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MWEN DI LI M’FE MALADI SIDA: AN EXPLORATION OF THE HIV SEROSTATUS DISCLOSURE EXPERIENCE OF HAITIANS LIVING WITH HIV IN HAITI AND THE UNITED STATES

A Dissertation in
Biobehavioral Health

by

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ABSTRACT

HIV remains a significant threat to global public health. According to the Joint United Nations Programme on HIV/AIDS, an estimated 33.3 million people were living with HIV in 2010. As early as 1987, prevention guidelines from the Center for Disease Prevention and Control recommended that people living with HIV (PLWH) disclose their HIV serostatus to their sexual partners. Self-disclosure of HIV serostatus to sexual partners is vital to addressing the global pandemic because it can promote condom use and prevent new HIV infections. In addition, self-disclosure of HIV serostatus to friends and family members, including children, has potential benefits to provide PLWH the social support needed to cope with the challenges associated with HIV. Although the Caribbean region has the second highest HIV rate in the world, few studies have examined the HIV serostatus disclosure experiences of people in the Caribbean and among Caribbean immigrants residing in the United States.

Paper 1 describes a qualitative study conducted in central Haiti between 2006-2007 with 25 HIV-positive mothers and 26 children ages 10-17. An extended HIV-focused adaptation of the Disclosure Decision Model was used to identify the factors influencing maternal HIV serostatus disclosure to children, examine the breadth of the mother’s disclosure, and understand the impact of disclosure on children in Haiti. Paper 2 uses baseline data from a randomized trial of a Cognitive-Behavioral Stress Management intervention to examine the factors associated with HIV serostatus disclosure to sexual partner among 258 HIV-positive alcohol users in Port-au-Prince, Haiti. In Paper 3, the Disclosure Processes Model was used to examine the disclosure experiences of 21 HIV-positive Haitian immigrants in New York City.

The findings from the first paper revealed that reasons for maternal HIV serostatus disclosure were children’s experience of HIV-stigma in the community, fear of death,
encouragement from psychosocial intervention workers, trust, and not wanting to hide the illness from their children. The main themes related to breadth of disclosure were brief disclosure and explicit disclosure with some mothers sharing information about how they learned about their illness diagnosis and their medication. Themes related to impacts of disclosure included emotional reactions for children and mothers, HIV education and concerns about transmission, and desire to assist mothers with illness. In the second paper, we found that only 38.6% of the participants disclosed their HIV serostatus to their sexual partner and that participants who had an HIV-negative partner or were unaware of their partner’s HIV serostatus were significantly less likely to disclose their HIV serostatus to their sexual partner than those with an HIV-positive partner. The themes related to reasons for disclosure that emerged in the third paper were close relationship with someone they trusted, comfortability, and the need for support and understanding about the illness. Reasons for nondisclosure were fear of being stigmatized, and rejected. Some of the outcomes of disclosure included social support, emotional relief and encouragement to take their medication, mistreatments. These findings highlight the facilitators, barriers, and outcomes of HIV serostatus disclosure among HIV-positive Haitians. The implications of these findings are discussed with regards to developing culturally appropriate interventions to assist PLWH in different context with the disclosure process.
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PREFACE

Chapters 2 and 3 of this dissertation thesis are multiple-authored works on which I, Donaldson F. Joseph Conserve, am the first author. For Study 1 (Chapter 2), I was responsible for the conceptual design of the study, conducting the data analysis, interpretation of the results, and writing. For Study 2 (Chapter 3), I was responsible for the conceptual design, conducting the analysis, interpretation of the results, and writing. The references in the manuscript are based on the reference guidelines of the journals the manuscripts were submitted to.
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This dissertation is dedicated to Jean Dominique Alexis, the man who raised me and made sure I received a solid foundation in school. As a child in Haiti, he used to always tell me that “Aucun chemin de fleurs ne vous enmene a la victoire” which translates to “No path covered with flowers can lead you to victory”. I never fully understood this maxim until I started my graduate school career. As I complete this part of journey I can surely say that the path to obtain my doctorate was not covered with flowers and I am victorious for having successfully completed this dissertation.

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CHAPTER 1

INTRODUCTION & BACKGROUND
HIV/AIDS in Haiti: Overview

According to the 2010 UNAIDS HIV prevalence in the Caribbean, prior to the earthquake an estimated 120,000 people were living with HIV in Haiti, of which 53% were women. The adult HIV prevalence was 2.2% and represented 47% of all people living with HIV in the Caribbean (UNAIDS 2010). The first case of AIDS in the Caribbean was reported in 1978 in Haiti’s capital, Port-au-Prince (Pape and Johnson 1993). Since then, poverty, limited access to healthcare and health-related information, stigmatization of people living with AIDS and their families, multiple sexual partnerships, sociopolitical instability, and Haiti’s isolation from international participation in AIDS forums have impeded efforts to combat the epidemic (Hempstone, Diop-Sidibé et al. 2004).

During the advent of the epidemic in Haiti, the Groupe Haitien d’Etude du Sarcoma de Kaposi et des Infections Opportunistes (GHESKIO) identified bisexual activities and blood transfusions as risk factors for HIV in 1983, with 50% of infected patients being homosexuals, 25% heterosexuals, and 25% who had acquired the infection through blood transfusion (Pape, Liautaud et al. 1986). In a decade, the risk activities associated with HIV shifted, resulting in an increase of infection among women from 15% in 1982 to 46% in 1992 and 6.6% for children in 1989 (Pape, Liautaud et al. 1983, Pape, Liautaud et al. 1986, Pape and Johnson 1993). An early study conducted among 4,474 pregnant women in Cite Soleil, an urban town, found that HIV infection was associated with being unmarried, age 20-29 years, having had more than one sex partner in the year prior to pregnancy, a positive serologic test for syphilis, and smoking (Boulos, Halsey et al. 1990). The association between HIV and smoking supports findings showing that compared to nonsmokers, women smokers in the same town reported higher rates of high-risk behaviors, including more lifetime sex partners and being less likely to be married (Halsey,
Coberly et al. 1992). Partner’s unemployment was also found to be related to HIV among pregnant women (Behets, Desormeaux et al. 1995). The effects of HIV among pregnant women in Haiti resulted in low birth weight children, malnourishment, and infant mortality (Halsey, Boulos et al. 1990).

Despite the challenges Haiti faced with the epidemic, a number of successes have been achieved. More recently, a notable decrease from 6.2% in 1993 to 3.2 in 2004 has been reported among pregnant women in Haiti (Gaillard, Boulos et al. 2006). Researchers have attributed the decline in HIV prevalence among women to a decrease in sexual partners and higher rates of condom use (Hallett, Aberle-Grasse et al. 2006). In addition to sexual behavior change, organizations such as GHESKIO and Partners in Health and its Haitian sister organization Zanmi Lasante have been providing integrated HIV prevention and care services in both rural and urban Haiti, with a reported 8,175 patients seeking VCT services in at GHESKIO in 1999 and more than 7,000 HIV-positive patients being monitored by Zanmi Lasante (Peck, Fitzgerald et al. 2003, Fraser, Jazayeri et al. 2004, Koenig, Leandre et al. 2004, Walton, Farmer et al. 2004). The rate of mother-to-child transmission of HIV have also decreased from 27% to 10% in 2005 (Noel, Mehta et al. 2008, Deschamps, Noel et al. 2009).

Voluntary Counseling and Testing and HIV serostatus Disclosure in Haiti

GHESKIO in urban Port-au-Prince and Zanmi Lasante in rural Cental Plateau have been providing voluntary counseling and testing (VCT) services in Haiti since the outbreak of the epidemic (Peck, Fitzgerald et al. 2003, Koenig, Leandre et al. 2004). An early study conducted at GHESKIO examined the effects of counseling on behavioral change in concordant couples (both partners are infected with HIV) and discordant couples (only one sexual partner infected)
between 1988 and 1990 and reported that 23% of both concordant and discordant women became pregnant during the 2-year follow-up period (Deschamps, Pape et al. 1991). In 1995, Zanmi Lasante started providing zidovudine, the first U.S. government-approved treatment for HIV therapy, free of charge to all HIV-positive pregnant women in order to decrease the rate of mother-to-child transmission of HIV, resulting in an increase of VCT uptake among pregnant women from 30% to nearly 100% (Initiative 2003). Similarly, a demand for voluntary counseling and testing increased by more than 300% when Zanmi Lasante started the HIV Equity Initiative to provide antiretroviral (ARV) therapy (Initiative 2003). GHESKIO also reported that the number of people seeking VCT services in urban Haiti rose from 142 in 1985 to 8175 in 1999 (Peck, Fitzgerald et al. 2003). The number of VCT centers in Haiti has also expanded from 2 prior to 2000 to 131 in 2008, resulting in more than a million people reported to have tested for HIV between 2008 and 2009 (Koenig, Ivers et al. 2010).

Although more people are seeking VCT services in Haiti, little is known about the HIV serostatus disclosure experience of Haitians. A review of the literature revealed one study conducted in Haiti that described the factors associated with HIV serostatus disclosure. Fitzgerald et al., (2004) identified poverty, being a female, and the belief that HIV can be transmitted by magic as significant predictors of sexual partner notification of HIV serostatus (Fitzgerald, Maxi et al. 2004). The authors further reported that some women are afraid to end a sexual relationship with a known HIV-infected partner or to disclose their serostatus to their sexual partners because of their economic dependence and the fear of domestic violence and physical violence. In another study conducted in the French Antilles French Guiana, it was reported that compared to French nationals, Haitians were less likely to disclose their serostatus to a partner or spouse, possibly due to the double discrimination of being Haitians and being
HIV-positive (Bouillon, Lert et al. 2007). Another study conducted in the U.S. found that Haitians living with HIV in Boston perceived the need to hide their HIV status in order to avoid rejection, humiliation, and isolation (Martin, Rissmiller et al. 1995).

The Need for This Study

During the summer of 2010, I participated in a two week internship with Zanmi Lasante’s psychosocial and mental health team in Haiti. I spent the time working with the social workers located in the Monseigneur Decoste Infectious Disease Pavilion at the St. Therese Hospital, the main hospital in Hinche. On my first day we saw around 25-30 patients, each with a complaint regarding a range of topics from wanting to start their own business but not having the money to do so, to not having money to pay their rent. These patients, I later found out, are individuals who are currently on treatment for tuberculosis, multi-drug-resistant tuberculosis and HIV/AIDS. Due to their illnesses, they can receive monthly or bi-monthly financial assistance if they are unemployed. Towards the end of the week, a young boy (9 years old) came complaining that he had not received the money to pay his school fees. I later found out from talking to the young boy that he was receiving financial support because his father had passed away while in the Dominican Republic and his mother died from an illness. I asked him what illness did his mother have and he responded saying that he did not know. Upon hearing his response, I was unsure of whether I should tell him that it was HIV or simply pretend I did not know either. I also wondered why he was not aware that his mother had died of HIV.

There are millions of children who have been affected by HIV as their parents or caregivers are living with HIV (Smith Fawzi, Eustache et al. 2010). Previous studies conducted among parents living with HIV indicate that while parents desire to disclose their serostatus to
their children, many of them are fearful of the consequences and struggle with when and how to tell them (Faithfull 1997). Although several researchers have examined parental disclosure of HIV serostatus to children and the impact of disclosure on children, there is scarce research on the disclosure experiences of PLWH to children in developing countries. Among the few studies that have been conducted in Africa, findings revealed that parents have difficulty discussing their HIV status with their children due to uncertainty about appropriate age to disclose to children or their inability to keep the information confidential, the emotional pain of disclosure, and the lack of knowledge on how to address the issue (Nam, Fielding et al. 2009, Palin, Armistead et al. 2009). Some of the factors promotive of disclosure included parents having tested their children, children being HIV-positive, the deterioration of the parents’ health, and the need for financial and social support (Rwemisisi, Wolff et al. 2008, Nam, Fielding et al. 2009). Parents also reported that they received inconsistent messages from testing counselors about whether or when to disclose to their children (Rwemisisi, Wolff et al. 2008). These concerns were supported by counselors’ statements regarding lack of training and a policy to address the needs of parents desiring to disclose their serostatus to their children (Rwemisisi, Wolff et al. 2008). Other studies of barriers to parental disclosure in India and China identified fear of rejection and stigmatization from children, and the psychological impact of disclosure on children as major concerns (Xu, Yan et al. 2007, Zhou, Zhang et al. 2012).

Self-disclosure of HIV serostatus to friends and family members, including children, has potential benefits to provide PLWH the social support needed to cope with the challenges associated with HIV (O’Brien, Richardson-alston et al. 2003, Smith, Rossetto et al. 2008). In spite of the benefits linked to disclosure of HIV serostatus such as improved psychological well-being and increase in adherence to medication regimens, a large number of PLWH hesitate to
disclose their serostatus due to low self-disclosure efficacy, fear of rejection, and stigma (Kalichman and Nachimson 1999). In addition, disclosure among PLWH can be influenced by a myriad of factors including gender and types of relationships. For example, individuals are more likely to disclose to female family members than to male family members (Kalichman, DiMarco et al. 2003, Clark, Lindner et al. 2004, Iwelunmor, Zungu et al. 2010, Hult, Wrubel et al. 2012). Motivations also play a role because PLWH disclose their serostatus to sexual partners for different reasons than to family members, friends, and health care providers.

The decision to disclose one’s HIV serostatus therefore is complex and remain a challenge for PLWH due to the stigma associated with the disease, leading to a high rate of non-disclosure to family, friends, and partners. An earlier study examined the prevalence of disclosure among 138 seropositive Hispanics men in Los Angeles and found that 52% had not disclosed their HIV serostatus to their sexual partners and that non-disclosure was associated with unprotected intercourse (Marks, Richardson et al. 1991). These findings are consistent with another study which revealed that of 266 sexually active PLWHA, 41% had not disclosed their serostatus and men who had not disclosed reported lower rates of condom use during anal sex. Self-efficacy disclosure was found to be lower among those who had not disclosed compared to those who had (Kalichman and Nachimson 1999). Types of relationship was reported as an influencing factor among 269 PLWH in New Orleans, with adolescents less likely than adults to disclose to a main partner, immediately family member, or a friend (O'brien, Richardson-alston et al. 2003). Similarly, Kalichman et al, (2003) investigated disclosure among 331 HIV-positive men and women and found that friends were disclosed to most often and perceived to be more supportive than family member (Kalichman, DiMarco et al. 2003).
The potential for culture to influence disclosure decisions may lead individuals who are defined as part of groups such as families to be less likely to disclose than those in individualistic cultures (Chandra, Deepthivarma et al. 2003). Among Asian American and immigrants it was found that the need to protect the family from obligation to help and shame served as barriers to disclosure (Yoshioka and Schustack 2001). In a study in East London, it was found that friends were more frequently informed (79%) than family members (53%) (Petrak, Doyle et al. 2001). Ethnicity was also a significant predictor of HIV serostatus disclosure in this study, with Black African and Asians less likely to disclose to family and friends than Caucasians. Similar findings have been reported in the United States. For example, compared to European American men African American men are less likely to disclose their status or discuss HIV-related worries with others (Mason, Simoni et al. 1997). Spanish-speaking Latino men and women are more likely to withhold their serostatus from significant others compared to English-speaking Latinos and Whites (Marks, Bundek et al. 1992, Simoni, Mason et al. 1995). Similar findings have been reported in the French Antilles and French Guiana, with Haitians being less likely to disclose their serostatus to a partner or spouse compared to French nationals.

Gaps in existing Literature

Although the Caribbean has the second highest HIV rate after sub-Saharan Africa, few studies have examined the HIV serostatus disclosure experiences among people of Caribbean descents. More specifically, little is known about parental HIV serostatus disclosure to children and the impact of disclosure on children in the Caribbean. In this study, I aim to address this gap by investigating the factors associated with HIV serostatus disclosure to children, sexual partners, and friends among Haitians living with HIV.
Purpose of Study

The purpose of this study is to examine the HIV serostatus disclosure experience among Haitians living with HIV in two different settings: Haiti and United States.

Research Questions:

Paper 1

1. What are the factors influencing maternal HIV serostatus disclosure to children?
2. What is the breadth of maternal HIV serostatus disclosure to children?
3. What are the impacts of maternal HIV serostatus disclosure on children?

Paper 2

1. What is the effect of antiretroviral therapy use on HIV-serostatus disclosure to sexual partner among HIV-positive alcohol users in Haiti?
2. What is the relationship between knowledge of partner’s HIV serostatus and HIV serostatus disclosure to a sexual partner among HIV-positive alcohol users?
3. How does number of sexual partners in the past 3 months relate to HIV serostatus disclosure among HIV-positive alcohol users?
4. Does partner drinking influence HIV serostatus disclosure to a sexual partner among HIV-positive women in Haiti?

Paper 3

1. How do Haitian immigrants living with HIV in New York City manage the process of HIV serostatus disclosure to family, friends, and sexual partners?
Literature Review

Disclosure to children

Most of the studies focusing on children living in HIV/AIDS affected families have been conducted in the U.S. Previous research has found that children of HIV-infected parents exhibit more emotional and external problems than children of non-infected parents (Forsyth, Damour et al. 1996, Forehand, Steele et al. 1998). One explanation offered for this finding is that learning of a parent’s HIV infection may decrease the adolescent’s adjustment due to increased fears about stigmatization and risk for their own infection and social rejection (Forehand, Armistead et al. 1997, Rotheram-Borus, Draimin et al. 1997). In fact, the impact of parent’s illness on children’s adjustment have been reported to be associated with parental bonds and parental HIV serostatus disclosure, with increased emotional distress found among children whose parents had disclosed their status (Lee, Lester et al. 2002). Regarding the behaviors of children aware of their parents HIV serostatus, it was found that adolescents who were informed of their parents’ serostatus engaged in more sexual risk acts, smoked more cigarettes, and reported more severe substance use than uninformed adolescents (Rotheram-Borus, Draimin et al. 1997).

A recent study conducted among children orphaned by AIDS in South Africa revealed that orphans were more likely to view themselves as not having good friends, to have marked concentration difficulties, and to report frequent somatic symptoms but were less likely to display anger through loss of temper (Cluver and Gardner 2006). Another study investigating the well-being of children in HIV/AIDS affected families in rural China reported that the children experienced psychosocial problems such as fear, anxiety, grief, and loss of self-esteem and stigma (Xu, Yan et al. 2009). These findings are consistent with studies conducted in rural Haiti demonstrating that the lack of social support, being an orphan, and HIV-related stigma
were associated with discrimination against HIV-affected children (Smith Fawzi, Eustache et al. 2010).

Given the variety of psychological and behavioral adjustments issues reported among children in HIV/AIDS affected families, it is therefore important to examine how different patterns of parental HIV serostatus disclosure influence children’s reactions and subsequent impact of learning about parent’s illness.

Disclosure to sexual partners

Similar to other countries, unprotected intercourse remains the primary mode of HIV transmission in Haiti (Deschamps, Pape et al. 1996). A number of studies have reported that people living with HIV remain sexually active and engage in high risk sexual behaviors, at times without disclosing their HIV serostatus to sexual partners (Marks, Ruiz et al. 1994, Conserve, Sevilla et al. 2012). From a public health perspective, disclosure of an HIV positive serostatus is important because it allows any current and potential sex partner the opportunity to adopt behaviors that protect them from HIV infection (Anglewicz and Chintsanya 2011).

Although the underlying reason for HIV serostatus disclosure to sex partner is the assumption that disclosure will promote safe sex practices, research has revealed mixed findings regarding disclosure and sexual practices (Simoni and Pantalone 2004). In a US sample of men who have sex with men (MSM), no association between disclosure and sexual activity was reported with primary partners (Wolitski, Rietmeijer et al. 1998). A study conducted among women in Hawaii and Seattle reported that women who disclosed to a recent sexual partner were less likely to use condoms than those who had not disclosed (Sullivan, Voss et al. 2010). In Cameroon, HIV serostatus disclosure was found to be a positive predictor of consistent condom use in sexually active women (Loubiere, Peretti-Watel et al. 2009). In Uganda, both men and
women reported that some of the outcomes of disclosure were risk reduction behavior, partner testing, and increased sexual communication (King, Katuntu et al. 2008). In Barbados, women who had disclosed their HIV serostatus were more likely to use condoms consistently and to have a partner who had been tested for HIV (Kumar, Waterman et al. 2006). The inconsistent findings from these studies suggest that disclosure does necessarily not mean individuals will use the information to protect themselves or others and that nondisclosure does not necessarily lead unsafe sex (Serovich and Mosack 2003, Simoni and Pantalone 2004).

In a review article that examined HIV serostatus disclosure among women in developing countries, it was found that the rates of disclosure reported in the studies reviewed ranged from 16.7% to 86% (Medley, Garcia-Moreno et al. 2004). Women attending free standing-clinic were VCT clinics were more likely to disclose their serostatus to their sexual partner than women who were tested while seeking antenatal care (Medley, Garcia-Moreno et al. 2004). Some of the factors associated with HIV serostatus disclosure to sex partners include gender, types of sex partner, socioeconomic status, education, social support, and self-efficacy. Several studies have found higher rates of HIV serostatus disclosure among women whereas other studies have reported the opposite or no gender differences (Olley, Seedat et al. 2004, Weinhardt, Kelly et al. 2004, Skogmar, Shakely et al. 2006, Deribe, Woldemichael et al. 2009, Deribe, Woldemichael et al. 2011). In general, both men and women tend to disclose their HIV serostatus to their steady partners more than to casual partners (Obermeyer, Baijal et al. 2011). In South Africa, it was found that communities with higher rates of disclosure also had more institutional sources of support, including nongovernmental organizations and hospitals (Norman, Chopra et al. 2007). A positive relationship was reported between education and disclosure to sex partners in India,
with 86% of literate respondents having disclosed compared to 44% of illiterate respondents (Taraphdar, Dasgupta et al. 2007).

Disclosure to family, friends, and sexual partners

During the summer of 2011, I participated in an internship at Diaspora Community Services I attended support groups for the Haitian and African American women participating in the Women’s Supportive Services Program. A variety of topics were discussed in the groups. For example, in one meeting a Haitian doctor discussed the side effects of the different HIV drugs. In another, there was a speaker who spoke about her experience with living HIV. At the end of all the groups, I asked the women questions about their experience related to disclosing their HIV status, whether they lived alone, or had a sexual partner. Based on the discussion I had with the women, some of them became celibate since they learned of their HIV serostatus. Spirituality came up often and is a major force in helping some of the women cope. A couple of the Haitian women expressed their desire to visit their families in Haiti but were restricted due to immigration status.

Although some studies have investigated the disclosure experiences of African and Caribbean immigrants, very few of them have focused specifically on Haitians. In one study that examined the disclosure experiences of African and Caribbean immigrants in the Netherlands, it was reported that the reasons for nondisclosure of their HIV serostatus were fear of stigmatization, previous negative experiences with disclosure, having observed the stigmatization of other PLWH, shame, the desire to protect others – particularly one's children and family – from stigmatization by association and/or worrying, and the belief that one's HIV serostatus is a private matter. Among those who had disclosed, they mentioned that being in a close and supportive relationship, having a perceived duty to inform, and desire to educate others
about sexual risk-taking were reasons for disclosure (Stutterheim, Shiripinda et al. 2011). In another study conducted among a nonprobability sample of HIV-positive women of African descent from outpatient clinics and scatter site housing in New York City, the authors found high rates of HIV disclosure to family, friends, and lovers, with disclosure associated with greater frequency of HIV-related social support. Additionally, disclosure rates were positively associated with the use of more adaptive coping strategies (i.e., spiritual resilience, constructive cognitions, and community involvement (Simoni, Demas et al. 2000).
References


CHAPTER 2

Paper 1: Disclosure and Impact of Maternal HIV+ Serostatus on Children Participating in a Psychosocial Intervention in Rural Haiti

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Mothers living with HIV in the United States have reported that one of their main challenges is the decision to disclose their HIV serostatus to their children and the potential consequences of disclosure. Little is known about the experiences of MLWHs regarding disclosing their HIV serostatus to their children and the impact of this disclosure on children in the island nations of the Caribbean. Study objectives were to identify the factors influencing maternal HIV disclosure to children in Haiti, examine the breadth of the mother’s disclosure, and to understand the impact of disclosure on the children. Baseline interviews were conducted between 2006-2007 with 25 HIV-positive mothers and 26 children ages 10-17 as part of a larger study that examined the feasibility of a psychosocial support group intervention for HIV-affected youth and their caregivers in central Haiti. Interviews were transcribed verbatim and coded for topical themes by two investigators. Analysis of the interviews yielded several themes relevant to reasons for disclosure including children’s experience of HIV-stigma in the community, fear of death, encouragement from psychosocial intervention workers, trust, and not wanting to hide the illness from their children. The main themes related to breadth of disclosure were brief disclosure and explicit disclosure with some mothers sharing information about how they learned about their illness diagnosis and their medication. Themes related to impacts of disclosure included emotional reactions for children and mothers, HIV education and concerns about transmission, and desire to assist mothers with illness. These findings suggest the need to provide more support to HIV-affected families in this region.
INTRODUCTION

The first case of AIDS in the Caribbean was reported in 1978 in the island nation of Haiti (Pape and Johnson 1993). Since then, poverty, limited access to healthcare and health-related information, stigmatization of people living with AIDS and their families, multiple sexual partnerships, sociopolitical instability, and Haiti’s isolation from international participation in AIDS forums impeded early efforts to combat the epidemic (Hempstone, Diop-Sidibé et al. 2004). In addition, the risk activities associated with HIV in the 1990s shifted, resulting in an increase in infection among women from 15% in 1982 to 46% in 1992 and 6.6% for children in 1989 (Pape, Liautaud et al. 1983; Pape, Liautaud et al. 1986; Pape and Johnson 1993). Despite the challenges Haiti faced with the epidemic, a number of successes have been achieved. In 1995, the non-governmental organization Partners In Health (known as Zanmi Lasante (ZL) in Haitian Kreyol) started providing zidovudine, the first U.S. government-approved treatment for HIV therapy, free of charge to all HIV-positive pregnant women in the prevention of mother-to-child transmission (PTMC) HIV program (Koenig, Leandre et al. 2004). Moreover, between 1996 and 2010 ZL recommended formula feeding for infants born to women with HIV infection in its healthcare programs and reported that milk substitution was safe, acceptable, and feasible for HIV-infected women in the PTMC program in rural Haiti (Ivers, Appleton et al. 2011).

In spite of these progresses, Haitian women and children remain severely affected by the epidemic with 53% of the 120,000 people living with HIV in Haiti in 2009 being women and 12,000 pediatric cases (UNICEF 2009; UNAIDS 2010). Given that women make up the majority of HIV-infected people in Haiti and are also the caregivers for their children, more research is needed to explore their HIV serostatus disclosure experiences. Previous research has shown that disclosure of their HIV serostatus to their young children is one of the main stressors.
that mothers living with HIV in the United States face (Murphy 2008). Although the Caribbean region has the second highest rate of HIV in the world, little is known about maternal HIV serostatus disclosure to children in the island-countries in this region (Qiao, Li et al. 2011). A better understanding of the factors associated with HIV serostatus disclosure to children in Haiti will assist in the development of the much needed family-centered psychosocial interventions for HIV-affected families in the region (Smith Fawzi, Eustache et al. 2010; Rochat, Bland et al. 2011; Pequegnat, Bell et al. 2012).

The Disclosure Decision Model and an extended HIV-focused adaptation of this model assume that individuals strategically manage their disclosure to control their social worlds and to achieve optimal social and personal goals (Omarzu 2000; Derlega, Winstead et al. 2004). The model proposes that the social environment in which someone lives, including cultural attitudes and contextual factors, can influence HIV disclosure/non-disclosure (Derlega, Winstead et al. 2002). In light of the specific socio-cultural context of Haiti, and based on this model we aimed to: 1) identify the factors influencing maternal HIV disclosure to children 2) examine the breadth of the mother’s disclosure and 3) understand the impact of disclosure on the children.

**METHODS**

This qualitative study was part of a larger feasibility study of a psychosocial support intervention conducted at six clinical sites in collaboration with Partners In Health/ Zanmi Lasante (PIH/ZL), a non-governmental organization working in central Haiti, and the Haitian Ministry of Health (Smith Fawzi, Eustache et al. 2012). The study sites from Haiti’s Central Department included Cange, Boucan Carre, Hinche, Lascahobas, Belladere, and Thomonde. Participants were recruited between January 2006 and February 2007 at these sites where comprehensive HIV treatment, including antiretroviral therapy (ART), was available. The
PIH/ZL comprehensive treatment program was initiated in 1998 and patients were enrolled in an electronic medical record (HIV-EMR) system. The participants for this qualitative study included mothers living with HIV (MLWHs) in the HIV-EMR system and their HIV-positive or HIV-negative children between the ages of 10-17.

Based on this study population, a sample was selected for participation in the qualitative interviews. A purposive sampling approach was used to identify and recruit eligible mothers (n=25) and their children (n=26). To be eligible for the study, the mothers had to be HIV-positive and have had disclosed his/her status to the children. The inclusion criteria for the children were: being 10-17 years of age; having a mother or female caregiver who was HIV positive; or having lost one or both parents to HIV.

In-depth interviews were conducted over 1.5-2 hours in Haitian Creole by trained psychologists or social workers. Mothers and their children were interviewed separately using an open-ended interview guide. Participants were encouraged to respond freely and assured confidentiality. The interview guide for the mothers included topics that covered their social and family history, medical diagnosis of HIV, methods of HIV serostatus disclosure to children, and the effect of their illness on the ability to support their children. The interview guide for the children included questions their social and family background, psychosocial functioning, the impact of their mother’s illness on their mood and their health status. The interviews were audio-recorded and transcribed verbatim by Haitian study personnel. Participants were informed about the content of the study and the caregivers provided informed consent for themselves and their children, while the children gave their assent. The study was approved by the Office for Research Subject Protection at Harvard Medical School and the Zanmi Lasante Ethics Committee.
All interviews were translated from Haitian Creole into English by the first author, a native of Haiti who is fluent in Haitian Creole. Following the guidelines of Strauss and Corbin 1990, the first author used open and axial coding to develop categories and subcategories from the participants’ responses (Strauss and Corbin 1990). The translated transcripts were also coded by the last author to ensure reliability and validity (Rolfe 2006). In an iterative fashion, the constant comparative method was used to compare and contrast differences and similarities across the participants’ responses in order to explore, organize and synthesize the data into meaningful categories that reoccurred in the transcripts (Field and Morse 1985; Boeije 2002). In the comparing data step, similarities and differences within and between responses were compared to detect patterns. Data were then analyzed for themes related to reasons for disclosure, patterns of disclosure, and impacts of disclosure. The categories of themes evolved during the analysis, as more patterns and variations were identified (Xu, Yan et al. 2009).

RESULTS

Reasons for Disclosure

Several of the mothers reported different reasons that influenced their disclosure decision. Analysis of the interview transcriptions yielded several themes relevant to reasons for disclosure: (a) children’s experience of HIV-stigma, (b) fear of death, (c) encouragement from psychosocial intervention workers, (d) trust (e) and not wanting to hide the illness from their children. For example, a mother recounted, “Yes he knows. I told him because they were teasing him, telling him that his mother is sick.” Another mother stated, “I spoke with him (11 year old) because I thought life was over for me because I saw that I was not well.” Some of the mothers who had not initially disclosed their HIV serostatus to their children before participating in the intervention reported that they eventually disclosed their serostatus. One woman with six
children reported that “When I was sick I did not really talk to her, it was when this program [psychosocial intervention] started to function here and when the health care professional came to talk to me that I told her about it.” Another woman stated “It has not been long since I have spoken to him about the illness. It was when the lady [health care worker] who was with me in this project last week asked me if I told my child that I was sick [that I did it].” Some parents shared their serostatus with their children because of trust. One woman stated “After several workshops at Zanmi Lasante, I started going around informing and explaining to other people about the illness. Then, while I was educating other people about the illness, I understood that it is normal for me to have someone in my family that I trust and I would be able to tell that I have HIV and that is her (my daughter).” Another parent stated “He (15 year old son) knows I am sick because he is sick too. He was the one who was the closest to me after I became ill.” Other parents simply did not want to hide it from their children. One mother stated “I had to not hide it. I told him (10 year old son) that I was fighting the HIV illness. I told them about it because they are my children.”

**Breadth of Disclosure**

Although most mothers had directly disclosed their HIV serostatus to their children, the amount of information they shared with their children varied. The major themes related to breadth of disclosure were: (a) brief disclosure; (b) explicit disclosure with information about medical examination and (c) medication. For example, one mother with six children told her 12-year-old son “I am sick. They told me that I contracted TB and I have HIV/AIDS.” Similarly, another mother stated “I sat him (13 years old boy) down. I told him ‘I don’t feel well. I am sick’ and after that I told him what sickness I have.” On the other hand, a number of mothers reported that they used their medical examinations as an entry point to not only disclose their HIV
serostatus but also to inform the children how they learned of their diagnosis. One mother with six children stated “I told her (14 years old) how things went. I told her that I came to get my test result here (hospital). I told her the results of my medical examination are not good. I am sick. I have HIV.” Another mother with nine children responded “When I arrived (home) I told the children that after I was examined the doctor told me that I am sick. He (14 years old) asked me ‘What illness did the doctor say you have?’ I told him, well, the doctor told me that I have a virus called HIV.”

In addition to informing their children about the medical examination, some mothers encouraged their children and reassured them that their health would improve by discussing their HIV medication with them. A mother with three children (12-17 years old) stated “I told him (15 year old) that I went to the hospital and they did an exam for me. I have an illness called AIDS but from the way I spoke to the doctor, he told me I don’t need to be scared. I will find medication that will help my body so that I can continue to help you and your siblings.” Another mother with 8 children (12-18 years old) stated, “I went to the hospital. They told me I have the HIV illness. I told him to not be discouraged…He said ‘Well, mother since I cannot change it then I will accept it, as long as God makes them give you medication.’” In one case, an older child (17 year old boy) became aware of his mother’s illness because she was taking medication. She stated “I told him ‘My son, your mother is sick’. He said, ‘Mother, I know you are sick because I see they give you medication all the time. Whenever I see them give you medication, I know it is because you are sick’.”

**Impacts of Disclosure**

Many of the mothers reported their children were emotionally affected after disclosing their HIV serostatus. The themes related to the impact of disclosure were: (a) emotional reactions
for child and mothers; (b) HIV education and concerns about transmission; (c) desire to assist mothers with illness. One mother stated “When I told him it he cried and said that he is going to lose his mother.” The children’s reactions also affected the mothers. One mother recounted “When I told her that (I had HIV), she became sad in front of me. You understand? Then I saw tears coming out of my eyes.” Sometimes the children were not only sad because their mothers were ill but also because of the stigma they experienced. One mother stated “He tells me that what makes him sad is that sometimes other children tell him that (your parent has HIV).” Another mother reported, “Also, what creates another little problem is that when she goes to school. Every time she has a dispute with the students in the school they always humiliate her. They tell her, ‘Don’t you see that your mother has HIV?’ and she always come and tell me that.”

Some of the children reported that they experienced a variety of emotions after becoming aware of their mothers’ illnesses while others did not express an emotional reaction. Many of the children were sad, hurt, or upset. In one instance, one 13 year old child mentioned that she felt angry towards her father after learning that her mother was sick. She stated, “I felt that it was my father’s fault since he knew that he was sick. I don’t know if it’s out of spite that he transmitted the virus to my mother. I told my mother that I wanted to hurt my father but after that she told me not to do that because God knows everything.” Other children were able to feel hopeful after learning more about the illness. One 14-year-old child reported, “It caused me a lot of problems, but afterwards I had a friend who became sick with the illness and I participated in a mini film. I played the role of the person with the illness and I saw that it was nothing. It’s an illness just like any other illness.” One younger child (11 years old) who did not know as much about the illness stated, “I did not feel normal because I know when a person has that illness he will not last long. I felt sad because once a person has this illness if you mistreat the person you might have it too.”
Other children wanted to help their parents. One 15-year-old child stated, “What we could do for her, if we had the money? We could look for a way to bring her to the hospital because once you are sick it’s at the hospital you can come to find treatment to calm the illness.”

**DISCUSSION**

Although several studies have explored the disclosure experiences of HIV-positive mothers to their children, to our knowledge this is the first study to have examined disclosure of maternal HIV serostatus to children in the Caribbean region. The primary purpose of this study was to identify the factors influencing maternal HIV serostatus disclosure to their children in a low resource setting. The reasons individuals chose to disclose their status included HIV-stigma in the community, fear of death, encouragement from health care workers in the intervention, trust, and not wanting to keep it a secret. Similar findings have been found among HIV-positive mothers in the United States who reported that disclosure prevented the tension and anxiety created by family secrets and prepared the children for indirect disclosure from gossip in the neighborhood and the possibility that their mothers may die from the illness (Ingram and Hutchinson 2000; Schrimshaw and Siegel 2002). Receiving encouragement from a health care professional regarding the disclosure process was also consistent with a study in the US where some mothers sought the help of a therapist or guidance from support groups to assist them with the process of disclosure to their children (Ingram et al. 2000). Some mothers in the US even included their children in support and educational programs for children of HIV-infected parents to help them express their feelings or prepare them for the death of the parents (Schrimshaw and Siegel 2002). Similar resources would be beneficial for children of MLWHs in Haiti, for children at risk of acquiring HIV, and those who have lost a parent or parents from HIV/AIDS (Nicholas, George et al. 2012).
Although most of the mothers had disclosed their HIV serostatus to their children, the breadth of disclosure or the different array of topics covered during the disclosure event varied greatly (Omarzu 2000). The difference in amount of information HIV-mothers share with children during disclosure has been attributed to maternal health status (Murphy 2008). In a study conducted in the U.S., mothers with higher T-cell count disclosed a broader range of information to their children compared with mothers with lower T-cell counts (Kirshenbaum and Nevid 2002). The authors suggested that mothers with better health feel comfortable disclosing more details to their children than mothers with compromised health. Although we did not count the T-cell for the mothers in this study, we found that mothers who provided information not just about the illness but also about their medication were able to comfort their children by reassuring that the medication would improve their health. Therefore, it becomes important for HIV-positive mothers to not only tell their children they are ill but also to inform and educate their children about the life saving treatments that exist, which allow their children to remain hopeful. These techniques could reduce the possible negative impacts of disclosure on children and promote positive reactions to disclosure such as family cohesion and improved communication among mothers and their children (Kennedy, Cowgill et al. 2010).

Consistent with studies conducted in other settings, children reported a variety of reactions such as desiring to care for the parents, worrying, and feeling sad (Schrimshaw and Siegel 2002). One explanation for the different reactions among the children is related to their cognitive development and their understanding of HIV/AIDS (Murphy, Roberts et al. 2006). Children who are unaware of how HIV is transmitted may believe they are at risk of becoming infected (O'Brien, Richardson-alston et al. 2003). In this study, one child reported that if people mistreated his parent, they might become infected. While most of the children expressed grief,
they did not describe whether their sadness was a result of fear for losing a parent or whether they understood HIV to be different from other illnesses. Other studies have reported that fear of parents death as one reason children experienced anxiety after disclosure (Murphy, Greenwell et al. 2006; Kennedy, Cowgill et al. 2010). Other factors causing grief may be the feeling of helplessness that children experience, resulting from lack of financial and social support to assist their parents (Casale and Wild 2012). Another finding from this study that resonates with the existing literature is illustrated by the child in this study who reported feeling angry at her father for infecting her mother (Kennedy, Cowgill et al. 2010). Children’s reactions were not only affected by their anxiety for their parents’ health but also the stigma they have experienced. Stigma and discrimination against HIV-affected youth have been reported to be common in central Haiti (Surkan, Mukherjee et al. 2010). Programs that can combat the stigma associated with HIV can be helpful in the children’s long term adjustment, as one child reported that he became less worried after learning more about the illness.

One of the strengths of our study is that we did not rely on mothers’ accounts for the effect of disclosure on the children. Another strength of our study is the recruitment of participants from more than one town. However, considering that the mothers all had access to and were receiving treatments, and were participating in a psychosocial intervention for HIV-affected families, the findings may not be generalizable to all HIV-positive mothers in Haiti. Although the study included participants from six different locations, all of the women were residing in communities where Zanmi Lasante has been providing services for several years. Another limitation is that only one of the mothers’ children was interviewed. Future studies should explore the disclosure experience of mothers prior to initiating treatment, and include
more than one family member, e.g. other children, in order to explore the impact of HIV disclosure on other family members.

In this study, we found that MLWHs tended to disclose their HIV serostatus to their children in the context of the medical system and after being encouraged by social workers. As expected, most of the children worried about their parents’ health initially, until they were reassured by their parents that their health would improve. Parents with declining health who had not disclosed to their children, however, were not able to benefit from the encouragement and hope experienced by individuals who had disclosed to their children directly. These children were often informed of their parents’ illness after being stigmatized in their school or neighborhood. Implications for health services suggest that care providers can use post-test counseling sessions as opportunities to discuss approaches to disclosure methods that parents can use with their children. In addition, HIV-affected families can benefit from psychosocial interventions aimed at improving communication, providing support, and providing socio-economic assistance.
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References


CHAPTER 3

Paper 2: Determinants of HIV Serostatus Disclosure to Sexual Partner
Among HIV-positive Alcohol Users in Haiti

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ABSTRACT

Disclosure of HIV serostatus to sexual partners is critical in promoting safer sexual behaviors that can prevent new HIV infections. The purpose of this study was to examine the factors associated with HIV serostatus disclosure to a sexual partner among HIV-positive alcohol users in Haiti. Data are from a baseline survey of a randomized trial of a Cognitive-Behavioral Stress Management intervention designed to enhance safer sex practices, adherence to antiretroviral therapy (ART), and reduce alcohol or other drugs use among 258 HIV-positive Haitians receiving services at the Groupe Haitien d’Etude du Sarcome de Kaposi et des Infections Opportunistes (GHESKIO) Center in Haiti between 2008-2010. Less than half (38.6%) had disclosed their HIV serostatus to their sexual partner. Logistic regression analyses revealed that participants who had an HIV-negative partner (OR =.36, 95% CI =.13 - .97) or were unaware of their partner’s HIV serostatus (OR=.09, 95% CI =.04 - .22) were less likely to disclose their HIV serostatus to their sexual partner than those with an HIV-positive partner. People who had sex with more than one sexual partner in the past 3 months were also less likely to disclose (OR=.41, 95% CI =.19 - .90) their HIV serostatus than those who had sex with one partner. There was no difference in disclosure between ART users and non-users. These findings suggest that couples based voluntary counseling and testing is needed to help PLWH disclose to their partners, especially among those who have more than one sexual partner and/or are in serodiscordant relationships.
INTRODUCTION

Disclosure of HIV serostatus to sexual partners is a cornerstone of the public health efforts to prevent new HIV infections (1). People living with HIV (PLWH) who do not disclose their HIV serostatus to their sexual partners and engage in unprotected intercourse place their sexual partners at risk of acquiring HIV (2). Some countries require that PLWH disclose their HIV serostatus to their current and prospective sexual partners (3, 4). Despite the law and the public health efforts to increase HIV serostatus disclosure, a substantial number of PLWH, especially women, do not disclose their HIV serostatus to their sexual partners in fear of being abandoned, and rejected as well as physically and verbally abused (4, 5). In Haiti where the adult HIV prevalence rate was 2.2% prior to the earthquake, little research has examined the factors associated with the disclosure of HIV serostatus to sexual partners (6).

A review of the literature revealed only one study conducted in Haiti that described the factors associated with HIV serostatus disclosure to a sexual partner (7). Fitzgerald et al., (2004) used case histories of HIV-positive clients who received voluntary counseling and testing (VCT) at the center of Groupe Haitien d’Etude du Sarcome de Karposi et des infections Oppotunistes (GHESKIO) in Port-au-Prince, Haiti between 1997 and 1998. Similar to other studies, the case histories indicate that the Haitian clients were in shock or in denial after learning of their positive HIV serostatus and that women did not disclose their HIV serostatus to their sexual partners in fear of being beaten, abandoned, or because they wanted to become pregnant. In one case, a man disappeared from his family and sexual partner after learning of his diagnosis because he did not want his family to pay for his burial. Further quantitative analyses from the same study revealed that poor women were afraid to disclose to their sexual partners or to end a sexual relationship with a known HIV infected partner because they were financially dependent on their sexual
partner. In addition, Haitians who believed in magical causes of HIV were more likely to refuse to disclose to their sexual partners. The authors suggested that poor HIV-positive Haitian women who are afraid of domestic violence may choose to believe in magical explanations in order to avoid disclosing their HIV serostatus to their sexual partners. As illustrated from the study conducted in Haiti, the process of HIV serostatus disclosure to sexual partners among PLWH is complex and influenced by a myriad of factors including gender, anticipated support and the sociocultural context.

According to Social cognitive theory, health-related behaviors, such as disclosure of one’s HIV serostatus to a sexual partner, is influenced in part by anticipated support or fear of rejection and that individuals are less likely to engage in behaviors that they believe will have negative consequences (8). According to this theory, a positive outcome of disclosure in Haiti would be absence of stigma, and change in sexual practices which could prevent HIV transmission while a negative outcome would be rejection, physical abuse, and abandonment (7). With regard to alcohol use and the associated “alcohol myopia,” Social Cognitive Theory posits that alcohol use may lead to a possible restriction in cognition due to inebriation which in turn might amplify immediate positive behavior cues, such as the prospect of sexual intercourse, and impairs one’s perception of the negative consequences, such as HIV transmission, of sex without disclosure (9). Researchers have reported that cumulative stressors contribute significantly to alcohol use in Haiti and that smoking and risky sexual behavior were positively associated with alcohol use (10). More specifically, Haitian youths who experimented with and regularly used alcohol were more likely to have had multiple sexual partners than those who were abstainers (10).

Studies have also shown that alcohol use is associated with domestic violence in Haiti (10). In a national survey conducted in Haiti, it was reported that 16% of women who were
currently married or in a cohabiting union experienced sexual violence and that alcohol use by the cohabiting male partner was a risk factor for partner sexual abuse (10). However, the role of alcohol use with regard to HIV serostatus disclosure to a sexual partner is largely unexplored in Haiti and other countries (8). Additional evidence supporting the need to investigate the influence of alcohol use on HIV serostatus disclosure to sexual partners can be found in studies that have revealed that alcohol use is associated with sexual risk behaviors and the spread of HIV in the Caribbean and sub-Saharan Africa (11-14). In a study that examined disclosure in recently HIV diagnosed patients in South Africa, it was found that individuals who used alcohol heavily before sex were less likely to disclose their HIV serostatus (15).

From a public health perspective, disclosure of HIV serostatus to a sexual partner is not only important for reducing risky sexual behavior but it is vital in helping HIV infected individuals access the support and care needed to adhere to their antiretroviral therapy and prevent further HIV infection (16). Also, the beliefs that HIV-positive individuals have about antiretroviral therapy also influences whether they disclose their HIV serostatus to their partners. For example, a study conducted in Cameroon found that women who believed that antiretroviral therapy can cure HIV or that someone treated with antiretroviral therapy cannot transmit the virus were more likely to conceal their positive HIV serostatus from their main partner (17). Considering that the only study in Haiti that examined HIV serostatus disclosure was conducted before antiretroviral therapy was introduced at GHESKIO and that public awareness of HIV has increased in Haiti, more research on the factors influencing HIV serostatus disclosure is needed in Haiti to determine how best to intervene and assist HIV-positive individuals with the disclosure process (7). Therefore, the purpose of this study is to investigate the relationship between antiretroviral therapy use, knowledge of partner’s HIV serostatus, number of sexual
partners in the past 3 months, perceived HIV infectivity and HIV serostatus disclosure to a main sexual partner among HIV-positive Haitian adults with a history of alcohol consumption.

METHODS

The study was performed at GHESKIO, the primary service, research, and training center in Haiti for HIV-related work (18). GHESKIO has been providing HIV voluntary counseling and testing (VCT) services in Haiti since the outbreak of the epidemic and was the first center founded in a developing country to address the HIV epidemic (19). Data for this study were collected from a baseline survey of a randomized trial of a Cognitive-Behavioral Stress Management (CBSM) intervention designed to enhance safer sex practices, adherence to antiretroviral therapy, and reduce alcohol or other drugs use among HIV-positive Haitians receiving services at GHESKIO in Port-au-Prince, Haiti (20). Audio-Computer Assisted Self Interview (A-CASI) technology was employed whenever possible.

Participants were included in the study if they met the following criteria: >18 but <60 years of age; fluency in spoken Haitian Creole which is required to complete assessments and to participate in the intervention groups; documentation of HIV seropositivity; at least one episode of unprotected anal or vaginal sex in the past 90 days; recent alcohol consumption by self report; currently not cognitively impaired since cognitive impairment may compromise the ability to comprehend and participate in the assessment and intervention; currently not showing symptoms of a major psychiatric disorder/ including psychosis, or a high risk for suicidality since these conditions might compromise ability to comprehend and participate in the assessment and intervention.

Based on the aforementioned criteria, 258 participants were recruited between 2008 and 2010. Participants were offered reimbursement for transportation costs and small gifts such as
telephone cards or coupons for grocery stores. Specific monetary value of incentives that participants received for study participation were not included in the consent document. This was done at the request of the GHESKIO Ethics Committee in order to conform to local cultural norms for research participation. The exact amounts were removed while noting that reimbursement for travel, refreshments, and other incentives such as phone cards or food coupons would be provided. Incentives for subject participation were provided immediately upon completion of each follow-up assessment and group session to provide further incentive for timely participation. Any participant who initiated withdrawal from the study was paid for only those assessments and intervention sessions that they completed. Interested participants were asked to sign a consent form. The measures used in the project were translated into Haitian Creole. They were translated and back-translated by bilingual individuals at the Florida International University and the GHESKIO Centers in Haiti with experience and knowledge about psychological interventions. The translated instruments were reviewed by a Cultural/Linguistic Planning group for conveyance of intended meaning. The group was composed of 3 clinician-researchers, all of whom were of Haitian descent and native speakers of Haitian Creole. The study was approved by the GHESKIO Ethics Committee and the Institutional Review Board at Florida International University.

Variables

The outcome variable measured disclosure of an individual’s HIV serostatus to their partner and was assessed by the following question: “Have you told your partner your HIV status?” The socio-demographic variables included gender, age, education, marital status. The age variable was categorized as 17-29 years, 30-39 years, and 40-56 years. The education variable consisted of the following two categories: 1) 6th grades or less, and 2) 7th grades or
more. Marital status refers to being married, cohabiting, single, or separated. HIV related questions inquired about the number of sex partners and knowledge of partner’s HIV status. The number of sexual partners was assessed by asking: “How many different people have you had sex with in the past 3 months?” Knowledge of partner’s HIV serostatus was measured by asking: “Do you know your partner’s HIV status?” The categories for knowledge of partner’s HIV status included: 1) HIV-positive; 2) HIV-negative; and 3) unaware to account for those whose partners had not been tested or did not know their partner’s status. Antiretroviral therapy use was determined by asking: “Are you currently taking any antiretroviral medications?” Participants were also asked if they agree or disagree with the following statement: “Have begun to be more open with people about being HIV positive since the news about the HIV medications.” To ascertain participants’ perceived HIV infectivity, they were asked the following questions: 1) “If an HIV-positive person’s viral load is undetectable, they can’t give HIV to anybody.” 2) “If an HIV positive person has sex with another HIV person they don't need to use condom.” Participants responded whether they agreed or disagreed with those statements. Other independent variables were related to alcohol use and included the following questions: 1) “Does anyone living with you drink alcohol?” and 2) “Does your partner drink alcohol?” Although both males and females were asked if their partner drink alcohol, only the responses from females are included in this study since the literature indicates that male drinking is associated with domestic violence in Haiti (10).

**Statistical analyses**

The analyses consisted of univariate, bivariate, and multivariate analyses. We conducted univariate analyses to examine the distribution of the socio-demographic, alcohol use, and HIV related variables. Second, bivariate analyses were performed between the disclosure variable and
the sociodemographic, alcohol use, and HIV related variables. The variables that were significant in the bivariate analyses were included in the multivariate logistic regression models to examine predictors HIV serostatus disclosure to one’s partner. SPSS for Windows, version 20.0 (SPSS Inc., Chicago, Illinois) was used for the analysis. Preliminary analyses indicated that the other variables that assessed relationship power, personal and public HIV-related stigma, alcohol use behaviors, condom use, and opinions about antiretroviral therapy were not significantly associated with HIV serostatus disclosure and therefore not reported.

RESULTS

The sample consisted of 258 HIV-positive alcohol users with an average age of 35 years and 38% were men and 62% were women (Table 1). The majority (61%) had a 6th grade education or less. Approximately 48% reported that they were cohabitating while more than half (63.4%) had sex with one person in the past 3 months. Similarly, more than half (57.5%) were unaware of their partner’s HIV status and 38.6% had disclosed their HIV serostatus to their partner. The majority of the participants (75.2%) were on antiretroviral therapy and 46.3% reported that they have begun to be more open with people about being HIV positive since the news about the HIV medications. Regarding perceived HIV infectivity, almost half of them (41.1%) believed that if an HIV positive person’s viral load is undetectable, they cannot give HIV to anybody and 30% believed that if an HIV positive person has sex with another HIV positive person they don’t need to use a condom. About half (51.2%) reported that they presently live with at least one person who drinks alcohol and 67.5% of the women had a partner who drinks alcohol.

Bivariate analyses revealed men (47.4%) were significantly more likely to disclose their HIV serostatus to their sexual partner than women ($\chi^2 = 5.14, p < .05$) (Table 2.). Compared to
individuals in the 17-to 29-year-old category those in the 30- to 39-year-old category were significantly less likely (27.3%) to have disclosed their HIV serostatus to their sexual partner ($\chi^2 = 10.90, p < .001$). Married individuals were more likely (73.1%) to have disclosed their HIV serostatus to their sexual partner than people who were cohabiting ($\chi^2 = 30.15, p < .001$). Participants who had sex with one person in the past 3 months were also more likely (46.6%) to disclose their HIV serostatus to their partner compared to those who had sex with more than person ($\chi^2 = 12.08, p < .01$). As expected, individuals whose partners were also HIV-positive were more likely (74.6%) to have disclosed their HIV serostatus than those who had an HIV-negative partner or were unaware of their partner’s HIV serostatus ($\chi^2 = 56.19, p < .001$). There was no statistically significant relationship between disclosure and antiretroviral therapy. Other variables that were associated with HIV serostatus disclosure were the beliefs the participants had regarding viral load and sexual practices. Participants who believed that an HIV-positive person with an undetectable viral load cannot infect another person were more likely (46%) to disclose their HIV serostatus than those who did not ($\chi^2 = 4.18, p < .05$). Similarly, participants who believed two HIV positive people don't need to use condom were more likely (49.3%) to disclose their HIV serostatus than those who did not ($\chi^2 = 4.38, p < .05$). Individuals who reported that they were not leaving with anyone that drinks alcohol were more likely (47.4%) to have disclosed their HIV-serostatus to their sexual partners compared to individuals who lived with anyone that drinks alcohol ($\chi^2 = 5.77, p < .05$).

When controlling for other variables significant in the bivariate analyses, the multivariate logistic regression model revealed that only age, marital status, partner’s HIV status, and number of sex partners were significant predictors of HIV serostatus disclosure (Table 3). Participants in the 30-to 39-year –old category were significantly less likely to disclose their HIV serostatus to a
sexual partner than those in the 17-to 29-year-old category (OR = .30, 95% CI = .12 - .76). Compared to married individuals, those who were single were significantly less likely to disclose their HIV serostatus to a sexual partner (OR = .15, 95% CI = .04 - .58). The strongest predictor of HIV serostatus disclosure was knowledge of partner’s HIV status. Participants who had an HIV-negative partner or were unaware of their partner’s HIV serostatus were significantly less likely to disclose their HIV serostatus to their sexual partner than those with an HIV-positive partner (OR = .36, 95% CI = .13 - .97), (OR = .09, 95% CI = .04 - .22), respectively. Lastly, participants who reported that they had sex with more than one person in the past 3 months were less likely to disclose their HIV serostatus to their sexual partner (OR = .41, 95% CI = .19 - .90).

**DISCUSSION**

The purpose of this study was to examine the predictors of HIV serostatus disclosure to a sexual partner among HIV-positive adults in Haiti who have a history of alcohol consumption. Overall, 38.6% of the participants disclosed their HIV serostatus to their sexual partner. The low rate of HIV serostatus disclosure found in this study has been reported in other developing countries (21, 22). About 75% were receiving antiretroviral therapy (ART) and 50% reported that they began to be more open about their HIV serostatus since the news about HIV medication. Although the proportion of people taking ART in this study is similar to a study conducted on ART adherence in three Caribbean countries, we did not find a correlation between ART treatment use and disclosure (23). The findings from the three Caribbean countries study also reported an unexpected positive association between ART adherence and unwanted disclosure. The authors proposed that PLWH whose HIV serostatus is known may attend more carefully to their health in order to prevent being ridiculed, blamed, and discriminated (23). The lack of association between ART and disclosure in our study supports the mixed findings.
reported in the literature. Similar to our study, a study conducted among 114 PLWH in Johannesburg, South Africa revealed no relationship between ART and HIV serostatus disclosure (24). In contrast, a more recent study with a larger sample size of 630 PLWH in Cape Town, South Africa reported that people who were on ART were more likely to disclose their HIV serostatus to a sexual partner (25). One potential explanation for our finding could be that efforts to promote HIV voluntary counseling and testing in Haiti combined with educational campaigns and the expansion of ART may have reduced the stigma associated with HIV, which in turn would encourage PLWH, regardless of whether they are on ART, to disclose their HIV serostatus to a sexual partner. It may also be the case that the individuals who were not on ART were expecting to receive ART in the near future and felt comfortable enough to inform their significant others about their HIV serostatus knowing that their health would eventually improve with the medication (26).

We did not find a significant association between alcohol use by partner, living with someone that uses alcohol and HIV serostatus disclosure. Preliminary analyses revealed no relationship between participants’ number of drinks, the effects of drinking on participants’ behavior in the past year and HIV serostatus disclosure. These findings support a recent study that examined disclosure among HIV-infected risky drinkers in St. Petersburg, Russia (8). The authors found no relationship between disclosure to a sexual partner and alcohol dependence, risky alcohol use, or alcohol use at time of sex. However, the authors reported that people who used alcohol at time of sex were more likely to disclose their HIV serostatus to a seroconcordant and casual sexual partner than those who did not (8). One explanation the authors offered for this finding is that alcohol use in the context of a sexual encounter might disinhibit one’s hesitation to disclose, transiently mitigate the perception of a potential negative reaction to disclosure (e.g.,
the partner not agreeing to have sex), and thus be more likely to consider disclosing one’s HIV infection (8). In another study that investigated HIV serostatus disclosure among youth in the United States, there was no relationship between alcohol use and disclosure to a sexual partner (27). In Haiti, alcohol use among male adolescents and emerging adults in Haiti have been shown to be associated with multiple factors including life-time smoking, and multiple sexual partnerships (10). Since all of the participants in our study had a history of alcohol use we were not able to compare disclosure patterns between alcohol users and abstainers.

The relationship between age and HIV serostatus disclosure remained statistically significant after controlling for other variables. Participants in the 30-to 39-year–old category were significantly less likely to disclose their HIV serostatus to a sexual partner than younger individuals. This findings differs from another study which found no difference in HIV serostatus disclosure patterns between younger and older individuals (28, 29). In another study of HIV-positive men and casual sexual partners, Serovich and Mosack (2003) found that age did not influence whether a respondent disclosed the status to all, some or none of their sexual partners (30). Although we did not include partner type in this study, other studies have reported that both younger and older individuals are more likely to disclose to a main partner than to a casual partner (1, 25, 27). The tendency for people of all ages to disclose to their main partner supports our finding that both married individuals and those who had sex with one person in the past 3 months were more likely to disclose their HIV serostatus than non-married individuals and those who had sex with more than one person in the past 3 months. This finding may be due to the trust and foundation that married individuals and those with a steady sexual partner have with their partner (25).
The strongest predictor of HIV serostatus to a sexual partner was knowledge of partner’s HIV status. This finding supports research conducted in developed and developing countries that have shown that knowledge of partner’s HIV status is associated with HIV serostatus disclosure to sexual partner (1, 31-34). In our study, individuals who had an HIV-negative partner or a partner of unknown HIV serostatus were statistically significantly less likely to have disclosed their HIV serostatus to their sexual partner than individuals with HIV-positive partner. The higher rate of disclosure among individuals with HIV-positive partners indicate that these individuals may have serosorted, which is a practice whereby individuals seek sexual partners of the same HIV serostatus in order to reduce HIV infection (35). An alternative explanation is that disclosure may have promoted partners to seek HIV testing and learn of their positive serostatus. The finding that individuals who knew their partners were HIV-negative were less likely to disclose is alarming because of the possibility of transmission risk if condoms are not used and partners are unknowingly exposed (36). It is also worth noting that 58% of the participants were unaware of their partner’s HIV serostatus, which may explain the high rate (61.4%) of nondisclosure found in this study. Being unaware of one’s sexual partner’s HIV serostatus may also be associated with unprotected sex because research has shown that HIV-positive individuals unaware of their partner’s HIV serostatus are less likely to use condoms than those aware (37). It is plausible that some of the participants may have been unaware of their partner’s HIV serostatus because they were casual sexual partners.

Our study has several strengths including the random selection HIV-positive alcohol users at GHESKIO, and the comparison of HIV serostatus disclosure by ART use. As ART becomes more readily available in developing countries, it is important to monitor how its use and the beliefs of the patients towards ART may influence their sexual behaviors and disclosure
patterns (24). The limitations of our study must be considered in interpreting the results. As previously stated, the sample was selected among people receiving services at GHESKIO and therefore the findings may not be generalizable to Haiti’s population. Second, although all the participants had a history of alcohol use, we did not inquire about alcohol use before sexual intercourse. Third, the sensitive nature of HIV may have led to social desirability bias in the responses. The use of client’s self-report for HIV serostatus disclosure and knowledge of partner’s HIV serostatus is limited because the partners were not interviewed to confirm whether the responses were congruent. Although several studies have examined HIV serostatus disclosure to a sexual partner, few studies have included the participants’ partners to ensure concordance of participants’ responses. Future research should attempt to interview both partners and a larger sample size.

The study supports the importance of knowledge of partner’s HIV status and the need for VCT workers to target older individuals and those who are not married and have more than one sexual partner for disclosure intervention. The low rate of HIV serostatus disclosure to a sexual partner found in this study indicate that more efforts are needed among counselors and health care workers to initiate discussion with PLWHI about disclosure to determine the best approach for each individual regarding disclosure. Given the strong association between knowledge of partner’s HIV serostatus on the sexual practices and HIV serostatus disclosure patterns among HIV-positive individuals, more widespread promotion of couples-based voluntary counseling and testing (CVCT) are needed in Haiti in order to increase HIV serostatus disclosure and prevent new HIV infections. Research has shown that CVCT is cost effective in helping couples learn about their and their partner’s HIV serostatus with the assistance of a professional and lead to greater protected sexual intercourse when compared with individual HIV voluntary counseling.
and testing (38-40). In one study that employed a facilitated couples counseling approach to
disclosure in Uganda, it was reported that 81.3% of HIV-positive males and 80.2% HIV-positive
females disclosed their HIV serostatus to an HIV uninfected partner (29). Some
recommendations to increase acceptance of CVCT include community mobilization, offering
home-based VCT, expanding clinic hours to accommodate individuals with conflicting work
schedules, and providing more couple-friendly services in general (38).
ACKNOWLEDGMENTS

This research was supported by Grant R01AA018084 from the National Institute on Alcohol Abuse and Alcoholism.
References


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Alcohol use
Living with someone that drinks alcohol

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χ² = 5.77, p < .05

Does your partner drink alcohol?

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χ² = .82 p < .37

Table 3. Multivariate logistic regression analyses of disclosure to a sexual partner

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<td>Perceived HIV infectivity</td>
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<td>Need to use condom use with HIV-positive partner</td>
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<td>1</td>
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<tr>
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<td>1.82 (1.04 - 3.18)</td>
<td>1.25 (.55 - 2.85)</td>
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<td>An HIV-positive person with an undetectable viral load can't infect another person</td>
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CHAPTER 4

Paper 3: An Examination of the HIV Serostatus Disclosure Process among Haitian immigrants in New York City

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ABSTRACT

Disclosure of sensitive information such as one’s HIV serostatus is an emotionally difficult task for people living with HIV. On the one hand, disclosure can lead to social support, condom use and medication adherence. On the other, disclosure can lead to rejection and stigmatization. Although the recent changes in the 22-year-old travel and immigration ban against people with HIV has led to an increase in the number of HIV-positive people who have traveled to the U.S, few studies have examined how HIV-positive immigrants living in the U.S. manage the disclosure process. In this paper, we employed the Disclosure Processes Model to examine the disclosure experiences of 21 HIV-positive Haitian immigrants in New York City. Data were collected through in depth interviews between May 2012 and January 2013. Analysis of the interviews yielded several enablers relevant to reasons for disclosure including participants being in a close relationship with someone they trusted or felt comfortable with, and the need for support and understanding about the illness. Some of the barriers to HIV serostatus disclosure were fear of being stigmatized, rejected, and not wanting to be perceived as promiscuous. For participants who had disclosed to significant others in the U.S. and in Haiti, they reported that they experienced both positive and negative outcomes including social support, emotional relief, encouragement to take their medication and on some occasions mistreatments, isolation, and stigma. These findings suggest the need for innovative interventions to address HIV stigma in immigrant communities in order to promote HIV serostatus disclosure.
INTRODUCTION

“I didn’t want them to think I was sleeping around because I don’t sleep around. I don’t want that to come to their mind. The reason I think they may think that way if I tell them I have HIV is because that is how society talks about people who have HIV.” (Participant A)

“He is still my son as well but he has another family. He will not hold secrets from his family. But the other two who are not married don’t have a spouse to tell any secrets to. I don’t tell the one who is married because I don’t need this secret to be shared with his family.” (Participant B)

Disclosure of sensitive information such as one’s HIV serostatus is an emotionally difficult task for people living with HIV (PLWH) and involves several components, including adjusting to the HIV diagnosis and the process of deciding whom to tell, why and how to tell (Huber 1996, Yoshioka and Schustack 2001). The balancing of potential risks and benefits of secrecy versus disclosure has been shown to be fundamental in coping with an HIV diagnosis (Bouillon, Lert et al. 2007). Individuals who keep their HIV serostatus a secret do so in fear of being rejected, abandoned, and verbally or physically abused (Stutterheim, Shiripinda et al. 2011). In contrast, disclosure can lead to social support, closeness in relationships, antiretroviral therapy adherence, psychological and physical wellbeing (Stutterheim, Shiripinda et al. 2011).

For example, a study which employed a biobehavioral approach to studying the effect of disclosure on physical wellbeing revealed that HIV serostatus disclosure was associated with improved CD4 cell counts overtime compared to concealment (Strachan, Bennett et al. 2007). One explanation offered for this finding is that concealing personally important thoughts, behaviors, and emotions, also described as psychological inhibition, is a discrete stressor that affects immune function and other markers of physical and mental health. On the other hand, disclosure can relieve some of the chronic stressors associated with concealment (Strachan,
Bennett et al. 2007). Other potential benefits of HIV serostatus disclosure include condom use and reduction of HIV transmission (Kumar, Waterman et al. 2006).

**Theoretical Framework**

![Disclosure Processes Model](image)

*Fig. 1. Disclosure Processes Model adapted for HIV disclosure. Adapted with permission: Chaudoir and Fisher (2010).*

The Disclosure Processes Model, shown in Figure 1, captures the complexity of self-disclosure for individuals who live with concealable stigmatized identities such as HIV/AIDS (Chaudoir, Fisher et al. 2011). Chaudoir and Fisher (2010) proposed that decision-making regarding self-disclosure and the resultant outcomes should jointly be studied to elucidate the context in which disclosure occurs. The model has the following five components: (a) Disclosure begins with antecedent goals or motivators, which they organize in a coping framework. They have labeled the forces that promote disclosure (e.g., to obtain support and understanding) as approach-focused goals, and those that promote concealment (e.g., fear of rejection and conflict) as avoidance focused goals; (b) The disclosure event, i.e., the verbal communication, may take
place over a period of time, which includes the details and emotional content presented by the discloser but also the reaction of the confidant; (c) The mediating processes, which include intra- and interpersonal or social changes that influence outcomes; (d) The outcomes which they classify are individual (e.g., health, mood), dyadic (e.g., intimacy and trust), and social/contextual (such as influencing norms for disclosure and decreasing stigma); and (e) The feedback loop which encompasses how disclosure impacts adjustment to outcomes and future disclosure events.

The mediating processes component of the model suggests that disclosure outcomes are impacted by three specific processes that function concurrently independent of the type of antecedent goals: (a) alleviation of inhibition, (b) social support, and (c) changes in social information. On an intrapersonal level, the alleviation of inhibition promotes the expression of concealed information which may result in increased psychological well-being. On an interpersonal level, the two impacting mechanisms of disclosure are social support and changes in social information (Chaudoir and Fisher 2010).

Although some studies have investigated the disclosure experiences of African and Caribbean immigrants, very few of them have focused specifically on Haitians (Simoni, Demas et al. 2000, Stutterheim, Shiripinda et al. 2011). Among the few studies that have focused on African and Caribbean immigrants, no theoretical framework was used and they only focused on reasons for or against disclosure without describing the actual disclosure event and outcomes. In one study that examined the disclosure experiences of African and Caribbean immigrants in the Netherlands, it was reported that the reasons for nondisclosure of their HIV serostatus were fear of stigmatization, previous negative experiences with disclosure, having observed the stigmatization of other PLWH, shame, the desire to protect others – particularly one's children and family – from stigmatization by association and/or worrying, and the belief that one's HIV
serostatus is a private matter (Stutterheim, Shiripinda et al. 2011). Among those who had disclosed, they mentioned that being in a close and supportive relationship, having a perceived duty to inform, and desire to educate others about sexual risk-taking were reasons for disclosure (Stutterheim, Shiripinda et al. 2011). In another study of HIV-positive women of African descent from outpatient clinics and scatter site housing in New York City, the authors found high rates of HIV disclosure to family, friends, and lovers (Simoni, Demas et al. 2000). This study also found that disclosure was associated with greater frequency of HIV-related social support. Additionally, disclosure rates were positively associated with the use of more adaptive coping strategies (i.e., spiritual resilience, constructive cognitions, and community involvement (Simoni, Demas et al. 2000).

Unlike other immigrant minorities in the United States, Haitians were the only ethnic group labeled as “AIDS carriers” and banned from donating blood by the Food and Drug Administration (FDA) in the advent of the HIV epidemic in the 1980s (Farmer 1990). As a result, on 20 April 1990 tens of thousands of Haitians marched across the Brooklyn Bridge into the streets of Manhattan to protest the policies of the FDA and the Center for Disease Prevention and Control (CDC) that labeled Haitians in the United States as a high risk group for HIV (Galarneau 2010). Although the CDC and FDA have removed Haitians from the 4H groups: Haitians, heroin addict, homosexuals, and hemophiliacs, Haitians, especially women, regardless of their HIV serostatus continue to face discrimination in the United States. A qualitative study of Haitian women living in Chicago found that stigmatization of Haitians as AIDS carriers had multiple long-term effects including feeling rejected by society, low self-esteem, self-doubt, difficulty developing intimate relationships, and rejection by fellow Haitians in their community.
(Santana and Dancy 2000). This stigmatization of Haitians is still prominent in certain media circles as evident by a 2010 radio statement by a New York based DJ who announced that the reason he is HIV-negative is because he does not engage in sexual intercourse with Haitian women (CNN 2010).

The recent lift of the 22-year-old travel and immigration ban against people with HIV has led to an increase in the number of HIV-positive immigrants living in the United States (Bristol 2009). Therefore, there is a need to investigate how immigrants manage the disclosure process to family members and friends as HIV-positive immigrants may need to share their serostatus in order to receive the support needed for translation and to access health care and treatment in the United States. In this study, we used the Disclosure Process Model to examine the experience before disclosure, the process of disclosure, and the positive and negative responses during and after disclosure among HIV-positive Haitians in New York City.

METHODS

The data were collected through in depth interviews conducted with Haitian immigrants in New York City. Participants were recruited from four community based organizations that provide HIV services in the New York City area: Diaspora Community Services, Haitian Center Council, Iris House, and African Services. One particular organization, Diaspora Community Services (DCS), was instrumental in helping the primary author gain access to the Haitian community in Brooklyn and connecting with other organizations serving the Haitian community. DCS was formed as the Haitian Women's Program in 1981 in response to the influx of Haitian. Subsequently DCS has become known for empowering individuals and families to succeed through DCS sponsored culturally sensitive health promotion, family support services and advocacy. As a result the DCS target population grew from only Haitians to include individuals
in Central Brooklyn impacted by poverty related socio-economic issues. Annually, DCS continues to serve over 200 HIV positive individuals and their families with case management and access to treatment and public benefits, eviction prevention, AIDS Drug Assistance Program (ADAP) health insurance, among DCS services and programs.

**Participants**

Purposive sampling in combination with snowball sampling approaches were used to identify and recruit eligible participants (n = 21). To be eligible for the study, the person had to be HIV positive, 18 years old or older, and of Haitian descent. Interested participants were asked to sign a consent form before the interview, which was approved by the Institutional Review Board at the Pennsylvania State University. The participants were encouraged to respond freely and were assured confidentiality. All the interviews were conducted in Haitian Creole and some of them lasted 20 minutes while others extended to more than an hour.

Some of the interviews were conducted in an office space provided by the organizations and others were conducted in the participants’ houses. Two of the interviews were conducted in the researcher’s car. In both cases, these participants were referred to the researcher by individuals who had participated in the study and they had recently migrated to the United States. Therefore, these two participants did not have their own place and were not comfortable conducting the interview in the place they were living because of their family members. In another case, one participant who was not comfortable with his conducting the interview at his brother’s house decided to come do the interview at another participant’s house. For some of the interviews conducted in the participants’ homes, the researcher often had to stop the interviews when family members such as children returned home from school or in one case when one participant’s mother and her friend came home from church. The interviews were audio-
recorded, transcribed, and translated by Haitian study personnel. To compensate participants for their time and contribution, they received $25-50 based on the length on the interview. The following are sample questions from the interview guide provided in Appendix A:

1) When someone finds out that they are HIV-positive, they usually have to decide whether to share their results with someone. If you have told one or more individuals that you are HIV-positive, can you tell me what those experiences were like for you?

2) If you have not shared your results with anyone, can you tell me what prevented you?

Data analysis

The analysis focused on the experiences of the participants regarding their decisions to disclose or not disclose their HIV serostatus, the disclosure event, and the reactions from individuals to whom they had disclosed. Following the guidelines of Corbin and Strauss (2007), the transcripts were read multiple times by the first author to become familiar with the data (Corbin and Strauss 2007). Next, the first author used the Disclosure Processes Model to compile the data based on the different components of the model. Then, the first author used open and axial coding to develop categories and subcategories from the participants’ responses (Corbin and Strauss 2007). The translated transcripts were also coded by two other researchers to ensure reliability and validity (Rolfe 2006). Frequently mentioned ideas were grouped into thematic codes. In an iterative fashion, the constant comparative method was used to compare and contrast differences and similarities across the participants’ responses in order to explore, organize and synthesize the data into meaningful categories (Boeije 2002).

RESULTS

Approach goals: reasons for disclosure

Whereas some participants only had avoidance goals others subscribed both to approach and avoidance goals. These goals varied based on the relationship the person had with the
participants. Participants disclosed to their family members they were close to, trusted or felt comfortable with as indicated in the following statements:

*I told two of my four children because I am closer to them.*

*She is someone that I trust. We have known each other since we were little. She is the only person I have told and her child.*

*I could not hold it to myself, and I was comfortable with my family.*

*After finding out that I was infected, I tried to tell my aunt because she was the most important person in my life.*

In other cases, some participants disclosed because they wanted to make their relatives feel comfortable. One woman who initially did not tell her children about her HIV serostatus decided to tell them after she found out that one of her sons committed suicide because he was diagnosed with HIV and afraid to tell her about. Realizing that she could have saved her son if she had disclosed her serostatus, she chose to share her serostatus with the remaining children for the following reasons:

*I wanted to make them comfortable with me. Now I tell them everything. Everything I am doing, I tell them. I was not comfortable before I told them. It took over two years for me to tell the other two children.*

Other reasons for disclosure were the need for support, understanding of the illness and to educate others.

*I just told the two people who were the closest to me just in case I had any other complications or was in need of something else who can help me. Even though they are giving you the medications, they still ask you for an emergency contact.*

*I could not hold it to myself. My mother also told me that when you hide something you will not get the help you need. If I hid it, it would become worse for me because I would not get the support they (other individuals) could provide me if they don’t know. Also, I wanted to have my family support when I was taking the treatment to remind me when I forget to take the medication.*

One participant reported that the reason she disclosed to her nephews was because they were taking care of her but were unaware of what illness she had. She stated:
My nieces were not aware why my aunt was behaving that way because I had not told them yet. But eventually they were taking care of me so much that I asked the doctor if I could tell my nieces about the illness. The doctor told me that my nieces are young (18 and 19 years old) and he is not sure how they will react after the news. He said that it was up to me to tell them and I said yes, I want to tell them. I made them come with me to the doctor’s office. I told them in front of the doctor.

Two other participants stated:

I told my brother right away. He is like a father to me and he was working in public health as a statistician in Gonaives. It’s him that I called to make him aware. Then, they made me come to Gonaives. I had a bunch of pimples on my feet and when he saw the test results he said that the test results are correct.

The reason I told them about it is because one of my sons is with a lady in Aux Cayes. He is crazy for the lady and ready to die for her. I told him, “No, you cannot be crazy for the lady. Do you know the lady? When I said that, he said” Oh no mother, the lady is beautiful”. I said did you go to the doctor to get tested for HIV? He said that is not necessary.

**Avoidant goals: reasons for nondisclosure**

Themes related to nondisclosure included reasons that affected the participants such as stigma, rejection, and factors that would have an effect on the confidant such as wanting to protect the family members from worrying. One common reason for concealing HIV serostatus was fear of stigmatization, isolation, rejection and wanting to keep it a secret. The following responses illustrate these points:

I don’t see where to share it. I don’t know how they will react. If I tell anyone that then they may humiliate me. They can become scared of you. Because of that I don’t tell anyone. As long as God knows, I don’t have to tell anyone else. If I tell anyone about the illness, they won’t do anything for me. They will tell other people about it if I tell them. So, I hand it over to God.

They will run away from me. They will be scared of me. It is worse in Haiti. They won’t even talk to you in Haiti. In the US, some people will be afraid of me as well.

The people in Florida are my sister in law. I couldn’t tell them the truth, they were the family of my sister’s husband I didn’t want him or them to know because maybe they would have rejected me because it was around the time that HIV was the big news.
He is still my son as well but he has another family. He will not hold secrets from his family. But the other two who are not married don’t have a spouse to tell any secrets to. I don’t tell the one who is married because I don’t need this secret to be shared with his family.

I didn’t tell everyone that so they could spread the word. I told my child and a few people in my family, and some of my friends. But I wasn't trying to let the news circulate around.

Another reason for nondisclosure was to prevent the perception that the participant was promiscuous, and not wanting to get in trouble with the law.

I didn’t want them to think I was sleeping around because I don’t sleep around. I don’t want that to come to their mind. The reason I think they may think that way if I tell them I have HIV is because that is how society talks about people who have HIV.

I will not tell anyone else even if I meet a woman. I will do what I need to do to protect her. I will not tell her because it may create a problem. The person knows that their blood is clean and if I transmit the virus to them, they can call me to court.

Additional reasons for nondisclosure were to spare others, particularly the family, from worrying and protect family members from losing health insurance.

I did not tell my parents because they lack the energy. They depend on me and if they find out that the person they are expecting to assist them is ill they will become weak. Their hope will be lost. So I didn’t want to tell them because of that. That’s why I told my brother (in Haiti) to not tell anyone in the family. The same man continued saying, “I haven’t told my brother (in the US) because he is very personal. He is younger than me and if he finds out then he will not respect the advice I give him. As an older brother, I should be his role model and if he learns that I am ill then he will think low of me and lose respect for me.

I never told the doctor outside of GHESKIO if I have HIV when I was giving birth. Because I did not tell the doctor, even though I was taking the medication my child was still born with the illness. During that time I didn’t want my husband to lose his health insurance. If someone has HIV you can’t use the health insurance to give birth. If I had told the doctor before I gave birth, he would have taken more precautions that could have prevented my daughter from becoming infected during the giving birth process.

Disclosure event

Little research has focused on assessing relevant aspects of the disclosure event - what PLWHA talk about and how their confidants respond (Chaudoir, Fisher et al. 2011). The
disclosure event may be characterized in terms of the breadth, depth, duration, and emotional content of communication and the reaction it garners from the confidant (Omarzu 2000).

Several of the participants reported that they simply told the confidants that they have the illness and the reactions of the confidants varied from supportive, to rejection. One woman who was inspired to disclose her HIV serostatus to her son while attending an HIV conference described her disclosure event to her son as the following:

> Upon returning from the trip (HIV-related conference), I bought two phone cards, and called Haiti. My son answered the phone and said ‘On sel manman, on sel pitiit (One mother, one son), how was the trip.’ But he doesn’t know anything. He only knew that I had pneumonia. I told him everything went well. I stayed at a hotel that only Laura Bush could afford to stay there. And then I said, you know what my son, “Thank you HIV”. Then, there was a complete silence on the phone for 30 or 40 seconds and the phone card ended. The first phone card ended.

The woman eventually called the son back and expressed that she was cold because she did not know what he was going to say. The son’s reaction, to the mother’s surprise, was very supportive and understanding. She stated the following:

> I called him and he said, ‘I tried to give you my response but the call ended. I just came from a funeral. My classmate’s mother died of cancer and we had to go support him. HIV can’t kill you mother. It’s all a matter of how you treat it. How many mothers do you see that throw away their child because the child is sick? No mother would do that even if the mother was crazy.’ The son continued by saying, ‘Mother, the love I had for you was nothing. It is today I am going to start loving you like never before. I said, “You know I love you too. He said, ‘The way you caught the virus was when our father left us and you probably tried to make some money with someone to help the family. Anyway, it doesn’t matter whether you caught the virus in Haiti or in the US. I love you even more now mother. Take your medication, enjoy life, and your son will be with you until death.”

Another woman stated that she told her son in Haiti during a conversation about her other son who was diagnosed with HIV and committed suicide afterwards without telling the mother his HIV serostatus. Her disclosure event occurred in the following manner:

> He said, “Mother, they told me that my brother had HIV.” I told him I know but they told me that late. If you had told me that earlier then he would not have died. I told him that even me as your mother I also have HIV. Then he said, “Oh, you also have it mother? I
said, do I look like someone who is going to die? Now, it's better to have HIV than to have cancer. He said, “No mother, you look too well to be sick.” I said, yes I have HIV but I take my medication. Then I told him, if when your brother was diagnosed with HIV, you had told me he would not have died. I told him to keep what I just told him a secret. He said, “I will pray for you mother and asked why I don’t come to Haiti so I can rest.

One man who disclosed to her aunt after being discharged from the hospital stated:

After being discharged from my one month stay in the hospital my aunt often called me to find out how I was feeling and how my recovery was going. I was diagnosed with pneumonia and told them I had pneumonia but during one phone conversation with my aunt I felt like I couldn’t hold it to myself anymore because I felt sad since I was just diagnosed with the illness and I didn’t think I was going to live long. So I told her here is (HIV) what the doctor told me I have. She felt worried because she never thought I had such a thing. I told her that I am person like anyone else and something bad can happen to me.

On one occasion, there was a mutual disclosure between one woman and her partner after she was diagnosed. Although her partner knew he was HIV-positive he did not disclose to her until she made him aware. She stated the following:

He eventually told me that he was sick. He said he didn’t tell me earlier because he didn’t want to lose me because he loved me so much. He knows if he had told me I could have left him. I said, at least if you had told me that there are preservatives for people to protect themselves. At least, I would have stayed with you but we could have protected ourselves. I don’t see a reason for you to hide something like that while you continue to have other women.

Another woman stated:

“I became ill and was taken to the hospital. After the medical exams the doctor asked me if he could invite my child inside to share the results of the exam. I gave the doctor permission to share the news with me while I was accompanied by my child. After the doctor told us the news, my child started crying and then his father, who was waiting outside, asked what was wrong but the child did not want to tell the father. The father threatened to beat him if he did not tell him, so the child told him. My husband left me ever since he found out. He told my friends and they humiliated me.

One woman who had two unwanted disclosure experiences described the following events:

There was a nurse who always came to take my blood pressure but she couldn’t come that day, so another nurse came instead. So she came and took my blood pressure, she put the meds on the table and fixed them. When she was completely done she was suppose
to leave but I don’t remember what she was explaining to me and then she said ma'am you have HIV. The other lady (home health aid worker) was sitting right next to me. I gave the nurse an angry look. I was very angry and I wanted to beat her for saying that out loud. The worker was sitting right there. I was angry and then I felt like something came over me, then the nurse called an ambulance and they took me to the hospital. I got to the hospital they told me that it was an indisposition.

While I was at the hospital, my kid came to see me. I don’t know what they did because I used to go the hospital before and they never used to do that. They did a paperwork and put on it that I have the disease. Then when my grandson saw the paper he said, “No my grandmother doesn’t have such disease”. I looked at the nurse then she told my grandson that it was a mistake, the paper was for another patient and not for your grandmother. Then she took the paper and went to speak to the doctor outside.

Mediating outcomes

Some of the individual outcomes of disclosure included emotional relief and encouragement to take their medication. One woman whose children live in Haiti stated the following:

*I am more comfortable with them now because they call me every time. They say they pray for me and asked me if I have eaten and taken my medication.*

Another woman whose son also lives in Haiti stated:

*He calls me every morning and asked me if I take my medication. After you put your clothes look at yourself and take your medication. If you love yourself, you will take your medication. The medications are your future. My son gives me more affection than before I told him I have HIV. He never spends a week without calling me. I have no complaints about my nieces, and my son. They are not afraid of me. My friend is still close with me. She said that I am a fighter because I fight to stay alive.*

The same woman continued talking about the day she disclosed to her nieces and the outcomes:

*Later that night after telling them, they both decided to sleep next to me in the living room. I really appreciated that. They spend time coming to the doctor with me, they translate for me; they tell me how to take my medication. They support me and encourage me to take my medication.*

Another individual outcome was rejection. One woman stated the following:

*It was not until I was preparing to come to the U.S. that I told my aunt who lives in the US. After telling her, I realized that I should not have told her because of the way she has behaved toward me since I have been living with her in the US. I thought that someone*
living in the U.S. would better understand how HIV is transmitted and treat someone with HIV better. When I first started to live with her, she would look at me on the side. If I did not have a good support group in Haiti, and used to encourage people to take their medication I would have been so discouraged by the way that my aunt has treated me since I came to the US. I used to see them drink in any of the cups and now my aunt called her kids to the side and told them to not use the cups that I use. She bought different cups for her children to use so that they would not use mine. The way she treats me is as if I was on the verge of dying. Even when I came to the US, she has not helped me find a doctor, or even said anything to me. It’s me that had to seek a doctor through the help of my friends.

However, some participants were not rejected as indicated by the following quotes:

They didn't really act in a bad way. In retrospect they encouraged me (to fight), because I came to a point where I was penniless and on unemployment for three months. Some people helped me out because I still had to pay for a place to live. I received all types of encouragement from my family. I never felt as though I was in a corner by myself trying to figure things out.

DISCUSSION

Disclosure is a crucial step in the adjustment for people who have been diagnosed with HIV. We explored the process of disclosure among HIV-positive Haitian immigrants in New York City. All of the participants interviewed had disclosed to at least one person, either a family member or a health care worker. The reasons for disclosure reported were because participants were in a close relationship with someone they trusted and felt comfortable with or wanted to become more comfortable with, and the need for support and understanding about the illness.

Some of the participants concealed their HIV serostatus because of fear of stigmatization, rejection, wanting to keep it a secret and to spare others, particularly the family, from worrying and protect family members and from losing health insurance as well as not wanting to lose respect from family members. The manners in which the participants disclosed and the reactions they received varied from direct to indirect and unwanted disclosure and positive and negative reactions. Some of the long term positive outcomes of disclosure included social support, emotional relief and encouragement to take their medication. On the other hand, some
participants reported that their family members doubted their diagnosis and on some occasions mistreated them after they disclosed their HIV serostatus. Most of the participants expressed that they were not planning to disclose their HIV serostatus to anyone else and at least one or two participants intended to tell one more person.

The motivations reported in this study for disclosure and nondisclosure parallel the findings of a qualitative study that examined disclosure among African and Caribbean PLWHI in the Netherlands and the United States (Barsky and Albertini 2006, Stutterheim, Shiripinda et al. 2011). Research has shown that PLWHI weigh the costs and benefits of disclosure during the decision process to determine whether they should disclose their HIV serostatus and whom to disclose to (Omarzu 2000, Bouillon, Lert et al. 2007). In this study, participants disclosed to their family members, and friends for several reasons. The first component of disclosure is when the adjustment the person experiences after receiving their HIV diagnosis (Huber 1996). During the interviews for this study most of the participants reported that they were shocked, angry, and sad after learning of their positive HIV serostatus. In the words of one participant, “At first I felt like committing suicide. Such news is never easy to take in. But after a while I learned to accept the truth and be okay with myself.” After adjusting to the diagnosis, patients can then decide if their relationships with potential confidants are strong enough to reveal such news (Huber 1996).

Some of the participants mentioned that they chose to disclose their HIV serostatus to people they trusted, felt close to, and were comfortable with. In addition, participants also disclose to their confidants because they wanted support and a better understanding of the illness. In contrast, stigmatization, the belief that HIV is associated with promiscuity, and other related factors prevented some participants from disclosing their HIV serostatus to family members as well as health care professionals. These findings are not surprising considering that other studies
have reported similar reasons for nondisclosure in Haiti and among Haitians in the United States (Fitzgerald, Maxi et al. 2004, Barsky and Albertini 2006). One study conducted among Haitian immigrants in Florida revealed that participants hid their illness from family members, church officials, friends and health care professionals in fear of being humiliated, and to prevent professionals and government officials from using their HIV serostatus against them for deportation (Barsky and Albertini 2006). These beliefs were also present during the interviews conducted for this study because the participants hesitated to partake in this study in fear that the information would be used against them. Although this perception may be common among ethnic minorities who mistrust the health care systems and government officials, Haitians have an added reason to believe that their HIV serostatus can be used against them because of the erroneous label that the CDC and FDA assigned to Haitians during the advent of the epidemic as a high risk group for HIV (Galarneau 2010). Until this day the stigma associated with this label exist and was manifested in 2010 when a New York based DJ announced on the radio that the only reason he does not have HIV is because he does not sleep with Haitian women (CNN 2010). For these reasons, Haitians living with HIV face a double stigma that may influence their disclosure decisions.

The manners in which the participants managed whom to tell and how to tell specific family members about their HIV serostatus support other research showing that disclosure is an ongoing process and involves several components (Yoshioka and Schustack 2001, Chaudoir and Fisher 2010). Some participants reported that after learning their HIV diagnosis they selectively disclosed to close family members such as their aunts, children, and spouses, and parents. The disclosure event varied for the participants depending on whether they were in Haiti or the United States when they were diagnosed. For individuals who were living in Haiti when they
were diagnosed with HIV, they tended to be more open and disclosed to a greater number of people in their family (parents, nieces, spouses) and took less time to disclose. One explanation for this finding is that a number of these individuals were also HIV activists in Haiti and were very involved in fighting for policy changes with respect with how HIV people are treated at the hospital, and HIV criminalization law. In contrast, most of the participants who were in the United States tended to be less open and disclosed to fewer individuals in their family. This finding may be due to the fact that the majority of the family members of these participants were living in Haiti. Therefore the participants may have felt less of a need to disclose to those individuals in Haiti since they were not in contact with their family members as often as the participants who were residing in Haiti. Similar to the participants who were HIV activist in Haiti, one participant who was diagnosed with HIV in the U.S. and eventually became an activists was the only one that was more open and disclosed to more individuals, including family, friends, and church members. These findings imply that support groups and community activities focusing on HIV awareness and stigma reduction can remove some of the barriers preventing HIV disclosure in Haiti and among Haitian immigrants.

The outcomes of disclosure also varied based on geographic location. Since fewer individuals residing in the United States disclosed to family members in the United States, they did not report as many benefits as individuals who were residing in Haiti when they disclosed. For example, more participants reported receiving encouragement and support from their family members in Haiti. In addition, participants who disclosed to family members in the United States tended to experience rejection and stigma from those family members more than participants who disclosed to family members in Haiti. However, participants in Haiti were more likely to experience stigma in their neighborhood and hospitals than participants residing in the United
States. Thus stigma manifests itself for these individuals in different venues and social circles based on their geographical location. For the individuals who disclosed to a close family member either in Haiti or the United States, they also reported several other benefits including assistance with medical appointments, translation, instructions with medications, love, emotional relief, and disclosure from others. These results support the explanation offered by the Disclosure Processes Model that disclosure outcomes are impacted by three specific processes that function concurrently independent of the type of antecedent goals: (a) alleviation of inhibition, (b) social support, and (c) changes in social information. On an intrapersonal level, the alleviation of inhibition allowed participants to feel relieved after spending two years or more contemplating how and when to share their status. On an interpersonal level, social support and changes in social information allows the participants to have additional strength as they cope with the stressors associated living with HIV (Chaudoir and Fisher 2010).

The findings that participants living in the United States were less likely to disclose their HIV serostatus and more likely to experience rejection and live in isolation may help explain the finding of a recent study that reported that compared to African Americans, and Hispanics, Haitian immigrants are less likely to achieve a suppressed viral load and more likely to have a low CD 4 count throughout the course of therapy (Colasanti, Nguyen et al. 2012). Previous research has found that consistent disclosure of HIV serostatus independently predicted increased CD4 cell counts over time controlling for important biobehavioral covariates (Strachan, Bennett et al. 2007). However, the relationship between disclosure and CD 4 count has not been explored among immigrant groups. Future research should prospectively examine the relationship between disclosure and physical wellbeing among racial and ethnic minorities. For example, a randomized controlled trial in which some participants receive assistance with the
disclosure process can reveal whether the intervention leads to increased disclosure, and improved psychological and physical wellbeing.

The results of this study are limited due to the nature of qualitative research and are not generalizable due to the small sample size. Second, despite efforts to interview an equal number of men and women, the community based organizations where the participants were recruited from consisted of mostly older women clients. In addition, there is potential for interviewer and social desirability biases. Nonetheless, the findings of this study contribute to the literature and point to directions for future research. First, data from a larger, more representative sample including younger and more acculturated Haitian immigrants can offer new perspectives on how familiarity with U.S. culture and higher socioeconomic status influence disclosure decisions. Moreover, future studies should attempt to interview family members, and friends of people living with HIV to examine the impact of disclosure on the significant others and learn what resources are needed to help them adjust and support the person living with HIV.

In summary, the findings of this study highlight the facilitators and barriers to HIV serostatus disclosure among Haitian immigrants in New York City. Reasons for disclosure included being in a close and trusting relationship and the need for support and understanding about the illness. Fear of stigma, isolation, and wanting to protect family members and one’s reputation were reported as barriers to disclosure. The disclosure event and outcomes varied based on the confidant and geographical locations.
Acknowledgments

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References


CNN (2010). HOT 97 DJ suspended over comment linking Haitian women to HIV.


CHAPTER 5

CONCLUSIONS AND IMPLICATIONS
In chapter 2, we used baseline qualitative interviews from a psychosocial support group intervention for HIV-affected youth and their caregivers in central Haiti to explore the factors influencing maternal HIV disclosure to children in Haiti, determine the breadth of the mother’s disclosure, and to understand the impact of disclosure on the children. We found that reasons for mother’s disclosure were because they trusted and did not want to hide the illness from their children. In some cases, the children first found out from people in the neighborhood or other children at school who stigmatized them before their mothers informed them of their HIV serostatus. Some of the mothers reported that they disclosed their HIV serostatus because they thought they were going to die from the illness or were encouraged to disclose to their children by the social workers in the intervention. The amount of information the mothers shared with their children during the disclosure event varied from simply telling the children they have HIV to discussing the HIV diagnosis process and medications prescribed. Some of the children reacted emotionally after learning of their mother’s diagnosis by crying while others were worried about becoming infected or wanted to assist their mothers financially and medically. Children who were more educated about the illness and were reassured by their mothers that the medication would improve their health were less concerned than children who were not as informed.

In chapter 3, we used baseline data from a randomized trial of a Cognitive-Behavioral Stress Management intervention to examine the determinants of HIV serostatus disclosure to a sexual partner among 258 HIV-positive Haitians receiving services at the Groupe Haitien d’Etude du Sarcome de Kaposi et des Infections Opportunistes (GHESKIO) Center in Haiti between 2008-2010. Most of the participants (75.2%) were receiving antiretroviral therapy and 53.7% reported that they had begun to be more open about being HIV-positive since the news
about the HIV medications. Less than half (38.6%) had disclosed their HIV serostatus to their sexual partner. Logistic regression analyses revealed that age, marital status, knowledge of partner’s HIV status, and number of sexual partners were significant predictors of HIV serostatus disclosure to a sexual partner. Participants in the 30-to 39-year-old category were significantly less likely to disclose their HIV serostatus to a sexual partner than those in the 17-to 29-year-old category (OR = .30, 95% CI = .12 - .76). Compared to married individuals, those who were single were significantly less likely to disclose their HIV serostatus to a sexual partner (OR = .15, 95% CI = .04 - .58). The strongest predictor of HIV serostatus disclosure was knowledge of partner’s HIV status. Participants who had an HIV-negative partner or were unaware of their partner’s HIV serostatus were significantly less likely to disclose their HIV serostatus to their sexual partner than those with an HIV-positive partner (OR =.36, 95% CI =.13 - .97), (OR=.09, 95% CI =.04 -.22), respectively. Lastly, participants who reported that they had sex with more than one person in the past 3 months were less likely to disclose their HIV serostatus to their sexual partner (OR=.41, 95% CI =.19 -.90).

In chapter 4, we used the Disclosure Processes Model to explore the disclosure experiences of 21 HIV-positive Haitian immigrants in New York City. Qualitative interview were analyzed to identify antecedent goals for or against disclosure, describe the disclosure event, and mediated outcomes. Findings revealed that the reasons for disclosure were because participants were in a close relationship with someone they trusted or felt comfortable with, and the need for support and understanding about the illness. Some of the participants concealed their HIV serostatus because of stigmatization, and rejection. The long term positive outcomes of disclosure included social support, emotional relief and encouragement to take their medication.
On the other hand, some participants reported that their family members doubted their diagnosis and on some occasions mistreated them after they disclosed their HIV serostatus.

**Implications**

The findings from the first paper indicate that interventions focusing on assisting parents and children with the HIV-serostatus disclosure process can enhance the outcome. The interviews conducted after the intervention indicated that the support groups the parents and children attended helped the children understand their parents and improved how they communicate with each other (Smith Fawzi, Eustache et al. 2012). The following quotes from one parent and child illustrate these points:

*We learned how we can talk with our children so that they will listen. Before I was in the groups, I spoke with my children as my parents did to me (in an authoritative way). Now, when I speak with my children they listen to me and I listen to them. (Smith Fawzi, Eustache et al. 2012)* *(Smith Fawzi et al., 2012 p.1499)*.

*I really liked the work that we did in the support groups. I now understand my mother better and I am able to better support her.”* *(Smith Fawzi et al., 2012 p.1499)*.

Although these statements do not mention disclosure, families affected by HIV in developing countries can also benefit from psychosocial support services providing individualized and culturally sensitive assistance in issues such as: how to deal with HIV in a child-adequate, age-specific way, what to tell and what not to tell, and balancing the advantages and disadvantages of parental disclosure in specific personal and family contexts (Nöstlinger, Jonckheer et al. 2004). Health care professionals should receive training on how to provide parents infected with HIV guidance and information regarding the potential negative and positive outcomes of disclosure to children. Health care workers should also encourage parents to seek ongoing counseling for children who are in need during the disclosure process (Vallerand, Hough et al. 2005). In addition, parents should disclose to the child before a major health crisis.
or disclosure from outside sources occur (Vallerand, Hough et al. 2005). In the first paper, some of the children found out about their parents’ illness from other children in school or in the neighborhood who would call them Ti SIDAyis (little person with HIV) or tell them that their parents have HIV. Efforts at the community level to prevent the stigmatization of families affected by HIV could involve increasing acceptance of HIV-positive people. Children who are educated about HIV in school or through cultural community activities such as storytelling, and plays may become less judgmental about HIV and adopt sexual behaviors to protect themselves.

The low rate of HIV serostatus disclosure to sexual partners found in paper 2 indicates that HIV-positive adults in Haiti can also benefit from assistance with the disclosure process to sexual partners. Although much progress has been made in Haiti in increasing HIV testing and counseling, providing free antiretroviral therapy and reducing HIV stigma, our findings suggest that fear of partner’s negative reactions may prevent PLWH from disclosing their HIV serostatus to the sex partner (Loubiere, Peretti-Watel et al. 2009). This fear may be more pronounced for individuals with HIV-negative partners because they were less likely to disclose their HIV serostatus to their partner compared to individuals with HIV-positive partners, possibly impeding HIV prevention efforts. A study conducted in Barbados revealed that women who had disclosed their HIV status were more likely to use condoms during all sexual encounters, and were more likely to have a partner who had been tested for HIV (Kumar, Waterman et al. 2006). The same study also reported that among women who did not disclose their HIV status to anybody, 30 (30%) gave fear of stigmatization as the reason for nondisclosure, while 23 (23%) did not disclose their status as they feared abnormal reaction from their current sex partner and possible violence directed at them (Kumar, Waterman et al. 2006). Counselors must address these fears and resources need to be allocated for the provision of ongoing support with the disclosure
process. Couples voluntary counseling and testing should be promoted through mass media, in schools, churches, and workplaces. The fact that older individuals were less likely to disclose their HIV serostatus to a sexual partner than younger individuals also imply that more efforts should target older individuals to decrease stigma and encourage acceptance of HIV-positive individuals.

Researchers who have conducted HIV research in the Caribbean propose that educators, social service and health care providers are also targeted for antistigma interventions as they are also subjected to the same prejudice of PLWH as the general population (Rutledge and Abell 2005). The participants interviewed in NYC for paper 3 shared several instances of discriminatory experiences they had at different health care settings in Haiti. In particular, the participants mentioned the condescending manners they were treated and that at one point people living with HIV could not receive surgical procedures at the general hospital in Port-au-Prince. In addition, one participant stated that she did not share her HIV serostatus to the doctor who helped her during labor in Haiti because “If someone has HIV you can’t use the health insurance to give birth.” The participant believed if she had told the doctor, he would have taken the precautions needed to prevent the transmission of HIV to her daughter during labor.

In order to prevent further HIV transmission in Haiti, the Haitian government and international health organizations need to address the larger structural forces (policies, poverty, social inequalities) that promote HIV-stigma and prevent HIV serostatus disclosure to significant others and health care professionals (Castro and Farmer 2005). The stigmatized attitudes that exist in Haiti are also prevalent among Haitians living in the United States as indicated in the following statement: It was not until I was preparing to come to the U.S. that I told my aunt who lives in the US. After telling her, I realized that I should not have told her because of the way she
has behaved toward me since I have been living with her in the US. I thought that someone living in the U.S. would better understand how HIV is transmitted and treat someone with HIV better.

The findings from paper 3 illustrate the complexities associated with HIV serostatus disclosure to children, parents, friends, and sexual partners. In addition, the transnational ties Haitian maintain to family members in Haiti also influence their disclosure decisions. In one case, a mother only disclosed to her sons and daughter in Haiti after one of her sons committed suicide because he was diagnosed with HIV. Her initial reason for not disclosing was because she did not want her children to think she was sleeping around. These beliefs stem from the structural/cultural factors combined with policies and popular discourse that marginalize PLWH as undeserving of assistance because they are socially constructed to be immoral, stupid, or weak (Rutledge and Abell 2005). Despite the potential negative outcomes, a number of the participants reported several positive outcomes of disclosure such as acceptance, social and emotional support, and encouragement to adhere to their medication. The findings showed that some of the participants decide whom to disclose and how to disclose on their own terms. Although most of the participants reported that they have not had sexual partner since they learned their HIV serostatus, there were at least two participants who expressed an interest in starting a relationship and engaging in sexual intercourse. For individuals who remain sexually active, there is a need for social services to engage these them in discourse about disclosure and provide them with the opportunity to practice different manners in which they can approach the topic with their partner in Haiti and the United States. With the recent changes in the HIV travel ban and immigration to the United States, there is a need to increase the resources allocated to prevent new HIV transmission among U.S. ethnic minorities.
**Future research**

Future studies should aim to assess HIV serostatus disclosure decisions during the HIV counseling and testing period in order to enhance the services provided to newly HIV diagnosed individuals with the ongoing disclosure process. In addition, further exploration is needed to: 1) determine how the increase availability of free antiretroviral therapy influences HIV serostatus disclosure to family members, and sexual partners, 2) identify quantitatively the different factors that are associated with HIV serostatus disclosure to children and family members compared to sexual partners, 3) investigate whether the possibility that HIV-positive individuals in Haiti can travel to the United States affects disclosure decisions, 4) examine the attitudes and behaviors of health care providers, educators, and other professionals toward PLWH in Haiti and the United States.
References


CHAPTER 6

REFLECTIONS
During my last semester in my undergraduate studies, I had the opportunity to discuss with Haitian Professor Francois Pierre-Louis the research projects I had worked on that focused on HIV in New York and South Africa. After I finished sharing my exciting stories and started feeling as if I had made an impression on him, he made a comment that changed the focus of my research. He stated that there was a time in the United States when Haitians were not viewed as human beings but as HIV/AIDS carriers and continued to talk about the discrimination Haitians faced in the United States because of the CDC and FDA labels assigned to Haitians during the advent of the HIV epidemic. Shocked at his comment, I questioned myself how come I was never taught about this incident in the two HIV/AIDS classes that I had taken at Queens College and the researchers in my circle. Having felt betrayed and miseducated, I started to understand part of the reasons why Haitian immigrants, including myself, were still experiencing discrimination at school, in public transportations in New York and so forth. This is apparent in the 2010 announcement by the NY based DJ that the reason he does not have HIV is because he does not mess with Haitian women.

As I embarked on my research in the Haitian community in New York, I often wondered how my focus on HIV-positive individuals might reinforce the beliefs that the Haitian community is indeed affected with HIV. On the other hand, I was also curious to learn how Haitians living with HIV in New York managed the double stigma of being Haitians and HIV-positive. Similar to me, some of the participants were not aware of the label. Among those who knew about the label, they simply felt that HIV does not discriminate because all ethnic/racial groups are affected by the epidemic. Similar to other people living with HIV, the findings from the 3 studies indicated that Haitians living with HIV have identical experiences regarding HIV serostatus disclosure to family members, and sexual partners.
The stigma that prevents HIV-positive people from disclosing their HIV serostatus also played a role in how I communicated with people when they asked me what my dissertation focused on. Initially, I would share that I am researching the experiences of HIV-positive Haitians. After awhile, I started to wonder if I was perpetuating the stigma by mentioning HIV and Haitians in the same sentence. Eventually, I simply stated that I was researching the experiences of HIV-positive individuals. After solving this issue, another one emerged. People started wanted to know why HIV? Why not obesity, cancer, and another less stigmatized disease? The facial expressions of some people let me know that they wanted to ask me: Do you have HIV or does someone in your family have HIV? A close friend of mine told me that in his church they have cured HIV and that my research on the topic only gives it more importance than it needs to receive. As I struggled to compose a response for people as to why HIV, I eventually learned that my uncle whom I never met might have died from HIV in Haiti during in late 1980s. Still, that was not enough for me.

After contemplating my conversation with her and other people, I realized that I should not become upset anymore. Perhaps, I can use this opportunity to inform people about how stigma affects people with HIV and that people are not dying anymore from HIV. I also thought about my own ignorance and experience as a researcher whose work focuses on HIV. Although I had read and became informed about HIV through my work, the experience of meeting a person who is HIV-positive, for some reason, makes the meaning of the work even more perplexed because of how healthy people who are HIV-positive look. I think a number of people do not think of people living with HIV as attractive, active, educated, mothers, fathers, sons and daughters, and dedicated workers, and people who have needs just like HIV-negative people.
Through the interviews I conducted, these multiple realities became more and more apparent as the participants spoke about how important their sons, daughters, and other family members were to them. In particular, I was reminded of my own mother as some of the mothers I interviewed would tell me that they have sons who are older than me or how I could be one of their sons. The following memo, in which I use car models for the participants’ names, highlights these realizations during the data collection:

Memo: January 3, 2013

These events (interactions with the participants through phone conversations and face to face) helped me to learn some of the basic needs that Subaru has and how similar they may be to my or anyone else’s needs and gave me more reason to start thinking less about HIV and more about the person. I also notice how my interaction with these women remind me of my interaction with my mother. For example, Toyota calls me her son or in Haitian Creole “Pitit mwen” which means my child. Some of the women have children who are older than me by many years and hearing how important it is for them when their children calls them and are concerned for them has made me more concerned for my own mother and have encouraged me to express more affection to my mother. Over and over, Subaru and Toyota tell me “Their sons and daughters are important to them and support them as they battle HIV, which is becoming less important to me as I interview them because they are full with other regular needs that I am starting to think that HIV creates another need or amplifies their regular needs”. My conversation with the executive director of Diaspora Community Services other day touched on this subject because she expressed her interest in learning whether the HIV-positive Haitians had the same basic needs as HIV-negative Haitians. Since she is the Executive Director of Diaspora Community Services, which serves both HIV-positive and negative Haitians, I think it’s a good question to explore. So far I think they are the same needs like housing, food, social support, love and affection.

One of the other important experiences worth discussing is balancing the goal of collecting data and doing something in return for the participants besides paying them for participating in the research. Their willingness to share sensitive information with me prompted me to change my perceptions about the interview process, especially among the two participants that I interviewed in 2012 and again in 2013. During my conversations with these two participants, I was often reminded that I could not just call them and request for a date to
interview them a second time. I had to establish a friendship with them and that meant our conversations over the phone were not just about when I could interview them but also about how they have been, what progress they have made and what needs they had. For example, on the day I was supposed to conduct a follow-up interview with one of the participants, she mentioned that she wanted me to bring her some Haitian food because there were no Haitian restaurants in her neighborhood. As most Haitians know, there is nothing like Haitian food! The fact that she felt comfortable enough to ask me to bring her Haitian food made me feel that I was not just the researcher coming to ask personal questions about her life. To me, I felt that she was becoming to trust and allowing me to reciprocate.

My interview skills also improved during the follow-up interviews as I mentioned earlier because I was not simply focused on asking questions anymore but more about understanding how the participant was feeling as she described her experiences and where to probe and where not to probe. In one follow up, one participant started crying as she was talking about her son who committed suicide after he became diagnosed with HIV. She was hurt because she felt that she could have saved him if she had disclosed to him on the day he went to get tested for HIV. Realizing that she was crying and since she mentioned that she did not want to talk about her son, I changed the subject to a less emotionally charged subject. To my surprise, I also cried when I was describing her experience to my committee members during my proposal meeting. Although this was not the first time I noticed the emotional impact my research was having on me, it was the first the time it caught me off guard. Early on when I was analyzing the qualitative data for maternal disclosure to children and impact of disclosure on the children in the first paper, it became apparent that the more I reviewed the transcripts the sadder my mood became.
The process of obtaining the three datasets for this dissertation is worth discussing as well as it provided its own lessons. Although I initially wanted to focus my dissertation research strictly on Haitians in Haiti because I thought that my research skills would be more needed in Haiti and that it would give me an opportunity to return to my native land and put in practice what I had learned in school, I eventually realized that there was not one article published on the experiences of Haitians living with HIV from the New York area, the part of the country with the second largest Haitian community in the U.S. Having lived in New York for 10 years, I decided that instead of focusing my research strictly on Haitians in Haiti, I would use the skills that I obtained in 2010 from working with the psychosocial and mental health team of Partners In Health in Haiti to design a study that focused on Haitians in New York. The experience in Haiti became vital in helping me prepare for my research project in New York. For example, the patience I developed when I was waiting to hear from Partners In Health about the internship in Haiti became important when I started looking for a community-based organizations in Brooklyn that provides HIV services to Haitians.

During the spring 2011 semester I sent out a few e-mails to different community-based organizations in Brooklyn, New York with no success for about a month or longer. As I persisted, I learned about an organization called Diaspora Community Services that received funds from the NYC Haitian Community Hope and Healing Funds with the goal of addressing the needs of individuals, families, and communities in the NYC area that were affected by the January 12, 2010 earthquake. After making a successful connection with the organization, the staff expressed to me that although they have existed since the 1980s and have had several student interns, they had never received a student researcher and wanted to develop a research capacity in the organization. I expressed my interest in volunteering my services as a researcher
and intern. Although my internship ended during the summer of 2011, I have returned to the organization to conduct two research projects focusing on the experiences of their Haitian clients: One project involved those who receive group support for HIV-related concerns and the other involved those who participate in the Haitian American Empowerment Program, designed specifically to meet the needs of clients after the earthquake. As a result, an abstract entitled “Post-earthquake challenges and successes of Haitian immigrants residing in Brooklyn, New York” was accepted and presented at the 24th Annual Haitian Studies Association Conference in New York. My work in the Haitian community in the U.S. and in Haiti led me to receive the Haitian Studies Association’s Emerging Scholars Award. One lesson I learned from this experience is that to do research in the Haitian community in the U.S., it is helpful to become familiar with the context Haitians live in Haiti. My experience in Haiti allowed me to better understand some of the stories the participants shared about the time they lived in Haiti.

In preparing for the project in New York, I wanted to recruit a large enough sample size for a quantitative study. To achieve this goal, I attempted to recruit participants in two cities, Miami and Brooklyn, with large Haitian communities. After reaching out to researchers at the University of Miami Medical School and Florida International University, I traveled to Miami in the summer of 2011 to explore the possibility of conducting a study among Haitians living with HIV in Miami. After discussing the goal of my research with the researchers at Florida International University, University of Miami Medical School and the Center for Haitian Studies in Little Haiti, I was advised against conducting the study in Miami because of the anticipated challenges I would face in recruiting Haitians living with HIV in Miami especially since I was not based in Miami. Instead, one of the researchers at Florida International University offered to share the baseline data from a 5 year project, “Intervening with Haitian HIV+ Alcohol Users: An
Environmental Psychosocial Framework”, funded by the National Institute on Alcohol Abuse and Alcoholism. This five year study is an adaptation and randomized trial of a Cognitive-Behavioral Stress Management (CBSM) intervention for simultaneously enhancing safer sex practices, adherence to ARV medication, and reducing alcohol or other drugs (AOD) use among HIV-positive Haitians in Haiti.

As I conclude, I am reminded of the Haitian proverb Men anpil chay pa lou (Many hands lighten the load) which recognizes that with the help of others we can accomplish our goals despite the challenges. As the Haitian proverb indicates, I was only able to carry out this research project due to the many hands that assisted and supported me including family, friends, advisors, funders, community leaders, and participants. Overall, I was deeply moved by some of the sacrifices the participants made in order to allow me to interview them. Some of the participants really valued the research I was doing, especially those who had been active in the HIV community in Haiti and the United States. They wanted to share their experiences and raise awareness about HIV in the Haitian community. To some of them, participating in this study was one of the routes to raising such awareness because they wanted to make sure that other people learn that HIV is not a killer. These sentiments were expressed when the participants would comment, “HIV doesn’t kill people, it’s people that kill people because they treat HIV-positive individuals scornfully”.
Appendix A

IRB Protocol ID: 37312

Examining the psychosocial, cultural, and sexual experiences of HIV-positive Haitian immigrants in Brooklyn, New York

<table>
<thead>
<tr>
<th>Participant # ________________</th>
<th>Date (month/day/year) __ __ / __ __ / __ __</th>
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<tbody>
<tr>
<td>Name of interviewer ___________</td>
<td></td>
</tr>
<tr>
<td>Please ask the participant which programs he/she is a member of:</td>
<td></td>
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</tbody>
</table>

### Sociodemographic Information

<table>
<thead>
<tr>
<th>Questions</th>
<th>Please circle one of the following options for your answer.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td>___ ____ (in years)</td>
</tr>
</tbody>
</table>
| 2. Gender                                     | 1) Male  
                                               | 2) Female                                                  |
| 3. What is your marital status?                | 1) Single/Never Married  
                                               | 2) Married  
                                               | 3) Separated  
                                               | 4) Divorced  
                                               | 5) Widowed  
                                               | 6) Living with Significant Other  
                                               | 7) Boyfriend/Girlfriend  
                                               | 8) Casual relationship                       |
| 4. Education – highest grade passed:          | ________________                                           |
| 5. Employment                                 | 1) Employed  
                                               | 2) Unemployed (ask for source of income)                    |
|                                               | 3) Other (please specify)………………………………………...|
| 6. What is your yearly household income?       | 1) 0 - $9,999  
                                               | 2) $10,000 - $14,999  
                                               | 3) $15,000 - $19,999  
                                               | 4) $ 20,000 – $ 24,999  
                                               | 5) $ 25,000 - $29,999                          |
1. DIAGNOSIS & DISCLOSURE

Now, I am going to ask you a few questions about how you think you contracted HIV and your experience after you found out that you had contracted it. Before I ask you about what happened after you found out that you were HIV-positive, it would help if you can tell me how you think you became infected.

A) I would like to know how you found out that you were HIV-positive. Can you tell me how you found out that you were HIV-positive?
   Probes: Traditional health-belief, blood donation, mother to child transmission. Doctor did an HIV-test, tried to donate blood, your partner told you he/she was positive. You got too sick and you were taken to the hospital. You were required to take a test for marriage. Other medical services non-HIV related, surgery?

B) After you found out that you were HIV-positive, can you tell me how you felt or what came to your mind?
   Probes: Were you shocked, upset? Did you think it was a death sentence? Were you hopeless? Did the doctor or family member make you feel positive about the future? Did you have any suicidal ideation, want to infect others because someone infected me? Were you in denial or say that it was not a medical thing? Did you
think someone sent it to you? Did you convince myself that it was not true or it was somebody else blood sample?

C) When someone finds out that they are HIV-positive, they usually have to decide whether to share their results with someone. If you have told one or more individuals that you are HIV-positive, can you tell me what those experiences were like for you? Probes: Were you scared? How long did it take before deciding to tell someone? Who did you tell and why? How did you feel afterward? Are the people you told living in the U.S. or Haiti? Were they supportive? Did they reject you?

D) If you spoke to your children about the results, can you tell me how you spoke to them about it and what their reactions were? Probes: Were they supportive? Did they reject you? Did they know about the virus? Were they old enough to understand the virus?

E) If you have not shared your results with anyone, can you tell me what prevented you? Probes: shame, guilt, stigma, self-stigma?

F) Would you need help telling anyone that you are HIV-positive? If yes, what kind of help?
Appendix B

Informed Consent Form for Social Science Research

Title of Project: Examining the psychosocial, cultural, and sexual experiences of HIV-positive Haitian immigrants in New York.

Principal Investigator: Donaldson Conserve, Doctoral Candidate
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(Please print your name) ___________________________ so that the person in charge of the research would know that you have had a chance to read the information below. This form may contain words you do not understand. Please ask the study personnel to explain any words or information you do not clearly understand.

1. Purpose of the study: The purpose of this study is to examine the psychosocial, cultural, and sexual experiences of HIV-positive Haitian immigrants living in Brooklyn, New York. This research involves data collection through the use of in-depth interviews on the effects of living with HIV on the psychosocial, cultural, and sexual experiences of Haitian immigrants. The results from this study will be used for a doctoral dissertation project by a student from The Pennsylvania State University in the United States. At the end of the study, the goal is to gain a better understanding of the successes and challenges of HIV-positive Haitian immigrants and to provide best approach to conduct research among HIV-positive Haitian immigrants.

2. Procedures to be followed: If you agree to participate in this study, you will be asked to answer questions on HIV diagnosis and disclosure, stigma, social support, cultural, and sexual experiences. The interviews will be audio-recorded and conducted in English or Creole.

3. Duration and time: The in-depth interviews will take about 60-90 minutes per participant. 30-50 interviews will be conducted within a 2 month period and the entire study will last for a year.

4. Statement of confidentiality: Your participation in this research is confidential. Your answers to the in-depth interviews will be kept confidential. Any answers provided would be coded in a way that it will not be connected to any information that would identify you. All completed interviews and discussions will be kept in secured files by the researcher. The researcher, his research assistant and his faculty advisor are the only people who will have access to the interviews. The data will be stored and secured at The Pennsylvania State University in a locked file. The interviews will be kept for three years after the project ends in 2014. The researcher administering the
interviews will keep anything he may know about you confidential. In the event of any publication or presentation resulting from the research, no personally identifiable information will be shared.

5. Right to ask questions: If you have any questions about your rights, or if you do not like what is being done, please contact the researcher, Mr. Donaldson Conserve, at dxc3412psu.edu

6. Payment for participation: You will receive a reimbursement for your participation in this study.

7. Voluntary participation: Your decision to be in this research is voluntary. You can stop at any time. You do not have to answer any questions you do not want to answer. Refusal to take part in or withdrawing from this study will involve no penalty or loss of benefits you would receive otherwise.

You must be 18 years of age or older to take part in this research study.

Completion and participation in the interview implies that you have been read the information in this form and consent to take part in the research. Please keep this form for your records or future reference.

This is to certify that you consent to and give your permission for your participation as a volunteer in the study entitled “Examining the psychosocial, cultural, and sexual experiences of HIV-positive Haitian immigrants in Brooklyn, New York”. You must be 18 years of age or older. You will receive a signed copy of this consent form.

______________________________ __________________________
Signature of Volunteer Date

___________________________________________________
Printed Name of Volunteer

______________________________ __________________________
Signature of Investigator Date

Additional Person Explaining the Research: Your signature below means that you have explained the research to the participant/participant representative and have answered any questions he/she has about the research.

______________________________ Date __________________________
Signature of person who explained this research Time Printed Name
VITA

DONALDSON CONSERVE

EDUCATION:

2013        Ph.D.  Biobehavioral Health
             The Pennsylvania State University

2011        M.S.   Biobehavioral Health
             The Pennsylvania State University

2009        B.A.   Psychology
             Queens College, City University of New York

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