Patterns of HIV Serostatus Disclosure Among HIV-Positive Young Adults in Haiti: a Mixed-Methods Investigation

by

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Thesis submitted in partial fulfillment of
the requirements for the degree of Master of Science
in the Duke Global Health Institute
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ABSTRACT

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Abstract

Background: By facilitating access to prevention and care services, HIV serostatus disclosure has been associated with improved physical health, psychological well-being, and improved health behaviors for people living with HIV/AIDS (PLWHA). Disclosure to sexual partners, in particular, can help prevent the forward transmission of HIV. Disclosure can increase social support but can also lead to negative social outcomes including stigma and discrimination. Thus, disclosing HIV status to friends, family, and sexual partners is a complex psychosocial challenge that PLWHA face, particularly adolescents and youth who have an increased lifespan due to current effective treatment protocols.

Objectives: This study had three objectives: 1) to determine gender-related differences in the rate and patterns of HIV serostatus disclosure to family, friends and sexual partners among HIV-positive youth in Haiti; 2) to identify gender-specific relational and psychosocial predictors of HIV disclosure to sexual partner; and 3) to qualitatively explore and describe motivations and experiences related to HIV disclosure in this population.

Methods: A cross-sectional study was conducted in a random sample of 680 sexually active HIV-positive young adults (18-29 years) from six clinics in Port-au-Prince, Haiti. Socio-demographic, health, sexual and reproductive history, sexual behavior, psychosocial and disclosure data were collected using a pre-tested interviewer-administered structured questionnaire. Rates and patterns of HIV serostatus were

described, and factors associated with disclosure to all sexual partners in the past 3 months were analyzed using hierarchical logistic regression models, separately by gender. Qualitative data was collected through individual in-depth interviews with a purposefully selected sample of 12 young adult participants to explore whom they chose to disclose to, how they disclosed to these individuals, and how these individuals reacted. Content analysis allowed for the description of motivations and experiences related to HIV disclosure in this population.

Results: Slightly over half (56%) of participants had told at least one person about their HIV status. Female respondents were more likely than male respondents to have disclosed to family or friends. Male youth were more likely to disclose their status for the first time to sexual partners (35%), while female youth were more likely to choose their mother as their first confidant (51%). Overall, 33% of participants reported having disclosed their HIV status to all their sexual partners from the last 3 months, with no significant difference across genders. For both genders, older age and being unaware of partners' HIV status were significantly associated with lower odds of HIV serostatus disclosure. Additionally for young males, disclosure stigma was negatively associated with disclosure while HIV acceptance and personalized stigma were significant predictors of disclosure. Female youth who were single, had casual or multiple partners, and experienced greater personalized stigma were less likely to disclose, whereas the availability of social support was positively associated with disclosure to all sexual partners. While disclosure to sexual partners was motivated primarily by a desire to

encourage partners to test for HIV and increase condom use, or by a sense of moral responsibility, important contextual differences emerged in qualitative analysis with regards to barriers to disclosure, particularly fear of stigma and fear of partner's reaction.

Conclusion: Rates of HIV serostatus disclosure to family, friends and sexual partners were low among this population of HIV-positive youth in Port-au-Prince. Context-specific gender-sensitive interventions are needed to increase social support, reduce HIV-related stigma, and assist youth living with HIV in making effective decisions on disclosure that will ultimately improve their well-being and quality of life. Further research is necessary to better understand the process and outcomes of HIV serostatus disclosure to sexual partners, as well as the relationship between HIV serostatus disclosure and sexual risk behaviors in this young HIV-positive population.

Dedication

This thesis is dedicated to the courageous and resilient HIV-positive youth of Haiti.

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List of Abbreviations

ART	Antiretroviral therapy
CSW	Commercial sex worker
DPM	Disclosure Processes Model
HIV	Human immunodeficiency virus
MARPs	Most-at-risk populations
MSM	Men who have sex with men
MSPP	Ministère de la Santé et de la Population
	(Haitian Ministry of Health and Population)
NGO	Non-governmental organization
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission of HIV
STI	Sexually transmitted infection
VCT	Voluntary counseling and testing

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1. Background

1.1 Overview of HIV Serostatus Disclosure

As the fight against HIV/AIDS enters its third decade, the emphasis worldwide is on adopting and scaling up the most effective strategies in order to prevent new infections and improve the quality of life of those who are already infected (Eustace & Ilagan, 2010). HIV testing and counseling is recognized as a critical prevention and treatment tool in the control of the HIV epidemic (Maman & Medley, 2004). With the advent of antiretroviral therapy (ART) and effective treatment protocols that have drastically prolonged survival, HIV is now perceived as a manageable chronic condition instead of a terminal illness (Holstad, Foster, Diiorio, McCarty, & Teplinskiy, 2010; Osinde, Kakaire, & Kaye, 2012). Therefore, it is important to ensure the physical, mental and sexual health of the growing number of people living with HIV/AIDS (PLWHA) (Golub, Tomassilli, & Parsons, 2009). HIV serostatus disclosure is the first step to implementing a range of prevention and care behaviors, which ultimately will improve overall well-being and quality of life for PLWHA and prevent the forward transmission of HIV.

1.2 HIV Disclosure: an Important Public Health Goal

Disclosure is defined as the autonomous revelation of one's status to another individual or group of individuals (Adejumo, 2011). Considered one of the most complex psychosocial challenges and an emotionally stressful event facing people living with HIV/AIDS, it is also viewed as an opportunity to "open up" the HIV epidemic in the

hopes of ending stigma and discrimination against HIV-positive individuals (Chaudoir, Fisher, & Simoni, 2011; Obermeyer, Baijal, & Pegurri, 2011; UNAIDS, 2000).

HIV disclosure has significant implications for public health outcomes (Chaudoir et al., 2011; World Health Organization, 2003). HIV serostatus disclosure to sexual partners supports risk reduction behaviors that ultimately decrease transmission of HIV, while also facilitating access to prevention, care and treatment services (King et al., 2008). Management of HIV can also be improved by health behaviors, such as participation in prevention of mother-to-child transmission of HIV (PMTCT) programs (Maman & Medley, 2004). Additionally, public health benefits can be obtained, as disclosure to family and friends can lead to increased social support, which can facilitate initiation of and adherence to HIV treatment that, in turn, lower the risk of transmission to prospective sexual partners (Ammassari et al., 2002; Strirratt et al., 2006; Thoth, Tucker, Leahy, & Stewart, 2012; Wadell & Messeri, 2006).

1.3 Individual-Level Benefits Versus Risks of HIV Disclosure

At the individual level, self-disclosure of one's HIV status can provide numerous benefits to PLWHA. HIV disclosure can lead to increased availability of social support (Hays et al., 1993; Medley, Garcia-Moreno, McGill, & Maman, 2004), reduced anxiety and depression, and beneficial effects on the individual's physical health and overall well-being (Collins & Miller, 1994; Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003; Thoth et al., 2012).

Despite these positive benefits, disclosure may sometimes have negative consequences. Potential risks of HIV serostatus disclosure include blame, abandonment and rejection (Pool, Nyanzi, & Whitworth, 2001), physical abuse and violence (Gielen et al., 2000; Temmerman, Ndinya-Achola, Ambani, & Piot, 1995), disgrace to self and family (Chandra, Deepthivarma, & Manjula, 2003), stigma and discrimination (Kilewo et al., 2001), accusations of infidelity, and loss of economic support (Medley et al., 2004). A person living with HIV/AIDS faces the complex decision of whether or not to disclose. The balance of potential risks and benefits of secrecy compared to disclosure is a fundamental step in coping with the disease (Bouillon et al., 2007; Medley, Kennedy, Lunyolo, & Sweat, 2009) and often leads to selective disclosure by PLWHA based on the importance of the relationships and the level of trust with the different types of confidants (Obermeyer et al., 2011).

1.4 Theoretical Frameworks for Understanding HIV Disclosure

HIV disclosure can be seen as a complex, multidimensional process of making a decision about whom to inform about one's serostatus, and why, when, where and how to disclose (Eustace & Ilagan, 2010). Several descriptive frameworks have been proposed to identify factors affecting disclosure likelihood. According to the disease progression theory (Serovich, 2001), PLWHA are likely to disclose only as their illness advances and the secret about their HIV diagnosis can no longer be kept. This theory, which has been supported by studies conducted during the pre-ART era revealing an association between worsening health and increased likelihood of disclosure (Hays et al., 1993), may be less

applicable in light of the current widespread availability and effectiveness of ART (Przybyla, 2009). The competing consequence theory (Serovich, 2001) has also found support in the growing literature on disclosure. It posits that PLWHA are more likely to disclose if the perception of expected benefits outweighs the potential risks (Emlet, 2006).

Building on previous theories, while expanding on the decision-making process for disclosure, Kimberly and Serovich (1995) proposed a framework that outlines the disclosure process in six steps: 1) adjustment to the diagnosis; 2) evaluation of personal disclosure skills; 3) evaluation of the appropriateness of disclosure; 4) assessment of the circumstances for disclosure; 5) anticipation of potential reactions of disclosure recipients, and 6) identification of the motivations for disclosure. Bairan and colleagues (2007) proposed a model based on types of social relationships to explain HIV disclosure. According to this model, social relationships are categorized as sexual and nonsexual, with different disclosure levels and patterns based on the nature of the relationship with the confidant (Bairan et al., 2007).

More recently, the Disclosure Processes Model (DPM) has been proposed to conceptualize disclosure as a single process within a continuous series of lifetime events that involves decision-making and outcome processes (Chaudoir & Fisher, 2010). The DPM highlights the impact on each disclosure event of: antecedent goals (approach or avoidance goals) affecting the likelihood of discrete disclosure events, the disclosure event itself, mediating processes such as social support, outcomes at the individual, dyadic or contextual levels, and a feedback loop (Chaudoir et al., 2011). As such, this

model provides a comprehensive framework for studying when and why interpersonal and verbal disclosure will be favorable for HIV-positive individuals, while putting special emphasis on connections between all aspects of the disclosure process (Chaudoir & Fisher, 2010).

1.5 HIV Disclosure Rates and Practices

There is considerable variation across settings in the rates of HIV serostatus disclosure. In developed countries, disclosure rates are high compared to developing countries. A review of the HIV disclosure literature reports that the average rate of disclosure to current and/or steady sexual partners was 79% (range 42 - 100%) in developed countries. Conversely, in the developing world, particularly in Africa, the average rate of HIV disclosure was 49% (range 16 - 86%) (World Health Organization, 2003). Several studies from the developing world have shown that 10% to 78% of women do not disclose their HIV test results to anyone, compared to only 3% to 10% in developed countries (Maman & Medley, 2004).These differences can be attributed to high levels of stigma and discrimination in certain settings as well as differential access to health and support services (Obermeyer et al., 2011).

The rates and patterns of HIV disclosure vary greatly within settings, by ethnicity and gender, with the lowest rates reported in studies among women attending antenatal care (World Health Organization, 2003). A study conducted in Tanzania found that HIV-positive individuals were most likely to share their HIV test results with their parents (49%), followed by their spouses (25%) and then their sexual partners (19%) (MacNeil,

Mberesero, & Kilonzo, 1999). In contrast, also in Tanzania, lower disclosure rates to family (5.6%) compared to partners (16.7 %) were found in a study among women enrolled in an HIV perinatal transmission trial (Kilewo, et al., 2001). One study conducted in the United States found that the highest rates of disclosure were reported to mothers among a sample of African-American women (Armistead, Morse E., Forehand, Morse P., & Clark, 1999), while other studies have reported higher rates of disclosure to non-family members (Simoni et al., 1995).

Disclosure is not a one-time event but rather a process that occurs over time (Chaudoir & Fisher, 2010; Obermeyer et al., 2011). Skogmar and colleagues (2006) found that nearly all (92%) respondents in a South Africa-based study disclosed to at least one person in their social network, with 15% waiting over a year to tell their partners. In Tanzania, it was found that only 22% of pregnant women had disclosed to a partner in the 2 months after their diagnosis while 40% had done so after 4 years (Antelman et al., 2001). Among a sample of gay Latino men in the United States, half had disclosed to someone on the day of their diagnosis, and another 15% disclosed within a few days, however about 20% did not tell anyone for a year or more (Zea, Reisen, Poppen, Bianchi, & Echeverry, 2005). Other studies have found that disclosure of HIV status had a positive association with the length of time since diagnosis (D'Angelo et al., 2001; Niccolai, King, D'Entremont, & Pritchett, 2006), and with disease progression (O'Brien et al., 2003).

Qualitative studies have also been used to explore differences among disclosers and non-disclosers, looking specifically at the process of communication during

disclosure as well as coping styles after disclosure (Obermeyer et al., 2011). Selective disclosure has been identified as one of the most frequent strategies used by PLWHA, as the decision to whom to disclose was often based of particular criteria related to the nature and quality of the relationship with the confidant (Hult, Wrubel, Branstrom, Acree, & Moskowitz, 2012; Sowell, Seals, Phillips, & Julious, 2003).

1.6 Factors Motivating or Hindering HIV Disclosure

People living with HIV/AIDS face the constant struggle of deciding whether or not to disclose, when and to whom. Factors motivating or hindering disclosure have been extensively studied in numerous settings and were found to be similar, especially in developing countries. Several studies have concluded that a sense of personal moral responsibility or the desire to have a partner tested for HIV was the major reason cited for disclosure to sexual partners, whereas the need for social support motivated disclosure to family and friends (Simoni, et al., 1995; Hult et al., 2012). Conversely, the most common barriers to disclosure included fear of blame and abandonment, fear of rejection (Pool et al., 2001), fear of violence (Temmerman et al., 1995), fear of upsetting family members and causing disgrace to self and family (Chandra et al. 2003), fear of accusations of infidelity, and fear of losing economic support (Medley et al., 2004; Sowell et al., 2003; Maman et al., 2003).

1.7 Legal and Policy Context of HIV Disclosure

Low rates of HIV disclosure to sexual partners raise questions about the ethics of balancing medical confidentiality and well-being of PLWHA with the rights of sexual partners (Bott & Obermeyer, 2013). In developed countries, like in Canada and in several states of the United States of America, PLWHA are required by law to disclose their HIV status to their current and prospective sexual partners (Galletly, Glasman, Pinkerton, & di Franceisco, 2012). Similarly, in a number of developing countries, including Benin, Burkina Faso and Cape Verde, legislation has been passed into law criminalizing HIV transmission by HIV-positive individuals, mandating disclosure to partners and authorizing involuntary disclosure by health workers (Bott & Obermeyer, 2013). These laws and policies have sparked intense debates in the legal and public health realms (Bott & Obermeyer, 2013; UNAIDS, 2008).

1.8 Influence of Socio-Economic Factors and Gender on HIV Disclosure

Disclosure rates vary according to the availability of institutional sources of support, especially in the urban areas (Norman, Chopra, & Kadiyala, 2007; Obermeyer et al., 2011). Level of education has also been linked to levels of disclosure. Akani and Erhabor (2006) found that Nigerian respondents with higher educational attainment were more likely to disclose compared to their less-educated counterparts. Gender plays an important role in the association of HIV disclosure to economic factors. A study conducted in Kenya found that women with limited resources were more likely to

disclose to their partners in order to secure continued economic support (Farquhar, et al., 2001). The evidence linking gender to disclosure has been mixed. Studies from Kenya and South Africa found higher rates of HIV disclosure by women (Katz et al., 2009; Olley, Seedat, & Stein, 2004), whereas other studies had found no significant differences like in Ethiopia (Deribe, Woldemichael, Bernard, & Yakob, 2009). However, there are substantial differences across genders regarding the reasons for nondisclosure including fear of physical violence or rejection among women and concern about infecting the partner among males (Deribe et al., 2009).

2. Introduction

2.1 HIV/AIDS Among Young Adults

The HIV/AIDS pandemic continues to be a major concern worldwide, with young people bearing a disproportionate HIV burden. In 2009, globally there were 2.6 million people who became newly infected with HIV, of whom approximately 40% were between the ages of 15-24 (UNAIDS, 2012). Young people are considered to be at the center of the HIV/AIDS epidemic (Monascha & Mahyb, 2006). They are especially vulnerable to HIV because of unsafe sex, substance use, and the lack of access to HIV information and prevention services (UNAIDS, 2012). Early sexual activity, unplanned and coerced sexual relations, sexual abuse and exploitation increase the vulnerability of youth. Moreover, there are biological, social and economic factors that render young women especially vulnerable to HIV (UNAIDS, 2010).

2.2 HIV/AIDS in Haiti

Haiti has been impacted by HIV/AIDS more severely than any other country in the Caribbean, with prevalence rates reaching nearly 5% in the 1990s (Gaillard, et al., 2006). Despite a spectacular decline in HIV prevalence among the general population, Haiti continues to bear the largest burden of HIV in the region with a national prevalence of 2.2% among individuals 15 to 49 years old (1.7% for men and 2.7% for women) (Haiti Demographic and Health Survey DHS, 2012). Primary factors associated with the HIV

epidemic in Haiti include poverty, socio-political instability, limited access to healthcare, HIV-related stigma, and social norms promoting multiple sexual partnerships (Hempstone, Diop-Sidibe, Ahanda, Lauredent, & Heerey, 2004). The number of PLWHA in Haiti is growing. Estimated at 120,000 in 2008 (UNAIDS, 2010), it is now estimated that there were close to 150,000 at the end of 2013, with approximately 40,000 PLWHA in the 15 to 29 age range alone (Ministère de la Santé et de la Population MSPP, 2013a.).

Characterized as a generalized epidemic in Haiti, HIV is transmitted primarily through sexual contact. Among the groups considered most-at-risk for HIV are young people, commercial sex workers (CSW) and men who have sex with men (MSM), with considerable overlap between the categories (MSPP, 2013b.). According to the Haiti Demographic and Health Survey 2012, female youth (15-24 years) have a higher prevalence than male youth, with the greatest gender disparity between ages 20 and 24. Overall, HIV prevalence stands at 1.3% for female youth compared to 0.9% for male youth (age range: 15-24). Poverty is believed to foster risk behaviors among young people who are unemployed and who may exchange sex for support (Fitzgerald, Behets, & Caliendo, 2000; Farmer, 2004). A recent seroprevalence study conducted by the Haitian Ministry of Health and Population Services International (PSI) using respondent-driven sampling among female commercial sex workers and men who have sex with men found HIV prevalence rates of 8.4% and 18.1% for CSW and MSM, respectively (MSPP, 2013b).

With the advent of antiretroviral therapy (ART), more people with HIV are living longer. Consequently, the continued spread of HIV may result from those who know their

HIV-positive status but nonetheless engage in high-risk sexual behaviors including unprotected sex and multiple concurrent partnerships (Crepaz & Marks, 2002; McGowan et al., 2004). It is also important to note that there are no laws criminalizing the transmission of HIV in Haiti (UNAIDS, 2013).

2.3 HIV Disclosure Research Among Youth and Young Adults

With an increased lifespan due to HIV treatment, HIV-positive youth and young adults are particular in that they will most likely be engaging in sexual activity for longer periods of time as compared to adults. HIV disclosure to family, friends and sexual partners is thought to play an important role in HIV prevention, as it can have positive outcomes related to social support and increased quality of life. The budding literature on HIV-positive youth disclosure, resulting from studies conducted for the most part in the United States and Canada, reports a wide range of rates of self-disclosure. In a study of disclosure of HIV status among HIV-infected youth, it was found that 87% of youth had disclosed to at least one family member and that 63% of female youth with no more than three partners had disclosed to all their partners compared to only 9% of females with more than 4 partners (Lee, Rotheram-Borus, & O'Hara, 1999). Other more recent studies have reported rates from 50% (Petersen et al., 2010) to 89% (Rongkavilit et al., 2010). Youth vary in whom they chose to disclose to, especially with regards to their mode of infection. Indeed, behaviorally-infected youth have faced challenges in disclosing to their parents, whereas concerns about revealing their mother's status have impeded disclosure in perinatally-infected youth (Michaud et al., 2009). Batterman, Rice and Rotheram-

Borus (2005) found that youth who had been diagnosed for a greater length of time were more likely to disclose to at least one person compared to youth who were recently diagnosed, a finding that was similar to that found in the adult literature. Seventy-seven percent of youth (under 25 years) had disclosed to their mothers, while 47% disclosed to their fathers in a study by D'Angelo and colleagues (2001). In this same study, youth of both genders were found to have disclosed their HIV infection preferably to their mothers. Other studies have found marked gender differences however, with young women being more likely to disclose to their families and young men being more likely to inform their friends (Rongkavilit et al., 2010). Moreover, sexual orientation has been associated with disclosure patterns as young HIV-positive MSM were less likely to disclose their serostatus to their families because it would raise questions about their sexuality (Rongkavilit et al., 2010). Social support to HIV-positive youth has been instrumental in reducing stigma and isolation. A positive association exists between disclosure and social support (Wiener & Battles, 2006). Disclosure and social support most likely interact in a cycle, with one predicting the other.

There is tremendous inconsistency in the literature where disclosure of HIV-positive youth to sexual partners is concerned. Various rates of disclosure to sexual partners have been reported in different settings, from 30% (Birungi et al., 2009) to more than 60% (Michaud et al., 2009). Other studies have looked at serosorting behavior among PLWHA, as a measure of increased positive mental health outcomes (Golub et al., 2009). The unpredictability in rates of disclosure is best understood when HIV status and relationship type of the partner is considered. Several studies have shown that disclosure

is more likely when the partner is HIV-positive and considered a main partner (D'Angelo et al., 2001; O'Brien et al., 2003). HIV-positive youth who have disclosed to their family and felt supported were more likely to disclose to their sexual partners (Parsons, Butler, Kocik, Norman, & Nuss, 1998; Wiener & Battles, 2006). More recently, in a study conducted in the United States with youth (16-24 years), researchers found that 40% of participants had had a sexual relationship with a partner without disclosing their HIV status to that partner (Dempsey, MacDonell, Naar-King, Lau, & Adolescent Medicine Trials Network for HIV AIDS interventions, 2012). Other findings included that disclosure was more frequent when the HIV status of the sexual partner or confidant was known and was less frequent when participants reported multiple sexual partners (D'Angelo et al., 2001).

HIV-positive youth have identified concerns related to both fear of the actual disclosure event and fear of the consequence of disclosure (Hosek, Harper, & Domanico, 2000). The fear of unauthorized disclosures subsequent to the initial self-disclosure was also a major cause of anxiety for HIV-positive youth (Leonard, Markham, Bui, Shegog, & Paul, 2010). The main barriers to disclosure reported in the literature include stigma, fear of rejection, lack of confidence, bad communication skills, lack of emotional resources (Thoth et al., 2012).

2.4 HIV Disclosure Research in Haiti

Very little research has been conducted in Haiti on HIV disclosure. A review of the literature revealed only two studies conducted in the Haitian context on this topic. In

the first study which used case studies of HIV-positive clients (Mean age = 33, SD = 8), women did not disclose their serostatus to their sexual partners because of the fear of violence, abandonment and loss of financial support (Fitzgerald, Maxi, Marcelin, Johnson, & Pape, 2004). In a more recent study of disclosure among HIV-positive alcohol users, Conserve, King, Devieux, Jean-Gilles, and Malow (2014) found that the disclosure rate to sexual partners was relatively low (38.6%) in a sample of 258 HIV-positive individuals (age range: 17-56). They also found that having an HIV-negative or HIV-unknown partner and having more than one sexual partner were associated with decreased odds of disclosure.

Prevention programs targeting young PLWHA are critical in reducing the spread of the virus. Positive prevention efforts target PLWHA to promote risk reduction behaviors including condom use as well as HIV serostatus disclosure. A major challenge to positive prevention interventions is the social context of high levels of stigma and discrimination, which makes the disclosure process very difficult. No studies have yet sought to understand HIV disclosure among the HIV-positive young adult population (under 30 years) in Haiti. A better understanding of the disclosure process and mechanism is needed in order to enhance positive prevention interventions targeting young people in Haiti.

2.5 Study Objectives

Given the high burden of HIV and the increasing number of HIV-positive youth in Haiti, a better understanding of the mechanisms through which young PLWHA

disclose their serostatus is crucial to inform programs targeting this population. Using the Disclosure Processes Model (Chaudoir & Fisher, 2010) as a theoretical backdrop, this study intends to add to the limited knowledge available in this area of interest in the Haitian setting and identify potential actions for secondary HIV prevention programming. The study's main objectives are: 1) to determine gender-related differences in the rate and patterns of HIV serostatus disclosure to family, friends and sexual partners among HIV-positive young adults in Haiti; 2) to identify gender-specific relational and psychosocial predictors of HIV disclosure to sexual partners; and 3) to qualitatively explore and describe motivations and experiences related to HIV disclosure in this population.

2.6 Research Questions, Hypotheses, and Conceptual Model

2.6.1 Research Questions and Hypotheses

In order to address the proposed study's analytical objectives, three main research questions and their associated hypotheses are proposed.

Research Question 1: What are the rate and patterns of HIV serostatus disclosure to family, friends, and sexual partners among HIV-positive young adults in Haiti? Do they vary by gender?

Hypothesis 1.1: HIV-positive young adults are more likely to disclose to their family compared to their friends and sexual partners.

Hypothesis 1.2: HIV-positive young adults are more likely to disclose to their family members first compared to their friends and sexual partners.

Research Question 2: What are the relational and psychosocial predictors of HIV serostatus disclosure to sexual partners among HIV-positive young adults in Haiti? Do they vary by gender?

Hypothesis 2.1: HIV-positive young adults are more likely to disclose their HIV status to main partners than causal partners.

Hypothesis 2.2: HIV-positive young adults are more likely to disclose their HIV status to other known HIV-positive partners than to HIV-negative or unknown status partners.

Hypothesis 2.3: HIV-positive young adults are more likely to disclose their HIV-status to their sexual partner if they previously disclosed to family members.

Research Question 3: To what extent do HIV Acceptance, Social Support, Stigma, Depression, and Subjective norms predict HIV serostatus disclosure among HIV-positive young adults? Do they vary by gender?

2.6.2 Study Conceptual Model

The conceptual model (Figure 1) was informed by the theoretical perspective of the Disclosure Processes Model (Chaudoir & Fisher, 2010) and empirical findings on

HIV disclosure in youth subpopulations of PLWHA. This model illustrates the relationship between predictor variables and HIV serostatus disclosure to sexual partners, the main outcome of interest for the proposed study which will focus primarily on the decision-making process involved in HIV disclosure.

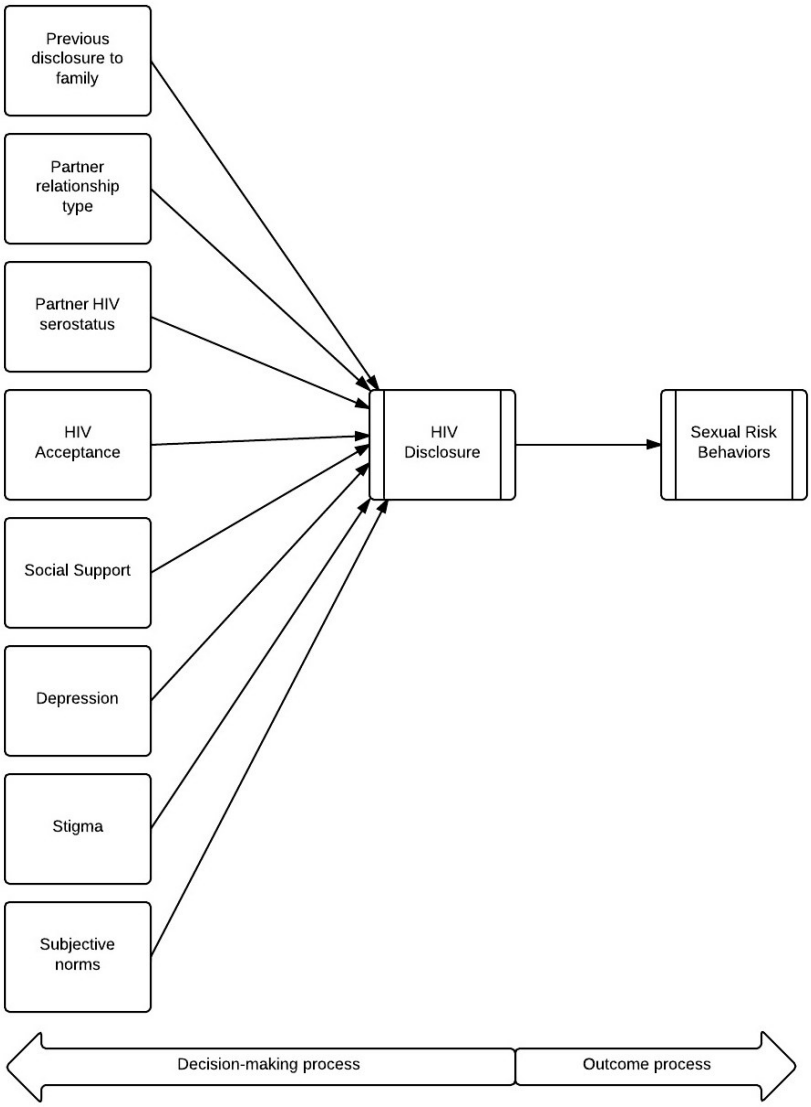

Figure 1: Study conceptual model

3. Methods

3.1 Setting

The setting for this project was Port-au-Prince, the capital city, located in the West department, the largest and most populated of the ten geographical regions of Haiti (Haiti DHS, 2012). In 2011, there were approximately 77,431 people living with HIV/AIDS (PLWHA) in this department alone, representing over half of all HIV infected individuals in the country (MSPP, 2013a.). This study was conducted at six sites randomly selected out of 17 possible sites located in the West department. All clinics are part of a nationwide network of clinics run by a local non-governmental organization (NGO) - one of the key partners of the Haitian Ministry of Health - providing a wide range of services including diagnosis and treatment of sexually transmitted infections (STI), family planning, HIV prevention services to youth and other most-at-risk populations (MARPs), including young commercial sex workers (CSW), men who have sex with men (MSM) and PLWHA. (FOSREF, 2013). The selected clinics and their respective catchment areas represent diverse and densely populated urban areas around Port-au-Prince, which have seen an influx of displaced populations in camps after the January 2010 earthquake.

3.2 Study Population

To be eligible for participation, individuals had to: (a) be HIV-positive, (b) be between 18 and 29 years old, (c) self-report at least one episode of sexual activity

(defined as anal or vaginal sex, with or without condom) in the past 3 months, and (d) have sufficient cognitive ability to provide informed consent.

3.3 Study Design

A two-phase mixed-methods sequential explanatory design was chosen for this study (Creswell & Plano Clark, 2007). A cross-sectional survey was followed by individual in-depth interviews with a purposefully selected subsample to explain and contextualize results obtained during the first phase (Creswell, Klassen, Plano Clark, & Smith, 2011). This design was used to gain a better understanding of the complexity of levels and patterns of HIV serostatus disclosure among male and female HIV-positive Haitian young adults.

3.3.1 Sampling and Recruitment

The sample size was calculated based on the results of a previous study conducted in Haiti which reported a percentage of disclosure to sexual partners of 38% (Conserve et al., 2014), a power of 0.80, and an alpha of 0.05, in order to detect a 10% difference in disclosure rate between genders. A sample size of 678 (308 males and 370 females) was needed, considering a female-to-male ratio of 1.2:1 at the selected clinics.

Potential participants were recruited by the clinics' HIV counselors and support group moderators who identified youth who met the eligibility criteria from patient and support group registries. After potential participants were screened for eligibility by the clinics' HIV counselors, two separate sampling frames for male and female youth were

created at each clinic, from which participants were selected by systematic random sampling with a sampling interval of 3. There were no pre-determined quotas by clinic or age. A total of 696 youth were selected for the cross-sectional survey, from whom a subset of 12 youth (5 males and 7 females) were subsequently purposefully selected to participate in in-depth interviews (Figure 2). Interview selection was conducted to have representation of age, gender, marital status and HIV disclosure experience.

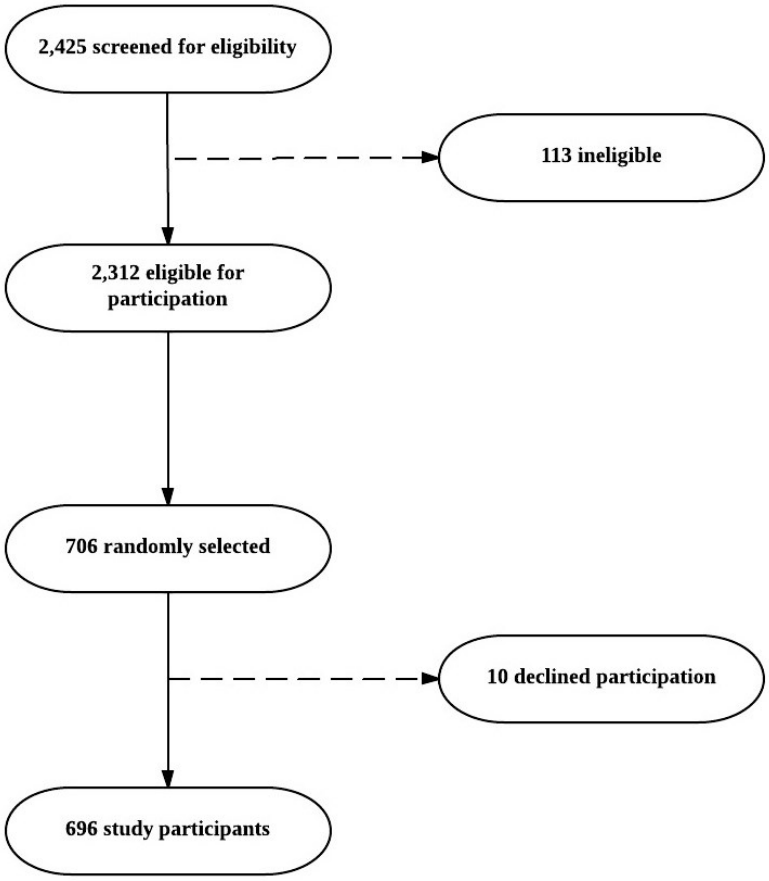

Figure 2: Sample selection process for study participants

3.3.2 Procedures

The structured survey was administered by 6 trained counselors recruited from within the NGO's network of clinics, based on their previous experience in counseling and working with youth as well as their non-affiliation to the study recruitment sites. Data collection training covered confidentiality issues, a review of research protocols, and mock interviews. Interviews were conducted in private rooms inside the clinics and lasted approximately 45 minutes. Participants received reimbursement for transportation costs as well as a telephone card worth 100 Haitian gourdes (about $2.50 US).

Several steps were taken to increase privacy, reduce social desirability bias and enhance the validity of responses to sensitive questions about disclosure and sexual behavior for the interviewer-administered survey with this HIV-positive population. First, participant confidentiality was stressed throughout the study. Additionally, interviews were conducted in private rooms with trained youth counselors, not affiliated with the study sites.

The individual in-depth interviews were administered by two local interviewers (one male and one female) experienced in qualitative data collection. The interviews took place approximately 8 weeks after the survey phase. Interviews lasted about 60 minutes and were conducted in private rooms at the clinic sites. All interviews were audio-recorded with the participants' approval. Following the in-depth interview, participants received reimbursement for transportation costs and a telephone card worth 100 Haitian gourdes (about $2.50 US).

3.3.3 Ethics

Ethical clearance was obtained from both the Duke University Institutional Review Board and the National Haitian Bioethics Committee. Permission to conduct the study was obtained from the administration of the non-governmental organization running the six selected sites. All subjects who participated in the study had received post-test counseling and were aware of their HIV status. Informed consent was obtained from all participants prior to data collection for both the quantitative and the qualitative components.

3.4 Measures

3.4.1 Structured Survey

The quantitative instrument was developed from measures used in previous research conducted with HIV-positive populations, which have demonstrated validity and reliability in various resource-limited and cultural settings (Center for AIDS Prevention Studies CAPS / UCSF, 2004; Dempsey et al., 2012; Deribe et al., 2008; Finger, Clum, Trent, Ellen, & Adolescent Medicine Trials Network for HIV AIDS interventions, 2012; King et al., 2008; Osinde et al., 2012; Przybyla et al., 2013; Simbayi et al., 2007; Smith Fawzi et al., 2010). The measures were translated into Haitian Kreyòl and back-translated in English by experienced linguistic professionals. In order to judge ease of interpretation and response burden, preliminary drafts of the survey were pilot tested with 12 HIV-positive youth who were not included in the study.

HIV disclosure to sexual partners. The primary dependent variable for this study was HIV serostatus disclosure to sexual partners from the past 3 months (Dempsey et al., 2012). After having the participant list up to 5 partners with whom they had sex in the past 3 months, they were asked about their HIV disclosure to each using the following question: "Have you personally told this partner that you are HIV-positive?" The data was recoded categorically as disclosure to all sexual partners (full disclosure) versus disclosure to none or some. Participants were also asked to list the main reason why they disclosed their HIV status for each partner disclosed to.

Partner relationship type. The nature of participants' relationship with their sexual partner(s) was assessed using the following question: " How would you describe your relationship with each partner: do you consider him/her as your main or casual partner?" The data was recorded for each reported partner and recoded into a 3-category variable: casual partners only, main and casual partners, and main partners only (CAPS / UCSF, 2004).

Partner HIV serostatus. Participants' knowledge of their partners' HIV status was assessed using the following question: "Do you know your partner's HIV status?" The data was recorded for each reported partner and recoded into a 4-category variable: HIV-negative partners only, Unknown status only, HIV-positive only and combination of HIV-positive, HIV-negative, and/or Unknown (CAPS / UCSF, 2004).

Disclosure of HIV status to others. Disclosure of HIV serostatus to others besides sexual partners was assessed in several ways. First, a series of sixteen structured items was asked to determine how many people the respondent had disclosed to since

diagnosis; to whom, why and when the respondent had disclosed first, second, and third, as well as the reaction of each confidant and how the respondent felt about subsequent disclosure decisions. Additionally, open-ended items were used to determine the size of their friend and family networks, and how many of those friends and family members were aware of their diagnosis. If a respondent did not disclose to anyone, the reasons for non-disclosure were sought.

Acceptance of HIV. The six-item acceptance subscale of the Illness Cognition Questionnaire for Chronic Diseases (Evers et al., 2001) was used to assess participants' acceptance of HIV disease. Specific items included: "I have learned to live with my HIV", and "I think I can handle the problems related to my HIV, even if it gets worse". Response options ranged from 1 to 4. Items were summed, with higher scores indicating greater acceptance (α=0.96).

Social support. Social support was measured using the Medical Outcomes Study (MOS) Social Support Survey (Sherbourne & Stewart, 1991). The twenty-item five-point rating scale measures four different aspects of social support: emotional/informational support, tangible support, affectionate support, and positive social interaction. Items were summed for a total social support score, with higher scores indicating more frequent availability of different types of support (α=0.98).

Depression. The Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) was used to assess self-reported depressive symptoms. Response choices range from 0 to 3, indicating the frequency of depression symptoms over the previous week. Answers to the twenty-item scale are summed to yield an overall depression score,

with higher scores indicating the presence of greater depressive symptomatology (α=0.77).

Perceived HIV Stigma. To assess the extent of perceived stigma as experienced by respondents with regards to their HIV diagnosis, the personalized stigma and disclosure concerns subscales of the HIV Stigma Scale (Berger, Ferrans & Lashley, 2001) were used. The 18-item personalized stigma subscale, which measures the consequences of others knowing about one's HIV status, included items such as " I have been hurt by how people reacted to learning I have HIV", and "As a rule, telling others that I have HIV has been a mistake". The 12-item disclosure concerns subscale, which measures issues related to disclosing or hiding one's HIV status from others, included items such as " I worry that people who know I have HIV will tell others", and "I told people close to me to keep my HIV a secret". Response choices on a 4-point Likert-type scale were summed to create a personalized stigma score (α= 0.96) and a disclosure stigma score (α=0.92), with higher scores indicating greater perceived stigma.

HIV disclosure norms. Subjective norms represent a construct of the Theory of Planned Behavior (TPB) (Ajzen, 1991). According to the TPB, individuals are more likely to follow a particular health action if they believe the people whose views they value think they should carry out the behavior (Montano & Kapspryk, 2002). Subjective norms regarding HIV disclosure are thus determined by the perceived social pressure to disclose one's HIV status. The construct was measured with a series of items asking for each of three reference groups (friends, family members and sexual partners) how much participants agreed or disagreed with the following statement: “Most of my (friends /

family members / sexual partners) think that people living with HIV should always tell their sex partner their HIV status before having vaginal or anal sex with them." Motivation to comply was then assessed for each reference group with the following: "In general, how important or unimportant is it to you what your (friends / family members / sexual partners) think you should do?" An overall total subjective norm score was obtained by multiplying scores for each normative belief by the corresponding score for motivation to comply and adding them together. Total scores ranged from -24 to +24, with positive scores indicating that the respondent experiences increasing social pressure to disclose.

Sexual and reproductive history. Age at first sex and number of lifetime partners were recorded as continuous variables. Any living children and STI diagnosis in the last 3 months were assessed and dichotomized into yes and no.

Health-related characteristics. Variables characterizing the participant's HIV illness included time since HIV diagnosis (categorized as: less than two years; two to four years; more than four years) and mode of HIV infection (categorized as: perinatally; sexual transmission; blood tranfusion; or I don't know). Antiretroviral therapy (ART) use was determined by asking: "Are you currently taking any antiretroviral medications?"

Socio-demographics characterisctics. Demographic variables included gender, age, education, religion, employment, and marital status. The age variable was categorized as 18-21, 22-25, and 26-29 years. The education variable consisted of the following four categories: no formal education; some primary; some secondary; secondary or more. Religion referred to being Catholic, Protestant, Christian or other.

Employment status was categorized as employed (full or part-time) and unemployed. Marital status consisted of the following two categories: single and cohabitating or married.

3.4.2 In-Depth Interview Guide

A semi-structured interview guide was developed based on preliminary findings from the quantitative phase. The topical guide for the in-depth interviews included open-ended questions and probes in order to capture contexts in which the disclosure event(s) had occurred and explore gender-related motivators and barriers for disclosure. Specific questions and probes regarding the first disclosure included: “Tell me about the first time you disclosed your HIV status”, “Why did you decide to tell this person first?”, “How did you expect this person to react?”, and “Did you feel more or less confident to disclose to someone else after this first experience?” Specific questions related to disclosure to sexual partners included: “What made you decide to share your HIV test result with your partner(s)?”, “How did you decide of the right time to tell him/her?”, and “What was their reaction?” Additionally, the interview schedule explored reasons for not disclosing to anyone or to sexual partners, as well as intentions regarding disclosure in the future.

3.5 Data Management and Analysis

3.5.1 Quantitative Analysis

The quantitative survey was administered to 696 HIV-positive youth. After excluding 16 participants (2.3%) because of incomplete data on disclosure variables, data for 680 HIV-positive youth were included in the statistical analysis. Data were double-entered using Epi-Info (version 7.1.3, Atlanta, GA, USA) and analyzed in Stata 12.0 (StataCorp, College Station, TX, USA).

Four sets of analyses were conducted. First, descriptive statistics were conducted for the full sample and for male and female participants separately on all key variables. Second, HIV serostatus disclosure patterns (whom disclosed to first, second and third; timing of each disclosure; and reasons for disclosing) were tabulated, disaggregated by gender. Third, sociodemographic, health-related, psychosocial and sexual behavior variables were then individually assessed for their association to the main outcome of interest (disclosure to all sexual partners in the past 3 months) for male and female study participants separately. Finally, gender-specific hierarchical (or nested) multivariate regression modeling predicting full disclosure (HIV disclosure to all sexual partners) was used to examine the contribution above and beyond each group of independent variables that were associated with the outcome at an alpha level of 0.10 based on bivariate regression. In the first model of the hierarchical regression procedure, sociodemographic variables (age and marital status) were block entered; in the second step, HIV-related characteristics (time since HIV diagnosis, currently on ART, and previous disclosure to family) were entered into the first model. Next, partner characteristics (partner relation-

ship type and partner HIV serostatus) were entered in order to get the third model. In the last step, psychosocial characteristics (HIV Acceptance, Personalized stigma, Disclosure stigma, Social support, Depression and Subjective norms) were entered as a block into Model 3. The likelihood ratio (LR) test, a measure of evaluation of the contribution of predictors to the base model, was used to compare two successive nested models. Akaike information criteria (AIC) and the Hosmer and Lemeshow test (Hosmer, Lemeshow, & Sturdivant, 2000) were used to assess the goodness of fit of successive models for each gender. All analyses were performed using logistic regression with 95% confidence intervals.

3.5.2 Qualitative Analysis

The in-depth interviews were transcribed verbatim in Haitian Kreyòl and subsequently translated into English for analysis. Transcripts were edited to remove identifiers and were read thoroughly multiple times. A codebook of key themes was developed around the main interview topics to guide the content analysis (Ulin, Robinson, & Tolley, 2005). Data were examined by themes, and key representative quotes from the transcripts were identified. The mixed methods analysis was done in a sequential but cohesive manner, such that data combination occurred at the level of data interpretation.

4. Results

4.1 Quantitative Results

4.1.1 Description of the Sample

The main characteristics of the study participants are described in Table 1. The sample consisted of 680 HIV-positive young adults (46% male; 54% female) with an average age of 23.7 years (SD = 2.0) for males and 24.1 years (SD = 2.1) for females. Overall, more than two-thirds of the sample was between 18 and 25 years old. 81% of male participants had some secondary school education level compared to only 64% of females.

The vast majority of participants was single (73%). More female youth (34%) reported cohabitation with a partner or being married than males (18%). Approximately 10% of males self-identified as homosexual. Sexual transmission was the main route of HIV acquisition for the sample (97%). At the time of interview, about half (46%) of participants were relatively recently diagnosed HIV-positive (less than 2 years), with males more likely to be recently diagnosed compared with females. A little over half of the overall sample (54%) was currently taking ART, with a higher proportion of females (60%) compared to males (48%). Alcohol and substance use were higher among males (41% and 23%, respectively) compared to females (14% and 12%, respectively).

Table 1: Sociodemographic and health characteristics of sample (N=680)

Characteristic	Male (N=316)		Female (N = 364)		$\chi 2$
	n	(%)	n	(%)	
Age					4.96
18 - 21	94	(29.8)	90	(24.7)	
22 - 25	146	(46.2)	160	(44.0)	
26 - 29	76	(24.1)	114	(31.3)	
Education					28.93***
No formal	20	(6.3)	24	(6.6)	
Some Primary	19	(6.0)	46	(12.7)	
Some Secondary	156	(81.0)	233	(64.0)	
Secondary or more	21	(6.7)	61	(16.8)	
Religion					11.14*
Catholic	136	(43.0)	141	(38.7)	
Protestant	81	(25.6)	92	(25.3)	
Christian	79	(25.0)	122	(33.5)	
Other	19	(6.0)	8	(2.2)	
Employment					1.21
Employed	82	(26.9)	105	(28.9)	
Unemployed	231	(73.1)	258	(70.9)	
Marital status					22.25***
Single	259	(82.0)	240	(65.9)	
Cohabitating/Married	57	(18.0)	124	(34.1)	
Sexual orientation					42.27***
Heterosexual	283	(89.6)	361	(99.2)	
Homosexual	33	(10.4)			
Bisexual / Other			3	(0.8)	
Time since HIV diagnosis					18.94***
Less than 2 years	169	(53.5)	142	(39.0)	
2 years - 4 years	111	(35.1)	188	(51.7)	
More than 4 years	36	(11.4)	34	(9.3)	
Mode of HIV acquisition					2.35
Perinatally	4	(1.3)	6	(1.7)	
Sexual transmission	309	(97.8)	350	(96.2)	
Blood transfusion	1	(0.3)	1	(0.3)	
Don't know	2	(0.7)	7	(2.0)	
Currently on ART					10.43**
No	164	(51.9)	147	(40.4)	
Yes	151	(47.8)	217	(59.6)	
Alcohol use					66.94***
No use	186	(58.9)	311	(85.4)	
Any use	130	(41.1)	50	(13.7)	
Substance use					13.76***
No use	245	(77.5)	321	(88.2)	
Any use	71	(22.5)	43	(11.8)	

**P < .05. **P < .01. ***P < .001.*

4.1.2 Sexual and Reproductive History

The sexual history of participants is shown in Table 2. The average age at first sexual experience was 12.7 years (SD = 2.3) for males, compared to 15.4 (SD = 1.7) for females. Male youth reported two times more lifetime sexual partners than females (13.1 partners for males compared to 5.8 for females). About 30% of participants had children, with female youth more likely to report any children than males. A substantial proportion (27% males and 22% females) had been diagnosed with a sexually transmitted infection (STI) other than HIV in the past 3 months. Close to half of respondents reported having just one sexual partner in the past 3 months. Males were more likely to report multiple partners, compared to females (60% vs. 40%, respectively). The average number of sexual partners in the past 3 months reported was 1.7 (SD = 0.7; range: 1 - 5) for males and 1.4 (SD 0.5; range: 1 - 3) for females.

Table 2: Sexual and reproductive history characteristics of sample (N=680)

Characteristic	Male (N = 316)		Female (N = 364)		$\chi 2$ or t
	n	(%)	n	(%)	
Age at first sex					-18.02***
Mean (SD)	12.7	(2.3)	15.4	(1.7)	
Number of lifetime partners					24.95***
Mean (SD)	13.1	(4.7)	5.8	(2.9)	
Sexual partners in past 3 months					20.19***
One	126	(39.9)	208	(57.1)	
Two or more	190	(60.1)	156	(42.9)	
Partner relationship type					3.93
Casual only	189	(59.8)	203	(55.8)	
Main and Casual	36	(11.4)	32	(8.8)	
Main only	91	(28.8)	129	(35.4)	
Partner HIV serostatus					2.06
HIV-positive only	36	(11.4)	54	(14.8)	
Unknown only	190	(60.1)	217	(59.6)	
HIV-negative only	90	(28.5)	93	(25.6)	
STI diagnosis in last 3 months					4.41
No	230	(72.8)	283	(77.8)	
Yes	86	(27.2)	79	(21.7)	
Living children					31.15***
No	253	(80.1)	220	(60.4)	
Yes	63	(19.9)	143	(39.3)	

*$P < .05$. **$P < .01$. ***$P < .001$.

4.1.3 Psychosocial Characteristics

In this sample of young HIV-positive individuals, males experienced greater stigma related to personalized stigma while females experienced greater stigma related to disclosure concerns. Statistically significant differences in mean scores for both subscales were found between genders (Table 3). The overall mean CES-D depression score was 19.8 (SD = 5.1), with female youth scoring on average 20.2 slightly above the mean score of 19.3 for males. However, a depression score of 23 or greater, considered an indicator

of probable depressive symptoms (Hays, Blazer, & Gold, 1993) was observed for 37% of females compared to only 26% of males. Overall, participants reported moderate acceptance of their HIV illness with no significant difference between genders. Higher levels of social support were reported by female respondents compared to males. Finally, participants as a whole experienced very little social pressure to disclose with a positive mean subjective norm score of 0.5 (SD = 5.7).

Table 3: Psychosocial characteristics of sample (N = 680)

Characteristic	Male (N = 316)		Female (N = 364)		t statistic
	Mean	(SD)	Mean	(SD)	
Personalized Stigma					5.58***
Range (18 - 72)	58.3	(7.0)	53.6	(13.3)	
Disclosure Stigma					-6.86***
Range (10 - 40)	28.2	(8.1)	31.5	(3.8)	
Depression					-2.29*
Range (0 - 60)	19.3	(4.6)	20.2	(5.5)	
HIV Acceptance					-1.71
Range (6 - 24)	14.3	(5.0)	15.1	(6.1)	
Social Support					-4.21***
Range (0 - 100)	38.7	(22.3)	45.9	(22.1)	
Subjective norms					-2.84**
Range (-24 to + 24)	-0.14	(5.4)	1.14	(5.9)	

**P < .05. **P < .01. ***P < .001.*

4.1.4 HIV Disclosure Patterns

At the time of data collection, 384 (56%) respondents had told at least one person about their HIV status (Table 4). A majority of female youth (70%) had disclosed to a family member or a friend, compared to only 35% of males. Among the youth who had

disclosed to at least one person (n=384), the majority had disclosed to 2 people (56%). Two times more female youth (24%) had disclosed to three or more people since their HIV diagnosis compared to males (13%).

The overall extent of disclosure was explored within participants' friends and family networks. The average proportion of people in each respondent's friend network that was aware of his/her HIV status was 0.12 (SD = 0.25; range: 0.00 - 1.00) for males and 0.16 (SD = 0.30; range: 0.00 - 1.00) for females. Sixty-two percent of respondents had ratios of 0.00, that is, they had not disclosed to any friends compared to 5% who had disclosed to their entire friend network (ratio 1.00). Within the family network, the average proportion of people aware of respondents' HIV status was three times lower for males (Mean = 0.13; SD = 0.32) compared to females (Mean 0.37; SD = 0.37). Forty-eight percent of respondents had not disclosed to any close family members (ratio 0.00) compared to 16% who had revealed their HIV status to all members of their family.

Among disclosers, the majority (57%) had disclosed to their first confidant in the first month after diagnosis and only about 4% of youth waited over a year to disclose for the first time (Table 4). A larger proportion of males (67%) disclosed in the first month after diagnosis compared to females (52%), although females continued to display higher rates of disclosure up to a year after their HIV diagnosis. Most first time disclosure events (46%) were to someone from the close social network of family and friends, whereas only 18% of first disclosures were to spouses or sexual partners. Male youth were most likely to disclose their HIV status to their sexual partners (35%), followed by their friends (28%), while female youth were more likely to share the news of their HIV diagnosis

with their mothers (51%) and sisters (27%). Fathers were infrequently used as confidants for both genders.

Overall, the most frequently mentioned reasons for first disclosures included: emotional support (92%), financial support (70%) and medical or home care (65%). While both genders were seeking emotional support with their first disclosure at comparable levels (about 92% each), females differed significantly from males with regards to financial support (89% for females vs. 30% for males) and medical care (77% for females vs. 40% for males). The two most frequent reasons for disclosure cited by young males, after emotional support were: because he/she should know (42%), and medical or home care (40%). Supportive reactions from first-time confidants were frequent (about 61%) while neutral responses were reported 33% of the time. Negative outcomes were rare and accounted for only 6% of the reactions to first disclosures. There were no significant differences between genders.

Spouses or sexual partners were the most frequent type of confidants for second disclosures for both males and females (55% overall). The most frequently mentioned reasons for second disclosures included: emotional support (72%), because he/she should know (53%), and to encourage HIV testing (52%). As for first-time disclosures, confidant reactions were mostly supportive for both genders (67%). Of the 68 PLWHA who had disclosed to three or more people, the majority was female (79%). Third disclosures were mostly directed towards friends (68%) and were seeking primarily emotional support (96%).

Over three-quarters of the sample (76%) reported that prior discussion about disclosure and safe sex with their counselors at their clinic had been very limited, with no difference between genders. Nearly all youth (about 96%) had no intentions to disclose their status to anyone new in the next 3 months (Table 4). Among the 296 individuals (44%) who had kept their HIV status a secret from everyone in their social networks, the main reasons for non-disclosure included: fear of rejection (41%), fear of negative consequences for self (37%), and fear of blame (33%).

Among those who disclosed to their sexual partners from the past 3 months, the most common motivators for disclosure were the desire to protect and encourage HIV testing among male respondents (49%), and the moral/ethical responsibility among female participants (44%).

Table 4: HIV serostatus disclosure characteristics of sample (N=680)

Characteristic	Male (N = 316)		Female (N = 364)		$\chi 2$
	n	(%)	n	(%)	
Ever disclosed to anyone					66.15***
No	190	(60.1)	106	(29.1)	
Yes	126	(39.9)	258	(70.9)	
Ever disclosed to a family member					84.64***
No	207	(65.5)	110	(30.2)	
Yes	109	(34.5)	254	(69.8)	
Ever discussed disclosure with counselor					0.68
A lot / somewhat	70	(22.2)	90	(24.9)	
A little / not at all	245	(77.8)	271	(75.1)	
Disclosure intentions in next 3 months					0.15
Not at all / somewhat important	304	(96.2)	348	(95.6)	
Very / extremely important	12	(3.8)	16	(4.4)	
Among those who have disclosed to anyone	Male (N = 126)		Female (N = 258)		$\chi 2$
	n	(%)	n	(%)	
Number of people disclosed to since diagnosis					29.23***
One	51	(40.5)	41	(15.9)	
Two	59	(46.8)	156	(60.5)	
Three or more	16	(12.7)	61	(23.6)	
Timing of first disclosure					16.06**
Within 24 hours of diagnosis	25	(19.8)	45	(17.4)	
In the first month after diagnosis	84	(66.7)	135	(52.3)	
1 - 6 months after	12	(9.5)	33	(12.8)	
6 - 12 months after	2	(2.4)	33	(12.8)	
Over 1 year after	2	(1.6)	12	(4.7)	
Confidant reaction to first disclosure					2.54
Supportive	80	(63.5)	154	(59.7)	
Unsupportive	10	(7.9)	13	(5.0)	
Neutral	36	(28.6)	91	(35.3)	

**P < .05. **P < .01. ***P < .001.*

4.1.5 Factors Predicting Disclosure to Sexual Partners

Among study participants, 226 (33%) had disclosed their HIV status to all their sexual partners (full disclosure) in the past 3 months.

4.1.5.1 Factors Predicting Disclosure to Sexual Partners Among Male Participants

Among young adult males, 32% had disclosed their HIV serostatus to all their sexual partners from the past three months. Table 5 presents results of unadjusted bivariate and hierarchical multivariate regression analyses for factors associated with HIV serostatus disclosure to all sexual partners among male participants. Bivariate analyses revealed that younger age, higher levels of personalized and disclosure stigma were significantly associated with lower odds of disclosure to all sexual partners ($P < 0.001$ for all variables). Male respondents with casual or a mix of main and casual partners in the past three months, and those who were unaware of their partners' HIV status were less likely to have disclosed their status compared to those with main partners only ($P < 0.001$) and those with knowledge of their partners' status ($P < 0.001$). Conversely, being married or cohabitating with a partner, longer period of time since HIV diagnosis, previous disclosure to family, increased acceptance of HIV, higher levels of social support and depression were associated with greater odds of HIV serostatus disclosure to all sexual partners, among HIV-positive males.

The results of the hierarchical regression modeling predicting full disclosure to sexual partners from demographic, HIV-related, partner and psychosocial characteristics among male participants are also reported in Table 5. Model 1 presents the relationship

between demographic variables and full disclosure to sexual partners from the past 3 months. Younger and older age categories were significantly less likely to disclose their HIV status compared to the 22-25 age group. Conversely, married or cohabitating male respondents were over 11 times more likely than single males to self-report disclosure to all sexual partners. In Model 2, HIV-related characteristics were added to the baseline demographics-only model. Having an average duration since HIV diagnosis of 2 to 4 years and having previously disclosed to family were significantly associated with greater odds of disclosure. Demographic variables remained statistically significant once the HIV-related variables were included in this model. Partner variables were added to the demographics and HIV-related characteristics model in order to obtain Model 3. Having casual partners and partners of unknown HIV status were significantly associated with lower odds of disclosure. Among variables entered in previous models, only being older (26-29 years) remained significantly associated with full disclosure once the partner variables were entered into the model.

The final model (Model 4) added psychosocial variables to Model 3. Increased HIV acceptance (AOR = 1.67, 95% CI: 1.06, 2.62) and higher personalized stigma (AOR = 1.26, 95% CI: 1.00, 1.58) were significantly associated with greater odds of disclosure, whereas higher disclosure stigma (AOR = 0.51, 95% CI: 0.34, 0.77) was significantly associated with lower odds of full disclosure. The only variables that remained significant predictors of disclosure once the psychosocial characteristics were added included older age (AOR = 0.00, 95% CI: 0.00, 0.31), being unaware of partners' HIV status (AOR = 0.00, 95% CI: 0.00, 0.05), and having HIV-negative partners (AOR = 0.01, 95% CI: 0.00,

1.01). Additionally, Model 4 had a significantly reduced log-likelihood compared to previous models, suggesting that the final model explained more of the variance in the outcome ($P < 0.001$). The Hosmer and Lemeshow test also suggested that this model was a good fit to the data as $P = 0.689$ (> 0.05).

Table 5: Bivariate and Hierarchical regression analyses evaluating factors predicting full disclosure to sexual partners among male participants (n = 316)

	Unadjusted			Model 1			Model 2			Model 3			Model 4		
	Crude OR	95% CI	P-value	Adj OR	95% CI	P-value	Adj OR	95% CI	P-value	Adj OR	95% CI	P-value	Adj OR	95% CI	P-value
Demographics															
Age															
18 - 21	**0.13**	**0.06, 0.29**	**<0.001**	**0.15**	**0.06, 0.34**	**<0.001**	**0.25**	**0.10, 0.67**	**0.005**	0.72	0.07,6.91	0.779	0.71	0.01, 58.15	0.879
22 -25	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
26 - 29	0.86	0.49, 1.52	0.602	**0.28**	**0.12, 0.64**	**0.002**	**0.11**	**0.04, 0.32**	**<0.001**	**0.02**	**0.00, 0.15**	**<0.001**	**0.00**	**0.00, 0.01**	**0.001**
Marital status															
Single	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
Cohabitating/Married	**11.39**	**5.81, 22.32**	**<0.001**	**15.37**	**6.59, 35.84**	**<0.001**	**16.05**	**6.32, 40.77**	**<0.001**	2.33	0.43, 12.73	0.327	0.35	0.00, 26.41	0.634
HIV-related characteristics															
Time since HIV diagnosis															
Less than 2 years	Ref	-	-				Ref	-	-	Ref	-	-	Ref	-	-
2 years - 4 years	**4.39**	**2.55, 7.55**	**<0.001**				**2.55**	**1.25, 5.20**	**0.010**	0.73	0.15, 3.64	0.706	1.26	0.04, 42.87	0.899
More than 4 years	**2.95**	**1.35, 6.42**	**0.006**				0.90	0.25, 3.20	0.871	0.40	0.06, 2.57	0.336	1.41	0.03, 61.27	0.858
Currently on ART															
No	Ref	-	-												
Yes	0.76	0.47, 1.23	0.272												
Previous disclosure to family															
No	Ref	-	-				Ref	-	-	Ref	-	-	Ref	-	-
Yes	**4.76**	**2.57, 8.81**	**<0.001**				**9.43**	**3.69, 24.11**	**<0.001**	4.00	0.98, 16.36	0.054	2.53	0.13, 50.27	0.543
Partner characteristics															
Partner relationship type															
Casual only	**0.00**	**0.00, 0.01**	**<0.001**							**0.03**	**0.00, 0.18**	**<0.001**	0.11	0.00, 2.45	0.166
Main and casual	**0.22**	**0.09, 0.52**	**0.001**							0.32	0.06, 1.62	0.171	0.35	0.01, 12.11	0.566
Main only	Ref	-	-							Ref	-	-	Ref	-	-
Partner HIV serostatus															
HIV-positive only	Ref	-	-							Ref	-	-	Ref	-	-
HIV unknown	**0.00**	**0.00, 0.01**	**<0.001**							**0.00**	**0.00, 0.04**	**<0.001**	**0.00**	**0.00, 0.05**	**0.008**
HIV-negative	**0.21**	**0.06, 0.75**	**0.016**							0.44	0.07, 2.72	0.379	**0.01**	**0.00, 1.01**	**0.050**
Psychosocial characteristics															
HIV Acceptance	**1.38**	**1.29, 1.49**	**<0.001**										**1.67**	**1.06, 2.62**	**0.025**
Personalized Stigma	**0.94**	**0.91, 0.97**	**<0.001**										**1.26**	**1.00, 1.58**	**0.047**
Disclosure Stigma	**0.76**	**0.72, 0.81**	**<0.001**										**0.51**	**0.34, 0.77**	**0.001**
Social Support	**1.04**	**1.03, 1.05**	**<0.001**										1.02	0.98, 1.07	0.326
Depression	**1.07**	**1.01, 1.13**	**0.016**										0.89	0.67, 1.18	0.421
Subjective norms	0.97	0.93, 1.02	0.283												
-2LL				300.2912			271.7508			89.4370			33.6180		
Likelihood ratio test				90.3, df = 3, p<0.001			28.54, df = 3, p<0.001			182.31, df = 4, p<0.001			55.82, df = 5, p<0.001		
AIC				308.2912			285.7509			111.4371			65.6192		
Hosmer and Lemeshow chi-square							2.79, df = 4, p = 0.593			3.89, df = 6, p = 0.691			3.91, df = 6, p = 0.689		

4.1.5.2 Factors Predicting Disclosure to Sexual Partners Among Female Participants

Among young adult females, 34.3% had disclosed their HIV serostatus to all their sexual partners in the past three months. Table 6 presents results of unadjusted bivariate and hierarchical multivariate regression analyses for factors associated with HIV serostatus disclosure to all sexual partners of female participants. Similar to their male counterparts, bivariate analyses revealed that being single, higher levels of personalized and disclosure stigma, having casual sexual partners, and partners of unknown or HIV-negative status were significantly associated with reduced likelihood of HIV disclosure to all sexual partners ($P < 0.05$ for all variables) among HIV-positive females. Additionally, younger (18-21 years) and older (26-29 years) age categories were significantly associated with lower odds of disclosure. Conversely, female respondents who had previously disclosed to family and who self-reported higher levels of HIV acceptance and social support were significantly more likely to disclose to their sexual partners (Table 6). Contrary to males, depressive symptomatology was negatively associated with disclosure among females ($P = 0.011$) and time since HIV diagnosis was not associated with disclosure.

The results of the hierarchical regression modeling predicting full disclosure to sexual partners from demographic, HIV-related, partner and psychosocial characteristics among female participants are also reported in Table 6. Model 1 presents the relationship between demographic variables and full disclosure to sexual partners from the past 3 months. Older and single females were significantly less likely to disclose their HIV status compared to the 22-25 age group and those who were cohabitating or married. In

model 2, HIV-related characteristics were added to the baseline demographics-only model. Those who had previously disclosed to family were close to 10 times more likely to have disclosed to their sexual partner(s). Only being single remained statistically significant among the demographic variables once the HIV-related characteristics were included in this model. Partner variables were added to the demographics and HIV-related characteristics model in order to obtain Model 3. Having casual partners and partners of unknown HIV status were significantly associated with lower odds of disclosure. Among variables entered in previous models, being older (26-29 years), being single, and previous disclosure to family remained significantly associated with full disclosure once the partner-level characteristics were entered into the model.

The final model (Model 4) added psychosocial variables to Model 3. Higher personalized stigma (AOR = 0.92, 95% CI: 0.88, 0.96) was significantly associated with lower odds of disclosure, whereas increased social support (AOR = 1.04, 95% CI: 1.01, 1.08) was significantly associated with higher odds of full disclosure. The variables that remained significant predictors of disclosure once the psychosocial characteristics were added included older age (AOR = 0.07, 95% CI: 0.02, 0.34), being single (AOR = 0.08, 95% CI: 0.02, 0.31), having casual or a mix of main and casual partners (AOR = 0.02, 95% CI: 0.00, 0.16, and AOR = 0.03, 95% CI: 0.01, 0.15 respectively), and being unaware of partners' HIV status (AOR = 0.09, 95% CI: 0.01, 0.68). Moreover, Model 4 had a significantly reduced log-likelihood compared to previous models, suggesting that the final model explained more of the variance in the outcome ($P < 0.001$). The Hosmer

and Lemeshow test also suggested that only Model 4 provided a good fit to the data with $P = 0.818$ (> 0.05).

Table 6: Bivariate and Hierarchical regression analyses evaluating factors predicting full disclosure to sexual partners among female participants (n = 364)

	Unadjusted			Model 1			Model 2			Model 3			Model 4		
	Crude OR	95% CI	P-value	Adj OR	95% CI	P-value	Adj OR	95% CI	P-value	Adj OR	95% CI	P-value	Adj OR	95% CI	P-value
Demographics															
Age															
18 - 21	**0.30**	**0.16, 0.56**	**<0.001**	0.43	0.18, 1.03	0.059	0.50	0.20, 1.25	0.140	0.44	0.12, 1.58	0.207	0.35	0.07, 1.66	0.185
22 - 25	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
26 - 29	**0.43**	**0.25, 0.73**	**0.002**	**0.26**	**0.12, 0.56**	**0.001**	0.48	0.21, 1.10	0.084	**0.20**	**0.06, 0.64**	**0.006**	**0.07**	**0.02, 0.34**	**0.001**
Marital status															
Single	**0.02**	**0.01, 0.05**	**<0.001**	**0.02**	**0.01, 0.04**	**<0.001**	**0.03**	**0.01, 0.06**	**<0.001**	**0.09**	**0.03, 0.28**	**<0.001**	**0.08**	**0.02,0.31**	**<0.001**
Cohabitating/Married	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-	Ref	-	-
HIV-related characteristics															
Time since HIV diagnosis															
Less than 2 years	Ref	-	-												
2 years - 4 years	1.32	0.82, 2.11	0.256												
More than 4 years	0.55	0.21, 1.42	0.215												
Currently on ART															
No	Ref	-	-												
Yes	0.78	0.50, 1.23	0.287												
Previous disclosure to family															
No	Ref	-	-				Ref	-	-	Ref	-	-	Ref	-	-
Yes	**17.65**	**6.96, 44.76**	**<0.001**				**9.43**	**3.17, 28.09**	**<0.001**	**6.67**	**1.72, 25.78**	**0.006**	2.45	0.45, 13.44	0.302
Partner characteristics															
Partner relationship type															
Casual only	**0.00**	**0.00, 0.01**	**<0.001**							**0.01**	**0.00, 0.07**	**<0.001**	**0.02**	**0.00, 0.16**	**<0.001**
Main and casual	**0.28**	**0.12, 0.62**	**0.002**							**0.08**	**0.02, 0.28**	**<0.001**	**0.03**	**0.01, 0.15**	**<0.001**
Main only	Ref	-	-							Ref	-	-	Ref	-	-
Partner HIV serostatus															
HIV-positive only	Ref	-	-							Ref	-	-	Ref	-	-
HIV unknown	**0.01**	**0.00, 0.03**	**<0.001**							**0.14**	**0.03, 0.66**	**0.013**	**0.09**	**0.01, 0.68**	**0.019**
HIV-negative	**0.03**	**0.01, 0.11**	**<0.001**							0.64	0.12, 3.23	0.587	0.48	0.07, 3.32	0.460
Psychosocial characteristics															
HIV Acceptance	**1.18**	**1.13, 1.23**	**<0.001**										1.04	0.86, 1.25	0.678
Personalized Stigma	**0.91**	**0.89, 0.92**	**<0.001**										**0.92**	**0.88, 0.96**	**<0.001**
Disclosure Stigma	**0.73**	**0.67, 0.81**	**<0.001**										0.96	0.85, 1.09	0.533
Social Support	**1.03**	**1.01, 1.04**	**<0.001**										**1.04**	**1.01, 1.08**	**0.017**
Depression	**0.95**	**0.91, 0.99**	**0.011**										0.95	0.87, 1.04	0.253
Subjective norms	0.98	0.94, 1.02	0.260												
-2LL				248.8930			226.6842			127.5838			99.7714		
Likelihood ratio test				197.16, df = 3, p < 0.001			22.21, df = 1, p < 0.001			99.10, df = 4, p < 0.001			27.81, df = 5, p < 0.001		
AIC				256.893			236.684			145.584			127.771		
Hosmer and Lemeshow chi-square							14.75, df = 6, p = 0.022			23.68, df = 7, p = 0.001			4.41, df = 8, p = 0.818		

4.2 Qualitative Results

4.2.1 Description of the Sample

A subset of twelve individuals (five males and seven females), ranging in age from 19 to 28 years (mean age 24 years) participated in the qualitative interviews. Six of the participants were cohabitating or married at the time of the interview (2 males and 4 females). Although some participants had been diagnosed with HIV for as little as 8 months, others had known their HIV status for as long as two and a half years (median time since diagnosis was 15 months). The majority (9/12) were unemployed. The breakdown by gender, age and marital status in the qualitative subsample mirrored that of the larger quantitative sample; however, participants with a history of disclosure (7/12) were oversampled in order to allow a broader exploration of factors linked to decisions to disclose.

Qualitative findings shed light on how youth decided to disclose or not disclose their HIV status, to whom they chose to disclose, and the reactions of their confidants.

4.2.2 Deciding to Disclose Their HIV Status

After learning of their HIV-positive diagnosis, all participants faced the tough decision of whether, how and to whom to disclose their status. Participants acknowledged that the anxiety over whether to disclose was taxing and that making the decision to disclose was one of the most difficult steps after learning of their diagnosis. Most recounted experiencing apprehension and stress not knowing whether their confidants would respond positively or would reject them. There was a wide range of disclosure

patterns between the seven participants who had disclosed their HIV status. All had shared their diagnosis with at least one person and most (71%) had told more than one person. They typically disclosed first to family or friends. Among the three males who had disclosed, only one had disclosed to his sexual partners. All but one of the four females who had disclosed shared their HIV diagnosis with a family member first. The young woman who disclosed to a sexual partner first reported having no close friends or relatives. Two of the women had disclosed to their sexual partners.

Most participants who had disclosed shared that they had disclosed their status to someone in their family because of a need for emotional or financial support and to feel less isolated. While most disclosed within the first month after diagnosis, two participants said that it took over one year for them to have enough courage to disclose to their families. Patterns of disclosure to family mirrored quantitative patterns of expected emotional and economic support for both male and female participants, especially those who were younger. One 19-year-old male youth expressed the following: "I told my mother because she is all I have and I need her support." A married female (24 years old) echoed the same feeling regarding her partner: "I lost all my family in the big earthquake. He [husband] is the only one supporting me even if I know he infected me."

Disclosure to sexual partners was perceived as one of the most difficult disclosure experiences by all participants, regardless of whether they had ever disclosed to a partner or not. For the three participants who had disclosed to sexual partners (2 females and 1 male), motivations for disclosure to partners were different than those for disclosing to family members. They recounted disclosing to their sexual partners as a way to

encourage them to get tested and encourage future condom use. Both females in particular expressed that they disclosed out of a sense of moral duty because their partner "deserved to know". The sole male participant who had disclosed to his sexual partner shared that the need for emotional support and help with medical care prompted him to share his diagnosis with his partner, especially since he had been previously rejected by his family after telling them the news. The 18-year-old male expressed the following: "I told my mom and my dad. They kicked me out on the street. I had nowhere to go. She [girlfriend] took me in even though she is HIV-negative and has been my greatest source of support. I love her for that."

4.2.3 Deciding to Keep Their HIV Status a Secret

At the time of the interviews, five participants (2 males and 3 females) had not disclosed their status to anyone. When asked for reasons for not disclosing to anyone, all cited fear of stigma and rejection. Additionally, fear of blame, gossip and subsequent unauthorized disclosures were also mentioned by both males and females as factors hindering disclosure. For most of those non-disclosers, both the fear of being stigmatized by others and self-stigma played an important role in their decision to keep their secret. One 19-year-old female expressed the following: "I feel worthless [long silence]. I keep telling myself that my blood is bad, I am bad. I don't know why this happened to me [participant crying]." One 24-year-old male had still not come to terms with his HIV status even though he received his results over 14 months before the date of the interview: "How could I have it [HIV]? I will never live a normal life with this thing."

When asked about the barriers to disclosure to their sexual partners, the participants who had not disclosed to sexual partners said they were concerned with their partners' reaction to the news. For young men, this fear was fueled by the possible exposure of their unfaithfulness, whereas for young women, this apprehension reflected not only the perceived anticipated loss of economic support but also anxiety over abandonment and physical abuse. For females, the fear of disclosing to sexual partners was persistent even after they had already disclosed and secured support from family members. As one unmarried 24-year old female expressed: "Yes, my mom and sister know [about my status]. They console me when I am sad because I can't tell my partner. He will leave me. How will I feed myself and our child? How will I be able to take care of my mom if he leaves?" Another female participant said that she would never disclose to her partner because of the fear of being "blamed as the source of the infection".

4.2.4 Choosing Whom to Disclose To

Of those who did disclose to family (2 males and 3 females), the most common person disclosed to was a mother or a sister. One overarching theme that crossed gender lines was the selectivity in the choice of confidant. Among those who had disclosed to family or friends, none had disclosed to their entire circle of family or friends. All participants selectively chose who among their inner circle of family or friends was worthy of their trust and limited their disclosure to only these people. One important aspect of choosing and trusting this confidant was the assurance that the secret would be kept safe. Both males and females viewed selective disclosure as an approach to protect

loved ones from potentially distressing news. A 25-year-old male said: “I will never tell my mother. She would die if she learned this news. She is counting on me to support her through her old days.” People who were perceived as having always been supportive, accepting and most importantly who could handle the upsetting news were disclosed to selectively.

The same selectivity in the choice of confidant held true for disclosure to sexual partners. The decision to disclose was often based on the nature, quality and seriousness of the relationship. Participants who were involved in casual relationships did not feel the need to disclose to their partners, as long as they were using protection. “I insist on using condoms. Why should I tell him? We will probably never get married anyway”, said a 20-year old female. Another important factor for choosing whom to disclose to was the confidant’s own HIV status, as one 26-year old female shared: “He [current partner] is HIV-positive like me. We met at a support group. We help each other a lot and I can be myself with him.”

4.2.5 Disclosure Outcomes

Most participants who had disclosed their HIV status to family, friends, or sexual partners reported at least one compassionate reaction. One 24-year-old woman recalls that her husband was very calm after she told him the news. “I told him I had tested positive for HIV. He said nothing for a long time, then said that he would be there for me. I asked him to go get tested. He refused. It’s been 2 years [long pause]. I believe he is the one who infected me because he refuses to use condoms.” She went on to explain how

difficult it had been to negotiate safe sex with him, prior to her testing HIV-positive, because of her financial dependence on him.

Only two participants recounted an adverse reaction to their disclosure. One was an 18-year-old male who shared the following: “My family kicked me out in the streets saying that I was a source of shame for all of them”. The other (a female) suffered physical abuse from her partner before he left her for another woman. Regardless of their confidant’s reaction to disclosure, all participants described feeling liberated, as if “an enormous weight had been lifted off their backs” after disclosing their result.

5. Discussion

5.1 Reflection on HIV Serostatus Disclosure Among Young Adults: Rates, Patterns and Predictors

This study described the patterns of HIV serostatus disclosure to family, friends, and sexual partners, and examined the predictors of HIV serostatus disclosure to all sexual partners from the past three months among 680 HIV-positive young adults randomly selected from six clinics in the metropolitan area of Port-au-Prince, Haiti. Just over half of respondents had disclosed to at least one person. A majority of female youth (70%) disclosed to a family member or a friend, compared to only 35% of males. This finding is consistent with results reported elsewhere with family members being the most frequent group disclosed to (Patel et al., 2012) and men being more reluctant to disclose to family and friends compared to women (Bouillon et al., 2007). Higher levels in general disclosure have been observed in other settings in the Caribbean or Africa, where rates have been as high as 70% (Bouillon et al., 2007) and 94% (Deribe, Woldemichael, Wondafrash, Haile, & Amberbir, 2008). It is possible that disclosure rates were relatively low in the Haitian setting because of a combination of factors including the younger age of participants, their lack of self-efficacy for disclosure given the very limited disclosure-specific counseling received from health care providers at the selected clinics, and the pervasiveness of HIV-related stigma in their communities.

The overall HIV disclosure rate of 33% to all sexual partners in this sample is comparable to HIV disclosure rates observed in a previous study conducted in Haiti

among HIV-positive alcohol users (Conserve et al., 2014) and also similar to disclosure rates among immigrant Haitian communities in the French Antilles (Bouillon et al., 2007). This low rate could be explained by possible self-stigma among Haitian nationals resulting from decades-old entrenched stereotypes constructing HIV as a "Haitian" illness (Farmer, 2001; Loufty et al., 2012). Nonetheless, comparably low rates of HIV disclosure to sexual partners have been found in settings in sub-Saharan Africa. Olley and colleagues (2004) found that only 22% of recently HIV-positive women and men in South Africa had disclosed to a sexual partner while 31% of female PLWHA from a mother-to-child HIV transmission prevention program in Kenya had disclosed to their sexual partner (Gaillard et al., 2002).

In the current sample, there was no significant difference in the rate of disclosure to sexual partners between genders. This finding is similar to that found in Ethiopia (Deribe et al., 2009) but differs from another study conducted in South Africa, which found that male gender was associated with non-disclosure of HIV status (Simbayi et al., 2007). In general, studies considering HIV disclosure in both men and women in different settings have produced mixed results (Kalichman et al., 2003; O'Brien et al., 2003). Although gender differences were not apparent in the overall rates of disclosure to sexual partners in this sample, hierarchical multivariable regression analysis allowed for the identification of a separate set of predictor variables for each gender.

Age was a significant predictor of HIV serostatus disclosure to all sexual recent partners for both genders. Older youth (26-29 years) were significantly less likely to disclose their HIV status to all of their sexual partners compared with younger

individuals, supporting similar findings from another study conducted in Haiti (Conserve et al., 2014). Likewise, in two studies conducted in an African setting, it was found that younger women (under the age of 24 years) were more likely to disclose to sexual partners than older women (Farquhar, et al., 2000; Gaillard et al., 2002). No association between age and disclosure to sexual partners was found in another investigation of HIV serostatus disclosure among MSM in casual relationships (Serovich & Mosack, 2003). The finding from the current study may be due to the fact that older participants may have had adverse experiences related to previous disclosures, have more casual partnerships than younger participants, or due to beliefs that disclosure is not essential, especially if they are on ART or have been on ART for longer periods of time compared to younger participants. Further studies are needed to elucidate the relationship between age and disclosure.

Previous research has shown that PLWHA are more likely to disclose their status to primary partners than casual partners (D'Angelo et al., 2001; Deribe et al., 2008; Przybyla et al., 2013; Vu et al., 2012). In this sample, only female participants who had casual partners or who reported having multiple sexual partners of different types (main and casual) were less likely to disclose their status to their partners compared to those with a main partner. This finding was further emphasized in the qualitative interviews where female participants described how the decision to disclose was often based on the nature, quality and seriousness of the relationship with their partners. Interestingly, the type and nature of the relationship with partner(s) was not significantly associated with

disclosure in the final male-only model; this may be due to the predominance of multiple concurrent partnerships in the male study population.

Individuals of both genders who reported being unaware of their partners' HIV status were significantly less likely to have disclosed their status to their partners compared to those who knew their partners' test results in the final adjusted models. Additionally, the highest odds of disclosure were observed among participants with HIV-positive partners. These findings support previous research conducted in many settings (Conserve et al., 2014; King et al., 2008; Przybyla et al., 2013; Simbayi et al., 2007). PLWHA sometimes choose sero-concordant partners to reduce stress and avoid the potential for rejection that might occur when disclosing to HIV-negative partners (Parsons, VanOra, Missildine, Purcell, & Gomez, 2004). In this population, serosorting behavior was likely facilitated by attending support group meetings, as was described in the qualitative interviews. It should also be noted that 62% of participants reported having one or several partners of unknown HIV serostatus, with an overall 67% non-disclosure rate. This is of particular concern, because research has shown that PLWHA who were unaware of their partners' HIV status were more likely to engage in sexual transmission risk behaviors, putting their partners at risk of infection or re-infection (Conserve et al., 2014; King et al., 2008; Przybyla et al., 2013).

The importance of social support from family and friends was highlighted in both the quantitative and qualitative components of this study, particularly for female participants. Using poignant ethnographic life stories from case studies with HIV-positive individuals, Whetten and Pence (2013) underlined the complexity of the relationship

between study participants and their families in the Deep South of the United States; however, in most cases, participants who had disclosed to a family member had received emotional support and much-needed help in future decision-making (p.150). Other recent qualitative studies conducted in Zimbabwe and South Africa found that family members played a similar role in providing emotional support, helping PLWHA come to terms with their HIV diagnosis, and assisting them in sharing their HIV diagnosis with others (Maman, van Rooyen, & Groves, 2013; Zamudio-Haas, Mudekunye-Mahaka, Lambdin, & Dunbar, 2012). Comparable results were found in the quantitative component of the present study since HIV-positive Haitian females who had increased social support were significantly more likely to disclose to sexual partners. The directionality of this relationship is not clear however. Previous research has examined social support as a predictor (Perry, Card, Moffatt, Ashman, & Jacobsberg, 1994) or more recently as a mediator of disclosure (Kalichman et al., 2003). It is probable that there is a bi-directional relationship between social support and disclosure, such that availability of social support would facilitate disclosure, and that disclosure would garner even more or less social support. The relationship between social support and disclosure can better be assessed with prospective and longitudinal studies.

Data from this study show that disclosure stigma (concerns about issues related to disclosing or hiding one's HIV status) was a barrier to the revelation of HIV status among males, whereas higher personalized stigma was a significant factor hindering disclosure among females. These findings are similar to other studies among PLWHA in developing countries, where fear of stigma and discrimination reduced the willingness to

disclose HIV status (Dias, Matos, & Goncalves, 2006; Medley et al., 2004; Simbayi et al., 2007). In this sample, the desire to control information and the worry that those who were aware of respondents' HIV status would tell others (Berger et al., 2001) were among the strongest predictors of reduced likelihood of disclosure among males. On the other hand, personalized stigma was a significant barrier to disclosure because of female participants' perceived negative consequences of disclosure including loss of support and rejection. Interestingly, higher personalized stigma was found to be associated with greater odds of disclosure among males. This finding may be related to a duality between the perceived negative consequences of disclosure and the desire to protect one's partner, as the majority of males in monogamous relationships in this sample cited the desire to protect their loved one from HIV as the main reason for disclosure. These gendered differences in perception of stigma and rejection also found support in the qualitative narratives.

Qualitative data highlighted important contextual differences in the way male and female young HIV-positive adults approached non-disclosure of their HIV status. On the one hand, male youth, especially those with multiple sexual partners, viewed non-disclosure as a protection against gossip about their tumultuous indiscretions and discovery of their unfaithfulness. On the other hand, some narratives from female participants recounted their inner struggles with the decision to disclose or not and how their fear of abandonment and fear of loss of economic support was the main barrier to disclosure to their partner. Research in Tanzania found similar results; HIV-positive

pregnant women who depended on their partner for food, rent or school fees were less likely to disclose their HIV status to their partner (Maman et al., 2003).

5.2 Cultural Context of Study Findings

It is important to consider the cultural context of this study's findings. First, Haiti is the poorest country in the Western hemisphere with a very low gross national income per capita of $560 and 80% of the population living below the poverty level (World Bank: Haiti, 2013). Second, multiple sexual partnerships are considered a social and cultural norm for men in Haiti (Hempstone et al., 2004). "Plasaj" is a long-term relationship with an unmarried partner and is very common in Haiti (Fawzi et al., 2010; Haiti DHS, 2012). Women who enter "plasaj" to support themselves and their children are particularly vulnerable because the lack of economic resources limits their ability to negotiate condom use and reduces their decision-making power (Rodrigo & Rajapakse, 2010). In "plasaj", while women are usually monogamous, men are usually "in plasaj" with several women at the same time. Third, gender inequality due to limited literacy and educational attainment among Haitian women increases their economic vulnerability compared to their male counterparts (Farmer, Connors, & Simmons, 1996). Given this pervasive gender inequality and severe economic adversity, women's economic security often entirely relies upon their partners' income-generating activities (Fawzi et al., 2010; Fitzgerald et al., 2000; Fitzgerald et al., 2004) or on economic survival strategies involving transactional or commercial sex, especially among young women (Dorjgochoo, et al., 2009; Reynolds, Beauvais, Lugina, Gmach, & Thomsen, 2010). It is possible that

the cultural, psychosocial and structural challenges deterring women from initially protecting themselves from HIV are the same factors that continue making them vulnerable once they are infected (Amaro, 1995; Zierler & Krieger, 1997).

The findings from this study lend support to the Disclosure Processes Model (DPM) (Chaudoir et al., 2011) according to which disclosure begins with a decision-making process based on antecedent goals which can be assimilated to forces promoting disclosure or concealment. The psychosocial and relational constructs measured in this population represent approach- and avoidance-focused goals. In this way, partner relationship type, partner HIV serostatus, acceptance of HIV, and social support, can be thought of as forces promoting disclosure. Conversely, stigma and depression can be considered as forces promoting concealment among this HIV-positive population. Finally, previous disclosure to family helped to assess the potential effect of disclosure on future disclosure events, through the feedback loop mechanism of the DPM.

5.3 Implications for Counseling and Prevention Programming

One of the goals of this study was to elucidate rate and patterns of HIV serostatus disclosure among HIV-positive youth in Haiti, in order to identify potential actions for secondary HIV prevention programming. The majority of participants indicated that they had had little or no time spent talking with clinic counselors about HIV disclosure. A previous study found that the rates of disclosure increased with the number of times that a health professional discussed issues of disclosure (De Rosa, & Marks, 1998). Similarly, in a qualitative study conducted at a voluntary counseling and testing clinic (VCT) in

Tanzania, both men and women mentioned the important role that counselors played in their decision to disclose (Maman, Mbwambo, Hogan, & Kilonzo, 2001). This suggests that counseling protocols should be adapted in order to include and reinforce discussions about disclosure. Therefore, specific training should be provided to HIV counselors and support group moderators in order to provide them with the skills necessary to talk about these important issues with this HIV-positive population and provide ongoing support. Counselors also need to be trained in the use of short culturally-adapted screening questionnaires to identify young PLWHA with depressive symptomatology or who are affected by HIV-related stigma, in order to offer or refer to appropriate services (Fitzgerald et al., 2004).

Other efficacious interventions include motivational interviewing and role playing exercises. Motivational interviewing is a promising intervention addressing behavior change which supports and encourages patients to change behaviors by exploring different options (Naar-King et al., 2006; Yeagley et al., 2012). Using role plays, counselors can also help PLWHA develop the communication skills necessary for disclosure as well as personal disclosure plans, in order to increase perceived self-efficacy for disclosure (World Health Organization, 2003). These two interventions can be tailored to the Haitian context to help HIV-positive youth aptly face the challenges of disclosure in their lives.

This study indicated that family can play an important role in helping HIV-positive youth, especially females, in coping with their diagnosis before disclosing to others. Therefore, HIV prevention programs should attempt to reach family members of

HIV-positive youth and include them in the counseling process. Other studies have shown that involvement of the family is extremely important and can have beneficial effects for future disclosure (Maman et al., 2013; Serovich, Craft, & Reed, 2012). However, this should be done in complete collaboration with the HIV-positive individual in order to avoid breaches of confidentiality and unauthorized disclosures.

While prevention services need to be reinforced in general for all HIV-positive youth, a special emphasis should be placed on individuals who would particularly benefit from these interventions. As suggested by the study findings, young PLWHA with casual or multiple partners and those who are unaware of their partners' HIV status should be the focus of more targeted interventions in order to reduce transmission risk behaviors, while tailoring interventions to address the gender-specific barriers that each face with regards to HIV disclosure. HIV-related stigma remains a significant barrier to disclosing one's HIV status (King et al., 2008; Osinde et al., 2012; Przybyla et al., 2013) and has been shown to be widespread in Haiti (Castro & Farmer, 2005; Fitzgerald et al., 2004; Surkan et al., 2010). Therefore, community-based programs addressing pervasive gender norms and social attitudes about HIV need to be reinforced in order to reduce HIV-related stigma (World Health Organization, 2003). Finally, programs and policies aiming to improve the economic and social status of women, such as literacy programs, income-generating activities and access to micro-credit, can help reduce the vulnerability of young women and empower them to make the right decisions for their lives (Fawzi et al., 2010).

5.4 Limitations

The findings of this study must be considered in light of several limitations. First, this study was cross-sectional and did not allow for exploration of causative relationships. It would be useful to investigate the relationship between disclosure to sexual partners and potential predictors prospectively to determine directionality and examine if differences remain stable over time and across relationships. Additionally, the sample was selected among HIV-positive youth receiving services at clinics, and it is unclear to what extent this group may be representative of other PLWHA not enrolled in a program. Third, we relied on self-reports of disclosure to sexual partners and recent sexual behavior. The sensitive nature of HIV may have led to social desirability bias in the responses. Also, some constructs like depression were measured using scales that were not culturally-adapted and validated specifically for the Haitian setting; possible cultural idiomatic differences should be taken into account. Despite these limitations, this study's findings can serve as snapshot of HIV disclosure rates and gender-specific predictors of disclosure among this population and have implications for interventions targeting young PLWHA in Haiti or in other similar settings.

6. Conclusion

The prevalence of HIV serostatus disclosure among HIV-positive youth in Port-au-Prince is among the lowest compared to rates in other settings across both developing and developed countries. The findings of the present study highlight the importance of addressing HIV-related stigma, enhancing communication between sexual partners, addressing factors related to nondisclosure, and adapting counseling protocols to the life context of young PLWHA, for example by putting greater emphasis on gaining social support to facilitate future disclosures. Although there were no gender differences in the overall prevalence of HIV serostatus disclosure to sexual partners in this sample, the study findings suggest that interventions targeting disclosure may be more effective to the extent that they adopt gender-specific approaches in HIV counseling in order to address barriers of disclosure.

Further research is necessary to better understand the process and outcomes of HIV serostatus disclosure to sexual partners, the perceptions and attitudes of health care providers towards HIV disclosure, as well as the relationship between HIV serostatus disclosure and transmission risk behaviors in this young HIV-positive population.

Although HIV serostatus disclosure is a daunting challenge for people living with HIV/AIDS (PLWHA), research conducted in multiple settings has shown that its beneficial effects far outweigh the potential negative implications, thus providing strong evidence for encouraging HIV serostatus disclosure in all HIV-positive populations. This is especially the case for HIV-positive young adults in Haiti, who have the most to gain from increased social support, reduced HIV-related stigma, and changing cultural norms

to reduce number and concurrency of sexual partners. HIV prevention programs should assist youth living with HIV in making effective decisions on disclosure that will improve their well-being and quality of life. This in turn will likely have a considerable impact on levels of stigma and discrimination as well as on the HIV epidemic, as we progress towards the global vision of zero new HIV infections, zero discrimination, and zero AIDS-related deaths (UNAIDS, 2013).

Appendix A

QUANTITATIVE SURVEY INSTRUMENT		
NO.	**QUESTIONS**	**CODES**
Introduction **I1 – I5 will be completed by the interviewer before the start of the interview**		
I1	Interviewer Code	Interviewer Code ___ ___
I2	Study site Identification Number (ID)	Study Site ID ___ ___
I3	Date (MM/DD/YYYY)	___ ___ / ___ ___ / ___ ___ ___ ___
I4	Study Participant Identification Number (ID)	Participant ID ___ ___ ___
I5	Study Participant Gender	Male 1 Female 2
Thank you for agreeing to participate in this study today. The purpose of this study is to help develop programs for young people living with HIV to help them stay healthy. This survey contains questions about sensitive topics such as drug and alcohol use, and sexual behavior. Everything you say will be kept private and strictly confidential. I will not share your individual answers with anyone from this youth center. I will combine what you tell me today with the answers from the same questions from all the other participants. No names will be used. All the information you can provide is important and will be helpful. But I do not want you to feel uncomfortable. Feel free to skip any questions that you do not feel comfortable answering. When you answer, please do so as honestly as possible. There are no right or wrong answers. We want to get a true picture of what you and other young people like you think or feel. I appreciate your time today as well as your important contribution to HIV prevention research. This survey will take approximately 45-60 minutes to complete. Do you have any questions before we get started?		
Demographics **I would first like to ask you some things that will help me know more about you.**		
DQ1	How old are you? [REGISTER AGE]	Age: ___ ___ years
NOTE: CONTINUE WITH INTERVIEW ONLY IF RESPONDENT IS BETWEEN 18 AND 29 YEARS OLD		

DQ2	What is the highest level of education you have completed?	No formal education 1 Some primary school 2 Primary School 3 Some secondary school 4 Secondary School 5 Post-Secondary 6 Refuse to answer -9
DQ3	What is your religion?	Catholic 1 Protestant (Denomination _____) 2 Christian 3 Other (_____) 4 No religion 5
DQ4	Are you currently employed?	Yes, full-time 1 Yes, part-time 2 No, not working 3
DQ5	During the last 12 months, on average, how much money did you personally make per month?	0 to 2,000 gdes 1 2,001 to 5,000 gdes 2 5,001 to 8,000 gdes 3 8,001 to 11,000 gdes 4 More than 11,001 gdes 5 I don't know -8
DQ6	During the last 12 months, from which of the following sources did you get any income? [READ EACH and SELECT ALL THAT APPLY]	A job (type: _____) 1 Spouse or partner 2 Other family 3 Friends 4 Sex work 5

		Other 6 Refuse to answer -9
DQ7	Describe your relationship status. [SELECT ONE]	Single / Never married 1 In a relationship (not living with partner) 2 Co-habiting 3 Married 4 Separated 5 Widowed 6 Other 7 Refuse to answer -9
DQ8	How many living children do you have? [IF ANSWER IS 0, CIRCLE CODE 0 AND SKIP TO QUESTION DQ10]	Zero 0 One 1 Two 2 Three 3 More than three 4
DQ9	How many of these children are HIV-positive? [IF DQ8 = 0, DQ9 = -4 (VALID SKIP)]	Number of HIV-positive children ___ I don't know -88
DQ10	Do you identify as: [SELECT ONE]	Straight / Heterosexual 1 Gay / Homosexual 2 Bisexual 3 Other 4 Refuse to answer -9
Health History.- This next sextion will ask you some basic information about your health.		
HQ1	We are doing this study with youth who are living with HIV. It is helpful for us to know how long you have been personally dealing with HIV. When did you first learn that you were HIV positive?	___ / _____ mm / YYYY Refuse to answer(Year) -9999

HQ2	What is the most likely way that you became infected with HIV?	Perinatal (at birth) 1 Sexual transmission (heterosexual or MSM) 2 Blood transfusion or other medical procedure 3 I don't know -8 Refuse to answer -9
HQ3	How many of your relatives have died of AIDS?	None 1 One 2 Two or more 3
HQ4	Are you currently taking HIV drug therapy to treat your HIV infection? [IF YES, GO TO QUESTION HQ5, IF NO SKIP HQ5 AND GO TO QUESTION HQ6]	Yes 1 No 2 Refuse to answer -9
HQ5	How many months have you been or have you ever been on combination HIV drug therapy? [ESTIMATE IF YOU DO NOT KNOW THE EXACT NUMBER OF MONTHS] [IF HQ4 = 2, HQ5 = 000]	# of months ___ ___ ___ Don't know -888 Refuse to answer -999
HQ6	How long has it been since you first started using services at this center?	Less than 6 months ago 1 6 months to 2 years 2 More than 2 years 3
HQ7	What types of services have you received from this center, since your diagnosis? [READ ALL and CHECK ALL THAT APPLY]	Medical care 1 Counselling 2 Nutritional support 3 Support groups 4 Positive prevention educational materials 5 Condoms 6 Other (_____) 7

HQ8	Do you have an HIV case manager at this clinic or at any other location (someone who helps you coordinate and access the medical and social support services that you receive)?	Yes 1 No 2 Refuse to answer -9
HQ9	During your visits to this or any other clinic, how much would you say that you and your counselor discuss HIV prevention issues such as safe sex and disclosure?	A lot 1 Somewhat 2 A little 3 Not at all 4 I don't know -8
HQ10	[FOR FEMALES ONLY] Have you used any of the following contraceptive methods in the last three months (other than condoms)? [IF I5 = 1, HQ10 = -4]	Intrauterine device (IUD) 1 Pill 2 Injectable 3 Other (_____) 4 None 5
HQ11	[FOR FEMALES ONLY] Do you have any desire for a pregnancy in the future? [IF I5 = 1, HQ11 = -4]	Yes 1 No 2
HQ12	In the last three months, have you been diagnosed and treated for any sexually transmitted infections (STI) such as gonorrhea, herpes, chlamydia, etc...?	Yes (which one:_____) 1 No 2
HQ13	In the last three (3) months, how frequently have you used alcohol? By alcohol, we mean wine, beer, liquor	No use 0 Less than once a month 1 1 to 3 times a month 2 Once a week 3 2 to 6 times a week 4 Daily use 5 Prefer not to answer -9

HQ14	In the last three (3) months, how frequently have you used marijuana?	No use 0 Less than once a month 1 1 to 3 times a month 2 Once a week 3 2 to 6 times a week 4 Daily use 5 Prefer not to answer -9
HQ15	In general, would you say your health is: [SELECT ONE]	Poor 1 Fair 2 Good 3 Very good 4 Excellent 5 Refuse to answer -9

NO.	QUESTIONS	CODES			
HIV Acceptance (Illness Cognition Questionnaire) Evers et al. **Here is a list of statements by people with a long-term illness. Please indicate the extent to which you agree with them by choosing one of the answers following the statement. Do not spend too much time considering your answer. Your first impression is usually the best .**					
		Not at all (1)	**Somewhat (2)**	**To a large extent (3)**	**Completely (4)**
IA1	I can handle the problems related to my HIV				
IA2	I have learned to live with my HIV				
IA3	I have learned to accept the limitations imposed by my HIV				
IA4	I can accept my HIV well				

IA5	I think I can handle the problems related to my HIV, even if it gets worse				
IA6	I can cope effectively with my HIV				

NO.	QUESTIONS	CODES			
Depression (CES-D) (Radloff) **Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the <u>past week</u>.**		**less than 1 day (0)**	**1-2 days (1)**	**3-4 days (2)**	**5-7 days (3)**
DS1	I was bothered by things that usually don't bother me				
DS2	I did not feel like eating; my appetite was poor				
DS3	I felt that I could not shake off the blues even with help from my family or friends				
DS4	I felt I was just as good as other people (R)				
DS5	I had trouble keeping my mind on what I was doing				
DS6	I felt depressed				
DS7	I felt that everything I did was an effort				
DS8	I felt hopeful about the future (R)				
DS9	I thought my life had been a failure				
DS10	I felt fearful				
DS11	My sleep was restless				
DS12	I was happy (R)				
DS13	I talked less than usual				
DS14	I felt lonely				
DS15	People were unfriendly				
DS16	I enjoyed my life (R)				
DS17	I had crying spells				
DS18	I felt sad				
DS19	I felt that people dislike me				
DS20	I could not get "going"				

NO.	QUESTIONS	CODES						
Beliefs and Attitudes **Enhancing Prevention with Positives Evaluation Center (EPPEC) Project – CAPS/UCSF** **For the next section, select the response that best reflects the degree to which you agree or disagree with the following statements.**								
		Strongly disagree (01)	**Disagree (02)**	**Neither agree nor disagree (03)**	**Agree (04)**	**Strongly agree (05)**	**I don't know (-88)**	**Refuse to answer (-99)**
Patient-Provider Communication								
AT1	The staff at this clinic understand how complicated my life is living with HIV							
AT2	The staff at this clinic understand how sex fits into my life.							
AT3	I get support from staff at this clinic for coping with the challenge of being sexually active as a person living with HIV.							
AT4	Information, fliers and pamphlets about HIV and HIV transmission are easy to get at my clinic.							
AT5	HIV prevention media campaigns (TV ads, commercials, billboards, posters) address my needs as a person living with HIV.							
Perceived seriousness of transmission risk								
AT6	Because of HIV drug therapy, I am less concerned about infecting someone.							
AT7	The availability of HIV drug therapy makes me less worried about having unprotected sex.							
Beliefs about condom efficacy								
AT8	Condoms are easy to get at my clinic							
AT9	Using condoms correctly is an effective way to prevent HIV transmission.							

NO.	QUESTIONS	CODES						
Moral norm								
AT10	Will using a condom every time you have vaginal or anal sex with a partner be considered a duty to you?	Yes (1)	No (2)					
Descriptive norm								
AT11	In your opinion, among the people you know who are living with HIV, how many use condoms every time they have vaginal or anal sex with a partner?	None ◯ (0)	Very few ◯ (1)	Most ◯ (2)	All ◯ (3)	I don't know ◯ (-8)		

NO.	QUESTIONS	CODES				
Attitudes towards Condoms **Now I am going to read to you some things that people think about sex and sexually transmitted infections (STI). For each one, tell me whether you agree or disagree by selecting the answer that best fits with what you believe. STEP (Thomas / Earp)**		**Agree a lot (1)**	**Agree a little (2)**	**Disagree a little (3)**	**Disagree a lot (4)**	**I don't know (-8)**
AC1	Just about any kind of sex feels better when you do <u>not</u> use a condom. Do you:					
AC2	Having to stop sex to put a condom takes the fun out of it. Do you:					
AC3	Using a condom during sex is like telling others that you might have an STI or HIV. Do you:					
AC4	Using a condom during sex feels uncomfortable. Do you:					
AC5	Using a condom during sex is embarrassing. Do you:					

NO.	QUESTIONS	CODES				
Intentions to avoid unsafe sex **(Roffman's Sex Check study)** **The next questions are about how you feel about having sex in the next 3 months with any partner. By sex, we mean vaginal or anal sex.**		**Not at all motivated (1)**	**Somewhat motivated (2)**	**Very motivated (3)**	**Totally motivated (4)**	**Refuse to answer (-9)**
US1	In the next 3 months, how motivated or unmotivated do you feel about having safer sex. Do you feel:					

US2	In the next 3 months, how important or unimportant will it be to you to use a condom every single time you have sex? Would you say that for you it is:					
US3	In the next three months, how important or unimportant is it to you to tell any new partner that you have HIV? Would you say it is:					

NO.	QUESTIONS	CODES			
HIV Stigma Scale **Next are some things that people living with HIV may have experienced in the past or may be experiencing right now. I realize that the next few questions may make you feel uncomfortable. For each question, please pick how much you agree or disagree with it by chosing the answer that best fits you. (Berger, 2001)**					
The first set of questions asks about some of your experiences, feelings and opinions as to how people with HIV feel and how they are treated.					
		Strongly disagree (1)	**Disagree (2)**	**Agree (3)**	**Strongly agree (4)**
SS1	In many areas of my life, no one knows that I have HIV				
SS2	I feel guilty because I have HIV				
SS3	People's attitudes about HIV make me feel worse about myself				
SS4	Telling someone I have HIV is risky				
SS5	People with HIV lose their jobs when their employers find out				
SS6	I work hard to keep my HIV a secret				
SS7	I feel I am not as good a person as others beacuse I have HIV				
SS8	I never feel ashamed of having HIV				
SS9	People with HIV are treated like outcasts				

SS10	Most people believe that a person who has HIV is dirty				
SS11	It is easier to avoid friendships than worry about telling someone that I have HIV				
SS12	Having HIV makes me feel unclean				
SS13	Since learning I have HIV, I feel set apart and isolated from the rest of the world				
SS14	Most people think that a person with HIV is disgusting				
SS15	Having HIV makes me feel that I'm a bad person				
SS16	Most people with HIV are rejected when others find out				
SS17	I am very careful who I tell that I have HIV				
SS18	Some people who know I have HIV have grown more distant				
SS19	I worry about people discriminating against me				
SS20	Most people are uncomfortable around someone with HIV				
SS21	I never feel I need to hide the fact that I have HIV (R)				
SS22	I worry that people may judge me when they learn I have HIV				
SS23	Having HIV in my body is disgusting to me				
Many of the items in this next section assume that you hve told other people that you have HIV, or that others know. This may not be true for you. If the item refers to something that has not actually happened to you, please imagine yourself in that situation, then give your answer based on how you think you would feel or how you think others would react to you.					
SS24	I have been hurt by how people reacted to learning I have HIV.				
SS25	I worry that people who know I have HIV will tell others				
SS26	I regret having told some people that I have HIV				
SS27	As a rule, telling others that I have HIV has been a mistake				
SS28	Some people avoid touching me once they know I have HIV				
SS29	People I care about stopped calling after learning I have HIV				
SS30	People have told me that getting HIV is what I deserve for how I lived my life				
SS31	Some people close to me are afraid others will reject them if it becomes known that I have HIV				
SS32	People don't want me around their children once they know I have HIV				
SS33	People have physically backed away from me when they learn I have HIV				

SS34	Some people act as though it's my fault I have HIV				
SS35	I have stopped socializing with some people because of their reactions to my having HIV				
SS36	I have lost friends by telling them I have HIV				
SS37	I told people close to me to keep the fact that I have HIV a secret				
SS38	People who know I have HIV tend to ignore my good points				
SS39	People seem afraid of me once they learn I have HIV				
SS40	When people learn you have HIV, they look for flaws in your character				

NO.	QUESTIONS	CODES			
Discrimination					
		Yes (1)	**No (2)**	**I don't know (-8)**	**Refuse to answer (-9)**
DIS1	Thinking of your experiences since learning of your HIV diagnosis, have you ever felt you were discriminated against because of HIV?				

NO.	QUESTIONS	CODES				
Social Support **The following questions ask about people in your life who provide you with help or support and the support that is available to you. Please answer all questions as best you can. All your answers will be kept confidential. (MOS Social Support Survey)**						
MOS1	About how many close friends and relatives do you have (people you feel at ease with and can talk to about what is on your mind)?	# of close friends and close relatives ___ ___				
People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?						
		None of the time (1)	**A little of the time (2)**	**Some of the time (3)**	**Most of the time (4)**	**All of the time (5)**
MOS2	Someone you can count on to listen to you when you need to talk					
MOS3	Someone to give you information to help you understand a situation					
MOS4	Someone to give you good advice about a crisis					
MOS5	Someone to confide in or talk to about yourself or your problems					
MOS6	Someone whose advice you really want					
MOS7	Someone to share your most private worries and fears with					
MOS8	Someone to turn to for suggestions about how to deal with a personal problem					
MOS9	Someone who understands your problems					
MOS10	Someone to help you if you were confined to bed					
MOS11	Someone to take you to the doctor if you needed it					
MOS12	Someone to prepare your meals if you were unable to do it yourself					
MOS13	Someone to help with daily chores if you were sick					
MOS14	Someone who shows you love and affection					
MOS15	Someone to love and make you feel wanted					
MOS16	Someone who hugs you					
MOS17	Someone to have a good time with					
MOS18	Someone to get together with for relaxation					

NO.	QUESTIONS	CODES				
MOS19	Someone to do something enjoyable with					
MOS20	Someone to do things with to help you get your mind off things					

NO.	QUESTIONS	CODES										
Sexual Behavior Self-Efficacy (Safer Sex Self-Efficacy) **The next section will ask you questions about your sexual activity. When we say "partner", we mean a boyfriend, girlfriend, spouse or person who you have sexual activity with. This can include kissing, oral sex and intercourse. For the next questions, please tell me on a scale from 0 to 10 how confident you feel that you could do each of the following TODAY if you decided to do it, with zero (00) being "not at all confident" and 10 being "completely confident". (Parsons, 1998)**												
		00	**01**	**02**	**03**	**04**	**05**	**06**	**07**	**08**	**09**	**10**
SE1	How confident are you that you can talk with your partner(s) about sex?											
SE2	How confident are you that you can use a condom correctly?											
SE3	What if you DID want to have vaginal or anal sex but you didn't have any condoms? How confident are you that you could switch to other sexual activities instead?											
SE4	How confident are you that you can convince your partner(s) to use condoms every single time you have sex?											
SE5	How confident are you that you could say NO to having sex with your partner?											
SE6	If a partner tells you that they would not use condoms, how confident are you that you would refuse to have sex with them?											

NO.	QUESTIONS	CODES										
SE7	How confident are you that you can talk about using condoms with every future partner?											
Now please rate how confident you are that you CAN USE condoms in each of the following situations today, if you decided to do it.												
SE8	How confident are you that you can use condoms if you are feeling depressed?											
SE9	How confident are you that you can use condoms when you've been drinking or using drugs before sex?											
SE10	How confident are you that you can use condoms if condoms are NOT readily available and you (or your partner) have to go and get them?											
SE11	How confident are you that you can use condoms if you are feeling good?											
SE12	How confident are you that you can use condoms if you are in love with your partner?											
SE13	How confident are you that you can use condoms with a new partner?											
SE14	How confident are you that you can use condoms if you won't see this partner again?											
SE15	How confident are you that you can use condoms with a partner who you have NOT used condoms with before?											
SE16	How confident are you that you can use a condom when your partner doesn't want to use a condom?											

NO.	QUESTIONS	CODES
HIV SEROSTATUS DISCLOSURE **Now I want to talk to you about whether or not you have ever talked to different people about your HIV status. Different people do different things when they learn they are HIV-positive. Some people tell their friends, families and sexual partners, others don't tell anyone.** **Please remember that I will not tell anyone what you tell me today.**		
SD1	How many people <u>besides</u> the medical staff at this clinic know about your HIV-positive status? [IF ZERO, SKIP SECTION AND GO TO QUESTIONS SD6 THROUGH SD8] [IF # GREATER THAN OR EQUAL TO 1, CONTINUE WITH QUESTION SD2]	# of people who know you are HIV(+) ___ ___
SD2	Of these, how many did you personally disclose your status to? [IF # EQUAL TO 1, CONTINUE TO SD3] [IF # EQUAL TO 2, CONTINUE WITH SD3 AND SD4] [IF NUMBER EQUAL TO 3 OR MORE, ASK QUESTIONS SD3 THRU SD5]	# of people you personally told ___ ___
SD3	[IF NO DISCLOSURE] What are the reasons why you have not disclosed your status to anyone? [READ EACH AND CHECK ALL THAT APPLY]	Fear of rejection 01 Fear of negative consequences for yourself 02 Fear of negative consequences for family 03 Blame 04 Loss of control of information 05 Lack of confidence 06 Shame 07 Lack of communication skills 08 Desire to become pregnant 09 Possibility of subsequent questions regarding how the disease was transmitted 10 Other (_____) 11

NO.	QUESTIONS	CODES
SD4	Who was the first person you disclosed to? [IF DISCLOSED TO MORE THAN ONE PERSON AT THE EXACT SAME TIME, CIRLCE ALL THAT APPLY]	Mother 1 Father 2 Any brother 3 Any sister 4 Spouse 5 Any friends 6 Pastor/religious leader 7 Any casual sexual partners 8 Any main sexual partners 9 Other (_____) 10
SD4.1	What are the reasons you disclosed your status to this person? [READ EACH AND CHECK ALL THAT APPLY]	Emotional support 01 Financial support 02 Medical or home care 03 Because he/she should know 04 Encourage partner to get tested 05 Desire to protect others 06 To encourage him/her to get tested 07 To encourage condom use in future 08 Need to educate 09 Because he/she is HIV-positive 10 Other:(_____) 11
SD4.2	When did you disclose your status to this person?	Within 24 hours of diagnosis 1 In the first week after diagnosis 2 In the first month after diagnosis 3 1 to 6 months after 4 6 to 12 months after 5

NO.	QUESTIONS	CODES
		Over a year after 6
SD4.3	After you told this person you were HIV+, would you say that their response was positive, negative or neutral?	Positive (supportive) 1 Negative (unsupportive) 2 Neutral 3
SD4.4	After you disclosed to this person, did you feel confident for future disclosures to other people?	Not at all confident 1 Somewhat confident 2 Completely confident 3 I don't know -8
SD5	Who was the second person you disclosed to? [IF DISCLOSED TO MORE THAN ONE PERSON AT THE EXACT SAME TIME, CIRLCE ALL THAT APPLY]	Mother 1 Father 2 Any brother 3 Any sister 4 Spouse 5 Any friends 6 Pastor/religious leader 7 Any casual sexual partners 8 Any main sexual partners 9 Other (_____) 10
SD5.1	What are the reasons you disclosed your status to this person? [READ EACH AND CHECK ALL THAT APPLY]	Emotional support 01 Financial support 02 Medical or home care 03 Because he/she should know 04 Encourage partner to get tested 05 Desire to protect others 06 To encourage him/her to get tested 07 To encourage condom use in future 08

NO.	QUESTIONS	CODES
		Need to educate 09 Because he/she is HIV-positive 10 Other:(_____) 11
SD5.2	When did you disclose your status to this person?	Within 24 hours of diagnosis 1 In the first week after diagnosis 2 In the first month after diagnosis 3 1 to 6 months after 4 6 to 12 months after 5 Over a year after 6
SD5.3	After you told this person you were HIV+, would you say that their response was positive, negative or neutral?	Positive (supportive) 1 Negative (unsupportive) 2 Neutral 3
SD5.4	After you disclosed to this person, did you feel confident for future disclosures to other people?	Not at all confident 1 Somewhat confident 2 Completely confident 3 I don't know -8
SD6	Who was the third person you disclosed to? [IF DISCLOSED TO MORE THAN ONE PERSON AT THE EXACT SAME TIME, CIRLCE ALL THAT APPLY]	Mother 1 Father 2 Any brother 3 Any sister 4 Spouse 5 Any friends 6 Pastor/religious leader 7 Any casual sexual partners 8 Any main sexual partners 9 Other (_____) 10

NO.	QUESTIONS	CODES
SD6.1	What are the reasons you disclosed your status to this person? [READ EACH AND CHECK ALL THAT APPLY]	Emotional support 01 Financial support 02 Medical or home care 03 Because he/she should know 04 Encourage partner to get tested 05 Desire to protect others 06 To encourage him/her to get tested 07 To encourage condom use in future 08 Need to educate 09 Because he/she is HIV-positive 10 Other:(_____) 11
SD6.2	When did you disclose your status to this person?	Within 24 hours of diagnosis 1 In the first week after diagnosis 2 In the first month after diagnosis 3 1 to 6 months after 4 6 to 12 months after 5 Over a year after 6
SD6.3	After you told this person you were HIV+, would you say that their response was positive, negative or neutral?	Positive (supportive) 1 Negative (unsupportive) 2 Neutral 3
SD6.4	After you disclosed to this person, did you feel confident for future disclosures to other people?	Not at all confident 1 Somewhat confident 2 Completely confident 3 I don't know -8

NO.	QUESTIONS	CODES
QUESTIONS SD7 THROUGH SD 8.1 FOR ALL PARTICIPANTS		
SD7	How many close friends would you say you have?	# of close friends ___ ___
SD7.1	How many of your close friends have you disclosed your status to?	# of close friends disclosed to ___ ___
SD8	How many immediate family members (mother, father, brother, sister, children) would you say you have?	# of family members ___ ___
SD8.1	How many of your immediate family members have you disclosed your status to?	# of family members disclosed to ___ ___

NO.	QUESTIONS	CODES
Sexual Behavior **The next questions are about your sexual behavior. Please remember that all your answers are strictly confidential. Your answers are protected and will not be share with anyone else outside of the research team.**		
SB1	How many lifetime sexual partners have you had overall? By sexual partners, we mean partners with whom you have had vaginal or anal sex.	# of lifetime partners ___ ___
SB2	Age at first sex (vaginal or anal sexual activity)	Age at first sex ___ ___
SB3	Since your HIV diagnosis, how many sexual partners have you had?	# of sexual partners since HIV diagnosis ___ ___
The following questions ask you about the sexual relationships you might have had in the last 3 months with partners who are HIV-positive, HIV-negative, as well as partners whose HIV status you are not sure of. Again these questions are about the last 3 months. *[USE CALENDAR]*		
SB4	How many sexual partners have you had in the last 3 months?	SB 4.1: # of male sexual partners ___ ___ SB 4.2: # of female sexual partners ___ ___

SEXUAL PARTNERS (UP TO 5) M / F		**P1** ____	**P2** _____	**P3** _____	**P4** _____	**P5** _____
SB5	How would you describe your relationship with each partner? Do you consider them as your main or casual partners? A *main partner (1)* is someone you have lived with or seen a lot, and to whom you have felt a special emotional commitment. A *casual partner (2)* is someone with whom you have no emotional connection.	1 2	1 2	1 2	1 2	1 2
SB6	What is your sexual partner's HIV status? Positive 1 Negative 2 Unknown 3	1 2 3	1 2 3	1 2 3	1 2 3	1 2 3

SEXUAL PARTNERS (UP TO 5) M / F		**P1** ____	**P2** _____	**P3** _____	**P4** _____	**P5** _____
SB7	Have you personally told this partner that you are HIV-positive? Yes 1 No 2 [IF NO: GO TO SB8, SKIP SB9 AND SB10] [IF YES: SKIP SB8, GO TO SB9 AND SB10]	1 2	1 2	1 2	1 2	1 2
SB8	Does this person know that you are HIV-positive? Yes 1 No 2 Maybe 3 [IF SB7 = 1, SB8 = -4 (VALID SKIP)]	1 2 3	1 2 3	1 2 3	1 2 3	1 2 3
SB9	What is the main reason you disclosed your HIV status to this partner?	P1: _____ P2: _____ P3: _____ P4: _____ P5: _____				
SB10	After yout told this partner that you were HIV-positive, how would you say that their reaction was? Supportive 1 Unsupportive 2 Neutral 3 [IF SB7 = 2, SB10 = -4 (VALID SKIP)]	1 2 3	1 2 3	1 2 3	1 2 3	1 2 3
	QUESTIONS SB11 AND SB12 FOR ALL PARTICIPANTS					
SB11	How many times did you have vaginal or anal sex with your partner?	_____	_____	_____	_____	_____
SB12	How many of these times was a condom used?	_____	_____	_____	_____	_____

NO.	QUESTIONS	CODES				
Socially Desirable Response Set (SDRD-5) / (RAND) **Listed below are a few statements about your relationships with others. How much is each statement True or False for you?**						
		Definitely True (1)	**Mostly True (2)**	**Don't know (3)**	**Mostly False (4)**	**Definitely False (5)**
SDR1	I am always courteous even to people who are disagreeable					
SDR2	There have been occasions when I took advantage of someone					
SDR3	I sometimes try to get even rather than forgive and forget					
SDR4	I sometimes feel resentful when I don't get my way					
SDR5	No matter who I'm talking to, I'm always a good listener					

NO.	QUESTIONS	CODES				
Subjective norms **The next questions will ask you about what three different groups of people think about whether or not people living with HIV should use condoms and tell their HIV status to partners. I will ask you about three different groups of people: your friends, your close family members, and your sex partners.**						
		Agree a lot (1)	**Agree a little (2)**	**Disagree a little (3)**	**Disagree a lot (4)**	**I don't know (5)**
SN1	Most of my friends think that people living with HIV should always wear a condom when having vaginal or anal sex.					
SN2	Most of my friends think that people living with HIV should always tell their sex partners their HIV status before having vaginal or anal sex with them.					
SN3	Most of my close family members think that people living with HIV should always wear a condom when having vaginal or anal sex.					

NO.	QUESTIONS	CODES				
		Agree a lot (1)	**Agree a little (2)**	**Disagree a little (3)**	**Disagree a lot (4)**	**I don't know (5)**
SN4	Most of my close family members think that people living with HIV should always tell their sex partner their HIV status before having vaginal or anal sex with them.					
SN5	Most of my sex partners think that people living with HIV should always wear a condom when having vaginal or anal sex.					
SN6	Most of my sex partners think that people with HIV should always tell their sex partner their HIV status before gaving vaginal or anal sex with them.					
		Not at all important (1)	**Somewhat important (2)**	**Very important (3)**	**Extremely important (4)**	**I don't know (5)**
SN7	In general, how important or unimportant is it to you what your friends think you should do? Is it:					
SN8	In general, how important or unimportant is it to you what your family members think you should do? Is it:					
SN9	In general, how important or unimportant is it to you what your sex partners think you should do? Is it:					

These are all the questions I have for you. Is there anything you would like to add about your experiences with living with HIV?

Do you have any questions for me?

Follow-up In-depth interview:
We will be contacting a small number of survey participants to see if they would consider talking to us a little more about their experiences with disclosure in one-on-one interviews. Would you be interested in participating?
Yes ( ) No ( )

If yes: Please complete separate locator form. Provide a phone number or email (that you are the only one with access to) so that we can contact you. No names will be used on this separate form; only your unique ID number will link your locator form to your survey.

All your information will be kept confidential and private.

THANK YOU very much for taking the time to be part of this study. The information you provided will help to improve services for young people living with HIV in Haiti.

LOCATOR FORM

Interviewer Code: ___ ___ Study Site ID: ___ ____ Study Participant ID: ___ ___ ___

Provide a phone number or email (that you are the only one with access to) so that we can contact you, in case you are chosen to participate in the in-depth interviews.

Email: _____

Phone number: _____

Appendix B

Qualitative Interview Guide

A) Introduction / Personal information

I would like to learn a little about yourself, before we begin this interview.

1. When were you born?
2. How much school did you complete?
3. What types of economic activities are you involved in? Has this changed since being diagnosed HIV positive? Do you get enough money to support yourself?
4. Where do you live now?
5. Who do you live with at home?
6. Are you currently married? Probe: Relationship status
7. Do you have any children? How many? Ages?

B) Experience with HIV

1. Is anyone else in your family HIV-positive? (Probe: who else? Spouse? Children?)
2. Has anyone in your family died of AIDS?
3. Please tell me about the events that led to you being diagnosed with HIV? (Probe: Motivation for being tested, illness, where tested)
4. When did you learn that you were HIV-positive? (Probe: How did you feel about that?)
5. How did your life change after learning of your HIV-positive status? (Probe: reactions, intentions, decisions about future)
6. How do you think you became infected?

C) Disclosure

I would like to ask you some questions about who in your life knows that you are HIV-positive, other than people at the clinic.

1. Tell me about the first time you disclosed your HIV status. Who was the first person you told? Why did you decide to tell this person first? (Probe: When? What was their reaction? Did their reaction make you more or less confident to ever disclose your status to someone else? Please explain.)
2. Who was the second person you told about your HIV status? (Probe: When? Why? What was their reaction? Did their reaction make you more or less confident to ever disclose your status to someone else? Please explain)
3. Same question up to 5 people
4. Who else knows about your HIV infection besides these people? (Probe: Did you personally tell them?)

5. How did you decide who you wanted to disclose your status to?
6. For each person mentioned:
   6a. How has your relationship with this person changed since telling them about your HIV status?
   6b. Has this person helped you in dealing with your HIV status? (Probe: How? Can you give me some examples?)
   6c. Did you get any unsupportive reactions after disclosing your status?
7. How do you feel about disclosing your status to your sexual partners?
8. What made you decide to share your HIV test result with your partner(s)? How did it go the first time you told a sexual partner about your HIV-status? (Probe: What did you say to them? Was it a stressful experience? How long had your relationship been going on at the time? How did you decide the right time to tell him/her? What was their reaction? Did their reaction make you more or less confident to ever disclose your status to another sexual partner? Please explain). Same questions for other sexual partners.
9. Did you consider not having sexual intercourse after learning of your HIV diagnosis? (Probe: Why or why not?)
10. What are your feelings about knowing your sexual partner's HIV status? (Probe: Would you want them to tell you? How would that change your decision to have protected or unprotected sexual intercourse? Please explain.)

D) Non-Disclosure

1. Why haven't you disclosed your status to anyone in your family or to just some of them? (Probe: What are your fears? Do you think that they know of your status even if you haven't told them?)
2. Why haven't you disclosed your status to your friends or to just some of them? (Probe: What are your fears? Do you think that they know of your status even if you haven't told them?)
3. Why haven't you told any or some of your sexual partners? (Probe: What are your fears? Does it matter how long you have been in a relationship with them? Do you think that they know of your status even if you haven't told them? How do you feel about condom use with your partners whom you haven't disclosed to? Can you please explain?)
4. What are your reasons for not telling these people about your HIV status? (Probe: Do you think you will eventually tell them? Why or why not?)
5. Has anyone learned of your HIV status without you wanting them to? (Probe: Who? How do you fell about that? How did they find out?)

Thank you for your time in answering these questions. Do you have anything else you would like to tell me?

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