diagnosed, Lourdes says simply, "I knew that people had it, but I didn't even know how [it was transmitted]. And when I got pregnant, well, I didn't know". Yet, despite her lack of knowledge, she feels responsible for her son's death. She stated that:

Sometimes I regret it: All of the stupid things that I wanted to do! Knowing how you can avoid this [HIV], that my daughter is infected and all of that. If I had known from the start that I could have avoided this, or that if I had taken an [HIV test], my daughter wouldn't be like this and my son would be alive. But unfortunately, when

one is close-minded, and doesn't know, you don't even do a test: 'Oh! I feel fine. I'm not sick.'

Only a minority of the women who lost a child to AIDS managed to transform their grief over the death of their child into a reason for living. Itzel conceives of her dead son as an "angel" who resisted death and suffered so that she and her husband could learn their diagnosis. In her words

I am going to keep on giving it my all because, like they say, if I gave him life, he gave it back to me. It was thanks to him that we found out what we have. I tell my husband: 'I am going to keep on giving it my all, I am going to get ahead'—in only six months I got better, like nothing had happened, because I was focused on that idea, that I owed something to him. And that what he did and all that he suffered won't be in vain.

Women also experienced guilt because they had, unknowingly, transmitted HIV to their children. Gisela said that being an HIV-positive mother of an HIV-positive child "isn't nice, because they are going to suffer. Right now my daughter is little and everything, but when she is bigger, she is going to say that it is my fault". In accordance with the dictum "a good woman is a good mother," the primary concern manifested by the women in my sample was the well-being of their children. When a child died of AIDS-related illnesses or became infected with HIV through vertical transmission, the majority of women became trapped in a cycle of grief and self-recrimination. A few women, such as Itzel, were able to transform her feelings about her son's "sacrifice" into a reason for living. But among the four women who had a child who died of AIDS with a confirmed diagnosis, and the 10 women who had an HIV-positive child, Itzel's reaction was uncommon. In general, women were stricken by guilt. In contrast, among women who were fortunate enough not to have an HIV-positive child, even though they gave birth without knowing their diagnosis, it appeared easier for them to overcome negative feelings associated with the diagnosis and to draw

on promotion of the well-being of their children as a motivation for caring for themselves. Camila, whose daughter is HIV negative, explained that

in the beginning I felt shame and guilt, but afterwards I said, well, onward, right? Life continues and if I want, I will live a long time, and I will live for my daughter. So, sometimes you feel, not grateful, but with more zest for life, and to give it your all, because you have someone to look out for.

A psychologist working at an HIV clinic suggested that the ability to prevent vertical transmission of HIV is redemptive for women diagnosed during pregnancy and allows them to assimilate the diagnosis and move forward with their lives with less difficulty than women who aren't pregnant at the time of diagnosis. He held the view that by adhering to their antiretroviral medications and the protocol for preventing mother-to-child transmission, pregnant women “compensate for it [guilty feelings] saying: this is how I can *salvar eso malo* (overcome this evil)”.

#### **6.4 Discussion**

The stories told by women with HIV of reproductive age, about how they came to be diagnosed, show the high cost of the failure to implement prenatal HIV testing and PMTCT for Mexican women and other family members. One of the central findings of my study is that these women *were* in contact with the health-care system before their diagnosis—*all* of the women in my sample attended prenatal care. Furthermore, AIDS-related illnesses caused many of them to wind their way through a labyrinth of repetitive illnesses and misdiagnosis for themselves, their children and their male partners, sometimes even unto death—without receiving an offer of HIV-testing. The study also suggests that the failure to offer HIV-testing is not truly an issue of resource constraints—either for the health-care system or for individual families. Frequently prenatal care included many tests and procedures which are more expensive than an HIV-test. In

fact, some of the care provided could be considered superfluous. The most dramatic example of this is that Karen's prenatal care included eight ultrasounds but not a single HIV test—this omission resulted in the death of her son from AIDS, the subsequent transmission of HIV to her younger daughter, and delayed her and her husband's HIV diagnosis until he was sick with AIDS. Rather than a simple issue of resource constraints, it seems that resource allocation and medical protocols for prenatal care could address many of the missed opportunities for HIV-testing during prenatal care.

In response to these AIDS-related illnesses, these low-income families sought explanations and spent a small fortune on health-care, sometimes for themselves but more commonly for their children. They were actively seeking health-care in both the for-profit and not-for-profit sectors, and paying for laboratory tests, medications, and surgery. In this context, the ten to twelve dollars that a family might pay for an HIV test in a private lab, or even better, a free test in the public system, are a very small price to pay in a context where a positive test result opens the door to free antiretroviral treatment and long-term survival.

The problem then, especially for women and children accessing testing, seems to be one of perception, medical knowledge, and HIV-related stigma. Many of the women presented to multiple physicians looking like casebook pictures of people with AIDS—weighing half their normal weight, with sores in their mouths, recurrent gynaecological problems, pneumonia, diarrhoea, and fever. Likewise, they took HIV-positive children to multiple visits with respiratory problems, throat infections and swollen glands, fever, and diarrhoea. Occasionally, a doctor recognized the symptoms and sent the woman for an HIV test. But more commonly, both women and children were misdiagnosed, and access to adequate care and, crucially, antiretroviral

treatment, was delayed. Some of the children died as a consequence. As for the women—I interviewed those who survived.

However, late diagnosis impacts on quality and quantity of life. Late diagnosis of HIV-infection, as indicated by having a lower CD4 count, higher viral load, or an AIDS-defining illness, has been associated with a greater probability of progression to AIDS and death (Egger et al. 2002). A modelling study based on assumptions of widespread access to health-care and multiple options for antiretroviral regimens available in a high-income setting has found that late diagnosis (symptomatic with 140 CD4 cells) is the greatest contributor to mortality among people with HIV, reducing life expectancy an average of 10 years (Nakagawa et al. 2012). A Brazilian study, which may be more representative of the conditions of HIV and AIDS care in Mexico (though Brazil has had more success at reducing AIDS-related mortality), also found that late diagnosis was the most important predictor of mortality; the probability of survival was only 48.0% for those who were diagnosed with HIV when they became hospitalized and median life span for these people post-diagnosis was only four months (Oliveira et al. 2011). Thus, we can see that late diagnosis negatively impacts the prognosis of people with HIV.

Late diagnosis is also a serious public health problem in Mexico. No national studies of health status at initiation of HAART have been published, but statistics from two tertiary level hospitals indicate that diagnosis only when people with HIV have advanced disease is a grave problem. At one large HIV clinic in Mexico City, 200-240 patients with HIV are hospitalized a year, usually they have not begun antiretroviral treatment when they are hospitalized (indicating recent diagnosis) and they have opportunistic infections and CD4 cell counts under 100 (Ormsby et al. 2011: 436). Another sample from a tertiary facility found that of the 390 patients who began HAART between October 2001 and November 2007, the median CD4 cell count was only 87 (32-

184) and 33% had had an opportunistic infection before receiving medical care at this center (Hoyo-Ulloa et al. 2011: 411). National guidelines recommend beginning treatment with a CD4 cell count of 350 (CENSIDA 2009: 11). Despite the significant increase in access to antiretroviral treatment in Mexico since 2003, and an investment of more than one billion pesos annually (approximately CAD 77,000,000) to purchase these medications, reduction in morbidity and mortality associated with AIDS was only significant in the period between 1996-1998 and has been stable since 1998. AIDS-related mortality remains between 4.2-4.4 deaths per 100,000 inhabitants—a smaller reduction than has been observed in other settings that have introduced antiretroviral treatment, like Canada, the United States and Brazil (Vargas Infante et al. 2011). Late diagnosis is a major contributor to these poor outcomes. My research suggests that implementing widespread HIV-testing during prenatal care helps to avert disease progression, especially among women and children, but also among male partners.

With respect to AIDS-related child morbidity and mortality, this research documented cases of perinatal HIV transmission that could have been averted, including younger siblings becoming infected with HIV because the woman wasn't diagnosed during a previous pregnancy. In addition, my research documents AIDS-related child mortality, including presumptive cases that had not been registered as AIDS deaths. Identification of these omissions corroborates the 50% underreporting of paediatric AIDS-cases in Mexico (Uribe-Zuniga et al. 2008: 77, 85). As discussed in Chapter 1, these types of omissions also feed the perception that AIDS-related mortality among children is a negligible problem, contributing to low political priority for PMTCT.

In addition to the economic and health-related costs of the delayed HIV-diagnosis, many women experienced crippling guilt associated with having transmitted HIV to their child, even

though they were unaware of their HIV status during gestation and the perinatal period. Despite the fact that in practice, these women with HIV didn't have access to any of the knowledge or medical interventions that could have allowed them to prevent vertical transmission, they still blamed themselves. This is part of a cultural construction of maternity which makes women wholly responsible for doing the possible and the *impossible* to protect and promote the well-being of their children. This construction was aptly expressed by the HIV psychologist who said "a good woman is a good mother". Clearly unfair and sexist, these constructions nevertheless constitute a pillar of the identity of the women whom I interviewed. In this context, depriving women of the tools they need to be able to protect and promote the well-being of their children seems a particularly cruel blow. A few of the women I interviewed were still struggling to come to grips with the AIDS-related death of a child. Others were living with their fears of HIV-related stigma and discrimination towards their HIV-positive children. Fear of disclosing to the community resulted in feelings of isolation. And fear of how the HIV diagnosis would affect their children in the future was a heavy emotional burden. As we work to transform gender roles and responsibilities and related identity constructions, it seems to me that the grief that HIV-positive mothers who have had children die of AIDS or are raising children with HIV experience, needs to be taken into account in discussions of the offer of HIV-testing during prenatal care. At the same time, when arguing for the scale-up of the universal offer of testing and PMTCT, we must avoid an unduly tight focus on children's health which reproduces the stigmatizing stereotype of "women as a disease vector". Rather, we need to emphasise the benefits of opportune diagnosis for women's own health, as well as for other family members.

The cases of women who were offered HIV-testing during prenatal care allow me to identify some good practices. First, the offer of testing needs to be routine and universal; in other

words, the offer of HIV testing cannot be based on the risk perception of either the woman or the health-care provider. Second, pregnant women need to be informed of the existence of the possibility of vertical transmission of HIV, and indeed, of other sexually transmitted infections such as syphilis, and the possibilities for preventing transmission. Pre-diagnosis knowledge of PMTCT was very low among the women in the sample. The two women who were offered testing but refused were not aware that HIV could be transmitted from a woman to her child, or that this transmission could be prevented. Third, women need an option to refuse testing. While it seems that the decisions of the two women who were offered testing and declined were uninformed, they made the decision to refuse testing. This is in line with the few existing national studies indicating that 10-15% of pregnant women will choose not to test when testing is offered (Romero-Gutierrez et al. 2007; Vera Gamboa et al. 2005). It is important to protect women's right to refuse medical interventions. Finally, the fact that two of the women initially tested negative during pregnancy suggests that offering a second opportunity to test during the third trimester of pregnancy would be reasonable, especially given that only 21 of Mexico's thirty-two states have accumulated HIV and AIDS incidence below one case per thousand inhabitants which is the floor for third trimester HIV testing recommended by the CDC (Branson et al. 2006: 9; CENSIDA 2011).

To address low levels of HIV testing during prenatal care internationally, both the Centers for Disease Control in the United States and the World Health Organization have advocated a move away from voluntary testing and counselling, also known as "opt-in" testing, to routine provider-initiated testing ("opt-out") (Branson et al. 2006; WHO/UNAIDS, 2007). Studies in both high and low-income countries have demonstrated that prenatal opt-out HIV testing results in significantly higher HIV screening rates and increased implementation of prevention of perinatal transmission without a corresponding drop in clinic attendance because of fears of HIV testing

(Creek et al. 2007; Manzi et al. 2005; Moses, Zimba, et al. 2008; Walmsley 2003). With HIV testing, traditional models of voluntary counselling and testing require that people need to seek out a specialized testing site or request the HIV-test from their health-care providers, answer questions about their sexual and drug using behaviour as part of the pre-test screening questionnaire, and receive counselling on how they would react in the case of an HIV-positive result prior to being given an HIV test. Proponents of the opt-out approach have hailed the end of “AIDS exceptionalism” which treats HIV as different from other kinds of medical tests. Normally, the medical provider explains what the test is for, why he or she is recommending the test, and the patient can accept or refuse the test (Creek et al. 2007). However, other authors have raised concerns that routine testing can easily contravene principles of informed consent and is not ethical in settings where the benefits of testing are outweighed by the negative social consequences of an HIV diagnosis. In particular, advocates have argued that women are more vulnerable to the negative effects of routine testing because they have greater contact with the health-care system than men, are less able to refuse testing given prevailing gender dynamics and power imbalances with health-care providers, and are more likely to suffer violence and loss of economic support as a consequence of disclosing an HIV-positive result (Maman and King 2008; Rennie and Behets 2006).

The women with HIV who participated in this sample were either diagnosed through provider-initiated testing and counselling, or after becoming ill with AIDS and/or having a child or male partner become ill with AIDS or die. When we consider the potentially negative consequences of the HIV-diagnosis for women during the prenatal period, it is essential that we also consider the consequences of the missed opportunity to provide an opportune diagnosis for a woman’s own health, for the prevention of vertical transmission, and for the health and well-being

of other children and sexual partners. As this analysis shows, these consequences are not negligible—and indeed may make the difference between life and death.

## **Chapter 7. Conclusions and Recommendations**

My journey towards writing this dissertation began with a shocking realization and a simple question: given existing health-care infrastructure and policy commitments, why were rates of prevention of perinatal HIV transmission in Latin America generally, and Mexico specifically, so low? Seeking to answer this question, I conducted documentary research, interviewed women with HIV, reproductive health and HIV activists, health-care providers, administrators and policymakers from across the region, and analyzed the relationship between risk behaviours for HIV acquisition and reactive HIV antibody tests in a large national sample of pregnant Mexican women.

### **7.1 Conclusions**

My regional research found that the perception that HIV among women and children is not an important issue among decision-makers and HIV and reproductive health activists creates a negative feedback loop which justifies the failure to implement PMTCT. This omission contributes to the invisibility of HIV and AIDS cases among women and children and failure to recognize related infant and maternal mortality, which perpetuates the perception that HIV is not an important issue for women and children, creating a vicious cycle. There has been little collaboration in the region between the HIV and feminist women's health movements to increase the political priority of PMTCT. As well as the focus on "high risk" populations by the HIV movement and perception that the issue of women and HIV is marginal among the women's

reproductive health movement, other barriers to the development of a joint advocacy agenda include: the perennial battle for resources between HIV and reproductive health; narrow framing of PMTCT as a health intervention which only promotes the baby's health at the cost of the woman's rights; and, the relatively weak position of women with HIV *vis-à-vis* both the broader HIV movement and the women's reproductive health movement. With specific reference to the lack of effective collaboration between the feminist women's health movement and women with HIV in the region, HIV-related stigma, class differences, and lack of knowledge about the international conferences that form the backbone for the feminist sexual and reproductive health (SRH) agenda among women with HIV have all been barriers. One of the key problems identified was that when feminists did work on HIV, they frequently did so without the meaningful involvement of HIV-positive women. The Greater Involvement of People Living with HIV and AIDS (GIPA) can be an effective antidote to feminist perceptions of women with HIV as "other" and broaden understandings of the benefits of PMTCT. In order to be stronger advocates for PMTCT and ambassadors of the integration agenda, and to dialogue with the feminist women's health movement and HIV civil society as colleagues and peers, women with HIV require specific training on the evidence-base for SRH/HIV integration and capacity building to frame their demands in the terms of the international conferences, including the Millennium Development Goals. During the past three years, the International Community of Women Living with HIV and AIDS in the region (ICW Latina) has been proactive in increasing their capacity to make arguments for the integration of SRH and HIV, making their agenda visible at feminist political events, and engaging in dialogue and cross-training with feminists at the national level.

In Mexico, the perception among policy-makers and health-care administrators that perinatal HIV transmission is not a serious public health problem, published research arguing

against the cost-effectiveness of universal HIV testing for pregnant women, and a dominant HIV prevention ideology focused on “high-risk” groups have been historical barriers to higher political priority and sufficient resource allocation. The movement towards multiparty representation and the decentralization of the Mexican health system over the past fifteen years has also impacted on the implementation of prevention of vertical HIV transmission. Multiparty representation has weakened the influence of the President, and his designates, such as the Minister of Health, and the motivation for obedience by politicians and bureaucrats that existed within the one-party system which maintained itself in power for seventy years. Health system decentralization also undermined the ability of the federal government to ensure the implementation of health programs by transferring the responsibility (and most of the budget) for health-care provision to the States. This means that despite recognition of the issue at the federal level since 2001 (as expressed in the National AIDS Plan), in the absence of earmarked funds provided by the federal government, the program was not implemented at the State level. Further, the National AIDS Plan is not the correct policy and planning instrument for PMTCT. The fact that administrative responsibility for implementation belongs to the National HIV Program, which does not have contact with pregnant women, has hampered implementation of PMTCT. Reproductive Health is responsible for establishing technical guidelines and supervising the quality of prenatal care, but HIV and syphilis testing of pregnant women are not included in their program targets nor are they indicators which are used to evaluate their success. Therefore, PMTCT is located in an operational-administrative abyss where the program that has the administrative responsibility for implementation doesn't have the means and the program that has the means doesn't have the administrative responsibility. The relegation of perinatal HIV prevention to a political no man's land has been exacerbated by the fact that, up until November 2010, universal offer of HIV-testing to pregnant women wasn't

included in the HIV NOM. Unfortunately, the NOM that governs prenatal care, labour and delivery, and the puerperal period still recommends HIV testing during pregnancy only for “at risk” women (drug users, sex workers, and women who have received blood transfusions). This wording provides administrative justification for not implementing perinatal HIV transmission and also expresses and perpetuates deeply rooted and stigmatizing cultural beliefs about the links between sexuality and HIV. The cultural construction of “at risk women” provides moral absolution in cases of perinatal HIV transmission for health-care institutions and providers, as well as continuing to obscure the gaps between Church doctrine on monogamy and the male sexual infidelity common in the dominant sex-gender system.

The Mexican social imaginary about women’s HIV risk is at the heart of the failure to implement PMTCT and indeed to respond to the HIV epidemic among women. As I discussed in the introductory chapter, there are two pertinent dimensions to HIV risk—the behaviours that result in HIV transmission and the culturally mediated signification of these behaviours for individuals and groups and how these are embedded in the material and ideational context of everyday life. My research addresses both of these dimensions. I encountered a huge gap in the Mexican literature on women’s HIV risk behaviours. With the exception of a few recent studies with female sex workers and injection drug users (Gayet et al. 2007; Strathdee et al. 2008) and a total of three studies which document pregnant women’s risk behaviours (Romero-Gutierrez et al 2009; Vera Gamboa et al. 2005; Viani et al. 2006), the only systematic information available about women’s risk behaviours for HIV-acquisition is the AIDS case registry. And this source only tells us that 99% of female HIV and AIDS cases registered in 2010 identified heterosexual transmission as the HIV exposure category (CENSIDA 2010:15). The quantitative analysis presented in Chapter 4 makes a significant contribution to describing the HIV risk behaviours of Mexican

women. The analysis (which included 78,557 pregnant Mexican women) associated a reactive HIV antibody test result with being older, being married, having more children and reporting Indigenous ethnicity (as measured by speaking an Indigenous language). These associations suggest that the longer a woman is sexually active the greater her likelihood of becoming infected with HIV, even within a stable relationship. In fact, rather than being protective, marriage was a risk-factor for HIV infection among pregnant women. That only slightly more than half of the pregnant women thought their male partner had been sexually monogamous with them during the past twelve months helps to explain this finding. After controlling for women's sociodemographic characteristics and the health-care site where the rapid HIV antibody test was applied, the only individual risk behaviour by women which remained statistically significant was having had multiple sexual partners during the past twelve months. In contrast, the association between male partner's risk behaviours for HIV acquisition and their pregnant female partners having a reactive HIV antibody test remained statistically significant even after controlling for women's sociodemographic characteristics and the health-care delivery site. Thus, we can conclude that male partner's risk behaviours and the state of the epidemic in the community where the woman resides are more important determinants of women's HIV vulnerability than are women's individual risk behaviours.

Having identified male partners' risk behaviours as a significant contributor to women's vulnerability to HIV infection, I then sought to explain the apparent paradox between women's knowledge of HIV transmission routes, awareness of men's risk behaviours for HIV-acquisition, and lack of HIV risk perception. To do so, I described the contexts in which a sample of 55 women with HIV from South-Central Mexico (Mexico City, Mexico State and Morelos) became infected and analyze their perceptions of HIV vulnerability prior to their diagnosis and the

meanings that they attributed to their male partner's risk behaviour for HIV acquisition. Using the most conservative definition of "stable relationship", 45 of the 55 women (81.82%) became infected with HIV in this context. The fetishisation of the "stable relationship"—the formation and maintenance of which is socially constructed as one of women's main aspirations and social responsibilities—and the purported demarcating line that being in such a relationship draws between "good women" and "bad women" and other "high risk groups" who are imagined to be "at risk" of HIV contributes to this apparent paradox. The other important contributor identified in my research, is how men's risk behaviours for HIV acquisition (principally having multiple sexual partners and using alcohol and drugs) are centrally located in dominant cultural constructions of masculinity. This nexus causes women to naturalize men's HIV risk behaviour as "men being men" and thereby contributes to their lack of HIV risk perception. Yet, the solution is clearly not as simple as pointing out to women that unprotected sex can result in HIV transmission: they already know it. Beyond individual women's constructions of HIV risk, the material and ideational foundation on which women's HIV vulnerability rests is economic and social gender inequality, including men's sexual ownership of women's bodies, and gender violence.

Lack of institutional and individual risk perceptions coalesce to delay women's HIV diagnosis, contributing to vertical HIV transmission, infant morbidity and mortality, and women's disease progression. The health system failures begin with not diagnosing women with HIV during prenatal care. All of the 55 women with HIV who participated in the research had had a pregnancy since 2001 and all attended prenatal care, going to between six and seven prenatal visits. In theory, all of them should have been offered HIV testing. In actual fact, only 22 of the 55 women (44.0%) were offered HIV testing during prenatal care. The health systems failure to respond to HIV among women and children continued as children who had acquired HIV through vertical

transmission and their mother's became ill with AIDS, and in some cases died. Throughout, women were seeking health-care for themselves and their children, with the corollary economic costs. In addition, a child dying or becoming infected with HIV because women were not given the opportunity to prevent vertical transmission had long-term detrimental emotional effects on HIV-positive women.

## **7.2 Contribution to the literature**

Policy analysis of health system and political barriers to the implementation of PMTCT has mostly focused on Africa. In this respect, my doctoral research makes an important contribution to understanding the culturally mediated political, institutional and individual barriers to successfully implementing PMTCT in Latin America broadly and Mexico specifically. The African literature explores how cultural constructions of HIV, including HIV stigma and discrimination by health-care providers, dominant gender roles, and culturally grounded ideas about maternity and child-raising, impact on women's access to and acceptance of prenatal testing and other PMTCT interventions (Chikonde et al. 2009; Hofman et al. 2009; Kebaabetswe 2007; Painter et al. 2004; Thorsen et al. 2008). This research is important in that it allows us to identify considerations which must be taken into account to minimize the negative social consequences of an HIV-positive diagnosis and to improve program outcomes. Nevertheless, African research also suggests that health system factors such as distance, waiting times, availability of counselling and test-kits, timely provision of ARV, and physical and programmatic integration of PMTCT programmes with other maternal and child health services are more important for determining whether women accept HIV testing and successfully complete antiretroviral treatment for PMTCT than women's individual sociodemographic characteristics, attitudes or perceptions of HIV-related stigma and

discrimination (Albrecht et al. 2006; Chopra and Rollins 2008; Colvin et al. 2007; Kinuthia et al. 2011; Manzi, et al. 2005; Nguyen et al. 2008; Nkonki et al. 2007; Laher et al. 2012; Le et al. 2008; Sprague 2011; van't Hoog et al. 2005). In particular, the implementation of the universal offer of free HIV testing during prenatal care has been shown to be effective in increasing PMTCT coverage in both high and low-income settings (Creek et al. 2007; Kasenga et al. 2010; Manzi et al. 2005; Moses et al. 2008a; Walmsley 2003). My research supports the contention that health system factors and issues related to access are more important than women's individual characteristics or fear of stigma and discrimination. It also indicates the need to inform women about the existence of vertical HIV transmission, the ability to prevent it, dispel myths about an HIV-diagnosis being an immediate death sentence, and counter the social imaginary that distances HIV as a problem of socially stigmatized "others".

Published research on PMTCT in the Latin American region is extremely scarce and policy-oriented research which seeks to understand the abysmal failure to scale-up vertical HIV prevention programs is almost non-existent. A multi-site clinical trial has demonstrated that extremely low rates of vertical transmission are possible in the region (1%) and identified the following health system failures as missed opportunities: late diagnosis of the HIV-positive pregnant woman; insufficient antiretroviral treatment (either in duration of time or the regimen offered); and problems with labour and delivery, such as women spending an extended time with ruptured membranes or the failure to conduct a caesarean section when it is indicated given the woman's viral load, both of which are associated with increased transmission of HIV to the infant (D'Ippolito et al. 2007; Read et al. 2007). An analysis of the implementation of Colombia's PMTCT program (2003-2005) also found vertical transmission rates under 2% and associated transmission with late diagnosis and not having access to prenatal care (Garcia et al. 2005). In

terms of input for policy development or policy analysis, three studies deserve mention. First, a Colombian mathematical modeling study showed that the universal, opt-out offer of HIV testing to pregnant women has a greater cost-benefit than voluntary testing and counselling (Gomez 2008). The two other costing studies argue against PMTCT. The Mexican study found that when compared to other interventions to promote maternal-child health, universal offer of HIV-testing to pregnant women was not particularly cost-effective and thus questioned whether it should be implemented (Rely et al. 2003). The negative impact of this study on attitudes towards PMTCT in Mexican policymaking circles was discussed in detail in the dissertation. A study from Peru which analyzed a variety of HIV prevention interventions in terms of their cost per disability-adjusted life year (DALY—disease burden expressed as the number of years lost due to ill-health, disability or early death) found that PMTCT was the most expensive intervention (Aldridge et al. 2009). Other studies of PMTCT from Mexico have both established that HIV testing is acceptable to pregnant women and associated late diagnosis (for example during labour and delivery) with vertical HIV transmission (Romero-Gutierrez et al. 2007; Vera Gamboa et al. 2005; Viani et al. 2010). None of these studies examined the cultural constructions, policy frameworks and political systems, or institutional practices that undergird the failure to implement PMTCT. A notable exception in this regard is Uribe-Zuniga and colleagues 2008 discussion of the causes and consequences of the failure to implement PMTCT in Mexico.

My dissertation moves observations made by Uribe-Zuniga et al. from the level of reflections based on the author's years of policymaking and clinical experience, to empirical evidence grounded in the experiences of women with HIV, health-care providers, policymakers and HIV activists. By doing so, I have provided incontrovertible evidence of the need to modify

the existing normative framework for prenatal care in order to support PMTCT scale-up and avert the deaths and disease progression of women, their children, and other family members.

In addition, my doctoral research contributes to discussions of HIV risk, models for prevention, and the growing global literature, which demonstrates how dominant gender constructions and gender discrimination contribute to women's HIV vulnerability (see for example Gupta et al. 2011; Jewkes and Morrell 2010; Krishnan et al. 2008; UNAIDS 2010b). More specifically, by analyzing the HIV risk perception, behaviour and access to HIV-testing for Mexican women within the context of perinatal HIV prevention, my research contributes to the literature on how dominant gender constructions impede Mexican women's capacity to prevent HIV transmission and to promote their own health and well-being when living with the virus (Allen Leigh and Torres Pereda 2008; Campero et al. 2007; Campero et al. 2010a; Campero et al. 2010b; Herrera et al. 2008; Herrera et al. 2009; Hirsch 2003; Hirsch et al. 2002; Kendall and Pelcastre-Villafuerte 2010; Kendall and Perez-Vazquez 2004). Some of this research has contextualized HIV and AIDS-risk denial within stable relationships and related lack of condom use among rural and migrant women from Jalisco and Puebla (Hirsch 2003; Hirsch et al. 2002; Kendall and Pelcastre-Villafuerte 2010). Research with women with HIV has documented that prior to diagnosis HIV is "unimaginable" (Campero et al. 2010a; Kendall and Perez-Vazquez: 94, 97). Existing research has also identified gender discrimination, including different forms of gender violence and HIV-related stigma and discrimination, as important barriers to the exercise of sexual and reproductive and other health rights among women with HIV (Allen Leigh and Torres Pereda 2008; Campero et al. 2010b; Herrera and Campero 2002; Kendall 2009b; Kendall and Perez-Vazquez: 92-100 ).

Building on this research, my doctoral work provides an in-depth analysis of the gendered sexual norms and perceptions of HIV that have stymied implementation of PMTCT and HIV prevention among women in the region. I am able to demonstrate the negative repercussions of the social imaginary of the “concentrated HIV epidemic,” and consequent invisibility of HIV and AIDS among women and children, at both the individual and institutional level. Unlike those who have argued that PMTCT is not cost-effective or has limited cost-benefit in concentrated HIV epidemics, I consider that precisely because of low risk perception among women and health-care providers, universal offer of HIV testing as part of prenatal care and better integration of HIV into maternal-child and sexual and reproductive health services is the doorway into HIV prevention and care for women in Latin America. Contact between women of reproductive age and the health system reduces the costs of education, testing, and early diagnosis. Therefore, inclusion of HIV in sexual and reproductive and maternal-child health services can begin a cascade of beneficial outcomes for women’s own health, that of their children, and for their families.

My research also makes a significant contribution towards explaining the gap between knowledge of HIV transmission routes, knowledge of male partner’s risk behaviour, and women’s perceptions that they were not vulnerable to HIV infection and failure to implement HIV prevention behaviours that has so troubled individually-oriented, rationalistic approaches to HIV prevention. Thus, I add my voice to those researchers, activists and policy-makers who are calling for structural interventions and cultural transformation as cornerstones of the international response to HIV and AIDS.

## **7.3 Study Limitations**

### *7.3.1 Qualitative Sample*

One of the limitations of the interviews on which the qualitative analysis is based is that experiences of Spanish speaking women residing in urban, peri-urban, and rural settlements that are within about four hours of an urban area, in the South-Central region of Mexico, may be very different from Mexican women from different parts of the country, for example, monolingual Tzotzil or Mayan women in rural Southern Mexico. Another limitation of the qualitative study is that the questions about women's own HIV risk behaviour, the risk behaviour of their male partners, and perceptions of HIV vulnerability were retrospective. Thus, the experiences that women shared are subject to recall bias and the process of constructing a narrative to explain their HIV infection, as well to the possible social desirability bias inherent in presenting oneself to the researcher.

### *7.3.2 Quantitative Sample*

The quantitative sample of pregnant Mexican women who accepted a rapid HIV antibody test has the inherent limitation of only including those women who were offered and accepted the rapid HIV antibody test. These women may be different from women who were not offered HIV testing during their prenatal care or who did not accept HIV testing during prenatal care. The database does not account for women who refused to be tested, so we don't know what the refusal rate was; previous studies of the offer of HIV testing during prenatal care have found an acceptance rate of 85-90% (Romero-Gutierrez, et al, 2007; Vera Gamboa et al, 2005).

My ethnographic fieldwork (July 2009-January 2011) identified other limitations with the database. I know there were stock-outs of rapid tests during the study period and therefore not all

of the women who attended prenatal care were offered testing. Furthermore, during the time period studied (October 2006-December 2009) not all of the surveys that were completed were entered into the database because of delays and omissions in sending the surveys from the individual health clinics, to the state reproductive health program, and to the national offices where they were entered into the database. However, the construction of the retrospective case-control study controlled for biases introduced by differences in access to HIV testing at different health-care delivery sites, as well as other unobserved differences.

Also, the database is limited to health-care delivery sites administered by the Ministry of Health and does not include information about women from Mexico's other health systems: the Mexican Social Security Institute (IMSS), which provides health services to private sector workers; the Social Security Institute for State Workers (ISSSTE), which provides health services to public sector workers; the health systems for the Army, Navy or state-owned Petroleum company (PEMEX); or the private sector. The final important limitation of the database discussed in detail in the section on the classification of women as "reactive" or "non-reactive" in Chapter 2, is that it provides reactive or non-reactive rapid HIV antibody test results for the pregnant women, but it does not include information about the results of confirmatory testing of HIV status.

#### **7.4 Future Research**

One of the key priorities for future research is to monitor and ensure that prenatal HIV testing and PMTCT are implemented in Mexico using the existing financing mechanisms, such as the Popular Health Insurance, and the normative framework which provides for the universal offer of HIV-testing expressed in the new HIV NOM. This research should examine how individual women and civil society organizations can hold policymakers, health-care institutions, and

individual health-care providers to account, because, as I have shown, promises on paper don't necessarily translate into practice. Another area for research in PMTCT, is to monitor the retention of women who test positive for HIV during prenatal care in subsequent HIV care and to better understand the role of male partners in allowing women to successfully implement PMTCT; both of these issues are emerging as priorities in Africa (Auvinen et al. 2010; Ginsburg et al. 2007; Horwood et al. 2010; Nassali et al. 2009; Peltzer et al. 2011).

In terms of HIV prevention, I have argued strenuously against providing HIV prevention interventions exclusively for “high-risk” populations. However, while I maintain that the offer of HIV testing during prenatal care should be universal throughout the country, and in addition, that testing should be available to any sexually active person who requests it, there may be arguments for focusing HIV prevention programs for the “general population” in certain geographic areas. I make this recommendation based on the fact that of the 9,506 health care delivery sites who provided information on prenatal rapid HIV antibody test results, only 541 (5.69%) had at least one reactive HIV antibody test result. Thus, if priorities must be established for resource allocation—almost a certainty given competing demands and the process of health-care decision-making—characterization of the geographic distribution of the health-care delivery sites that reported rapid HIV antibody tests could be useful for prioritizing HIV prevention programs for women and male partners.

Finally, in the quantitative analysis, Indigenous women were more likely to be reactive to the rapid HIV antibody test than non-Indigenous women. Overlaying the geographic mapping of reactive HIV antibody test results and with reactive HIV antibody tests among Indigenous women could provide information about which communities are most affected. The vulnerability of different Indigenous communities to HIV, and particularly the vulnerability of Indigenous women

to HIV infection and progression to AIDS, is an area which has received almost no attention in the Mexican literature and is deserving of both research and action.

## **7.5 Recommendations**

Based on the preceding analysis, I venture some policy and programmatic recommendations for scaling up access to PMTCT, as well as responding to Mexican women's lack of HIV risk perception in the short-to-medium term to promote HIV prevention. I then make some suggestions for transforming the gender norms that undergird women's HIV vulnerability.

### *7.5.1 Increasing PMTCT Coverage in Mexico*

I have sought to demonstrate that the gaps between the cultural construction of HIV risk and women's actual exposure to HIV through a culturally normative behaviour—unprotected sex with a stable male partner—makes it imperative that the offer of HIV testing during prenatal care be universal, rather than based on the health-care provider or the woman's perception of "risk". In the national sample of women tested for HIV between October 2006 and December 2009, more than a quarter of those who were reactive to the HIV antibody test did not report any risk behaviours whatsoever (for themselves or their male partner). This is strong evidence for the universal offer of HIV testing during pregnancy in Mexico, and good evidence against the continued policy and practice of offering HIV testing to pregnant women based on risk-perception (see also Chou et al 2005: 40). The trajectories of women through the health system also demonstrate that the routine offer of HIV testing during prenatal care can be an important antidote to disease progression and even death. How can this be achieved?

As a case study of implementation of prevention of vertical HIV transmission, the delivery of 800,000 rapid tests to primary care clinics across the Republic in 2007-2008 permits

identification of lessons learned and highlights some of the steps needed to move towards program sustainability. First, putting the tests in the hands of the health-care workers in primary care clinics who actually have contact with pregnant women was a significant step forward. This initiative showed that with appropriate training, some health-care providers working in the trenches in primary care became interested in and supportive of the perinatal HIV prevention initiative. Unfortunately, their efforts were limited by stock-outs of HIV tests. The National AIDS Plan (2007-2012) sets a target of 100% coverage with HIV testing among women attending prenatal care (Secretaria de Salud 2008b). To sustain and expand the program through large scale training and the purchase of the medical supplies needed to reach the desired coverage, HIV testing during prenatal care must become a responsibility of the Reproductive Health Program and the offer of HIV testing to all pregnant women, not only those who are “at risk,” must be established in the normative framework.

The ideal mechanism for doing so is the inclusion of the universal offer of prenatal HIV testing in the NOM which governs prenatal care, labor and delivery and the puerperal period (NOM-007) and, subsequently, the inclusion of prenatal HIV testing for every woman in the catalogue of services covered by the Popular Health Insurance (CAUSES). As of March 2012, despite having been under review for more than a decade, NOM-007 still hadn't been published. However, the General Health Law is also under review and the version that has been approved by Congress and sent back to the Senate includes an article which would address HIV and other STIs in pregnant women in order to prevent perinatal transmission (personal communication, Martha Juarez, March 13 and March 15, 2012). Modification of either the General Health Law or the NOM 007 would place the responsibility for widespread HIV testing during prenatal care on the institutions that have the potential to implement the program because they have contact with

pregnant women. This change is crucial for addressing political will and sustainability because, as I have sought to show, the administrative frameworks for health-care delivery are a central mechanism for resource allocation as well as mobilizing political will at the State and health-care institution level through monitoring and evaluation. As yet, the failure to publish the NOM continues to influence administrative and operational documents. Despite the fact that, during the spring of 2012, the Ministry of Health was supporting a radio campaign promoting HIV-testing among pregnant women, the latest version of the Catalogue of Health Services (CAUSES) covered by the Popular Health Insurance continues to recommend HIV-testing during prenatal care exclusively for “high risk women” (Secretaria de Salud 2012: 135).

My analysis of the aftermath of the delivery of the tests to primary care clinics in 2007-2008 shows that when the program is discretionary, it is ignored by some States and health-care institutions. To the extent that even when the rapid HIV tests were made available to them, rather than implementing prenatal HIV testing, some States allowed the tests to expire in warehouses or turned to civil society at the last minute to apply the tests with whatever populations they could find. My interviews in 2009-2010 documented that the federal Reproductive Health program was dedicating their core funding to other priorities; that the National AIDS Program was not providing State AIDS programs with sufficient HIV tests to cover the needs of pregnant women; and that, despite assurances given by some health-care administrators, there were stock-outs of HIV testing in primary care. In and of itself, the modification of NOM-007 or the General Health Law will not automatically transform institutional cultures in which there are significant gaps between paper and practice, appearance and reality. However, the specification that health-care institutions and providers are responsible for offering HIV testing during prenatal care can provide the justification for modifying funding streams and formulae, and a way for organized civil society

and women with HIV to hold institutions and individuals to account for cases of preventable perinatal HIV transmission.

### *7.5.2 Turning the tide of Mexican HIV epidemic: Promoting HIV Prevention among women*

#### *7.5.2.1 Short-term interventions: HIV Prevention Education*

The statistically significant association between pregnant women reporting multiple sexual partners and having a reactive HIV antibody test indicates that partner reduction and condom use should be promoted to Mexican women as HIV prevention strategies. Second, a proportion of pregnant women reported that their male sexual partner had HIV risk behaviour, and this was statistically associated with having a reactive HIV antibody test. Women's awareness of their male partner's risk behaviours can be an important motivation for reducing unprotected sex. An intervention study among low-income African American and Hispanic women in the United States who had a steady male partner and identified that the male partner had some type of HIV risk behaviour (other sexual partners, using drugs, or having been diagnosed with a sexually transmitted infection), found that a six session intervention focused on reducing HIV transmission risk in the context of a relationship decreased the number of unprotected sex acts and increased condom use at three months and a year follow-up (El Bassel et al. 2003, El Bassel et al. 2005). What is particularly important about this intervention is that both women who participated in the program with their male partner and women who participated in the program in a women-only group reported reduction in risk-behaviours for acquiring HIV (El Bassel et al 2003, El Bassel et al 2005). My study suggests the need to adapt and implement evidence-based strategies for reducing HIV transmission for Mexican women in stable relationships who identify that their sexual partner engages in risk behaviour for HIV acquisition such as sex with multiple partners, sex with other

men, drug use, or sex work. These models need to be adapted, piloted, and implemented in the Mexican context. HIV prevention and risk-reduction within the context of marriage and other marriage-like relationships must be the priority for HIV prevention among women in Mexico.

In the case of men who have sex with men and women, qualitative research from Mexico points to the need to implement HIV prevention interventions that are neutral with regards to sexual identity and take place in venues where high-risk behaviour for HIV-acquisition occur (Kendall et al. 2007:468-470; Ligouri et al. 1996; Silenzio 2003). Again, promising results exist from HIV prevention interventions with Latino men who have sex with men and women. For example, in the San Diego area, evaluation of a condom social marketing campaign tailored for heterosexually-identified Latino men who have sex with men and women found decreased unprotected sex with women as compared to baseline and significant increase in the number of men who said they were carrying a condom (Martinez-Donate et al. 2010). For Latino men from the “general population,” an intervention which trained lay health promoters from soccer teams in North Carolina found that men on soccer teams with a lay health promoter were more likely to report condom use, to have tested for HIV, and to have greater knowledge of HIV transmission and prevention when compared to men on soccer teams without a health promoter (Rhodes et al 2009). In addition to the evidence-based HIV prevention strategies, which are being implemented with men who have sex with men and male sex workers and drug users as part of the Global Fund project, these strategies targeted at men who have sex with men and women and men from the general population should be considered for implementation in Mexico.

#### *7.5.2.2 Short-to-Medium Term Interventions: SRH/HIV Integration*

In addition to providing universal access to HIV testing as part of prenatal care, allowing women to access interventions to prevent vertical transmission of HIV and know their HIV

diagnosis before they progress to AIDS, my analysis suggests the importance of effective integration of HIV and sexual and reproductive health. Two key actions in this regard are: 1) the need for health-care providers to address linkages between other sexually transmitted infections, HIV, and women's own sexual risk behaviour or that of her male partner; and 2) to respond to the linkages between HIV and gender-violence through screening and counselling.

With respect to integrating diagnosis and treatment of other sexually transmitted infections with HIV, I identified several cases of women who were in contact with the health-care system for sexually transmitted infections and did not receive appropriate counselling about the ineffectiveness of unilateral monogamy, recommendations to use condoms, or referrals for HIV testing. Research carried out in 2000 by the National AIDS Program found a lack of integration between treatment of sexually transmitted infections and HIV in the counselling and treatment plans recommended by Mexican physicians. While 63% of the physicians could correctly identify the sexually transmitted infection in the hypothetical case study and recommended appropriate treatment, only 43% said they would offer treatment for the sexual partner, 33% said they would counsel the patient to use condoms, and under a quarter (23%) said they would refer the patient for HIV-testing (Kendall 2009a: 155). Women diagnosed with sexually transmitted infections are either engaging in sexual risk behaviour themselves or have a sexual partner who is engaging in risk behaviour. When women present with an STI, it is a golden opportunity for physicians to raise the possibility of male sexual infidelity with women and promote condom use.

It is crucial to use this opportunity to highlight linkages between men's risk behaviours and women's vulnerability to HIV infection, thus "denaturalizing" men's risk behaviours. Partner-tracing of women with STIs not only prevents re-infection and is the standard of care, but also could provide an opportunity to promote men's use of condoms during extra-relational sexual

relationships. In this situation, the cultural authority of the physician may provide some counterweight to that of the man, thus increasing prevention behaviour. Clearly, people with sexually transmitted infections are at risk of HIV, as they are having unprotected sex, and they should be routinely referred for HIV testing. As well as the clear benefits for behavioural counselling of recognizing and responding to the links between HIV and other sexually transmitted infections, treating other sexually transmitted infections reduces the biological probability of HIV transmission (Grosskurth et al. 1995; Grosskurth et al. 2000; Rotheram-Borus et al. 2009: 151). The promotion of testing for sexually transmitted infections, including HIV, as a regular part of preventative health-care for sexually active adults can go a long way toward reducing the stigma of sexually transmitted infections and combating the HIV epidemic in Mexico.

Given dominant sexual norms and the fact that identifying STIs (including HIV) among women in stable relationships reveals the illusion of the Church doctrine on monogamy and the existence of the sexual double standard, it is important to promote this integration as part of clinical protocols rather than leaving it to the discretion of the treating physician. Mexico's Popular Health Insurance covers the diagnosis and treatment of most sexually transmitted infections, providing a financial mechanism for greatly expanding these kinds of programs within the context of family medicine and maternal-child health care (Secretaria de Salud 2012).

My research echoes the findings of international studies which also suggest that the exercise of gender-based violence by men is associated with higher rates of other types of HIV risk-behaviours, such as unprotected sex with high-risk partners and excessive drug and alcohol use; this nexus of violence and men's HIV-risk behaviour puts female partners at higher risk of HIV. To date, there has been little programmatic response to the linkages between HIV and gender-violence in Mexico. However, Mexico does have federal legislation to combat violence

against women and specific legally mandated clinical protocols obliging health care providers to screen for domestic and sexual violence and make referrals to legal and social support services (Secretaria de Salud 1999, 2009b). Effective implementation of this legislation and accompanying health care protocols have been slow in large part because many health care providers and decision makers share cultural norms that rationalize violence against women or consign gender-based violence to the private sphere as a “personal” matter (Herrera et al. 2006). My research suggests the need for health care provider training and programmatic actions that recognize the links between gender violence and HIV. Necessary steps include integration of clinical protocols and cross-reference between HIV and violence services (Gielen et al. 2000; Maman and Medley 2003). Specifically, women who report violence should be counseled on HIV, and HIV positive women should be screened for gender violence. Identification of gender violence needs to be an integral part of women’s health services, along with counselling and testing for HIV.

#### *7.5.2.3 Social transformation through progressive policy/programs*

I continue to believe that greater material equality and social recognition of women’s rights are needed to stem the tide of HIV infections among women. Research with Mexican women has shown that the very few who showed “new reproductive patterns and ideologies” were those who could exercise choice in all aspects of their lives because they were economically independent (Hirsch 2003; Sanchez-Bringas 2003). Clearly, the women with HIV who participated in my research are socially disadvantaged. At the time of my interviews with them, these women with HIV were living in financially precarious situations and few had the formal education or work experience to allow them to improve their economic situation. Despite this, many demonstrated that they were able to reconstruct their lives after the HIV diagnosis, frequently without the man who had transmitted the virus to them. Unfortunately their rejection of their male partners’

domination and struggle to make it on their own didn't come until after the diagnosis. The ability to walk away, combined with greater risk-perception for HIV, can provide women with an incentive for and real negotiating power to effectively address HIV and other sexually transmitted infections within the context of stable relationships. Mexico has much of the necessary legislation in terms of gender equality and gender violence in place to support women's rights. The challenge is making the vision of gender equality encoded in these legal frameworks a reality on the ground.

In addition to dissemination of the law and their obligation to follow it among public servants (e.g., teachers, physicians, judges and legislators), implementation of gender transformative interventions is a promising approach. Several interventions that focus on transforming dominant constructions of masculinity and femininity have found reductions in risk behaviours that are associated with increased HIV transmission, particularly gender-based violence. Some characteristics of these models are that they are participatory, work with groups and the larger community, and often incorporate structural interventions, such as microfinance. The Stepping Stones program, which was originally developed in Uganda and has now been used in more than forty countries in Africa, Asia, and Latin America, takes a participatory gender transformative approach involving critical reflection on gender inequality as a means of encouraging safer sexual practices. Evaluation of the program showed that it reduced herpes infections among men and women and intimate partner violence at two years follow up (Jewkes et al 2008). In Brazil, a participatory program with young men which critically analyzes dominant constructions of masculinity and provides positive male role models has been shown to reduce gender violence and increase condom use (Pulerwitz et al. 2006). The IMAGE project implemented in Southern Africa provided micro-finance to the poorest women in different communities alongside a participatory curriculum of gender and HIV education for the women and

for other community members. While the intervention was not found to significantly reduce unprotected sex with non-spousal partners or HIV incidence, it did reduce women's experience of intimate partner violence by half (Pronyk et al 2006).

To have the necessary impact on national gender norms, these programs would need to move from projects to institutional scale; for example, within school curriculum or by implementing critical participatory analysis on gender roles as part of the large scale conditional cash transfer, poverty alleviation program, *Oportunidades* (Opportunities). Undoubtedly, such challenges to dominant gender norms, and indeed the existing social order, will be fraught with resistance, as demonstrated by lags in implementation of Mexican legislation around gender-violence in health-care settings (Herrera et al. 2006). Nevertheless, given the role of dominant gender norms in increasing women's vulnerability to HIV infection in Mexico and globally, the fact that we have some proven tools at our disposal for transforming gender norms to promote HIV prevention is hopeful. One aspect of this transformation must be changes in perceptions of who is at-risk of HIV.

In Latin America, transformation of the social imaginary about women and HIV in the region can be kick-started by universal access to HIV testing during prenatal care. Like no other intervention, prenatal HIV testing can demonstrate that women with HIV are not "the other," but rather, they are us. PMTCT must be reframed, discarding arguments which reinforce the traditional and stigmatizing construction of women as vectors of disease, and focusing on the multiple benefits of perinatal HIV prevention for the woman as well as for the child. On the issue of marriage and HIV the jury is in: in both concentrated and generalized HIV epidemics, women's HIV exposure tends to occur in stable relationships. HIV has revealed as a fraud the patriarchal sex-gender system which gives men ownership over women's bodies and holds out the stable

union as women's highest aspiration and a safe haven. Actions which promote women's autonomy and self-determination are the way forward in response to this epidemic.

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<sup>1</sup> I use the terms prevention of mother-to-child transmission (PMTCT), perinatal HIV prevention and vertical transmission interchangeably. However, I recognize that some women with HIV prefer the term vertical or perinatal transmission because in the words of one activist “no mother wants to transmit HIV to her baby”.

<sup>2</sup> Review of relevant technical guidelines and national strategic plans confirmed that either long course AZT (from 14 weeks) or HAART are the treatments prescribed for women with HIV in Colombia, Guatemala, Honduras, Nicaragua, Mexico, and Peru. No specific written information was available for Bolivia or Paraguay but expert interviews confirmed that HAART or long-course AZT is what is offered. Single-dose nevirapine is not regularly used in any of these countries.

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<sup>4</sup> The average exchange rate of a Mexican peso for a Canadian dollar from August 2009 to May 2010 was .80 cents (see <http://www.bankofcanada.ca/rates/exchange/10-year-converter/>)

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<sup>5</sup> In fact, the INEGI estimate is 930 USD but, during the period under study, the Canadian and American dollar were at par in terms of exchange rate to Mexican pesos.

<sup>6</sup> See note 3.

<sup>7</sup> The literal translation of *pariendo chayotes* is giving birth to prickly pears. I believe the appropriate colloquial expression in English is “shitting bricks”.

<sup>8</sup> After completing the analysis presented in Chapter 1 which was based on 26 interviews with Mexican experts (decision-makers, United Nations representatives, HIV activists including women with HIV, and feminists active in reproductive health), I completed 7 more interviews with Mexican experts. The analysis of these interviews is included in Chapter 2.

<sup>9</sup> The literal translation is: “the one with more saliva swallows more pinole”. Pinole is a pre-hispanic drink from the State of Tabasco made from roasted and ground corn.

<sup>10</sup> The study published in 2003 modeled the cost-effectiveness using zidovudine or nevirapine monotherapy which are significantly less effective than HAART. This study also estimated infected children’s life expectancy at 7 years. The authors recognized these limitations and called for more research to pilot and validate the costs and effectiveness of the different models of HIV testing for pregnant women evaluated in the mathematical model (Rely et al. 2003).

<sup>11</sup> I discuss the precise wording of the CAUSES on the offer of HIV testing to pregnant women in the section on the normative framework.

<sup>12</sup> The literal translation is “Between words and deeds, there is a big distance”.

<sup>13</sup> Source: CONASIDA (Consejo Nacional para la Prevención y Control del SIDA), Comité de Monitoreo y Evaluación. 2007. Boletín del Grupo de Información Sectorial en VIH/SIDA No. 5 (2007), No. 6 (2008), No. 7 (2009), No. 8 (2010). Mexico City: CENSIDA.

<sup>14</sup> The questionnaire included a control number for each rapid HIV test, a check box to indicate the woman’s informed consent, the identifying information of the healthcare site and healthcare provider who applied the HIV rapid test, and sociodemographic information and risk-behaviors reported by the woman for herself and her male partner. An analysis of the questionnaire is presented in Chapter Three.

<sup>15</sup> As noted in the preface, the analysis conducted for this chapter was conducted with Dr. Estela Rivero of the Colegio de México. Dr. Rivero and I both participated actively in designing the research. With my input Dr. Rivero designed the statistical analysis and ran the models, while I conducted the literature review and wrote the manuscript. Given our equal contributions to this portion of the manuscript, I use “we” rather than “I” throughout this chapter.

<sup>16</sup> The questionnaire asked women about experiences of sexual violence. Rates were high, with 55.63% of the total sample reporting that they had experienced sexual violence. Non-reactive women were more likely than reactive women to report that they had experienced sexual violence (55.72% vs. 46.59%  $p < 0.001$ ). The statistically significant association between having experienced sexual violence and not having a reactive HIV antibody test remained in our analysis of the case-control sample ( $p < 0.001$ ). This finding is contrary to the international body of literature which associates experiences of sexual and physical violence with a higher probability of HIV infection among women (Campbell et al. 2008; Dunkle et al. 2004; Silverman et al. 2008). We have chosen not to present the data on sexual violence. However, this finding of our retrospective analysis suggests the need to analyze the relationship between violence against women and HIV infection in Mexico through a large prospective study.

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<sup>17</sup> Source: Centro Nacional de Equidad de Género y Salud Reproductiva and Centro Nacional para la prevención y control de VIH/SIDA, Secretaria de Salud. [National Centre for Gender Equity and Reproductive Health and National Center for the Prevention and Control of HIV/AIDS, Ministry of Health], Cedula para prevenir la transmisión vertical del VIH, Mujeres Embarazadas, Pruebas Rápidas [Form for preventing vertical HIV transmission, Pregnant Women, Rapid Tests], October 2006-December 2009. Tables 4.1 through 4.8 are based on analysis of the same source.

<sup>18</sup> This question was not asked of 15 of the respondents; no woman refused to answer how many lifetime sexual partners she had had, though the respondent with the greatest number of sexual partners reflected the social stigma by saying “*me da pena decirte*” (it embarrasses me to tell you). She chose to answer after being assured that the researcher would not judge her.

<sup>19</sup> The number of lifetime partners may be greater among women with HIV than women in the general population because of widowhood, divorce or separation related to the HIV-diagnosis.

<sup>20</sup> Fabiola became infected when cutting herself to make herself a “blood sister” with her younger sister. The younger sister (who was fourteen at the time of the transmission) was infected by a boyfriend who used and sold drugs and subsequently died of AIDS. Vanessa believes that she became infected when “one day on the street I got a tattoo and the needles weren’t clean”. She said she had always used condoms, except with the father of her child who she believes to be HIV-negative but she hasn’t discussed her HIV-status with him nor asked him about his status for fear of losing custody of their child. Paola most likely became infected through an occupational exposure (she is a health-care worker exposed to blood regularly who didn’t always use gloves), but could have been exposed by a previous sexual partner whose HIV diagnosis is unknown and who she believes had multiple sexual partners.

<sup>21</sup> Monitoring of pregnancy was much more intense post-diagnosis; women who were diagnosed during pregnancy or became pregnant knowing their HIV-positive status attended up to 30 prenatal visits.

<sup>22</sup> The CD4 is a test that measures the amount of CD4 (t-cells) in a millilitre of blood. It is used to monitor immune function of people with HIV. Viral load, which measures the amount of HIV virus in a millilitre of blood, is also used to measure disease progression and whether or not antiretroviral medications are working effectively. These tests are taken at a specialized laboratory. In Mexico City, Mexico State, and Morelos these tests are all processed by the specialized HIV laboratory at the National Institute of Respiratory Disease (INER). The standard medical protocol to confirm an HIV-positive test result would be an ELISA test which detects antibodies to the HIV virus, followed by a Western Blot which is used as a confirmatory test. Completing both of these tests in the public health-care system may take months, and going to a private lab is expensive. In order to expedite the confirmation of an HIV-positive result for pregnant women, HIV clinics in Mexico State send women to the INER for a viral load which permits confirmation of the HIV diagnosis, and allows them to begin antiretroviral treatment.

<sup>23</sup> Immunosuppression results in candidiasis or thrush, a fungal infection commonly known as a yeast infection. It can occur in the mouth and throat or genitals. Immunosuppression also seems to make women more predisposed to infection with HPV and the development of cervical cancer. Some studies have shown that asymptomatic shedding of herpes simplex virus is increased by HIV infection (Augenbraun et al. 1995). *Treponoma palidum* is the bacteria that causes syphilis and other related diseases. Cytomegalovirus is latent in about 60% of the adult population, but can activate and cause serious health consequences, such as blindness, in immunosuppressed individuals.

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