Women and HIV in Mexico: An exploratory analysis about experiences, expectations and health care needs in Oaxaca, Mexico

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ABSTRACT

Background: Women represent 25% of people living with HIV/AIDS (PLWHA) in Mexico. The prevalence of the infection among women is increasing, particularly in sub-urban and rural areas of the country. Most of the HIV transmission among women occurs by heterosexual transmission, through the woman's stable partner. Approximately 62% of HIV positive women in Mexico are diagnosed in advanced stages of the disease, in the presence of symptoms related to AIDS defining conditions. Mexico currently lacks tailored interventions to address women's risk of HIV acquisition.

Objective: Our objective was to explore risk perception, diagnosis circumstances and attitudes towards health care providers among HIV positive women in Oaxaca, Mexico.

Design: This was an exploratory qualitative study of HIV+ women living in Oaxaca, Mexico. The study was be conducted at the Ambulatory Center for HIV and STI's care (CAPASITS) located in Oaxaca, Mexico between May and July 2014. Each participant took part in a one time in-depth interview. We stratified our analysis by CD4+ count at the time of diagnosis: participants were divided into two subsets defined as early (CD4>200) and late (CD4<200) stage disease.

Results: Women living in this setting are not considered at risk of acquiring HIV infection. Their circumstances of diagnosis vary, according their age and their stage of diagnosis; but mainly respond to three different scenarios: during pregnancy, symptomatic and AIDS defining conditions or after a family member is diagnosed (usually with advanced disease too). HIV testing during pregnancy although mandatory, is still not universal. Most of the women narrated multiple quests seeking healthcare when symptomatic, in which they were not tested for HIV. HIV diagnosis as a screeening procedure was not described in non-pregnant women in our study.

Conclusions: Increasing the timely diagnosis of women in a is a priority, both from the individual perspective as well as from its implications for HIV MTCT. Specific preventive and therapeutic measures, tailored for these populations should be designed and implemented. We suggest starting by optimization of HIV screening during pregnancy and universal testing strategies.

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CHAPTER 1

1.1 Introduction

Women represent 25% of people living with HIV/AIDS (PLWHA) in Mexico. This proportion has been increasing progressively over the last 10 years (1,2). According to population-based studies, most HIV transmission among women occurs heterosexually and in the great majority of the cases, the source of the infection is the woman's stable partner (3). Especially in rural settings, marriage is the single greatest risk for HIV acquisition (4).

A unique set of social determinants seem to shape women's risk of HIV acquisition in Mexico: gender roles, migration, domestic violence and economic dependency. According to the limited published information regarding the HIV epidemic among women in Mexico, the likelihood of being diagnosed in asymptomatic stages of the disease is very low for non-pregnant women (5).

A recent quantitative study conducted by Martin-Onraët et al, explored the diagnosis characteristics of a sample of 300 women from Mexico City, Puebla and Oaxaca. They observed that approximately 62% of HIV positive women in Mexico are diagnosed in advanced stages of the disease, with symptoms related to AIDS defining conditions (5). Of the 38% who are diagnosed in the asymptomatic phase of the infection, 68% are tested only after a relative's diagnosis (partner or children) has been established (5). Although offering HIV testing during pregnancy is mandatory according to national guidelines, testing remains under 60% according to recent data (6). Interestingly, healthcare seeking related to ADC symptoms represents one of the most important determinants of late diagnosis among HIV+ women in Mexico (5). As the number of medical visits before diagnosis increased, the CD4+ cell count significantly decreased. Regardless of the increase in HIV incidence among women in stable relationships, the existing scientific literature has primarily focused on populations of women who are considered to be “high risk”: migrants (7), sex workers (8), drug users (9) and women living near the US-Mexico border (10). Despite evidence to the contrary, monogamous women with stable partners are often not considered by healthcare providers to be at risk for HIV. This reveals a lack of awareness among health care providers and highlights the potential impact of missed opportunities on late diagnosis.

From women’s standpoints, little is known about their perceptions, attitudes and beliefs regarding their relationships, HIV risk awareness and diagnosis disclosure. Due to cultural and social norms, Mexican women often have little decision-making power regarding their own sexuality, particularly in matters of condoms and contraception (11). They may consider themselves incapable of influencing their partner’s sexual behaviors, even when they are aware of their risk of acquiring HIV (12). Belief in partners’ sexual fidelity and monogamy may hinder preventive measures and even risk perception (4). A recent study by Kendall et al revealed that HIV status disclosure by Mexican women to their partners often resulted in physical (7.2%) and psychological (26.5%) violence. HIV-related discrimination from healthcare providers was reported by 60% of the women in this study (13). There are therefore multiple barriers to the implementation of appropriate preventive strategies targeting this vulnerable population.

Oaxaca State is one of the poorest states in the country. It has the second highest rate of migration to the United States, surpassed only by Michoacán, and the 9th highest rate of HIV prevalence (1,14). In recent years, the male-to-female ratio of AIDS cases in Oaxaca has decreased, from 4.5 men per woman to 3 men per woman. Mortality rates for both men and women remain high despite universal access to antiretroviral therapy (ART). When excluding diagnosis during pregnancy, HIV diagnosis occurs in the presence of symptomatic disease or a relative's HIV diagnosis.

Effective culturally appropriate programming is a critical need in today's HIV epidemic. In both the academic and policy arenas, women living with HIV/AIDS require more attention. In order to adequately address this vulnerable and understudied population, we need evidence-based and effective interventions that can promote timely diagnosis and retention in care for Mexican women. We conducted this qualitative study to improve our understanding of the experiences of women living with HIV in Oaxaca, Mexico. The Ambulatory Centers for Prevention and Care of AIDS and STI's (CAPASITS) is the largest center for HIV treatment and prevention in Oaxaca State. The data presented here will help us to better understand the context of these women's lives and inform intervention strategies in order to improve the diagnosis and treatment experiences of women in the region.

1.2 Significance

Although the proportion of HIV+ women is increasing in the country, there are currently few interventions attempting to improve HIV treatment and prevention in this specific population. The delay in HIV diagnosis among women of reproductive age has critical implications for women's health, as well as the potential risk of mother to child transmission (MTCT).

1.3 Problem statement

The high proportion of HIV+ women who are diagnosed in advanced stages of disease reflects a lack of awareness among health care providers, as well as misperceptions on the part of women themselves in their risk of becoming infected.

1.4 Objective and specific aims

The goal of the proposed project is to understand the circumstances that surround HIV diagnosis and care seeking among women living with HIV in Oaxaca, Mexico.

Specific aims

- To assess women's perception of healthcare providers' attitudes towards their diagnosis.
- To understand the social factors involved in HIV diagnosis among Mexican women, including HIV status disclosure, household dynamics, and risk perception.
- To provide feasible recommendations that could increase timely diagnosis and improve linkage to and retention in care among women living with HIV in Oaxaca.

CHAPTER 2

2.1 Epidemiology

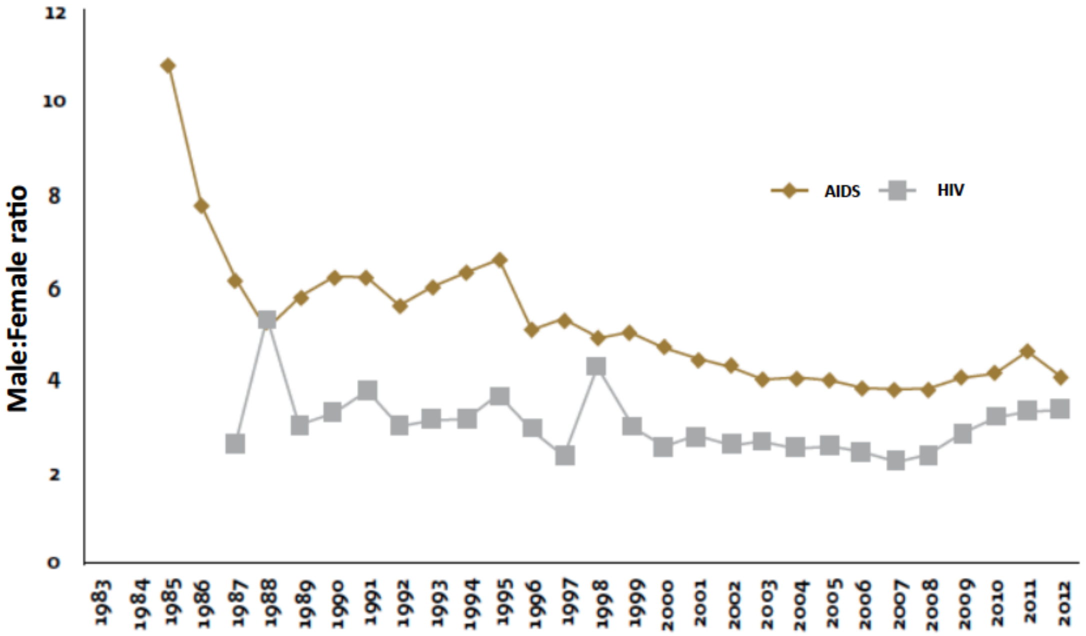
2.1.1 The HIV epidemic in Mexico and its prevalence among women

It is estimated that there are approximately 225,000 PLWHA in Mexico, with a global prevalence of 0.3%. The majority of PLWHA in Mexico are men who have sex with men. However, changes in transmission dynamics and new at-risk populations are being identified. In 2013, there were 5,449 new HIV diagnoses. The states with the highest incidences were Mexico City, Veracruz, Chiapas, Guerrero and the State of Mexico (1).

Women represent 25% of PLWHA in Mexico (1), with an overall prevalence of about 0.2%. In the first trimester of 2014, there were 44,395 reported cases of women living with HIV/AIDS in the country. Thirty-seven percent of new infections occur among women between 15-29 years of age (2). The proportion of women living with HIV/AIDS in Mexico has changed drastically in the last 10 years. At the beginning of the epidemic, the male-to-female ratio for HIV infection was approximately 11:1. The highest prevalence among females was observed in women in prison (1.4%) and sex workers (0.35%) (15). Currently, this ratio ranges from 3:1 to 5:1, depending on the region of the country (Figure 1). The geographic distribution of women living with HIV/AIDS is highest in the U.S. border states (Baja California Norte and Baja California Sur) and in the most marginalized regions with higher proportions of indigenous populations, gender inequality, and migration rates (Chiapas, Veracruz, Guerrero, Oaxaca, Tabasco) (16).

Figure 1. Male-to-female ratio of HIV and AIDS cases in Mexico from 1983 to 2012.

Source: CENSIDA (17)



Of the 44, 395 ever-diagnosed cases of women living with HIV/AIDS in Mexico, only 27,054 were alive by 2013 (60% of the total). This figure includes both AIDS-related and non-AIDS related deaths. Since the availability of universal access to antiretroviral therapy in 2001, overall mortality due to AIDS has declined in the country, with a total reduction of 0.7 deaths per 100,000 habitants (18). However, the AIDS-related mortality rate among women living with HIV/AIDS has increased in the last years, from 1.19 in 1999 to 1.48 in 2004 and 1.64 in 2012 (14). There is no clear etiology of the cause of this rise in mortality, but it may be related to an increase in the number of detected cases among women.

Population-based studies conducted across the country have shown that most HIV transmission among women occurs heterosexually, and in the great majority of cases the source of infection is the woman's stable partner (3). Especially in rural settings, there has been an increase in heterosexual transmission, and marriage represents the single greatest risk for HIV acquisition (4). This has also been observed among women living in urban areas (19). Women living with HIV/AIDS may be unaware of their HIV status for two main reasons: either their male partners are also unaware of their infection, or they are hiding their HIV status from their wives.

Despite the increase in HIV incidence among women in stable relationships, the existing scientific literature has primarily focused on populations of women who are considered to belong to "high risk" groups. Thus, previous published works addressing the HIV epidemic among women in Mexico included migrant populations (7), commercial sex workers (8), intravenous drug users (9) women living near the US-Mexico border (10) and women in prison (11). Other special populations described in the literature are women whose partners are military personnel, intravenous drug users, migrants or prisoners (11). Literature addressing monogamous women with stable partners is scarce in Mexico and the Latin American region in general.

2.1.2 HIV in Oaxaca

Oaxaca is the capital of Oaxaca State, one of the poorest states in the country. Fifty-eight of the 125 "highly marginalized regions" in Mexico are located in this region. Marginalization is an indicator that summarizes the impact of shortages observed in a given population. It includes lack of access to education, household conditions, monetary income and size of the locality. By 2013, Oaxaca had nearly 4 million inhabitants, which makes it the 10th most populated state in Mexico. Seventy-seven percent of the population is urban. Sixty percent of the municipalities with "high gender inequality" (measured by an index based on indicators of reproductive health, empowerment, and workforce participation), are located in Oaxaca (20). The state has the highest number of people who speak an indigenous language in the country, at 34%, and the second highest rate of migration to the United States, surpassed only by Michoacan (14). It is largely Roman Catholic (81%), as is the rest of the country (83%).

Oaxaca has the 8th highest HIV prevalence in Mexico, and a significant proportion of the indigenous population who are HIV infected is located in this state (1). When only considering women, the state has the 4th highest number of accumulated HIV/AIDS cases in the country, preceded by Chiapas, Guerrero and Veracruz (1,2). Altogether, various determinants of vulnerability among women seem to converge in this region of Mexico: marginalization and poverty, low levels of education, high migration rates and gender inequity.

In recent years, the male-to-female ratio of AIDS cases in Oaxaca has decreased (4.5:1 to 3:1), and mortality rates for both men and women remain high in spite of universal access to antiretroviral therapy (ART) (1). A recent quantitative study (5) addressing women living with HIV/AIDS from Mexico City, Puebla and Oaxaca showed that the mean CD4+ cell count at diagnosis was significantly higher among women from Oaxaca than other participating sites. This appeared to be related to a greater proportion of women being diagnosed during pregnancy in Oaxaca in asymptomatic phases of the disease. When excluding diagnosis during pregnancy, circumstances for HIV diagnoses seem to be very similar to those observed in other regions of the country: women were diagnosed in the presence of AIDS defining conditions, or a relative's HIV diagnosis. Forty-four percent of the participants in this study had a history of seeking medical services before they were diagnosed. Other interesting findings were that the proportion of women diagnosed with HIV who were under age 30 and who spoke an indigenous language was higher among participants living in Oaxaca. Many questions remain regarding the dynamics of HIV diagnosis that could logically explain these findings.

2. 2Women and HIV: Vulnerability and other social determinants

2.2.1 Defining vulnerability and its relationship to HIV: General overview

Women face specific circumstances and challenges in terms of their risk for HIV acquisition, some of these relate to cultural norms, education and socioeconomic status**.** Even in developed countries, differences in clinical characteristics and outcomes between men and women living with HIV have been identified. These differences seem to be explained mainly by socio-economic factors, as women generally have lower socioeconomic status when compared to men. Data from a Swiss cohort study with a 10-year follow-up of both men and women, observed that women had lower educational levels. They also showed lower levels of virological suppression after one year of ART (22), which may be related to higher ART discontinuation rates among women. In the National French Cohort, which looked at causes of death by gender, they observed that women living with HIV/AIDS often originated from Sub-Saharan Africa, and had worse socioeconomic conditions when compared to men. Although gender was not a risk factor for death in this cohort, the proportion of men who died from AIDS decreased from 2000 to 2005, while in women there were no changes in AIDS-related mortality during the same time period (23).

To our knowledge, there is no scientific literature in Mexico comparing clinical and mortality outcomes between men and women living with HIV.

Women can be vulnerable to HIV for many different reasons, alone or in combination. Some authors include inequity, domestic violence and sexual violence in their definitions of vulnerability (24). In general, any situation that puts an individual in a disadvantageous circumstance, whether physical or social – including stigma, discrimination or human rights violations – can be considered vulnerability. In the specific case of women, those who live in patriarchal societies, who have been physically or emotionally assaulted, and those living in remote and marginalized areas with poor access to services are considered vulnerable.

2.2.2 Domestic violence

Violence against women is an important determinant of HIV risk. Existing evidence from different countries and ethnicities has shown intimate partner violence to be an independent risk factor for HIV acquisition (25-27). In a study conducted in Mexico in 2011, 41.6% of women reported experiencing violence from their male partners. The most frequent form of violence was emotional (40.6%), followed by economic (23.8%), physical (13.5%), and sexual (7.3%) (28). Socioeconomic structures that favor women's dependence exacerbate these forms of violence, hindering autonomy and reducing the possibility for women to reject undesired sexual encounters.

Studies conducted in developing countries other than Mexico have identified clear relationships between violence and HIV risk. In a longitudinal study conducted in South Africa (29), the authors observed a temporal association between intimate partner violence and the risk of HIV acquisition in the female partner. Women experiencing more gender inequality and different forms of violence were more prone to acquire HIV in a two-year period than women with lower exposure to these situations (41% vs. 30%, p=0.019). Thirty-five percent of the women who had acquired HIV by follow-up reported being victims of violence (both sexual and physical) at least once, and 23% of newly HIV infected women reported five or more episodes of sexual or physical abuse, compared to 12% of those who remained HIV negative (p <0.0001).

Although recent information is lacking, mixed methods studies conducted in the late 1990s showed that women living with HIV/AIDS in Mexico (like HIV-negative women) were responsible for all the domestic duties in their households (22,30). HIV diagnosis did not influence the sharing of domestic duties among family members, even in the presence of illness. Although domestic duties are part of the gender construction of women in the country, in this context they reflect the inequality experienced by women living with HIV/AIDS in the household context.

2.2.3 Gender inequity and men's risk of HIV infection as determinants of women's risk

As expected, women's vulnerability to HIV is closely linked to that of their male partners. In addition to the poverty, exclusion and violence that men suffer, dominant ideas about masculinity shape heterosexual men's risk. These ideas can encourage men's involvement in high risk sexual relationships, including when they are under the influence of alcohol and drugs (31). Data from a survey conducted in 2001 in Mexico City among men who were married or in a consensual union for at least one year revealed that 15% had extramarital sexual intercourse, with only 22% using a condom with their secondary sexual partner. Eighty percent of the men surveyed considered themselves to be "without risk" for HIV acquisition. This suggests that the lack of risk perception is present for males as well as females. Is it notable that no more recent studies have been conducted addressing this issue in Mexican population.

Access to education is unequal by gender in Mexico. As another marker of social inequity between genders, lack of knowledge has been associated with worse health outcomes, limited access to healthcare, and fewer preventive practices. It has been proposed that women's sexual behavior may be related to a lack of knowledge. However, according to available data, Mexican women seem to be aware of the existence of HIV infection and its modes of transmission. In a study conducted in Morelos among women accompanying migrants, 95% of them were aware of routes of HIV and other STI's transmission (32). However, they found themselves unable to negotiate condom use with their male partners during sexual intercourse. This inability to negotiate safer sex is therefore likely related to other socio cultural factors affecting the circumstances under which sexual encounters take place; and not to a lack of knowledge regarding routes of HIV transmission.

2.2.4 Indigenous women and women living in rural areas

Indigenous women and those living in rural areas are especially vulnerable to HIV acquisition for several reasons, including poor access to healthcare (living in remote communities, geographic dispersion), economic dependence, gender inequity, and socially-prescribed submissive behavior (33). Demographic surveys conducted among indigenous women aged 15-54 years looked at condom use during sexual encounters as well as reasons for not using them. Among those who reported not using them, 23% of women stated that they did not know how to use them or were unaware of their existence; 20% stated they were menopausal and 16% declared that either they or their sexual partners were not comfortable with using them (32). Furthermore, indigenous populations may be more difficult to include in both qualitative and quantitative research projects. Language can be a barrier for indigenous women to participate in in-depth interviews, in the absence of a skilled interpreter.

2.2.5 HIV and migration

Both internal migration and migration to the United States have been identified as risk factors for HIV acquisition in the Mexican population, and studies suggest that the ruralization of the HIV epidemic in Mexico is directly related to migration patterns. In the last 30 years, the migratory influx to the United States has increased 13-fold; and a considerable proportion of these migrant populations originate from rural and remote areas in southern Mexico (7,22). Numerous published works have found that migrant populations frequently have more high-risk behaviors, more sexual partners, and higher substance abuse rates than non-migrant populations (9,21,32). The risk of acquiring HIV among migrant males is 10 times higher than the general population in the United States, and this risk is transmitted to their female sexual partners when they return to Mexico. By the time Mexican young men are looking for a relationship with marital intent, they have already had migratory experience. In fact, it seems that migration has become a ritual of masculinity in some rural settings (31,34). The process of HIV infection in these settings occurs in two phases. First, men who travel without their wives have unprotected sexual encounters with sex workers, other women, or men (34); they may also experience intravenous administration of antibiotics, vitamins or illegal drugs. When they return to their communities in Mexico, they then have unprotected sexual intercourse with their female partners.

Similar risk factors have been identified in the case of internal migration. Internal migration refers to migration within the country, from one state to another, frequently related to the availability of work. This occurs predominantly in the states of Veracruz, Puebla, Oaxaca, the State of Mexico and the Federal District. In a study conducted in 2000, the risk of HIV infection among internal migrants was 1.6 higher than the general population (35). A qualitative study on women who migrated internally found that labor migration was frequently a consequence of previous relationships dissolution, and often led to new sexual relationships. The majority of the participants in the study reported either known or suspected infidelity from their previous or current male partners. Nevertheless, condom use among interviewees was low. Therefore, their risk of HIV was related to their previous male partner's behaviors, in addition to the absence of a social network, autonomy, economic independence, and an inability to negotiate safer sex practices (13).

2.3 Social construction of sexuality in Mexico and its impact on HIV risk

To understand the HIV epidemic among women, we must first understand gender roles and expectations. In Mexico, the social organization of sexuality is based on a lack of recognition of women's sexual desire (36). This hinders preventive practices that assume planning and anticipation of sexual encounters. Moreover, the dominant social construction of gender identifies motherhood as the primary duty of women. This role is often associated with blame, abnegation and superimposing others' needs over women's personal wellbeing. Some of these cultural perceptions may help explain why women living with HIV/AIDS in Mexico experience late presentation and high mortality rates, despite universal access to cART for more than 10 years now.

Another important piece in the construction of sexuality is based on "social class". According to Hirsch et al, (37) attitudes toward fidelity are related to economic independence and education. When asked what their reactions would be if they discovered a partner's infidelity, educated and economically independent women answered that they would leave their husbands, as opposed to women with lower levels of education and economic dependence. Women expressed that they needed a male partner in order to be socially respected, under the argument that the man represents "the respect of the house"; social stigma around divorce is remains strong in rural Mexico.

Marriage is linked to strong beliefs about sexuality and reproduction, many derived from Catholic religious practices. Female virginity is not only appreciated by men, it is a socially required attribute for a woman to be considered marriageable. In rural settings, especially in Michoacan and Oaxaca, kidnapping a virgin woman, getting her pregnant, and migrating to the United States now symbolically represent masculinity; it gives prestige and social status among men living in the same community (32). As a man, being able to impregnate a young woman proves virility; since sexual intercourse implies a reproductive goal in this case, this could partially explain men's reluctance to accept condom use.

On the other hand, "condom negotiation" with male sexual partners is usually interpreted as mistrust. This situation may result in an undesirable distance among couples in the case of love-based relationships. Qualitative studies have shown that in both courtship and marriage, suggesting condom use is interpreted as a "threat" to the relationship. According to social norms, asking for condom use during sexual intercourse is inconsistent with the cultural constructs of trust and fidelity. In the case of more contractual encounters, the suggestion of condom use could trigger violence and accusations of infidelity (4,15).

It is still common in some regions of the country –including Oaxaca- to observe “women kidnapping”. Currently, the “kidnapping” is no longer non-consented, but occurs as a consensual escape between the woman and her “kidnapper”. Women in union through “kidnapping” must be 15 years old or younger, and their virginity must be proven the day of the abduction. After the night of the robbing, the “kidnapper’s” family looks for the father of the new “bride”, to apologize and decide the civil wedding date. If the woman’s father agrees, then the woman’s new residency is settled at the man’s paternal house. Women in union after kidnap suffer from stigma from those women who are married under religious Catholic tradition. This situation impacts these women’s social network. After the ritual, men migrate to the United States, and women stay with their (now) husband’s family. These dynamics often involve economic dependence, and domestic violence frequently exerted by the mother in law (32). Since the main reason of this union is reproduction, this in some way explains the lack of condom use during sexual intercourse. It is a widespread belief that pregnant women will be “easier to control”, and that the possibilities of the woman being unfaithful while they are pregnant are reduced.

On the other hand, men’s extramarital sexual encounters, although not openly accepted, are often tacitly known by women. These extramarital sexual encounters can occur with men or women who are paid for sex, as well as casual acquaintances with neighbors or male friends, and form part of the social construct of masculinity in rural Mexico. The strong concept of sexual reputation in the Mexican context obliges men to seek “socially safe” sexual partners over “physically safe” ones (37). Since social reputation is fundamental in rural societies in Mexico, the “socially safe” sexual partner is considered as one that can be “hidden” from the man’s wife and social network. Men should be able to keep their extramarital relationships private. Preventing the dissemination of knowledge of their infidelity is a sign of respect to their wives and children, as well as a feature of masculinity. “Socially safe” partners are usually either women or men living in different towns or cities; they may also be commercial sex workers or bisexual men. Apparently, “physical safety” (understood as presenting a “low risk of acquiring HIV”) is not a characteristic that men take into account when choosing extramarital sexual partners. Homoeroticism among men who are socially considered “heterosexual” - although present in many communities in Mexico - is constantly denied and considered socially unacceptable (38). These “clandestine” sexual practices increase the HIV risk for monogamous wives.

2.4 Barriers to HIV care among women

Prior research has identified several barriers that prevent women from enrolling in HIV care and starting ART. In developing countries, a considerable proportion of patients are lost to follow up or have poor adherence to their ART (39). Among women, economic dependency and fear to disclose HIV status are among the frequent barriers that hinder healthcare. Stigma associated with being identified as HIV infected by other members of the community when seeking center forces women to receive medical care from traditional healers and other informal services (40, 41).

Women interviewed in Morelos, Mexico stated that family members often represented a control mechanism. Family members (particularly the mother or the mother in law) would accompany them to their medical consultations; compromising their privacy and making it difficult for women to access sexual and reproductive health services (32).

They perceived a lack of independence and ability to freely ask for sexual and reproductive health services, including both preventive care and treatment. In order to attend a medical consultation unaccompanied, women often kept their medical visits secret from other family members, which adds difficulties to obtaining regular services and follow up.

These barriers to health care are directly related to the worsening health circumstances, poor quality of life, and lack of opportunities for successful treatment among PLWHA. Approximately 62% of HIV positive women in Mexico are diagnosed in advanced stages of the disease, and exhibit symptoms related to AIDS defining conditions. Of the 38% who are diagnosed in the asymptomatic phase of the infection, 68% are tested only after a relative's diagnosis (partner or children) has been established (5). Interestingly in one of the studies conducted among women, healthcare seeking related to symptoms of AIDS defining conditions represents one of the strongest determinants of late diagnosis among women in Mexico. These results suggest that single, non-pregnant women are currently not being reached by HIV testing strategies in Mexico.

2.4.1 HIV testing during pregnancy

One of the main opportunities for timely diagnosis among women is HIV testing during pregnancy. Prenatal HIV testing has a double impact, by detecting the infection of the mother and by preventing vertical transmission. Although in Mexico offering HIV testing during pregnancy is mandatory according to national guidelines (42), testing remains under 60% according to recent data (6). This proportion varies from one public institution to another, however, all public healthcare institutions are far from meeting the 100% HIV testing during pregnancy requirement (16).

Data from a general hospital in Guanajuato, Mexico showed that 85% of women who were offered HIV testing during pregnancy accepted being tested. Of those who did not accept, 32% said that they only had sexual intercourse with their husbands and 23% stated that they had no authorization from their husbands to be tested. It is worth mentioning that the two main reasons to reject testing during pregnancy clearly relate to arguments presented above. First, monogamous women do not perceive themselves to be at risk for HIV infection, and second, societal roles and power-based relationships negatively impact the acceptability of HIV testing during pregnancy. Women who rejected HIV testing had lower wealth quintiles and were more likely to be in their first pregnancy (43). Although these data only represent one state in the country, this study suggests that that acceptance to get tested among pregnant women is high. The low proportion (about 60%) of HIV testing among pregnant women may therefore be due to professionals not offering the test. Furthermore, women receiving prenatal care seem to be unaware of the mandatory character of HIV testing during pregnancy.

2.4.2 Other potential barriers to health care among women living with HIV/AIDS in Mexico

Qualitative studies conducted in Mexico City, Querétaro and Oaxaca have shown that Mexican women associate HIV infection with death and domestic violence (5,44). The fact that the infection is perceived in such a negative way could also affect attitudes towards testing and healthcare centers that focus on HIV+ patients.

There is also evidence that HIV+ women in Mexico have unmet healthcare needs, and that the quality of healthcare is perceived to be suboptimal, both in interpersonal and technical aspects (15). Some studies have revealed that women perceive their healthcare providers as non-empathic or uncaring about their health or personal issues.

A recent study by Kendall et al revealed that Mexican women's HIV status disclosure to their partners sometimes resulted in physical (7.2%) and psychological (26.5%) violence. HIV- related discrimination from healthcare providers was also reported by 60% of the women (44). The sum of these conditions may partially explain late diagnosis, and the current lack of appropriate preventive strategies directed to this vulnerable population.

2.5 Current interventions

Successful interventions for HIV prevention in Mexico have been predominantly implemented and evaluated among particular groups considered "at risk:" migrants, women living on the US-Mexican border and intravenous drug users (45). Informational talks, workshops and other strategies to improve awareness have been shown to be effective in these populations. Studies on the US-Mexican borders have used approaches based on community healthcare workers ("promotoras") holding "informal meetings" for women, as well as the use of social networks ("Pasa la Voz" strategy) (46). Some of the positive results observed with these interventions include, 1) a reduction in the rate of sexually transmitted diseases (STD's), 2) an increase in condom use, 3) an increase in acceptability to be tested for HIV.

During 2014, a Guideline for Women's Sexual and Reproductive Health and HIV (47) was designed in order to offer more comprehensive sexual and reproductive health services to women. The guideline was developed by a multidisciplinary group comprised by physicians, anthropologists, sociologists and gender specialists; it addresses multiple topics, such as women's rights, sexual assault, STDs, HIV counseling and care.

Nevertheless, many of Mexican women's needs regarding HIV infection are still unresolved. Diverse mechanisms deter women from seeking appropriate healthcare services, both for prevention and diagnosis. Once diagnosed, HIV positive women still lack well-designed interventions that adequately address their health and wellbeing. The design of adequate preventive care, counseling, and treatment strategies for women should be a priority. Our aim is to understand their experiences and contribute to the process of building comprehensive services for this vulnerable and underserved population.

CHAPTER 3

Methods

3.1 Study design

This qualitative study complements a previous quantitative analysis conducted in three different regions of Mexico, including Oaxaca State. Since this is a highly sensitive topic, we chose to conduct individual in-depth interviews, as they allow adequate privacy and confidentiality while also allows gathering data on diverse personal experiences and thoughts about specific questions (48, 49). Participants were HIV+ patients currently receiving health care at the Ambulatory Centers for Prevention and Care of AIDS and STI's (CAPASITS). Two different subsets of HIV + women were interviewed; the sample was stratified by their clinical status at the time of diagnosis. The first subset consisted of women diagnosed in advanced stages of the disease, defined for the purposes of the study as having less than 200 CD4+ cells/mm^3 and/or AIDS defining conditions at the time of diagnosis. The second subset were women diagnosed in asymptomatic stages without AIDS defining conditions, and/or with CD4 cell counts > 200 cells/mm3. . The rationale for this stratification was to observe the different patterns of diagnosis and risk perception between these two subsets of participants.

In-depth interviews

The interview guide (Appendix 1) was used to orient questions throughout the interview. It started with opening questions that helped build rapport between the interviewer and participant and proceeded with key questions covering seven main domains as well as probes to facilitate further discussion on some of the questions. The specific domains were explored as follows:

Theme/Domain	**Research questions**	**Interview guide questions**
HIV general knowledge:	What is the current knowledge women have regarding HIV transmission? Could their knowledge regarding HIV help explain their risk perception as well as their understanding of potential measures to prevent their risk of HIV acquisition?	*First, what did you know about HIV before you were diagnosed?* *How do you think you acquired HIV infection?* *Why do you think infection could not be prevented?*
Risk perception	How did women perceive their own risk of HIV acquisition? What factors influence this "risk perception"?	*How did you perceive your risk for HIV before diagnosis?* *If you ever felt at risk, can you tell me what you did?*
Diagnosis circumstances	What was the situation in which diagnosis was established? What were the reasons for HIV testing? How was women's experience regarding their trajectories through healthcare services?	*Can you tell me about when you were diagnosed with HIV?*
Household dynamics	How are duties and responsibilities in the household distributed? How is women's relationship with the members of the household?	*Who do you live with?* *Who are the persons of your family that you trust the most?* *Tell me, what does the typical day of your life look like?*
Partner dynamics	How was participant's relationship with her male	*How is your relationship*

	partner before and after HIV diagnosis? How is this relationship related to her diagnosis circumstances and risk perception?	*with your partner/husband?*
HIV status disclosure and social support	When did disclosure occured and to whom was the diagnosis disclosed? What were the reactions of those to whom the diagnosis was disclosed?	*When you were informed about your HIV diagnosis, whith whom did you share the results?* *What was the reaction of those people when you told them about your diagnosis?*
Perception of healthcare services and providers	What are the attitudes towards healthcare providers among the interviewees? How do they envision healthcare professionals? How are their attitudes towards HCP related to their circumstances at diagnosis?	*Can you tell me your opinion of health care providers, in relation to your diagnosis?* *Tell me about the different health care providers you have seen, regarding your HIV diagnosis.*
General recommendations	What are the needs of Oaxacan women living with HIV ? What recommendations do these women have to better cope with HIV diagnosis in their daily lives?	*What do you think could help HIV positive women?* *What would you tell to other women your age about HIV?*

3.2 Setting

Recruitment and interviewing was conducted at CAPASITS. CAPASITS is an ambulatory center located 10 miles from Oaxaca City, the capital of the state. This center offers integrated services for HIV positive patients from different regions and municipalities. Oaxaca state has two of these centers: one in Salina Cruz, the coastal region of the state, and one in San Bartolo Coyotepec, where we conducted the study. There are approximately 1000 HIV positive patients receiving HIV care in this venue. The services include laboratory testing, psychological consultations, social services (financial aid, transportation, etc), medical consultations, pharmacy (patients pick up their medication monthly), dermatology, dental care and gynecology. Both antiretroviral therapy and laboratory testing for HIV routine care are free of cost for all patients. Patients who require hospitalization are referred to a tertiary care center or a general hospital, both located in less than 15 miles from CAPASITS.

3.3 Procedures

Interviews were conducted in comfortable settings that prevented interruptions and maintained participants' privacy, most often in medical or psychological offices within the CAPASITS facilities.

At the beginning of the interview, participants received a brief introduction informing them of the purpose of the interview, and providing information related to confidentiality. The interviewees received information regarding their right to stop the interview, or to decline to answer specific questions at any time during the interview. All participants signed a written informed consent, and were asked for permission to record the interview. For illiterate women, a rubric or fingerprint was used in lieu of a written signature. In these cases, informed consent forms were read to the participant and explained. Interviews had an average duration of approximately 40 minutes and were conducted in Spanish. All in-depth interviews were conducted by a Mexican female infectious disease physician with training in qualitative methods. Two pilot interviews were conducted before the interview guide was finalized; some slight modifications to the guide were made according to the feedback we obtained. Notes were taken during and after the interview, and these were also part of the data utilized for the qualitative analysis.

3.3.1 Selection and enrollment of subjects

Subjects invited to participate were women living with HIV/AIDS who were receiving their regular HIV care at CAPASITS. Participants were required to be 18 years old or older, and their HIV diagnosis had to be established after Jan 1st 2011. The somewhat arbitrary limit of 3.5 years since diagnosis reflected our aim of understanding the experience of recent diagnoses under current diagnosis circumstances. Other requirements were ability and willingness to understand and complete a written informed consent; and ability and willingness to participate in an in-depth interview.

Women who acquired HIV through vertical transmission were excluded from this study, as the dynamics and circumstances of their infection are different, and do not involve the topics of interest for this research study. Other exclusion criteria were being under age 18, being unwilling or unable to understand and sign a written informed consent and/or being unwilling or unable to participate in an in-depth interview.

This protocol was submitted to both Emory University's Institutional Review Board (IRB) and the CAPASITS Ethics Committee and was approved by both institutions prior to implementation. Potential candidates were identified by the CAPASITS staff when they arrived for services and referred to the interviewer. The interviewer then invited women to participate in the study. We conducted 20 in-depth interviews in each subset of the eligible population, at which point we reached saturation in both groups.

3.3.2 Participant compensation

Patients did not receive economic compensation for their participation in the study. This was explained to all participants prior to their enrollment in the study.

3.3.3 Data Collection

In order to maintain a certain level of consistency, the interview guide was followed as closely as possible in each interview. However, given the semi-structured nature of the interview, some domains were approached in a different order, using additional or fewer probes, or different wording.

3.4 Data Analysis

3.4.1 Transcription and data management

Digitally recorded interviews were downloaded by research staff on password protected laptops. No personally identifying information was recorded. The recordings were transcribed verbatim and then stripped of all identifying information by the interviewer.

3.4.2 Data analysis

The transcripts were then imported into MaxQDA 11 (Verbi GMBH, Berlin), a qualitative analysis software package which permits the analysis of extensive amounts of textual data. The first interviews to be selected for analysis were the richest interviews in each group. From these interviews, we identified key themes and developed codes and definitions based on study domains and inductive themes. The codebook was created through an iterative process (49), after which we applied all codes to all 40 interviews. The following codes/themes were analyzed:

Codename	**Description**	**Example**
Social construct /community beliefs HIV/AIDS & Gender roles	Community perceptions about PLWHA, as well as gender role expectations.	*Le digo ahorita ya . . le dije pues que era lo que yo tenía, claro que el se. . . se impactó pues. Me dice te veo y no lo creo. Porque tu no eres una mujer loca de la calle, de esas mujeres, eres una ama de casa.*
Household dynamics	Activities performed by women on a daily basis, both inside the household as well as formal or informal jobs. Relationships between participants and family members living in the same house, with exception of their male partners.	*No pues este pues este. . . . pues me pongo a hacer mis cosas, lavo mis trastes, ya de ahí le doy a almorzar a mi niño, de ahí pues lavar, todo lo que tengo que lavar, y ya salir un rato pues para que el se distraiga también salir un rato al parque en la tarde y así para estar ocupado en algo pues, para que uno no esté pensando así pues. . .*
Partner dynamics	Relationships with their male partners. Data from their current and previous relationships, and how HIV infection affected these	*Y no se que dirán, no se en que momento el se fue con ella y yo cuando nos separamos dije yo pero porqué?* ***Si ya lo acepté así como era, y todavía me va a dejar, ya me infectó. . . y se va. . .***
Risk perception	Interviewees' perceptions related to their risk of acquiring HIV; suspicion or considering the possibility of acquiring it. Actions taken or suggested to their male partners in case they	*No pues ni me lo imaginaba. Yo le echo la culpa al. . . al segundo porque venía de Estados Unidos. Venía. . . se estuvo seis años allá.*

	felt at risk of acquiring it.	
HIV knowledge	Information regarding awareness of the infection, routes of transmission, symptoms, ART or prognosis mentioned by the participants.	*Sabía que existía ese virus pero no sabía sobre. . . sobre que era porque escuchaba comentarios sobre que al tener el virus, luego, luego te morías pues. Que no tenía cura.*
HIV diagnosis:		
Circumstances	Specific situation when HIV diagnosis was established. Reasons why the test was conducted, medical conditions experienced when the diagnosis was made	*Que me iban a hacer unos estudios, y pues de ahí salió. Primero fue mi esposo pues. Y de ahí fui yo. Y ya de ahí mi niño. Ya después supe porqué era, porque era el motivo que el se enfermaba mucho de diarrea, de vómito, adelgazaba mucho. .*
Feelings	Emotions and thoughts the interviewee experienced since the establishment of the diagnosis	*Porque yo siento. . . siento que esto ya. . . como si . . . como le diré? . . . que ya se acabó todo para mi pues.*
Life changes	Circumstances that the interviewee mentioned as *different* from how they were before, when comparing her life before and after HIV diagnosis.	*Uyy dio un giro de 360 grados. Ya no salgo, a ningún lado, ni con mis amigas ni con. . . con nadie. No salgo. No, yo era muy bailarina, me gustaban los bailes las discos las fiestas, ya no. Ni pienso en tener novio no nada. . . Cambió completamente.*
ARV experiences	Women's experiences with antiretroviral therapy (ART) as well as their perceived communication with physicians about counseling before	*Si, al principio si fue muy difícil porque. . . este. . .tuve alucinaciones, en las primeras tomas, vomité las pastillas el primer mes para mi fue la muerte. Porque pues. . era algo nuevo para mi y me sentía tan*

	initiating treatment	*mal conmigo misma que. . . que lo que hacía era llorar. . .*
Motherhood	References that interviewees made regarding their role as mothers, and the importance of being mothers in their lives. Mother-son relationships and how the diagnosis affected these	*Yo no lo dejé le digo por mis hijos. No el día de mañana le digo me van a reprochar mis hijos ay mamá usted supo así mi papá y así lo dejó y se vino mejor para acá o. . . Yo no quiero reproches de mis hijos*
Attitudes towards healthcare providers	All mentions about perceptions regarding HCP involved in their HIV diagnosis Counseling and communication regarding cart and its adverse events	*Ya asisto a las clínicas y ahí a veces este. . . incluso con una doctora aquí en [región de Oaxaca] como que me rechazó por tener VIH.*
Social support	All kinds of social support both seeked and received after HIV diagnosis was established	*. . . me empezaron a. . . a dar pláticas las psicóloga me dijo, me explicó y me levanté muchísimo eh? porque yo venía yo no sabía que era una psicóloga. No sabía yo. . . Pero aquí me ayudaron bastante la verdad.*
Status disclosure	Information regarding who they disclosed their status to, and when this disclosure occurred. Reactions after disclosure.	*Nada más lo saben dos de mis hijos pero pues son los únicos que saben de mi estado, Porque no mi papá ni mis hermanos saben. Ósea trato de que me traten bien y normal no?*

Concurrently with the coding process, memos were written to reflect on the text and identify patterns that could help to better explain the coded information, potential relationships, and comparisons between study subgroups. We continued to write analytic memos during the process of creating the codebook.

Once the coding process was completed, data were analyzed code by code, initially focusing on descriptive analysis. Later, a comparative analysis of the coded segments by subgroup was conducted. Patterns and intertwining of themes were identified in this process. A theoretical framework explaining the relationship between the observed results in the two groups was then constructed using diagrams and maps.

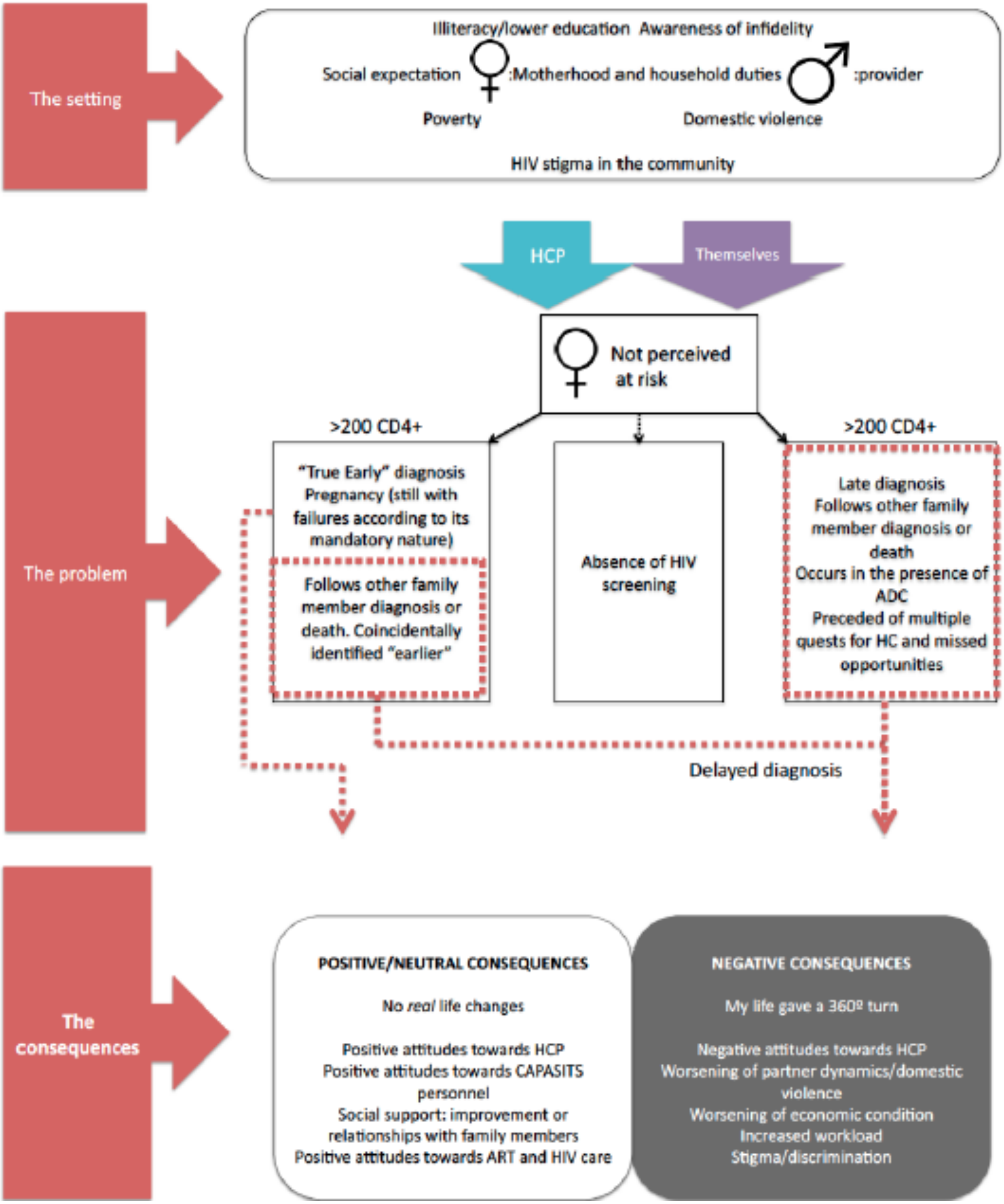
CHAPTER 4

Results

The analysis presented in this chapter was initially conducted based on the two CD4+ cell count subgroups outlined in the study design, however it soon became clear that the more meaningful comparison had to do with the diagnosis circumstances women experienced. About half of the women in the subgroup with CD4+ counts above 200 had been diagnosed asymptomatically by a screening test, usually during pregnancy. The diagnosis pattern of the other half of these women looked much more like their "late" diagnosis counterparts. Many had sought medical care on a number of occasions and had never been offered a test until a partner or child was diagnosed or died. They were simply a bit "luckier" to be diagnosed before their CD4+ count had gone below 200. In what follows, we refer to these two groups as the "**early diagnosis**" group, who were mainly diagnosed asymptomatically by screening during pregnancy, and the "**delayed diagnosis**" group, who generally experienced delays in being tested and diagnosed.

A first section presents a general overview of all participants and their social context. Then, the women's experiences are presented separately for each group, based on core aspects of their experiences: setting, problem and consequences (see Figure 1). *"The setting"* presents the particular social context and vulnerability factors of the women before establishing their HIV diagnosis. *"The problem"* analyzes their specific diagnosis circumstances and trajectories through healthcare services. Then, *"the consequences"* address the multilevel repercussions of HIV diagnosis in different aspects of women's lives. Finally, we explore outcomes that were shared across women in both groups as common experiences after receiving an HIV diagnosis.

Figure 1. Conceptual framework. The study problem, its determinants and consequences



4.1 General overview of study participants

Participants were 36 years old on average when the interviews were conducted. Their level of education generally ranged from elementary to middle school; four women were illiterate. The majority came from three regions of Oaxaca state: Valles Centrales (Central Valleys), Istmo and Costa (coastal region). Table 1 summarizes participants' general characteristics.

Table 1. General characteristics of the 40 participants.

Variable	**Frequency/average**
Average age at time of interview	36
Average age at diagnosis	35
Education level	
Illiterate	4
Elementary school	19
Middle school	11
Higher	6
Marital status	
Married/in union	22
Married	
In union	13
Single	5
Widowed	
Average number of children	3
Family structure	
Nuclear families	6
Extended families (living with in- laws)	12
Woman lives with her parents and children	8
Woman lives with her children only	11
Woman lives alone	3
Region	
Costa	13
Valles Centrales	11
Istmo	7
Mixteca	4
Papaloapan	4
Sierra Sur	1

Household and work

About half of the interviewees were married or in a consensual union, and the rest were single or widowed. All were mothers, with an average of three children. Over one fourth of the women lived in a house or on a piece of land owned by their in-laws. At least in half of these cases, their relationship with their mother–in-law, or sisters-in-law was described as not good, and in-laws promoted some forms of domestic violence. About two thirds of the women depended on their male partners for economic support, either because he was the main provider for the household, or because he or his family owned the house where the woman lived.

Practically all of the women were dedicated mainly to household duties: cleaning, cooking for other family members and taking care of children. About half received help from others living in the household: in-laws, daughters, mother, sisters or their husband. Other than their husbands, there was no mention of other male family members helping with household duties. In addition to domestic activities, almost half provided at least a portion of the earnings used to support the family's basic needs. For those living in nuclear families, their financial contribution to the household was usually less than one third of the families' total earnings. The women who had an income worked as food vendors, made handmade products (hats, napkins), provided domestic help, or cooked at a small local restaurant. As expected, a greater proportion of women not living in nuclear families worked outside the household.

Women stated that they often had difficulties finding work in their communities. Education was one of the main barriers that limited their options regarding the type of work they could perform. Interviewees also noted that there were few jobs for women in their towns or villages, as work in agriculture, farming and masonry were exclusively for males.

Community beliefs and social constructs

Community beliefs played an important role in shaping risk perceptions as well as creating discriminatory attitudes towards PLWHA. Misconceptions about routes of transmission were associated with stigma that links “unacceptable” social behaviors with the infection. For about a third of participants, this led to reactions such as prohibiting friendship with someone living with HIV, or asking interviewees to bring their own plates and utensils when inviting them for lunch.

About a quarter of interviewees had misconceptions regarding HIV transmission before diagnosis, believing that it could be transmitted by sharing kitchen or bathroom utensils or by being bit by mosquitoes. Other misconceptions included not knowing the difference between HIV and AIDS, thinking that withdrawal could prevent HIV infection, considering that the “blood of HIV infected people looks different,” and believing that an “undetectable viral load” was equivalent to a cure.

> *They say “you are going to infect me,” or that they’ll catch it when they go to the bathroom “I am going to catch it,” right? It’s like…How can I say it? They discriminate against you, when they talk to you that way (Interview 6).*

In women’s communities, people had ideas about how HIV infected individuals look - being “very thin” or “looking sick.” The image of a typical 1980’s AIDS patient was still the concept in people’s minds. On the other hand, “looking healthy” or fat was considered almost incompatible with HIV infection. Women stated that people in their communities wouldn't believe their diagnosis, because they looked healthy or even overweight.

> *And I said. . . Oh! But I didn't believe that he had it (HIV), he looked very strong and well. . . (Interview 12)*

HIV infection was also associated with certain activities or "lifestyles" for about a quarter of the interviewees. In general, men who migrated to the United States were perceived to be at risk for HIV, whereas monogamous women and housewives were not. Some participants identified their rural setting as protective against HIV infection: *"It's a small town, I never thought about people having HIV there."* About one in five participants said that women who were at risk for HIV were labeled "women of the street" (*mujer de la calle*) or "whores, " as they are perceived to engage in "unacceptable moral behaviors." For men, drinking alcohol and going to bars were behaviors that about a quarter of participants considered to be associated with HIV risk.

> *As I was saying now. . . I told him what it was that I had, of course, he. . . he was affected. He said, I see you and I can't believe it. Because you are not a crazy woman on the street, one of those women. You are a housewife (Interview 13)*

Two thirds of participants said they knew how HIV was transmitted, however one quarter of them did not specify the routes of transmission they knew. Among those who talked specifically about different routes of transmission, the most frequent route mentioned was sexual transmission, followed by blood contact/blood transfusion. About a third of interviewees raised religious beliefs as an explanation for their HIV status. They talked about HIV infection as *"fate"*, something that "*was meant to be,*" or that "*God decided to send me*".

Gender roles, reputation and infidelity

Men were seen as economic providers, not usually involved in domestic duties or childcare. In fact, the perception of love and a well-functioning relationship was somehow based on the man's ability to perform his role as provider. Some women talked about men being "insensitive" and "unattached." They also perceived them as "stronger", "superior" and "able to understand" complex or harsh life situations. In contrast, women were expected to take care of the household duties and childcare. Their social life must occur at home, or close to home.

> *But, since they are men, they do not feel, that is what I am saying, they have other heart. Because they are men. (Interview 9)*

Traveling or being outside the house, especially without their children, raised suspicions about infidelity. Also, most women (2/3) made reference to the importance of teaching their sons and daughters by example; specifically in issues related to gender roles and socially acceptable behavior. By protecting their reputation, they protected their children's reputation. The fact that their sons/daughters could suffer social rejection as a consequence of their "unacceptable social behavior" was a matter of concern.

Sexual desire appeared to be almost a male characteristic: men were envisioned as needing sex or needing additional sexual partners. In some way, men were expected to have extramarital sexual relationships, and these attitudes were perceived as something that men cannot resist. This perception was mentioned by half of the interviewees. On the other hand, sexual desire was almost absent from women's social construct. Engaging in sexual relationships was understood as an activity to "please" or "fulfill" men's desires. Four in five interviewees mentioned that men did not "like" to use condoms. Their male partners complained about "not feeling the same" or "not feeling pleasure" when using them.

> *Many of us women are afraid to ask for it (condom use) because men are very macho and do not want to use it sometimes. For example, in my case. . . my husband did not want to use it. I told him that we should use it but no, he does not like it, because he says that it hurts. . . That is what he said. But now, I do tell him, but what is the point? But maybe it is still important just for the fact of asking him to use it. But before I used to think, what is the point if I am already sick? (Interview 11)*

In contrast to men's "understood" infidelity, extramarital sexual relationships were completely unacceptable for women. Women establishing relationships with married men or having multiple sequential partners were socially isolated and stigmatized. These behaviors often led to blaming attitudes from people in the community, women's families and women themselves. In the case of men's infidelity, wives would blame other women as responsible for the situation. *"They are the ones looking for the man, insisting until he cannot help it".*

4.2 Case 1: Early stage diagnosis

Interview 29, Esperanza (23yrs)
Esperanza is married and lives with her husband and her 18 month year old child. She is dedicated to household duties, including childcare. Her husband is a cook, and they have been together for the last 5 years. She had other sexual partners before him, but never lived with any of them. Esperanza was diagnosed during the third month of her pregnancy, when she was asked for some routine tests in a prenatal care visit. *"At first, I felt depressed and desperate, I thought I was going to die"* she said. After HIV test was confirmed at CAPASITS, Esperanza was started on antiretroviral therapy. Her male baby has been tested negative for HIV and continues in follow up. Her husband is HIV negative. Esperanza had good experiences both with the gynecologist who asked for the test, and later in the CAPASITS. She has been helped by her husband and family during this process, and has remained adherent to treatment. Esperanza thinks that her relatonship with her husband improved after the diagnosis, and that he has shown to be very empathic and supportive. She doesn't feel sick, and thinks other women living with HIV should not do so. She thinks of HIV as a learning experience, and is confident that she will do fine as long as she remains adherent to her treatment and physician's recommendations

The setting

Seven participants experienced early diagnosis, usually through mandated testing during pregnancy. Participants in this group were mostly living in nuclear families. They were somewhat younger (25 yrs average) and more educated than women with delayed diagnosis. Women experiencing early diagnosis had one child on average, and in general mentioned having good relationships with their male partners. Although husbands were primarily breadwinners, they also helped with some household duties or childcare. There were no women in this group reporting domestic violence prior to HIV diagnosis.

The problem

Women in this group were diagnosed during pregnancy, as part of mandated screening for HIV. One of the women was diagnosed at 20 weeks of gestation, after her husband died from AIDS. It is not possible to know if she would have been screened for HIV in different circumstances, but according to National Guidelines she should have been tested for HIV earlier in her pregnancy.

In general, the trajectory of these interviewees through healthcare services initiated with a routine prenatal care visit. HIV test was offered, and subsequently done in small private clinics. After being diagnosis with HIV, the women were immediately referred to the CAPASITS, where they continued receiving care. All women were asymptomatic at the time of diagnosis. Two women in this group had HIV negative male partners.

Pregnancy was "fortunately" an opportunity for these women to be diagnosed in an early stage of the disease. Participants shared general social beliefs about PLWHA in their communities. Almost all of them perceived HIV to be a deadly disease and were not aware of the existence of antiretroviral therapy. Practically all mentioned never feeling at risk of HIV infection. There was no mention of prior suspicion of being HIV infected. One participant said that her husband had been told before that he was HIV positive, but "*he did not believe in the results.*" Another explained that she had several unprotected sexual encounters with different partners before she got married, and was aware of the risk associated. However, none of these women had been tested voluntarily for HIV before pregnancy.

There was one exception in this group, a woman who was diagnosed when donating blood at the hospital and was asymptomatic. Her husband was diagnosed after her, also asymptomatic.

The consequences

In general, these women's attitudes towards primary healthcare providers were positive, however their contact with these providers was limited to a single visit. Participants thought highly of providers and thought that "*they knew what they had to do.*"

After their diagnosis, all of the women continued living with their male partners and children. Regardless of their partners' HIV status, there was no mention of domestic violence or accusations. In fact, those with negative partners explicitly mentioned their husbands as an important source of emotional support. Most said that their relationships got better after HIV diagnosis, explaining that it enhanced their communication and how *they took better care of them* now. Besides providing emotional support, male partners were healthy and able to fill their role as main providers for the family. Most of the women continued performing household duties after diagnosis, as well as taking care of their children.

Since they were diagnosed during pregnancy, all women in this group started antiretroviral therapy immediately after diagnosis and were adherent to it. Concerns about vertical transmission exceeded antiretroviral side events and/or unwillingness to take the medication. Women in this group barely talked about antiretroviral adverse events.

Participants expressed their fears of infecting their babies during pregnancy as the main stressor after diagnosis. Apparently, all children born to these women are HIV negative and continue in follow up at the CAPASITS. Other than that, women diagnosed in early stages of the disease did not identify HIV infection as a turning point in their lives. They argued that they continued feeling the same way, and tried to think that they were not "sick." Both their asymptomatic diagnosis and the "less disruptive" nature of their household dynamics seem to shape this opinion. Some women in this group mentioned that HIV diagnosis modified their “way of thinking.” They were now more aware that their actions had consequences, and had become more responsible and thoughtful. Part of their recommendations for other women living with HIV included not thinking very much about their status, and trying to conduct a normal life.

> *Well, honestly, I do not feel any different. I feel. . . I have HIV as if I had any other condition. Maybe it is because my husband provides support and all that. But I do not give much importance to it. Of course I take my medicines, I know they help prevent AIDS and all that. But besides that, I barely think of HIV. . . (Interview 27)*

4.3 Case 2. The "delayed" diagnosis

Interview 13, Soledad (36 yrs)
Soledad is widowed, and currently lives with her 19 year old son and his wife. She cooks food at home that her daughter-in-law helps her sell. Soledad was already a widow when she was diagnosed with HIV. She got married when she was 16 years old, and experienced intimate partner violence practically since the beginning. Her husband had a history of alcohol abuse. She was aware that he had extramarital relationships and asked him to "take care of himself" whenever he had other sexual partners. She did not know the cause of death of her husband until she discovered she was HIV positive. Soledad thinks that he already knew he had HIV and never told her. After being widowed, she developed chronic diarrhea and wasting; she sought care multiple times with primary healthcare providers in her community. Since symptoms were persistent, she started suspecting that she could have HIV. She asked the doctor to test her for HIV and the doctor refused, saying that "*she did not look like she had HIV.*" When she was diagnosed, Soledad had an HIV negative partner who was still married to another woman. She disclosed her status to him, and he decided to end their relationship. Currently she continues receiving care at CAPASITS and also receives economic and social support from her sisters and son. Her ability to perform her job was substantially affected by her symptoms, and she now requires help from her daughter-in-law since she is no longer able to sell the food herself.

The setting

The majority of interviewees in this study (four fifths) experiencing "delayed" diagnosis. Women in this group were older, 37 years on average, and were less educated than those in the early diagnosis group. Participants with delayed diagnosis had varied family structures, including nuclear families, living with their parents and children or living by themselves. Women had three children on average.

Over a third of the women experienced some form of domestic violence from a current or previous partner, or both. Intimate partner violence was usually both physical and psychological. A similar proportion of participants in this group reported that their male partner abused alcohol. About one in ten interviewees reported that their partners had been in jail or had migrated to the United States at some point.

> *And I don't know who told him that since I am younger, I could easily cheat on him. So he has always thought about me that way, and started hitting me, he began to mistreat me and my children. My children saw how he mistreated me. (Interview 21)*

The problem

Half of the participants in this group were only diagnosed after a husband or child was identified as HIV positive, regardless if they already had suggestive symptoms of HIV infection. The rest were mainly diagnosed in the presence of AIDS defining conditions.

About a half of the women in this group were symptomatic at diagnosis, and their symptoms strongly suggested immunosuppression. One third of participants had a history of multiple attempts to seek a diagnosis and care due to their symptoms. However, the presence of symptoms was not why they got tested: a third of women with multiple attempts to seek care were diagnosed *only* after their partners' diagnosis was established.

For women who were diagnosed after their partners, there were three main reasons why they hadn't been diagnosed before: they were asymptomatic and never screened, they sought healthcare due to symptoms but an HIV test was not offered, or less commonly, they never sought healthcare despite having symptoms. Participants who sought care were typically seen multiple times in both private and public healthcare facilities, and received symptomatic treatment, but were not offered an HIV test. A few women who had previously sought care (about one in ten) thought that their male partners already knew about their HIV diagnosis long before, but had not disclosed it to them. Some men never disclosed their status, and women only learned about their condition after they died.

Women who did not seek healthcare although they had symptoms reported not having time to go because of work or household responsibilities, or attributed their symptoms to another known condition such as diabetes. Others said they were ashamed to visit a doctor.

Among those whose diagnosis were not prompted by partner's HIV status, about one quarter were separated or divorced at diagnosis and did not know if their prior partners were aware of their HIV status. Most of these participants were symptomatic, and also had sought healthcare multiple times before being diagnosed. The rest of the women were either diagnosed at the same time as or before their male partners.

Two women in this group did not seem to fit the overall general pattern observed across delayed diagnosis. The first one, a sex worker, was asymptomatic despite being considerably immunosuppressed at the time of diagnosis. A friend advised her to get tested for HIV after she decided to leave the man that obliged her to perform sex work. The other is a woman with an HIV negative male partner; the cause of her HIV infection was not clear.

Reasons for delayed diagnosis

We identified three main reasons for delayed diagnosis. One - and possibly the most important one - was the lack of HIV testing offered by physicians. A second reason was the absence of risk perception, and a third was the inability to negotiate safe sex with male partners.

Participants with multiple attempts to obtain care described persistent symptoms which were their chief complaint for medical consultation. Usually they were experiencing chronic diarrhea, weight loss, oral thrush, persistent fever, and wasting. Many of them saw the same physician several times; every time they had not improved with the prescribed treatment. Others visited different health care providers, both in the public and the private sector.

> *And I asked the doctor for the test. I told her, "I want you to test me for, for… AIDS", I said, because as my neighbor would say, that is the way we call that disease. So the doctor said, "no Ma'am, you do not have that, because it is visible when a person has it" (referring to HIV) (Interview 13)*

Much like the women with early diagnoses, more than half of the women in this group stated that they did not consider themselves to be at risk of acquiring HIV, and never suspected they could acquire it. However, about half were aware that their partner had other sexual partners. Women said they "tolerated" or "ignored" infidelity, explaining that "*they had everything they wanted*" (usually referring to economic security). Despite awareness of infidelity and knowledge of modes of HIV transmission, women still did not see themselves to be at risk for HIV infection.

> *What is true is that. . . I knew, I always tried to. . . let's say ignore that part, that he was always messing with other women. He was always messing with other women so. . . people would talk right? But, in my house I always had what I needed. I had him and. . . the economic part right? There was no problem there. I had no financial limitations. But since he left, everything changed. (Interview 19)*

> *I didn't even imagine it. . . I blame the. . . the second one because he came from the United States. He was coming back. . . he was there for six years (Interview 10)*

On the other hand, about a third of the women said that they *did* feel at risk of acquiring HIV, primarily because of their husband's sexual behaviors. Women were asked what actions they took to avoid this risk; most said they did nothing to prevent it. The rest said that they asked their husbands about other sexual partners, suggested HIV testing, and also proposed condom use. Some asked husbands to use condoms with extramarital partners, and others asked them to use condoms with them. The response was practically always the same: men denied having other sexual partners and refused to get tested for HIV or use condoms. About half of the women said that men interpreted women's negotiation of condom use as a way to avoid future pregnancies, or as a "sign" of women's infidelity: *"you want me to wear a condom because you cheated on me while I was away"*.

> *Because when we got back together, many times I asked him if he had been with someone else and. . . "Hey, what happened, did you mess with someone else?" because there is a risk, right? I asked that not because of infidelity, but for the risk for me. . . And he answered that he didn't. He said that he was always there, home when. . . that month when he was by himself. But you know that, when the woman leaves, they would be drinking. . . But even so, I believed in him (Interview 22)*

The consequences

Attitudes towards healthcare providers

Women with delayed diagnoses tended to have a less favorable attitude towards primary care physicians (about three quarters). In general, they expressed disappointment or anger when asked about the medical attention they initially received. Negative attitudes towards health care providers increased with the number of times that women sought medical attention, especially when they had repeatedly sought care for persistent symptoms without resolution and without being offered HIV testing. Participants' husbands and children had similar experiences.

Other reasons they noted for their negative attitudes were that physicians were frequently absent from their offices, and they almost never got a prescription during these visits. Participants felt this showed a lack of commitment from doctors, often leading to medical complications as a consequence of misdiagnosis. There were two "types" of physicians fitting this description. In general they were primary healthcare physicians working in the public sector, or private health care providers giving medical consultations in drug stores or private clinics in their communities.

Women expressed their beliefs about why these providers did not ask for an HIV test, even when it now seems very clear that their symptoms suggested HIV infection. Over two thirds of women believed that an HIV test was not requested because of a lack of awareness. A few also suggested that perhaps "they did not want to," or they did not care.

About a quarter of these women reported discrimination within the healthcare setting. They noticed that they were treated differently than other patients; providers were unwilling to touch them during a physical examination or to draw blood samples.

> *And the doctor that took care of me, a month ago or so, she was "uncomfortable" when I told her I had HIV. Yes. . .Actually she didn't do a physical examination. Because I had chest pain. Yes. So she didn't examine me, she just gave me some forms to get an electrocardiogram done. (Interview 17)*

Others felt that doctors were "judging" them for being HIV positive. They stated that some doctors asked questions like, "*How come you are HIV infected? How did that happen?"* These questions were perceived by interviewees as stigmatizing and unnecessary. A smaller proportion of women (one in ten) disliked providers because a doctor or nurse had disclosed their HIV status to another family member without their consent.

Partner relationship and household stability

About half of the women expressed anger, disappointment, and bitterness towards their male partners for infecting them with HIV: *"he could have prevented me from becoming infected*." Their resentment was exacerbated by the perception that their children's stability and economic safety was threatened, which they felt men did not take into account. Other interviewees felt resigned (*"what can I do now?"*). A few, (less than one in ten) experienced worsened domestic violence after being diagnosed, noting that their partner blamed them, and accused them of infidelity or "unacceptable social behavior".

> *I told him, be careful eh? You will get infected with some disease and will infect me then. And I am in my house. No, he said. One day, I did ask him. No, he said. I am not infected with anything. But, how awful he was, if he would have told me, I would have gone to get tests done. Instead of waiting to be in this state. . . as I am now. . . (Interview 13)*

Women's negative descriptions of their relationships were not linked to separation or marital dissolution. Women would stay with their men, regardless of these feelings or attitudes, usually because they needed economic support, especially for their children. Another reason to stay was the social expectation of a wife in their communities, and they didn't want their children to suffer because of their parent's separation. Women wanted to protect their partners' image; they didn't want their children to "hate" or blame their father for what happened (1/4). They would stay with their partners, trying to preserve the family at least until their children were old enough to take care of themselves.

> *And I do not know what they would say, I do not know when it was that he left with her. So when we separated I asked myself why? If I had already accepted him as he was, and now he is going to leave me. . . .He already infected me and now he leaves. . .And will keep infecting others (Interview 15).*

HIV was a threat for household stability for three reasons: a) men were also sick and unable to perform their roles as providers b) men died, leaving women alone, or c) the union ended after diagnosis. In this latter case, which was the least frequent one, men were the ones who decided to leave; women rarely left their partners after diagnosis (less than 1 in 10). In these situations, participants were forced to find jobs and work harder to support their children (3/5). Some were working to support the household, taking care of their sick husbands, and doing all domestic duties.

Missing work was an important obstacle to HIV care for these women. They had to ask their employers for permission once every month or two to attend their medical consultation and pick up their medication. Their employers were not typically aware of their HIV status, so women lied to attend medical visits, and employers showed discontent over absenteeism. The fact that they had to choose between taking care of their health and keeping their jobs was an important stress factor. This may explain why most were engaged in informal commerce, where they could more freely control their time. However, participants also reported that HIV limited their ability to perform "tough" activities; they were no longer able to work for long periods or under difficult conditions.

Repartnering

Many participants considered the idea of re-partnering almost impossible. For those who were not living with their partners, HIV diagnosis was considered "*a call*" to stay single and take care of their children. They felt that re-partnering with an HIV negative man was unacceptable; they were afraid of disclosing their HIV status to a potential new partner, and of infecting an HIV negative partner.

About a quarter of women in this group did repartner or were currently with an HIV negative partner. Despite their fear to disclose their status, almost all (7/8) told their male partners. The responses of their partners varied from support to anger and abandonment. Secondly, having sexual intercourse with HIV negative partners generated stress for these women. Interestingly, women in the "early stage" group who had HIV negative partners did not raise this issue.

Women who were not yet taking ARV's but had an HIV positive partner associated sexual activity with fear of reinfection or acquiring other STI's. A small proportion of women mentioned that their partners did not want to use condoms "even after knowing their HIV status." This was also a reason for some to decrease the frequency of sexual intercourse with their partners. Some agreed to have sexual intercourse without a condom, and others did not, obliging their partners to use condoms. They said that men who refused condoms after HIV disclosure argued that *"they already had it"*, or if they were negative, "*they are going to get it anyway, so what's the point?* Some mentioned that the frequency of sexual intercourse decreased because men were no longer interested after diagnosis.

ART experience

The perception of "*feeling sick and having to take medication daily*" was brought up by about one in ten participants. They felt that taking daily medication was a burden, and that being compliant was a new responsibility they had to assume. Reasons to initially refuse to take medication were mainly denial (3), fear (1) and difficulties in attending exams and picking up the drugs (1). Denial was always associated with late care seeking, a refusal to link to medical care, and poor medication adherence. These women later talked about their personal processes in order to comply with HIV care.

> *When I arrived here (CAPASITS) and for about two months I did not want to take the medication. I was still denying it. . . and I think that still now. . . it has been a year now and I sometimes do not realize. . . I refuse to believe it. And I think:" I am not sick, I am not sick". . . But it is something I cannot change. . . (Interview 10)*

4.4 Shared outcomes and hopes

This section, compiles outcomes and recommendations that were observed across our study groups, and which occurred as a consequence of women's HIV status. These outcomes range from emotional and personal experiences, to social and programmatic adjustments suffered as a result of HIV infection in women's lives. The final segment, titled "the bright side" summarizes interviewees recommendations or cues to action for other women: both HIV positive and negative.

The first reaction

More than half of the women expressed feelings of sadness, depression, hopelessness and loneliness when diagnosed with HIV; most said they thought their lives would be over after diagnosis. These feelings seemed to be related to the common perception that HIV is a deadly disease. Uncertainty about their future and concerns about status disclosure were mentioned by about a quarter of the women. Among participants who expressed depression and sadness, about a third talked about suicidal ideas, or "preferring to be dead." About a third of participants said that their main concern was the inability to perform their role as mothers and caregivers due to sickness. Women agonized over their childrens' future if they became sick or absent.

Fear of infecting other members of the family was mentioned by one in five participants. Although they were aware of the routes of HIV transmission, they expressed that they were "more careful" now and were constantly trying to protect other family members from becoming infected. Cooking, using knives, sewing, sharing bath accessories or clothes and disposing of tampons/sanitary pads all mentioned as activities that required more attention now to prevent "accidental infection" of other family members.

CAPASITS and ART experiences

In general, almost all interviewees (nine in ten) had positive opinions about their current physicians. When asked about the physicians, social workers and psychologists at CAPASITS, women said they felt "support" and "empathy" regardless of their diagnosis experience. A few interviewees reported negative opinions of their current attending physicians, which seemed mainly related to misunderstandings and poor communication.

Regardless of diagnosis circumstances, about three quarters of interviewees reported receiving information at the moment of HIV diagnosis, including prevention strategies (condom use mainly), explanations of risk factors, and the current prognosis for people living with HIV/AIDS. Information related to antiretroviral therapy adherence and potential adverse events was also given.

Two thirds of women who were on medication had positive attitudes towards ART, and said that they tolerated it adequately. About a quarter of these associated taking ART with feeling healthier, stronger and able to perform their daily activities again. They knew that the medication was *"good for them*" and perceived a positive change since they started taking it. The same proportion stressed the importance of adherence to antiretroviral therapy, and specified that they strictly followed the doctors' instructions on when they should take the medication. Among these women, the understanding that the medication was not *"curing but controlling"* the infection was clear. About half mentioned that taking the medicine according to the physician's instructions was the most important way to stay healthy. The majority of women in the study – three quarters – were not aware of the existence of antiretroviral therapy before they were diagnosed with HIV.

At the same time, about half of the interviewees reported having adverse events with ART when they first started taking it. The most common complaints were central nervous system symptoms, such as insomnia, dizziness and nightmares, all frequently associated with the use of Efavirenz (EFV). For a few women, adverse events led to poor adherence; women said, "*the medication cannot be good for me if it is making me feel bad.*" About one in ten women experienced side effects that led to a change their ART regimen.

Discrimination and status disclosure

Discrimination within the household was mentioned by about one tenth of interviewees; it was one of the most important stressors for those who experienced it. Discrimination came both from direct family members and in-laws, and was usually associated with misconceptions about transmission and social attributions of PLWHA. When women experienced discrimination from their sons/daughters, interviewees thought their children were ashamed or felt that they deserved to be infected. Some women also saw their relationships with in-laws become more complicated after HIV diagnosis, especially when the disclosure was involuntary. In-laws "*did not seem to care*" about disclosing the woman's HIV diagnosis among extended family and other members of the community. Usually, existing negative relationships with in-laws worsened after HIV diagnosis and women were frequently accused of being responsible for her partner's HIV infection.

> *And it is hard because instead of helping you it (discrimination) kind of. . . it turns you off, it like. . . it wears you out, so you don't have the strength to continue.(Interview 36)*

> *I talked to my eldest daughter, and then with the middle one. Yes. What really hurt me was that. . . still now it hurts. With my middle daughter, she said: It is good that this man infected you. Because they do not know that I worked in the street in Puebla. They thought I worked at a restaurant. They never knew. They don't know. Only my youngest daughter knows. And. . . my daughter, what hurt the most was that she said:*

> *"oh, it's good that this man infected you." And still now, I remember and it hurts that she responded that way. Maybe I wasn't expecting her to pity me, but. . . the fact that she answered so rudely, so cruelly, right? Well, I don't know. . . (Interview 17)*

The fear of discrimination (15/40), shame (5/40), and the perception that their family members "would not understand" (5/40), influenced the disclosure of their HIV status. One of women's most feared circumstances regarding status disclosure was that their children will have to face the community's hostility or prejudice. They feared that their children will be subjected to discrimination and social exclusion if their friends or other community members discovered their HIV status (1/3).

> *As I told you, I try not to tell them, I keep it secret right? The only ones who know are two of my sons, but they are the only ones who know about my status. My father and siblings do not know. I mean, I want them to treat me well, normally right? Because I feel that if they know that I have this disease. . . they will treat me as a welfare case, and then they would be wary of me. And I feel that it should not be that way. (Interview 19)*

Over four fifths of the interviewees disclosed their diagnosis to some family member, and about half disclosed to their sons and daughters - primarily to older children (over 12-13 years). Most commonly, women disclosed to another woman in the family: mothers, sisters or daughters. In a few cases (1 in 10), a close female friend was the first one to know. Those who were diagnosed *before* their male partners communicated their status immediately to their partners, asking them to also get tested and start receiving medical care.

Social support

Immediate family members responded positively to disclosure in the majority of cases (nine in ten); practically all interviewees received emotional support from their families. Negative reactions towards their male partners were expressed by some family members (usually brothers), arguing that the partner was responsible for the infection due to infidelity and carelessness (about 2 in 10). A small proportion of interviewees experienced negative reactions, including discrimination and guilt from parents, siblings or children (less than one tenth). Social support was expressed as emotional, (about two thirds), help with childcare and household duties (one in four), or economic aid that was typically offered by a male family member such as a brother (about one third). In the majority of cases, children provided strong social support. Women said that children helped with household duties, asked about their medical consultations, and reminded them to take their medication. One quarter of participants said that a female extended family member or close friend was their main emotional support after diagnosis. Six interviewees said that female in-laws had helped them both economically and emotionally.

As a component of emotional support, women talked about the need to "*talk about their status to someone else.*" About a quarter of participants mentioned a support group where they could talk to other women in the same circumstances. Three women described how their experiences talking to other patients helped them accept their diagnosis when they first arrived to the CAPASITS.

Over one quarter of women identified sources of social support outside their family. The most frequently mentioned support was CAPASITS's personnel; women explained that their discussions with their psychologists and physicians at CAPASITS encouraged them and helped them to have a positive attitude towards life. Similarly, about one fourth highlighted the importance of their religious beliefs, and religious groups were mentioned as part of their social support network. Some said that religion gave them *"the strength to carry on and fight."*

A small group of the interviewees (one in ten) perceived no social support after diagnosis, especially when they were sick and required intensive medical care. These participants said they felt "abandoned" soon after diagnosis, when they were hospitalized or attending medical consultations almost every week.

Women as mothers

About a fifth of the interviewees mentioned motherhood when talking about family advice, social support, and even compliance -they almost always noted that their children need them. Almost none of the women considered their own well-being over that of their children. Interviewees talked about "living long enough" to make sure that their children would be independent and able to take care of themselves. Becoming grandmothers was another important goal that encouraged them to persevere. A small proportion of women (1 in 10) also assumed that they should never become pregnant again. For them, HIV diagnosis was interpreted as the end of their fertile life.

Healthcare costs and transportation

Healthcare expenditures represented a concern for over half of the interviewees. Most participants had to pay for public transportation to go to their medical consultations and pick up their medication. The cost of transportation sometimes represented 10-20% of their total household income. For women with children at home, finding someone to take care of their children was a major concern. For women who were ill, transportation costs were twice as high since they were unable to travel long distances alone, and required the assistance of a family member. In addition to the cost of transportation, distance was another identified barrier - some participants had to travel eight hours to get to CAPASITS (Figure 2). For this reason, some women thought that it would be helpful to have centers such as CAPASITS closer to their hometowns. Nevertheless, the fear of being seen at CAPASITS sometimes prevented them from visiting healthcare centers that were closer to home.

__The bright side__

Nonetheless, over a third of interviewees stated that they were optimistic and ready to face the difficulties associated with their diagnosis. Some of them felt relieved by finally knowing their diagnosis, or because their sons/daughters tested negative for HIV. One woman said, *"I already knew that there was treatment available, and that I was not going to die."* Women generally had positive advice for those who were recently diagnosed; they thought that recently diagnose women should not give up, and should continue fighting for their lives in order to take care of their families.

> *Tell them that. . . . that they are not alone. I would really like that, and I have thought about it. Spend time with women like them. Women who feel alone, because.I've been through that. To hug them, give them my phone number, so when they feel lonely they could call me or I could call them. To make friends because here I don't have friends*

> *like that. That is why I just come for a little bit and I leave. I think that would help because I know how it feels to be in that position. Thinking that you will die some day and how are you going to wind up. . . it's horrible. (Interview 26)*

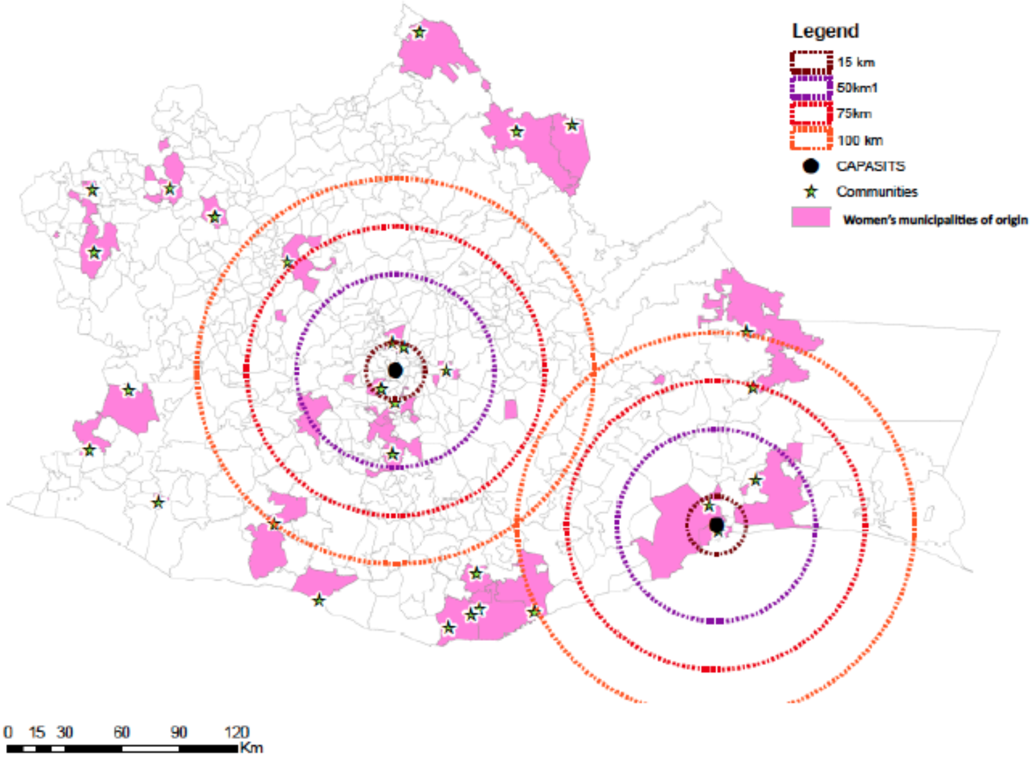
The vast majority of participants expressed their desire to prevent other women from acquiring HIV. They talked about the importance of making preventive information available to women who were still HIV negative. A few women suggested that sex education programs should be implemented in school at early ages, to raise awareness among adolescents regarding these topics. Women should advise their sisters, female friends, sons and daughters about HIV prevention strategies. Those who disclosed their diagnosis to their family members should use their specific experience as an "example" to promote preventive behaviors among their loved ones. They advised their sons and daughters to take care of themselves in order to avoid a situation like the one that they are currently living. They talked to their children about their own "mistakes" as an example of what they should not do. Interviewees reflected on preventing their children from having the same "life" that they had. "*I do not want them to experience these things*", they said.

Finally, women noted that HIV information should be provided as a tool for prevention, especially for women who were still HIV negative. Generally participants talked about taking care of themselves ("cuidarse"). This term, although very ambiguous, was brought up by 31 of the 40 interviewees. Women were then asked *"How can women take care of themselves?"* The answers varied. Some stressed the importance of *"knowing who you are messing with"* and suggested doing an HIV test before having sexual intercourse or getting married. They talked about “not trusting” people based on the way they look: *“they could be HIV positive even when looking healthy.”* When we asked if HIV infection could occur after marriage, they all thought it could, and concluded that their proposed strategy could only be effective if both men and women were faithful to each other.

Some interviewees said that “*cuidarse*” could only be achieved by using condoms in all their sexual relationships or by abstinence. However, in general women were aware of the difficulties of condom use negotiation with stable sexual partners. A smaller proportion of women considered “cuidarse” as being tested for HIV routinely in order to be diagnosed on time. These women identified “cuidarse” as a timely HIV diagnosis strategy and not as an HIV preventive one.

> *I think that. . . even if women are taking care of themselves, if the man is messing with other women, he brings the disease. . . . It is useless for married women to take care of themselves. For me, I do not even know how I got this disease. I don’t know. And my husband had lots of women. . . So he went out and messed with one and then with another one so. . . It’is hard to know. (Interview 32)*

Figure 2. Commute distances between women's hometowns and CAPASITS



* For participants living in areas >100 km away from CAPASITS, the average commute time from their hometowns to medical consultation were 5-6 hours . CAPASITS showed on the center of the state is where interviews were conducted.

CHAPTER 5

5.1 Discussion and recommendations

This study describes the HIV diagnosis experience of a group of women living in one of the poorest states of the country. Our main finding is that the needs of women in Oaxaca are not being adequately addressed by HIV prevention programs and screening strategies. We intentionally interviewed women who were diagnosed at different stages of HIV infection, in order to compare and contrast their healthcare trajectories and life experiences.

According to our results, women were diagnosed mainly in three circumstances: during pregnancy, after their sexual partner was diagnosed, or when they were already symptomatic and had AIDS defining conditions. Our findings suggest that most non-pregnant women are currently outside the scope of HIV testing in Mexico, as timely offering of HIV testing occurred exclusively during pregnancy. This fact is not due to an absence of medical infrastructure (Figure 1), but is instead attributable to the fact that providers are not offering HIV tests in primary healthcare settings, both private and public. Our results regarding diagnosis circumstances are also consistent with those of Martin-Onraët in a recent quantitative study -conducted in Mexico City, Puebla and Oaxaca- addressing the HIV epidemic among women in Mexico (5). Fifty percent of the women in Martin Onraët's study were late diagnosis (diagnosed with less than 200CD4+ cell/mm^3) and a lack of antenatal HIV testing as well as missed opportunities for diagnosis among symptomatic women were observed.

Women diagnosed during pregnancy -the "early diagnosed"- experienced a less disruptive journey through their disease process when compared to women with delayed diagnosis. Their cases were characterized by the absence of symptomatic disease, the appropriate prevention of mother to child transmission (PMTCT) the ability of their partners to continue performing their role as providers and a positive relationship with their male partners.

We must stress that one of the participants in the early diagnosis group, although diagnosed during pregnancy (20 weeks), was diagnosed after her husband died from AIDS. Furthermore, two participants from the "delayed diagnosis" group had HIV+ children. These facts support that, despite being mandated by national guidelines (42), HIV testing during pregnancy is still suboptimal in this setting (10). The lack of HIV test offering does not seem to be related to an absence of antenatal care, but to a failure to implement HIV testing during these consultations. Although there is insufficient data, it also appears that women receiving antenatal care generally do not refuse to get tested for HIV (43). Since this policy is already implemented and active in Mexico, we suggest optimizing HIV testing during pregnancy as a first strategy to enhance opportune diagnosis among Mexican women. In addition to its obvious benefits in terms of PMTCT, HIV testing during pregnancy offers an opportunity for women to learn their diagnosis before advancing to symptomatic illness.

On the other hand, the journey of the "delayed diagnosis" cases is somewhat different. Late diagnosis has multiple negative implications, at the individual level as well as from the public health perspective (50-51). It is well known that HIV prognosis differs among those who receive a timely diagnosis as compared to those who are diagnosed when they already have AIDS defining conditions and advanced immunosuppresion. Increased morbidity and mortality due to the presence of opportunistic infections, immunologic failure and lower proportions of virological supression are the most important clinical consequences. From a public health standpoint, late diagnosis increases the possibility of new HIV infections, since it has also been documented that the majority of HIV transmission occurs among individuals who are unaware of their status (51). Furthermore, costs associated with the treatment of AIDS defining conditions frequently exceed those of timely testing and ART initiation.

Late diagnosis also affects an individual's life experience in a more complex and profound way beyond medical consequences. Delayed diagnosis negatively affected women's lives and well-being in many ways - emotionally, economically, socially - that are often overlooked. In this study, major life changes such as divorce, need for employment, economic instability, were reported by a majority of women diagnosed in late stages of the disease. Hussen et al (52), reported similar results regarding the differences in perceived life changes between symptomatic and asymptomatic HIV+ young black men who have sex with men. The study showed that progress towards self-sufficiency among black MSM adolescents was hindered for those who experienced symptomatic illness.

Unfortunately, it seems that women's possibilities of timely diagnosis decrease not only if not pregnant, but also if not partnered. Ironically, illness or death of stable male partners served as the primary trigger for testing non-pregnant women for HIV in our study, while also serving as their main source of risk for HIV acquisition at the same time. Sixteen out of the 33 women who experienced a delayed diagnosis were tested for HIV after their partners were found to be HIV positive. More than a half of these women were already symptomatic and seeking care. However, their symptoms were not the trigger for HIV testing, even when highly suggestive of HIV infection. Furthermore, more than a half of those women with delayed diagnosis whose HIV test was not prompted by their partners, actually did not have a partner at the time they were diagnosed. For this reason, single, non-pregnant women in this study were the least likely to be tested for HIV. Single women in our study were tested in the presence of Toxoplasmosis, End Stage Renal Disease (ESRD), Lymphoma and other severe opportunistic infections, most of them requiring in-hospital care.

It is clear that testing in the presence of symptoms does not necessarily occur in a timely fashion. The lack of test offer from healthcare providers, in addition to women's absence of risk perception and their inability to negotiate safe sex, seems to shape the circumstances of delayed diagnosis for these vulnerable population.

Participants related that their communities had strong misperceptions about PLWHA; both related to physical characteristics and to risk behaviors and modes of transmission. The literature has shown that HIV-associated stigma among healthcare providers may resemble that of the community in which they are embedded, regardless of their medical knowledge about transmission and risk of acquisition (53-56). Published data from both developed and developing countries has also found an association between HIV related stigma among healthcare providers and delayed testing and treatment (54-56). A recent study conducted in Mexico City among more than 600 healthcare providers revealed that physicians had considerable deficiencies in terms of HIV knowledge. The lack of suspicion for HIV among primary healthcare providers (PHCP) in Oaxaca appears to be related to these knowledge gaps. PHCPs' failure to request HIV testing may be due to a genuine lack of clinical suspicion due to limited exposure to HIV and its clinical manifestations. In this same study, lack of HIV training was associated with higher stigmatizing attitudes towards PLWHA (57). Although it was not explored here, this stigma may play a role in providers' failure to request an HIV test due to shame or social unacceptability. Asking a married woman to have an HIV test may appear disrespectful or even offensive in their communities.

Many countries are moving towards universal testing strategies (58,59). According to national data as well as to UNAIDS, approximately 50% of the PLWHA in Mexico are unaware of their HIV status (60-61), meaning that the epidemic is actually twice the size of the population that we are currently facing. A universal testing policy would promote early diagnosis for women regardless of their pregnancy status. Furthermore, this strategy would help to challenge communities' and physicians' stereotypes as the major drivers of HIV testing practices. Periodic HIV training and sensitization workshops for medical providers may also be helpful in raising awareness among physicians about the importance of timely diagnosis. Education and promotion of universal testing should be enhanced among women, in order to increase acceptability of HIV testing and minimize stigma. The main goal would be to convey the message of HIV testing for all ("everybody is at risk of acquiring HIV"), and not based on personal characteristics or some pre-established risk factors.

Our main recommendations are directed at finding solutions for improving timely HIV diagnosis among women in Oaxaca. However, we also consider it extremely relevant to address HIV negative women, who share the same vulnerability profile as our interviewees. We found that even for those women who perceived themselves to be at risk of acquiring HIV, safer sex negotiation was practically impossible. Additionally, since more than 90% of women's HIV is acquired through heterosexual transmission from their stable male partners, attention must be focused on males as well. Qualitative research among heterosexual men who are married/in union may allow us to better understand their perspectives and specific risk of acquiring HIV. In order to design realistic solutions for women living with HIV, we need to address their male partners.

5.2 Study limitations

This study was conducted in an HIV care facility and women were invited to participate during their regular HIV consultation. This fact may have implications for the characteristics of the interviewed women. Our study cannot depict the characteristics of women who are not linked to care, or of those who are lost to follow up. Willingness to participate in a 1 hour-long interview could also be related to other social factors that may have an impact in the characteristics of the interviewees. It is possible that those who had social support, help with childcare or more flexible work conditions were the ones who were able to participate in the intervew. In addition, the threshold of CD4+ cell count that we defined to establish “early” and “late” diagnosis may seem very low to some readers. The WHO utilizes <200 CD4+ cells/mm^3 as an indicator of “advanced disease”. Since late diagnosis is more the rule than the exception, it was necessary to define a realistic threshold that would allow a reasonable number of participants in each study group. This threshold in some way might explain the similarities between those women who were considered in our analysis as “delayed diagnosis” (due to their diagnosis circumstances and NOT to their CD4+ cell count) and those meeting the clinical definition of advanced disease (less than 200 CD4+ cells/mm3).

5.3 Future research

To our knowledge, this is the first qualitative study addressing the attitudes of HIV positive women towards healthcare providers in Mexico. The multiple missed opportunities for diagnosis both for interviewees and their family members resulted in negative attitudes towards primary healthcare providers, including mistrust, disappointment, and a perception of carelessness. Apparently, the initial missed diagnosis has implications in women's perception of the health system in general. Women who expressed negative opinions about healthcare providers due to a delay in diagnosis, also mentioned other negative attitudes including discrimination and disclosing their status to family members without their consent. This could potentially have negative repercussions in the subsequent HIV continuum of care that must be explored through cohort studies. Outcomes such as linkage, retention and virological suppression could be analyzed among women with different diagnosis circumstances, in order to understand the dimension of missed opportunities of diagnosis in long- term care.

Another potential area of research is the evaluation of the feasibility of microfinancing interventions as a tool to empower women in these communities. Specific approaches evaluating instrumental barriers to HIV care such as transportation and childcare could also be helpful to improve retention in care and adherence to antiretroviral therapy. Support groups and peer-based interventions should also be explored as potential strategies for helping women cope with their disease and adhere to medical treatments. Although unpublished, successful interventions using peer based approaches have previously been used in Mexico City among women living with HIV. Such interventions have the potential to empower women living with HIV while providing a space to be heard, develop social support and empathy.

5.4 Conclusion

Although the HIV epidemic in Mexico is concentrated mainly among men who have sex with men (MSM), the male to female ratio has decreased considerably in the last decade. Despite these changes, women are still an overlooked population in terms of HIV prevention and treatment strategies. Lack of awareness of HIV risk among Mexican women results in late diagnosis, especially for those women outside of the "mandatory" recommendation of HIV testing during pregnancy. Late diagnosis has multiple negative consequences both from the individual and the public health perspective. Increasing the possibilities of timely diagnosis among Mexican women should be a priority. We suggest starting by enhancing both pregnancy-based and universal testing as a first strategy. Other tailored interventions must be implemented, to improve the whole trajectory of women through the HIV continuum of care (Figure 2).

Figure 1. Healthcare facilities in a 10 km radius from participant's localities

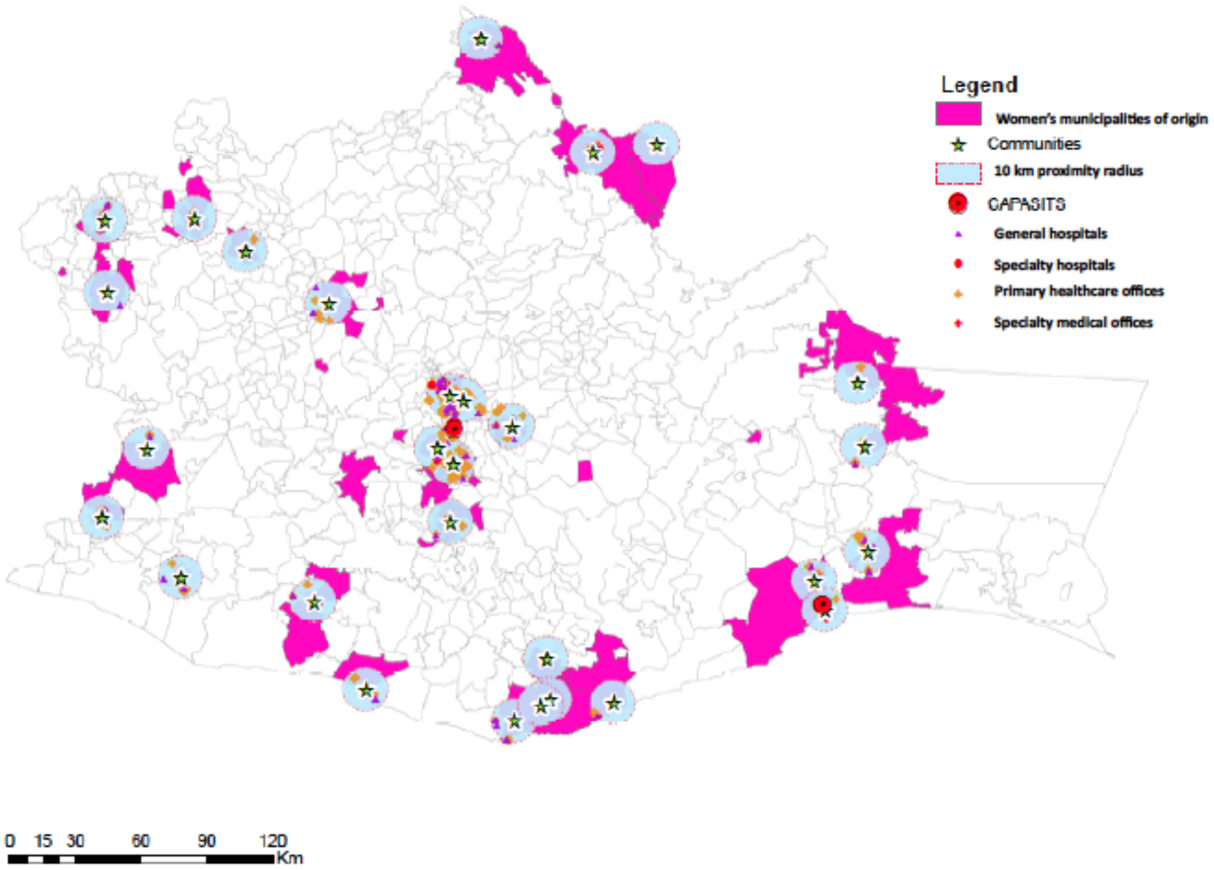
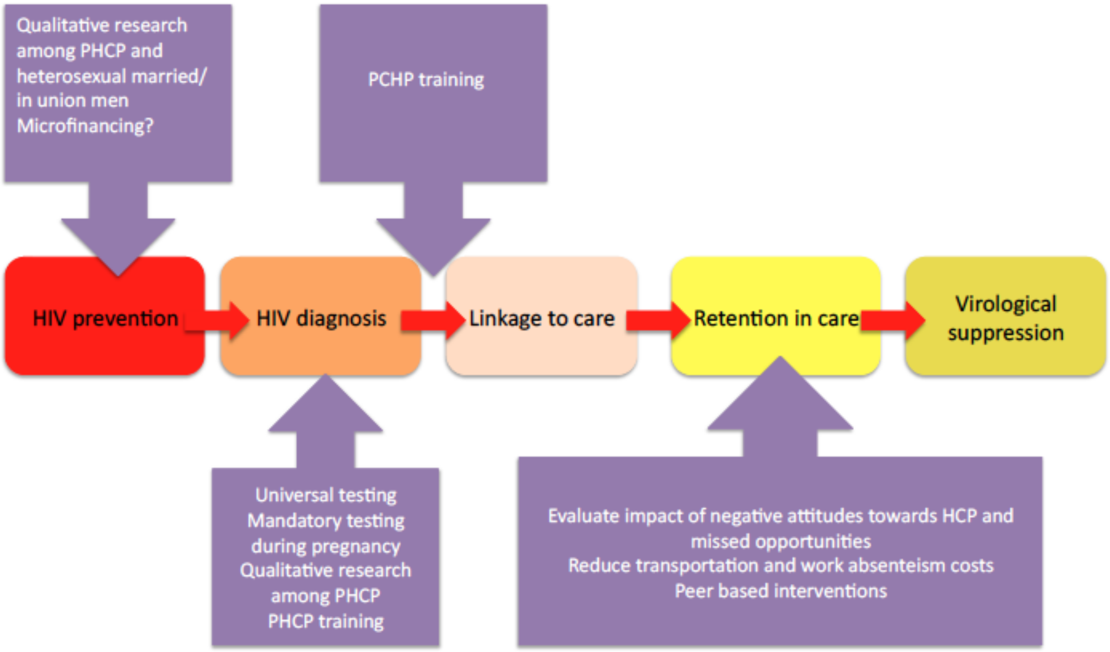


Figure 2. Addressing the HIV continuum among women living with HIV in Oaxaca: Potential interventions



PCHP: Primary healthcare providers. HCP: Healthcare providers

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7. Appendix 1

INTERVIEW GUIDE

Introduction

Good morning, Mrs <Name of the interviewee>. My name is <Name of the interviewer>. I would like to ask you to answer some questions, related with your HIV diagnosis. The reason why we are asking these questions, is because we would like to know how are Oaxacan women being diagnosed, in order to create appropriate interventions to improve opportune diagnosis and HIV care in general. We will ask information about your family (your partner and kids, and extended family) as well as questions related with your personal life and your experiences since your HIV diagnosis. The information that you and other women will provide, will help us to understand these reasons. Also, this information could be published as a way of informing scientists and other public health profesionals our experience. Publications will not contain any personal data of participants. All the information will be kept confidential: your name or personal data will not be shared. If you agree, the interview will be recorded, and posteriorly analyzed. The recordings will not contain your name or any other data that could identify you. They will be captured and only accessed by the researchers participating in this study. If at any time during the interview you wish to stop answering, you can do so. You will only answer the questions you want to.

Do you have any questions?
Do you agree with the interview being recorded?

Opening questions

I would like to start asking you some questions about your family.

1.- Who do you live with? **Probe:** Husband/partner, sons/daughters, parents, siblings)	Household dynamics
2.- Who are the persons of your family that you trust the most? **Probe**: Husband/partner, parents, siblings	Household dynamics
3.- How is your relationship with your partner/husband? **Probe:** income contribution, domestic duties, emotional support, fidelity	Household dynamics
4.- Are there other persons that you trust more that are not members of your family? **Probe:** Neighbors, friends	Household dynamics

We will now move on, to some questions related to HIV and your HIV diagnosis

5.- First, what did you know about HIV before you were diagnosed? **Probe:** Transmission, symptoms, treatment.	HIV general knowledge HIV Risk perception
6.- Can you tell me about when you were diagnosed with HIV? **Probe**: Year at which it occured, where it happened, why was the test offered, symptoms, members of their nuclear family already diagnosed HIV+	HIV Diagnosis circumstances
7.- How do you think you acquired HIV infection? **Probe:** family members	HIV general knowledge HIV Risk perception
8.- Why do you think infection could not be prevented?	HIV general knowledge HIV Risk Perception
9.- How has your life changed since the diagnosis?	HIV Diagnosis circumstances
10.- When you were informed about your HIV diagnosis, whith whom did you share the results? **Probe:** Partner/husband, parents, siblings, others. How long did it take to reveal the diagnosis if she did.	HIV status disclosure
11.- What was the reaction of those people when you told them about your diagnosis?	HIV status disclosure/ Social networks
12.- How does your diagnosis has influenced your relationships with your partner? Probe: domestic violence, economic dependence/independence	HIV status disclosure /Household dynamics
13.- Can you tell me, how does your HIV diagnosis has influenced your relationships with other members of your family?	HIV status disclosure/Household dynamics/Social networks
14.- What have you done after your diagnosis to look for support?	Social networks
15.- How did you perceive your risk for HIV before diagnosis?	HIV risk perception
16.- If you ever felt at risk, can you tell me what you did? **Probe:** safe sex negotiation, abstinence? HIV test?	HIV risk perception

17.- Can you tell me your opinion of health care providers, in relation to your diagnosis?	Attitudes towards HCP
18.- Tell me about the different health care providers you have seen, regarding your HIV diagnosis.	Missed opportunities
19.- Tell me about your experience with HIV treatment Probe: HIV information, counselling	Attitudes towards HCP

We are now getting to the end of our interview, and I wouls like to ask you, these last questions. . .

20.- What do you think could help HIV positive women?	General recommendations
21.- What would you tell to other women your age about HIV?	General recommendations

22.-Is there any other think that I didn't ask you that you would like to add?
Thank you for your participation in this study. We really appreciate your help and your sharing of experience. We hope that all this information can help other women like you.

No. of interview ______
Age (yrs) ______
Place of birth ______
Current address (Poblate) ________
Education level: ______________
Ocupation: ___________________
Year of HIV diagnosis _______
Age at HIV diagnosis ________
Marital status ____________________
Number of children _______