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**Optimism related to treatment and high risk behaviors among People living with HIV/AIDS under follow up in public health clinics in Rio de Janeiro:
Scale of Attitudes and Beliefs about HIV treatment.**

By

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Dissertation

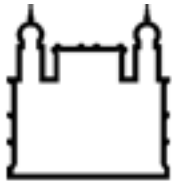
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To my parents for their unconditional love, care and endless support in my life. The best teachers I have ever had.

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RESUMO

O estudo teve por objetivo realizar uma análise exploratória da escala de Otimismo relativo ao tratamento para HIV/AIDS (*Highly Active Antiretroviral Therapy* - HAART) e testar a sua validade quando aplicada em Pessoas Vivendo com HIV/AIDS (PVHA) em acompanhamento em seis ambulatórios públicos municipais do Rio de Janeiro, Brasil. Um estudo transversal foi realizado entre 2007/08 com 900 PVHA (67% em tratamento HAART), 66.7% homens. Os participantes foram questionados acerca das 11 afirmativas acerca da HAART. Foi realizada análise fatorial exploratória, após a qual se obteve uma escala com 7-itens, composta por dois fatores. O primeiro fator com 5-itens representando Otimismo relativo à HAART e o segundo com dois itens que representam percepção de risco e severidade do HIV/AIDS. A escala de Otimismo relativo à HAART apresentou consistência interna satisfatória ($\alpha=0.696$). Os participantes que estavam em HAART e aqueles que não estavam tratamento obtiveram escores de Otimismo relativo à similares (43.5% vs. 43.8% com escores altos de otimismo). Nosso estudo identificou que a versão resumida do Otimismo de HAART pode ser útil para avaliar o papel do otimismo relativo à HAART e sua influência na aderência ao tratamento e na adoção de comportamentos mais seguros entre PVHA no Brasil.

PALAVRAS CHAVE

HIV; AIDS; TERAPIA ANTIRETROVIRAL; HAART; AMERICA LATINA; VALIDADE; ESCALA

ABSTRACT

The objective of this study was to explore the HAART (Highly Active Antiretroviral Therapy) optimism scale and test its validity among people living with HIV/AIDS (PLWHA) under follow-up in six public clinics of Rio de Janeiro, Brazil. A cross sectional survey was conducted between 2007/08 with 900 PLWHA (67% under HAART), 66.7% male. Participants were asked how much they agreed or disagreed with 11 statements about HAART. Data were subjected to Exploratory Factor Analysis, which yielded two factors, the first factor composed of a 7-item scale representing HIV treatment optimism, and a second factor representing risk and severity perception of HIV/AIDS. HIV Treatment Optimism scale showed moderately high internal consistency ($\alpha=0.696$). Participants who were under HAART and those who were not on HAART had similar HAART optimism scores (43.5% vs. 43.8% had high optimism scores). Our study identified that a shorter version of the HAART optimism scale may be useful to further study the role of HAART optimism on treatment adherence and protective behaviors among PLHWA in Brazil.

KEYWORDS

HIV; AIDS; ANTIRETROVIRAL TREATMENT; HAART; LATIN AMERICA; VALIDITY; SCALE

INDEX

BACKGROUND AND ETHICAL CONSIDERATIONS.....	1
I. INTRODUCTION	
THE HIV/AIDS EPIDEMIC.....	2
HAART (Highly Active Anti-retroviral Treatment).....	3
LIFE WITH HIV/AIDS.....	6
OPTIMISM.....	11
II. OBJECTIVES AND SPECIFIC AIMS	16
III. METHODS.....	17
IV. RESULTS	
Demographics.....	24
<i>Aim 1 Results</i>	28
<i>Aim 2 Results</i>	32
V. DISCUSSION.....	38
VI. CONCLUSION AND RECOMMENDATIONS.....	41
VII. STUDY LIMITATIONS.....	43
VIII. BIBLIOGRAPHY	44

LIST OF TABLES AND GRAPHS

Table 1: Selected information on the 6 health units chosen for the study, with their respective caseloads, geographic and administrative location. Rio de Janeiro, July 2007	18
Table 2. Participants socio-demographic characteristics (n=900). Rio de Janeiro, Brazil, 2007-8.....	25
Graph 1. Time with HIV (years).....	26
Graph 2. Time with HIV (years)	26
Table 3. Item factor loadings (n=873, TG & NTG).....	30
Table 4. Item factor loadings for the TG (n=642).....	30
Table 5. Item factor loadings for the No-Treatment Group (n=231).....	31
Table 6. Table 6. Pattern Matrix with Factor Loadings for each EFA.....	32
Table 7. Factor Loadings, KMO and Bartlett, alpha for 7 item-scale.....	34
Table 8. Optimism score by group and Scale.....	35

APPENDIX

Page	62
I. Research Proposal as submitted to the Fiocruz Institutional Review Board	
II. Institutional review Board approval for Ford Project	
III. Health Professionals Focus Group Informed Consent Form	
IV. Focus Groups Informed Consent Form	
V. Participant In-Depth Interview Consent Form	
VI. Participant Survey Consent Form	
VII. Baseline Questionnaire	
VIII. Fiocruz Ethics Committee Approval for Present Study	

BACKGROUND

I graduated from the University of California San Diego in 2004 with a B.S. in Biology. During 2008-2009 as a Fulbright Scholar in Rio de Janeiro, Brazil I participated in a research study funded by the Ford Foundation titled "Psychosocial and Structural Factors Associated with the Sexual Health and Well-Being of People Living with HIV/AIDS Attending Public Health Clinics in Rio de Janeiro, Brazil". The principal investigators for this study were Dr. Francisco Inacio Bastos and Dr. Monica Malta. During this time I was in charge of data collection of participants' medical records at two of the participating Municipal Clinics, Santa Cruz and Madureira, in Rio de Janeiro. In 2010 I returned to Rio de Janeiro to continue with my graduate studies and was able to use part of the data collected in this larger project to perform the following exploratory analysis for my thesis dissertation. Information and protocols about the larger study funded by the Ford Foundation, Ethics Committee Approval for Ford Project, Ethics Committee Approval for the present study, Informed Consent Form, Survey and Questionnaire, data from which was used to perform this exploratory study, can be found annexed (Annex I-VIII).

ETHICAL CONSIDERATIONS

The study that collected the primary data that was used in this present study was approved by the Institutional Review Board, Parecer No. 241A/2007 in Rio de Janeiro on December 17th of 2007 . The present study was approved by the Ethics Committee of the National School of Public Health (Escola Nacional de Saúde Pública, Sergio Arouca ENSP/FIOCRUZ) on August 16th 2011, Parecer No. 172/11 CAAE: 0183.0.031.000-11.

I. INTRODUCTION

THE HIV/AIDS EPIDEMIC

Current Status of the HIV/AIDS epidemic worldwide

According to the 2011 Report from UNAIDS on the current status of the HIV/AIDS epidemic, the number of annual AIDS-related deaths has steadily decreased from an estimated 2.1 million in 2005 to 1.8 million in 2009. Worldwide at the end of 2010 there were approximately 34 million people living with HIV (PLWHA), with 15-16 million of them eligible for HIV treatment in low and middle-income countries, an increase of 17% since 2001. This increase partly reflects the increased availability of Highly Active Antiretroviral Treatment (HAART), care and support interventions and programs, which have significantly reduced AIDS-related deaths (1, 2).

To date, Sub-Saharan Africa is still the area with the greatest HIV burden – 23 million PLWHA. The epidemics in sub-Saharan Africa vary considerably, with an estimated 1.9 million people infected in 2010 and one third (34%) of all PLWHA globally in 2009 residing in only 10 countries of southern Africa (3, 4). In 2010 there were approximately 4.8 million PLWHA in Asia. In the same year in South and South-East Asia there were an estimated 270,000 PLWHA. Eastern Europe and Central Asia have shown an increase of 250% from approximately 410,000 in 2001 to 1.5 million PLWHA in 2010 and an estimated 160,000 people infected with HIV in 2010 (4, 5).

Overall, the highest prevalence in Eastern Europe and Central Asia is in the Russian Federation and Ukraine, which together account for almost 90% of newly reported HIV diagnoses in 2010. At 1.1%, the adult HIV prevalence in Ukraine is higher than in any other country in Europe and Central Asia. In the Middle East and North Africa the number of people newly infected with HIV has risen from 43,000 in 2001 to 59,000 in 2010. In 2009 there were approximately 2.3 million PLWHA in North America and Western and Central Europe. (4, 6).

In the Caribbean although the number of PLWHA is relatively small with 200,000 people in 2010, the adult prevalence is 1.0%. The lowest prevalence in the region is found in Cuba with

0.1% in 2009, which contrasts with the high prevalence in adults in the Bahamas, with 3.1%. In central and South America there were 100,000 new infections in 2010. The number of PLWHA in the region is growing partly due to the availability of antiretroviral therapy, with approximately 1.5 million PLWHA in 2010 compared to 1.3 million in 2001 (4).

Current State of the Epidemic in Brazil

Approximately one-third of all PLWHA in Central and South America live in Brazil, where early and ongoing HIV prevention and treatment efforts have contained the epidemic. The adult HIV prevalence in Brazil has remained under 1% with most of the HIV epidemics in this region concentrated in and around networks of men who have sex with men (MSM), drug users (DU) and female sex workers (FSW) (4, 7).

Brazil has an average number of 35,000 new AIDS cases per year. Since 1980 until June of 2011 there were 608,230 identified AIDS cases. In 2006, approximately 630,000 (15-49 years) people were estimated to be living with HIV/AIDS in Brazil, with a 0.6% prevalence in the adult population. The incidence rate in 2008 was 18.2 per 100,000 habitants (8-10). Prevalence estimates have remained stable over the past few years while incidence rates have declined since 2002 (11). The male:female ratio declined consistently from 1986 to 2010 (from 15.1:1 to 1.7:1), and has remained stable since then. Mortality rates started to decline in the early 1990s as a result of better management and the introduction HAART, in 1996. From 1980 to 2008 there were 217,091 deaths reported due to AIDS (8, 9, 12). Currently in Brazil there are approximately 250,000 HIV+ patients taking anti-retroviral therapy (9).

HAART (Highly Active Anti-retroviral Treatment)

The history of HAART

The history of HIV/AIDS treatment development in the 1980's was marked by the presence of activists groups who initially pressured American and European governments to increase further research of azidothymidine (AZT), the first drug to effectively stop the effects of HIV in the human organism, which initial high doses were more detrimental than beneficial for patients. Later, pressure was focused on the next drugs to be developed after AZT, such as didanosine (ddl) or zalcitabine (ddC), to increase their availability and access (13).

In 1996 during the International Conference on AIDS in Vancouver, British Columbia, Canada, it was reported that new drugs given in combination could substantially reduce HIV viral load (14-17), AIDS-related hospital admissions and death rates (18-20). HAART comprises of a combination of nucleoside analogue reverse transcriptase inhibitors and at least one protease inhibitor and/or one non-nucleoside analogue reverse transcriptase inhibitor (21, 22). Initially regimen complexities, adverse effects, and toxicity (23, 24) and costs (12) of HAART were some of the challenges to be faced. During the past decade HAART regimens have become markedly simpler, better tolerated, less toxic, and more effective (25-27).

HAART has significantly reduced the frequency of many secondary events caused by HIV infection, such as oral lesions (28-30), mainly as a cause of a reduction in viral burden and improvement in cellular immunity (22, 31). Life expectancy, treatment efficacy, physical health and overall quality of life (32, 33) have greatly improved for PLWHA over time (34). HAART also influenced a reduction in mortality among PLWHA, in countries where HIV-treatment has been made widely available (35).

The high costs and patent disputes allowed only a small group of the population to access such medications, in particular to those of developed countries or with vast economic resources to pay for such costs. At the end of the 1990's the increasing pressure from civil society towards larger treatment access, lower drug prices and against human rights violations influenced an intensified the fight for treatment access among developing countries around the world (36).

Brazil was one of the first developing countries to offer universal and free integral health services to PLWHA. This right was reaffirmed in a specific law issued in November of 1993 (37). In the process of creating and implementing this policy, Brazil faced several challenges particularly because of the health needs and limited resources at a time that was marked by a political process of re-democratization, after a military dictatorship that lasted 20 years (38). As a result of the society's involvement and participation as well as government efforts, nowadays in Brazil all those diagnosed with HIV/AIDS can have access to top-of-the-line antiretroviral medications (39, 40).

To ensure the affordability of a new generation anti-HIV drug, in 2007 Brazilian government has decided to break patents of Merck's efavirenz and decided to source the drug from low-cost destinations like India. In May, 2012, Brazilian president Dilma Rousseff reissued this patent-breaking.

Adherence to HAART treatment

As previously mentioned, initially HAART regimes and dose concentrations were more detrimental than beneficial to patients' health, due to side effects and development of multi-drug resistance. As a consequence of research and drug development, combined therapy are nowadays much more tolerable and simple to take. One such example is the single pill, called the ADONE pill (ADherence to ONE pill), which aims to improve adherence and simplify the treatment (41).

Adherence to HAART plays a critical role in the effectiveness of HIV treatment, and its availability has obviously changed the natural history of HIV infection by reducing AIDS-related mortality and the prevalence of opportunistic infections among PLWHA (42). In spite of all the advances, some factors that may affect adherence may include: pill burden (depending on the regimen) (43); dosing frequency (44); dietary instructions accompanying medication (44); patient's lifestyle, convenience and ability to incorporate treatment regimen into a daily routine (45, 46); and patient-provider relationships (42). In spite of these factors, it seems that the most important challenges faced in regard to treatment adherence are related to the experiences that PLWHA go through in order to cope and live with HIV/AIDS. Experiences with stigma and discrimination may affect PLWHA's mental health well-being and hence their ability to adhere to treatment and quality of life experienced.

A prospective study with 445 patients, in France, analyzed the relationships between short-term adherence to HAART and HIV-infected patients' characteristics before initiation of treatment and the factors related to patients' subjective experience with HAART. The study found that at the fourth-month follow-up visit, 26.7% participants self-reported non-adherence behavior. Non-adherence was also related to high levels of depression, symptoms associated with treatment side effects, perception of individual state of health, beliefs towards effectiveness and toxicity of HAART, increases in alcohol and tobacco consumption (47).

It is believed that adjustment of the drug schedule to the patient's specific lifestyle, and management of side effects are strategies that can optimize adherence and patient's willingness to remain on HAART (42, 48). Also it has been observed that patients who are more engaged with their health care provider report greater adherence to medication regimen (49-51).

How HAART may affect behavior

According to some authors, changes in beliefs about HIV/AIDS due to HAART availability may promote unsafe sex practices (52). The fact that HAART reduces HIV viral load, sometimes to undetectable levels, may potentially lead to the perception that the virus can no longer be transmitted (52). This assumption might promote beliefs that HIV is no longer a serious and deadly disease because people are living longer, considering HIV/AIDS as a chronic disease (53).

Several studies have found that secondary effects of HAART might influence risk behaviors among PLWHA (54-56), as the sole perception of these HAART-related side-effects can induce psychological ailments (57).

A study conducted in 2002 by Spire et al. among PLWHA in France, found HAART adherence to be related to patient's poor experiences with the treatment (47). A cross-sectional study of HIV symptoms and medication side effects, conducted with 165 people in Boston, Massachusetts, Fresno, California, and Victoria, Texas found that the quality of life was significantly related to adherence and that non-adherence was related to symptomatic HIV disease (such as lipodystrophy) and side-effects of medications (58).

LIFE WITH HIV/AIDS

Conceptions and beliefs about HIV/AIDS

Treatment availability has changed the quality of life of PLWHA, changing the natural history of HIV/AIDS disease as well as the attitudes and beliefs about severity and risk of transmission of HIV/AIDS.

According to Scandlyn, living with a chronic disease requires a redefinition of the self of the illness and one's life (59). Early in the HIV/AIDS epidemic, being diagnosed with HIV was similar to receiving a death sentence. The lack of knowledge and information about the disease

and the lack of efficient treatments initially gave rise to a conception about HIV/AIDS as a dangerous and deadly disease.

As public health campaigns at the time aimed to reduce transmission of the virus, by promoting safer sexual behaviors, they in turn created fear and stigmatization of those living with HIV/AIDS. Unlike other less stigmatized diseases, like diabetes or hypertension, HIV is less likely to be disclosed, probably because of fear of the associated stigma, discrimination, and isolation. The experienced stigma and discrimination is even more intense among already stigmatized groups, such as sex workers and drug users.

For years, experts, researchers and people living with HIV have identified stigma and discrimination as major drivers of the HIV epidemic. In 1987, Jonathan Mann, then director of the World Health Organization's Global Programme on AIDS, forecasted three components to the HIV epidemic: the first would be HIV, the second AIDS, and the third would be stigma, discrimination, and denial. He predicted that stigma, discrimination, and denial would be as central as the illness itself (60). Thirty years later, stigma and discrimination continue to be major problems, even in an era where treatment for HIV is more and more accessible, and prevention of HIV is not only more and more possible, but is critical.

HIV/AIDS Stigma and discrimination

According to Goffman each society defines how a healthy person should appear, act, feel and think. The attribute(s) that causes a person to stray from the norm is a *stigma* given that this attribute violates the expected behavior or appearance. Those who are *stigmatized* are conscious of the society's view of what is normal and know they fail to match the model of normality. Stigma may prevent the individual from fully participating in society. Goffman mentions that a coping strategy may be withdrawal by having a limited participation in society or creation of a social movement to fight the negative stereotypes attached to a given stigma (61).

In many countries and communities, the stigma associated with HIV and the resulting discrimination can be as devastating as the illness itself: abandonment by spouse and/or family, social ostracism, job and property loss, school expulsion, denial of medical services, lack of care and support, and violence. These consequences, or fear of them, mean that people are less likely

to seek testing services, disclose their HIV status to others, adopt HIV preventive behavior, or access treatment, care and support (43, 62, 63).

The fear of discrimination can prevent PLWHA from disclosing their status impeding them from seeking support from family and friends. Stigma undermines the person's ability to cope with the disease and impacts behavior changes as it limits the possibility of using certain safer sexual practices, such as not wanting to use condoms because it may be seen as a marker of promiscuity and/or HIV (62).

Discrimination based on factors such as race, gender and sexual orientation increase the burden of living with HIV/AIDS. Stigma and discrimination may also manifest in complex and varied ways and operate at multiple levels throughout society: within individuals, families, communities, institutions and media, and in government policies and practices (64, 65).

Stigma and discrimination are daily realities for people living with HIV and for people belonging to groups particularly vulnerable to HIV infection. Such groups include sex workers, men who have sex with men, people who inject drugs, and prisoners (66). Members of these groups are already stigmatized and are more likely to face more discrimination than others when diagnosed with HIV, including being refused services (67, 68). The layered stigma that people in these groups experience further heightens the challenge of meeting their needs with respect to HIV (69-71). Members of these groups often avoid, or delay, seeking needed services for fear of being identified as having HIV/AIDS, humiliated, and/or treated differently by health workers, and, in some instances, prosecuted and imprisoned (72, 73). Among some groups of the population, women tend to experience greater stigma and discrimination and violence than men and usually have fewer resources to cope with it (74-77).

Disclosure of HIV serostatus is key for outcomes ranging from condom use to care-seeking. The inability to disclose HIV status can increase stress and social isolation as well as depression (78). Freedom to disclose HIV/AIDS status can be instrumental in providing adequate testing and health services and social support networks to diminish the effects of stress from perceived discrimination and other social problems (79-83).

Other sources of stigma and discrimination related to HIV/AIDS include the physical changes the disease produces on the body, either as a consequence of opportunistic and communicable diseases or due to the side-effects of anti-retroviral medication. Lipodystrophy, a common side-effect of HAART medication, refers to body changes and metabolic abnormalities commonly observed in HIV-infected patients. These body shape changes can be a source of distress to patients and may compromise treatment adherence while also causing aesthetic stigma (84). The stigma, discrimination and exclusion that PLWHA still experience has a great burden on their quality of life and can certainly affect the course of the disease.

Changes in beliefs about HIV/AIDS

In 1989 at the International AIDS Conference in Montreal, Quebec, Samuel Broder, declared that AIDS was a chronic illness that should follow the treatment model for cancer (85). According to Scandlyn (2000) this public statement marked the shift in the social definition of AIDS from an acute to a chronic illness (59). HAART availability facilitated this change in conception of HIV/AIDS, from an acute to a chronic disease, by mediating the decline of morbidity and mortality associated to HIV and diminishing the burden of the disease (53).

One of the areas where these changes in beliefs have been observed is the increase in fertility desires among men and women living with HIV/AIDS. As life expectancy is extended, and anti-retroviral treatments reduces vertical transmission rates, more PLWHA are now deciding to have children (85-87). In a study conducted in Switzerland which evaluated fertility intentions and condom use among 114 PLWHA, found that a significant proportion of participants expressed a wish for parenthood (86). In Ontario, Canada, a cross-sectional study conducted with 490 HIV-positive women of reproductive age (18-52) found that 69% desired to give birth and 57% intended to give birth in the future (85). Another study by McClellan et al. with 200 HIV-positive women in Zimbabwe found a correlation between higher perceived quality of life and fertility desires (88).

Other behaviors that might be related to these changes in perceptions of risk and severity of HIV/AIDS include safe-sex fatigue (89-91), barebacking (92, 93) and serosorting (92-94). Safe-sex fatigue among PLWHA has been related to the inability to maintain sexual safety

(89-91) over time - mainly in long term relationships. A study conducted in Amsterdam among 1,568 MSM found that safe sex fatigue was a mediator of rectal gonorrhoea (91). Barebacking is the practice of intentional unprotected sex (92, 93). This term was initially used among the gay community to refer to unprotected anal sex but currently is also used to refer to any sexual act of penetration without protection among the general population (94). This practice seems to be common among the HIV-negative population.

Serosorting is the practice of choosing a sex partner with the same HIV serostatus to have unprotected sex with (95-97). A study conducted among MSM between 1997 and 2002 in San Francisco found an increase HIV prevalence in the sample population from 19.6% to 26.8% as well as an increase in sexual risk. Average number of partners and number of unprotected sex acts increased when the partner had a different or unknown HIV status, with the largest increase observed among men who reported engaging in serosorting (89).

Mental Health and HIV/AIDS

Because there can be no health without mental health, as it is an essential part of overall health, (98) it is highly important to address the mental health stressors and issues faced by PLWHA, and those aspects that might influence their overall quality of life (99, 100). As previously mentioned the process of being diagnosed, coping and living with HIV/AIDS may greatly impact the mental health and well-being of PLWHA. According to the New York State Department of Health, depression is the most commonly observed psychiatric disorder among PLWHA (<http://www.hivguidelines.org>). The prevalence rate of depression in HIV-positive clinic populations ranges from 22 to 32% which is about 3 to 5 times higher than that in the general population (101, 102).

Depression has been associated with a threefold increase in non-adherence to treatment in general (103) and tends to be associated with lower adherence to HAART (104-108), with missing appointments (105), failure to initiate treatment (109-112), to access care for HIV (113) and treatment failure (114). Depression and substance abuse can accelerate the progression of HIV and people with pre-existing psychiatric disorders can be at a greater risk of becoming HIV infected (115, 116).

Other mental illnesses that are commonly experienced include anxiety, and post-traumatic stress disorder (99, 100). HIV infection can also result in psychiatric disorders through several mechanisms affecting the central nervous system, causing neuropsychiatric complications, mania, cognitive disorder and frank dementia (100).

OPTIMISM

General view of optimism

When we think of optimism we immediately assume it to be a positive concept. In fact, optimism usually refers to a positive trait of the personality (117, 118). Optimism represents the extent to which people hold generalized favorable expectations for their future and has been associated with taking steps to protect one's health (119), with self-esteem, low depression, low negative emotions, and life satisfaction (119-121) it also reflects the human capacity to anticipate a positive future (122).

Optimism research in the areas of psychology and mental health view optimism from two points of view, the first as an instrumental personality trait in the production of positive outcomes and the second as unrealistic optimism which yields negative outcomes and is therefore seen as a disadvantageous trait. People who are confident about eventually reaching an outcome will persevere even in the face of great adversity. On the other hand, having an optimistic view has also been associated with an underestimation of risks as optimists might be more likely to take part in high-risk activities (119, 123-125).

Optimistic traits are believed to affect the quality of life experienced, as it influences how the individual approaches and reacts to critical life situations (121) with studies suggesting it as a significant predictor of physical well-being (126).

HIV Treatment Optimism Construct

HIV/AIDS has impacted the life of millions in a dramatic way, but in spite of great advances and improvements in treatment and interventions there are still gaps in efforts to prevent further spread of the virus and to secure a quality of life for PLWHA. In developing countries, access to HAART is improving (35, 127) and as HIV treatment becomes more widely

available in developing countries, the relationship between treatment and sexual risk behavior in these countries becomes more important (128, 129).

HIV Treatment Optimism takes a different approach to the general view of optimism. Optimism in this case is a construct that represents the interplay of several factors such as availability of an effective treatment, changes in quality of life, increased life expectancy and ability to lead a more normal life. HIV Treatment Optimism also represents the potential negative consequences of having an optimistic view of HIV/AIDS as a less severe and less dangerous disease. Therefore, it is feared that this new found HAART-related optimism may affect the sexual behavior and adherence to treatment of PLWHA.

In this research project the construct of optimism will be used as a category that represents these shifts in attitudes and beliefs about the risk related with HIV/AIDS due to the availability of HAART. Hence, people who are 'optimistic' about HAART treatment may be more prone to adopt higher risk behaviors such as unprotected sex, multiple sex partners, or even stop taking their medication.

It is important to mention that optimism for the purposes of this research is not used as a category that determines normality in participants' behavior. Instead this construct will be used to observe if these beliefs and attitudes are related to having high-risk behaviors.

HIV Treatment Optimism Research

As the provision of HAART plays an important role in the overall strategy to control the advance of the HIV/AIDS epidemic, in Brazil and many other areas of the world, research has focused on the development of an HIV/AIDS treatment that can be sustained over extended periods of time through behavioral interventions and long-term follow up of PLWHA who are taking HAART.

According to researchers there are two potential changes in beliefs about HIV/AIDS that may have occurred since the appearance of HAART, specifically beliefs about susceptibility to (42) and severity of HIV infection (43). People may believe that HAART reduces the likelihood that an HIV-infected sex partner will transmit HIV, and may also believe that, HAART decreases the severity of HIV infection (52, 130).

Therefore, it is believed that PLWHA under HAART who are optimistic will be more prone to take part in high-risk activities such as unprotected sex and non-adherence to treatment (130-132). Treatment optimism may be directly related to HIV acquisition behaviors, hence understanding risk behaviors associated with treatment optimism is of interest in planning prevention programs for PLWHA.

These optimistic beliefs based on the availability of HAART have been associated with high risk sex behaviors in several studies (32, 34, 130, 133-138) and these associations have reported to be significant in a recent meta-analysis (2009) of thirty US studies (129).

Van de Ven et al. studied HIV optimism among gay men in several industrialized countries using a standard scale to survey them (2000) in Australia, England and France. Although nearly 6,000 gay men were surveyed, no consistent relationship between mean optimism score and HIV status was found as very few were optimistic considering the new drug therapies for HIV infection.

Another research group lead by Elford conducted a study to determine if HIV optimism could account for increases in high-risk sexual behavior among 2,938 gay men in London gyms surveyed annually, between 1998 and 2001, found no difference between those who were optimistic and those who were not at risk of increase in high-risk sexual behavior. Study findings suggest that HIV optimism was unlikely to explain increases in high-risk sexual behavior in that group of the population (139).

Kalichman et al. surveyed 498 MSM in Atlanta in 1997, 448 in 2005, and 503 in 2007 (140). Results found an increased belief over time that HIV treatment reduced transmission risk because of undetectable viral load. This belief was associated with concomitant increases in unprotected anal sex.

In 2002 a study conducted to examine treatment optimism as a variable for increased behavioral risk among 329 HIV-infected and 218 uninfected MSM, reported that HAART-related attitudes were a significant determinant for high-risk sexual activity. The authors suggest that treatment optimism was emerging as a widespread phenomenon among MSM in the United

States and so called for a tailoring of HIV prevention efforts based on this increasing attitude (137).

A simulation study by Boily et al. (2004) evaluated the various effects of anti retroviral treatment on risk behaviors and sexually transmitted infections (STI) to assess the impact of the wide-scale use of anti-retroviral therapy on risky behavior, STI, and HIV/AIDS. The study found that increasing risk behaviors only had an impact on HIV if treatment coverage was not efficient (141). A cross-sectional study (2005), conducted in New York City and San Francisco among HIV+ men under HAART (n=456), examined the specific belief that unprotected sex among two HIV-infected men could result in infection with drug resistant virus, found that very few men had reported having unprotected sex and out of those who did they were less likely to believe that unprotected sex carried a risk for reinfection with drug resistant virus (142).

Even though HAART treatment optimism has been studied since 1997 (132-134), mainly among MSM, opinions about the relationship between HIV treatment optimism and high-risk sexual behaviors among other population groups are yet to be established (143). Kaida et al. (2009) conducted in Uganda a study that, evaluated HIV treatment optimism construct among HIV+ women under HAART and the relationship between fertility intentions and risk behaviors (144). The study found that women who were sexually active and had reported unprotected sex had a significantly higher HAART optimism score than women that used protection during intercourse and those who were not sexually active. Other studies have found similar associations between treatment optimism and high risk sexual behaviors (133-135, 145).

To date in Brazil few studies have directly examined the association between HAART-related optimistic and risky behavior among PLWHA. In São Paulo a cross-sectional survey conducted by Da silva et al. studied the association between optimistic perceptions about AIDS and unprotected sex among a sample of 161 MSM, from June to August of 2003, to see if such associations (as found internationally) exist among young MSM in Brazil. This study found those who had an optimistic perception were 1.8 times more likely to engage in unprotected anal sex compared to those who were less optimistic (146). In Rio de Janeiro, Kerrigan et al. performed a qualitative study in 2001 with 30 PLWHA, which explored the influence of HIV

treatment optimism on sexual behavior of PLWHA receiving HAART at public health clinics. The study was conducted with heterosexual men and women and MSM living with HIV under HAART treatment. Results found that the availability of HAART was conceptualized as a rationale for unsafe sex among a minority of study participants and that this was more common among men than among women (143).

As seen in the studies mentioned above the effect of HAART treatment on behavior varies from group to group and from country to country. Other cultural and social factors that must be taken into consideration include the fact that the idea/concept of optimism in each setting may vary drastically. Given the differences in access to care, education and resources, the different cultural norms regarding HIV, and the fact that Brazil is one of the first countries in Latin America that has offered free access to HAART my thesis will shed light on the relationship between HAART treatment and high risk behaviors among PLWHA (heterosexual and MSM) in Rio de Janeiro. Part of the analysis of my thesis will also include determining the reliability of the Portuguese version of the optimism scale developed by Van de Ven et al. (32).

HIV Treatment Optimism Scale

The HIV treatment optimism scale was analyzed for the first time among representative heterogenous sample of Brazilians (heterosexuals, bisexuals and homosexuals). Evaluation of the scale will provide the opportunity to study the efficacy and relevance of using this instrument among other culturally diverse groups.

II. OBJECTIVES AND SPECIFIC AIMS

To assess HAART-related optimism among PLWHA receiving treatment and care in public health facilities from Rio de Janeiro.

Specific Aims

Aim 1. To perform an Exploratory Factor Analysis (EFA) of the Portuguese version of the HAART-Optimism scale developed by Van de Ven et al. (30);

Aim 2. To assess associated factors between knowledge, beliefs and practices related to HIV and HAART and the adoption of unsafe sexual behavior among PLWHA, treatment adherence and prevalence of syphilis and chlamydia.

III. METHODS

As previously mentioned, this study was based on the research performed by a larger study funded by the Ford Foundation and lead by Dr. Ignacio F. Bastos and Dr. Monica Malta as principal investigators. The project proposal titled “*Psychosocial Factors Associated with the Sexual Health and Well-Being of People Living with HIV/AIDS Receiving Treatment From Public Health Clinics in Rio de Janeiro, Brazil*”, ethics committee approval, informed consent forms, survey and questionnaires for this larger project can all be found in the appendix. The methodology used for this present study followed a similar design to the larger study.

Research Design

This analysis was based on a cross-sectional survey conducted from 2008-2009, funded by the Ford Foundation, to determine the relative importance of psychosocial (optimism) and structural factors (availability of HAART treatment) believed to be hypothetically associated with protected sex and adherence to HAART among PLWHA engaged in public clinical care in Rio de Janeiro.

Study setting: Participants were recruited from 6 key facilities from a larger pool of 29 public health centers, managed by the Rio de Janeiro Health Secretariat. The health centers were municipal primary care units. Antiretroviral drugs were monthly dispensed in the pharmacies at the same units where patients received their medical care.

Recruitment and selection criteria for the survey component: participants were referred to the study by their health providers. Members of the study team included trained health workers, e.g. a nurse or social worker who were in charge of recruiting participants. Patients were eligible for the proposed study if they met the following criteria:

- 1) Between 18-50 years old;
- 2) Had a confirmed HIV-positive status;

- 3) Were receiving HIV treatment and care from any of the 29 outpatient units managed by the Rio de Janeiro Health Secretariat (i.e. NOT including those visiting the health care unit with the sole purpose to get free ART and under follow-up with a private doctor);
- 4) Were willing to participate in interviews, to sign the informed consent form, and to provide urine samples for STI testing.

Study population: A sample of 900 PLWHA were interviewed, ages 18 to 50, currently under treatment at that time, in 6 public health facilities in Rio de Janeiro, Brazil. From the sample 242 of the participants were currently not under HAART (subsample B) and 658 PLWHA were under HAART (subsample A), representative sample of the clientele of the 6 health centers.

Table 1 is a summary of the data from a set of 6 (six) health units concentrating approximately 47.4% of the overall clientele. Sets were defined using a combination of units with high and middle caseloads and a diversity of geographic locations, scattered all over the municipality of Rio de Janeiro. The geographic criteria considered both the physical geography of Rio (e.g. North, South or West zones), as well as its divisions in Administrative macro-units called APs (e.g. AP1, AP3.1).

Table 1: Selected information on the 6 health units chosen for the study, with their respective caseloads, geographic and administrative location. Rio de Janeiro, July 2007

Unit	Caseload	Zone	APs
H. São Francisco de Assis	823	Center (Downtown)	AP 1
PAM XIII de Maio	1,524	Center (Downtown)	AP 1
PAM de Copacabana	978	South	AP 2.1
PAM da Penha	656	North	AP 3.2
PAM de C. Grande	645	West	AP 5.2
PAM de Santa Cruz	1,108	West	AP 5.3

Data collection procedures and measures

Survey

The questionnaire was administered face-to-face by trained interviewers in private rooms, taking about 50 minutes to complete. This instrument obtained data on: (a) sexual activity and relational factors, such as numbers and types of sexual partners, condom use per partner type, knowledge, as well as alcohol and drug use; (b) attitudes and beliefs related to HIV and HAART; (c) HAART experiences (adherence, side-effects, therapeutic regimen switch); (d) psychosocial and structural factors surrounding HIV treatment, including HIV-acceptance, stigma, socio-economic stability (e.g. monthly income, distance from home to clinic), and overall quality of life; and (e) available social support, both related to the public unit where participants received HIV treatment and related to social network outside the clinic (NGOs, friends, family).

Measuring HAART Treatment Optimism: was assessed using an 11 item scale based on a scale developed by Van de Ven et al. (31). was used. The original scale developed by Van de Ven et al had a few items culturally adapted others excluded because it was not relevant to the setting, and this new scale that was implemented was analyzed using EFA. Risk behavior (i.e. condom use in the last 6 months) was used to determine association of HAART optimism with high risk behaviors. Below are the 11 statements used in our study.

Scale of Attitudes and Beliefs about HIV Treatment Scale. (response options: Totally agree [4 points], Somewhat agree [3 points], Somewhat disagree [2 points], and Totally disagree [1 point]).

1. *“HIV treatments take the worry out of sex.”*
2. *“If every HIV positive person took the treatments, the AIDS epidemic would be over.”*
3. *“An HIV person on treatments is unlikely to transmit HIV.”*
4. *“Treatments for HIV/AIDS make safe sex less important than it was.”*
5. *“People with undetectable viral load do not need to worry so much about infecting others with HIV.”*
6. *“Until there is a complete cure for HIV/AIDS, prevention is still the best practice.”*
7. *“HIV/AIDS is a less serious threat because of the treatments.”*
8. *“It's never safe to have sex without a condom, regardless of viral load.”*
9. *“It is just as important to practice safe sex now, than it was before the treatments.”*

10. *“I am less worried about HIV now that treatment has improved.”*

11. *“Treatments have made me more willing to take risks with my partner”*

Measuring High risk behavior-Behavioral Outcomes: Information on behavioral risks for STI acquisition was collected, mainly related to unsafe sexual behaviors. Sexual practices included number and types of partners (gender and relationships), type(s) of sexual acts (oral, vaginal and anal intercourse), condom use, “survival” sex (sex for money, drugs, shelter, food and protection), and STI prevalence.

Data Management

Interview responses were recorded on Teleform® scanable data forms and were reviewed by the interviewer for completeness and consistency before departure of the participant. When needed, clarifications were elicited. Following the interview, data forms were reviewed by the Field coordinator and returned to the interviewer to rectify missing or incomplete data. The coordinator scanned the forms for computer entry. Scanned data was reviewed by the Project coordinator. The Teleform® program flags missing data and other problems with the data forms. The Field coordinator rectified data forms. Scanned data was reviewed and prepared for analysis by the Principal investigator.

Data Analysis

Preliminary analysis. For the variables of interest, a consistency analysis was performed (analyses included checks for missing values, data range, and outliers).

To reach specific aim # 1: to evaluate the Portuguese version of the HAART-Optimism scale developed by Van de Ven et al. (32), the following analytical strategy was used:

1) Summary analysis with tabulation of frequency response of each of the 11 items of the scale was first performed. Responses for each of the items were recoded in to agree or disagree to observe the pattern of responses for each of the items in the scale (see annex 6 for original response options for the scale).

2) Exploratory Factor Analysis (EFA)

Before EFA, Kendall's bivariate analysis was performed on the data to determine if the data were suitable for EFA. Afterwards, EFA was used to identify a small number of factors that would better represent the relationships among sets of interrelated variables.

EFA was used to find optimal ways of combining variables or factors into a small number of subsets, to be able to explain the phenomena of interest with fewer than the original number of variables.

First, a correlation matrix was created which shows the variances of all the items. The eigenvalues represent the variance explained for each of the 11 items considered in the EFA, and were expressed as percents of the total variance.

The Kaiser-Meyer-Olkin (KMO) and Bartlett's test of sphericity are used to determine sample adequacy and suitability of the variables for EFA. KMO measures whether the distribution of the values is adequate and provides an index between 0 and 1 of the proportion of variance among the variables that might be common variance. Values equal or greater to 0.5 are acceptable (147). Bartlett's test of sphericity tests the multivariate normality of the set of distributions and if the correlation matrix is an identity matrix given that EFA is performed based on the assumption that the variables are correlated. The null hypothesis for this test was that the original correlation matrix is an identity matrix. Significant results ($p < .05$) reject the null hypothesis and indicate a high probability that the variables are correlated (148).

Another method used to determine if the variables are suitable for the analysis was the anti-image matrix. The diagonal of the matrix shows the correlations of the variables. Values equal or greater to 0.5 are acceptable and any variables that show lower values can be removed from the analysis.

The selection of factors was made using first the Kaiser criterion which states that only factors with eigenvalues greater than one are retained (147). Since the Kaiser criterion is a less conservative method for retaining factors, the scree-plot was also used to determine how many factors to maintain. The scree-plot is a graphical method used to plot the eigenvalues. The scree refers to the deposits at the base of a landslide and interpretation of the scree-plot is done by ignoring this scree and selecting the factors on the top portion of the graph, to the left of that point. Factors with eigenvalues higher than 1.0 are rotated for further interpretation (149).

After identifying the factors to retain, the squared multiple correlation of an item was used with all other items to estimate the communalities for each variable in the factor. Communalities show the proportion of variance that the factors contribute to explaining a particular variable. The values range from 0 to 1. Item communalities in the ranges of 0.40 to 0.70 were considered acceptable.

Afterwards, Cronbach's alpha was used to demonstrate the internal reliability of each of the identified factors. Since this is an exploratory study and although a scale is generally considered reliable if the Cronbach's alpha coefficient is equal to or greater than 0.70 (150), a coefficient of 0.60 was used and considered acceptable - cutoff also used in a similar study, the development of the WHOMEN's scale for HIV positive women in Uganda (144).

After testing internal consistency, factors were rotated to to optimize the factor structure and facilitate factors interpretation. We used the Promax rotation suitable for large data sets, based on the assumption that the variables (each scale statement) were correlated. The goal of rotation is to simplify and clarify the data structure and facilitate interpretation of the results, offering a simple structure with high factor loadings on one factor and low factor loading on all others. Rotation was performed to identify the data points closer to the rotated axes, therefore allowing the interpretation of each factor. The pattern matrix which shows information on factor/

item loadings and the factor correlation matrix revealed any existing correlation between the factors. Item loadings above 0.30 and no or few item cross-loadings were chosen.

Factor loadings between ± 1 indicate the strength of the relationship between a particular variable and a particular factor. The minimum loading of an item is usually 0.32, which equates to approximately 10% overlapping variance with the other items in that factor. Items were dropped if there are several strong loaders (0.50 or better) on each factor and if there were several cross-loaders. Finally the obtained factors are interpreted.

After performing EFA, the 11-item scale and the 7-item scale scores were calculated to determine participants' optimism. First, both variables were dichotomized at the median since it is the midpoint of the scale. Item response values ranged from 1 to 4 with totally disagree having a value of 1 and completely agree a value of 4. Higher scores indicated higher optimism. For the 11-item scale the median was 26; study range values were 14-44 (possible range 11-44). The 7-item scale was dichotomized at 13, study range values were 7-28 (possible range 7-28). Subsequently, the obtained scores for the 7-item scale were compared with high risk sexual behaviors and syphilis and chlamydia prevalence and treatment adherence (aim #2).

To reach specific aim # 2: to assess associated factors between knowledge, beliefs and practices related to HIV and HAART and the adoption of unsafe sexual behavior among PLWHA, treatment adherence and prevalence of syphilis and chlamydia the following strategy was used:

Bivariate analysis: Comparison of frequency data was performed with Cross-tabulations. Chi Square test of independence was used to determine whether the observed values for the cells deviated significantly from the corresponding expected values to evaluate the effect of independent variables on major outcomes: HAART optimism (measured by the 7 item scale obtained from EFA) unsafe sex behavior, prevalence of syphilis and gonorrhea and treatment adherence.

IV. RESULTS

Demographics

Table 2 shows sociodemographic information for all participants. The population of study was composed of 658 people in Treatment (TG) and 242 participants that were not under treatment (NTG). The time under HAART treatment ranged from 30 days - 23 years, with an average number of years under HAART of 6.6 and a median of 6.4 years. The participants average time living with HIV since diagnosis was 7.5 years, with a minimum of 3 years, median of 7 years and a maximum 26.1 years. Six hundred of the participants were male (66.6%), 293 were female (32.5%) and 7 transgenders (0.7%). The majority of participants identified as heterosexual with 58.8%. Both male and female participants who identified as lesbian or gay were included in the category of homosexual, with 32.5% of participants. Almost sixty percent of participants had, at least, high school education and around a half identified themselves as mulatto. Overall, 38.1% of the participants were single without a fix partner.

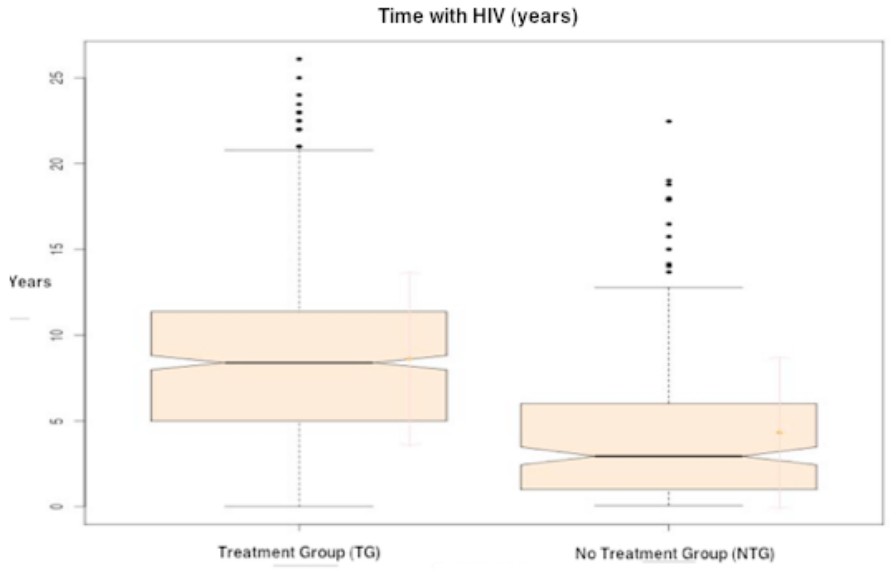
Table 2. Participants socio-demographic characteristics (n=900). Rio de Janeiro, Brazil, 2007-8

Variable	N	%
<i>Median age [IQR]</i>	41 [18-67]	
Sex		
Male	600	66.7
Female	293	32.6
Transgender	7	0.8
Sexual Orientation		
Heterosexual	528	58.8
Bisexual	73	8.1
Homosexual	292	32.5
Transexual	5	0.6
Race/Ethnicity		
White	236	26.2
Black	164	18.2
Yellow	20	2.2
Mulatto	477	53
Indigenous	3	0.3
Education		
Primary school or less	390	43.4
Secondary school or higher	509	56.6
Marital status		
Currently married/living with partner	337	37.4
Divorced/separated	70	7.8
Widowed	48	5.3
Single with fix partner	102	11.3
Single w/o fix partner	343	38.1
Average Household income (last 6 months)	R\$868.35 [0-10,000]	
Work		
Currently working	385	42.8
Not currently working	515	57.2
Current HAART use		
Yes (TG)	658	
No (NTG)	242	

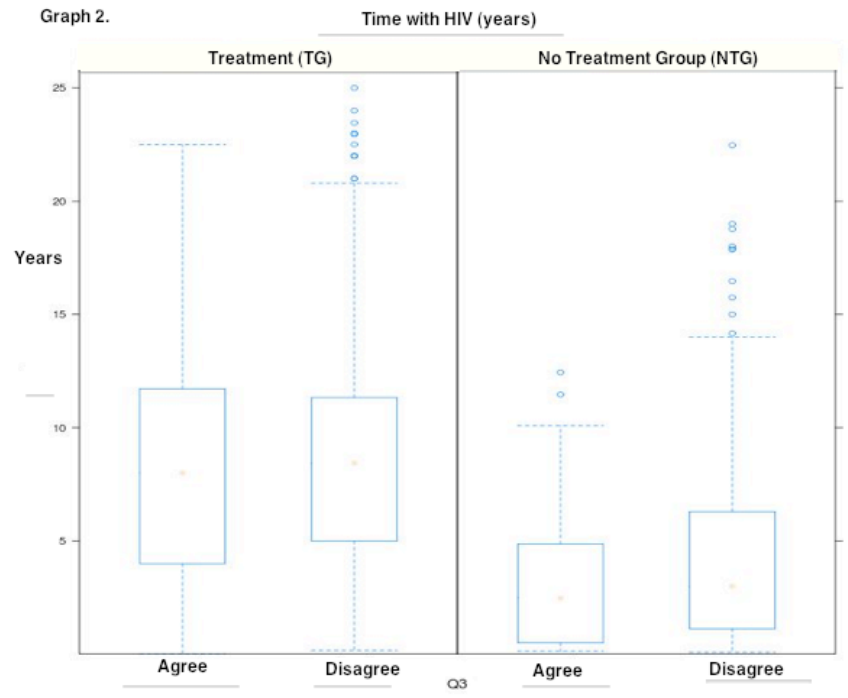
Time with HIV/AIDS by TG and NTG was also showing, as expected, that in average the time with HIV was higher for the TG (Graph 1). Another variable that was analyzed was “Time with HIV/AIDS” and response patterns to the scale’s items (by agree or disagree) which showed that although in average time with HIV/AIDS was higher for the TG, no relationship was observed between agreeing or disagreeing with each HAART-optimism statement, neither was observed a relationship between those statements and being in treatment or not. Graph 2 shows Time with HIV for TG and NTG and observed responses for Items 3 (Q3) of the scale. This

analysis was analog for all the items.

Graph 1. Time with HIV/AIDS (years)



Graph 2. Time with HIV/AIDS (years)



Treatment group.

For the TG there were 658 participants taking HAART. The average number of months since HIV diagnosis was 9.6 years with a median of 8.4 and a maximum of 26.1 years. The minimum time under HAART treatment was 30 days, with an average of 6.4 years and a maximum of 23 years.

There were 449 males and 202 females and 7 transgender in this group. Overall education level showed that 509 (56.6%) had secondary school or higher education. A majority of participants in this group identified as Other with 363 (55.2%). Two hundred and fifty (38%) participants were single; with a majority of them identifying as heterosexual 284 (43.2%).

No-Treatment Group.

The NTG was composed of 242 participants. The average number of months since diagnosis was 45.03 months with a median of 24.50 and a maximum of 269 months. Average number of years with HIV and without treatment was 4.31, with a median of 2.95 and a maximum of 22.46 years.

There were 151 (62.4%) males and 91 (37.6%) females and 0 transgenders. Overall, 142 (58.7%) of participants in this group had secondary school or higher; with 137 (56.6%) of participants identifying as Other in regard to race; 94 (38.8%) of these participants were married; and 144 (59.5%) identified as heterosexual.

AIM 1 RESULTS

Individual items responses were performed for the TG (n=658) and for the NTG (n=242) separately. No significant difference were observed between the results obtained for each group.

Item responses by the TG.

For item 1, related to a decrease worry in regards to sex because of treatment, 86.2% of the sample disagreed. Item 4, a statement related to treatment optimism, 86% of the participants disagreed. Item 5 which states that people with a low viral load do not need to worry about infection, 94.7% disagreed. A similar pattern was observed for items 6, 8, 9, 3 and 11 with 98%, 90.4%, 97.1%, 82.4% and 73.6%, respectively. Overall a majority of participants disagreed with the optimistic statements (3 & 11) and a majority agreed with realistic or pessimistic statements related to safe sex and prevention and risk of severity and transmission (items 6, 8, & 9).

For the TG there were 3 items (2, 7 & 10) that showed response rates that were not as defined as for the other items. For item 2, which states that AIDS could have ended if everyone who was HIV+ took anti-retroviral treatment, a majority of participants agreed with this treatment optimism statement (62.8%). For item 7, stating that HIV/AIDS is a less serious threat because of the treatment, 50.6% disagreed. Similarly for item 10, stating that there is less worry with HIV because treatment is more developed or perfected, 52.6% agreed.

Overall, results rates showed that a majority of participants were not optimistic in the light of HAART therapy and on the contrary were realistic or pessimistic.

Item responses by the NTG.

In the analysis of individual item responses of the NTG, item responses rates were similar as to the ones observed in the TG: item 3 (treatment optimism statement) 82.4% disagreed; item 4 (treatment optimism statement) related to availability of treatment, 86% disagreed; item 5 (treatment optimism) 94.7% disagreed; item 6 (pessimistic or realistic statement) 98% agreed; item 8 (pessimistic or realistic) 90.4% agreed; item 9 (pessimistic or realistic) with 97.1% agreeing on the relevance of safe sex before and after availability of treatment; and item 11,

(optimistic statement) with 73.6% disagreeing that treatment makes the person feel less worried about running risks with sexual partner.

The following three items also showed pattern responses similar to the ones obtained for the TG. For item 2, 62.8% agreed with the statement that if everyone who had HIV+ took antiretroviral it would be possible to end with AIDS. For item 7, 49.4% of the NTG were optimistic about HIV/AIDS being a less serious threat because of HIV/AIDS treatment. For item 10 (treatment optimism statement) 52.4% agreed to having less worry with HIV because the treatment is more perfected.

Overall all participants were mostly realistic in the light of HIV/AIDS treatment with 3 key statements (items 2, 7 & 10) representing optimistic views and attitudes among the sample. After individual analysis of each item it was proceeded with EFA.

Exploratory Factor Analysis (EFA)

First, kendall's bivariate analysis was performed on the data set with 40 correlations out of 55 (72.72%) being significant at the level of 0.01. Subsequently the same analysis was performed on the TG with 37 out of 55 (67.27%) correlations being significant at the level 0.01 and 18 out of 55 (32.72%) significant correlations for the NTG.

Initially, EFA was performed on the complete dataset (n=873), which included the TG and NTG, on the 11 Treatment Optimism items. Correlations were low but significant ($p < 0.0001$) for all items except for items 6, 8 and 9. The KMO test (0.79) and Bartlett's Test of Sphericity (1090.236) were performed with values in the acceptable range. The anti-image matrix diagonal showed normality with all values higher than 0.5. The lowest values observed were for items 6, 8 and 9 with 0.592, 0.688 and 0.631, respectively. The communalities were all above 0.3 confirming that the items shared some common variance with other items, except for items 5, 8 with values of 0.283 and 0.203, respectively. A three factor solution was obtained explaining a total variance of 46.185%. The eigen values were 2.748, 1.273 and 1.060. The leveling off of the eigen values on the scree plot occurred after the third factor.

Table 3 shows information of the items that loaded on each of the obtained Factors for the TG/NTG. Factor 1: Treatment Optimism; Factor 2: Severity of HIV/AIDS; Factor 3: not definable.

Table 3. Item factor loadings (n=873, TG & NTG)

	Factor 1	Factor 2	Factor 3
Items	1, 2, 3, 4 & 11	7 &10	5, 6, 8 & 9

Due to the inability to define the third factor and because it was of interest to see if there were any differences between the TG and the NTG, separate EFAs were performed for TG and for the NTG.

EFA of Treatment Group

For the TG (n=642) low but significant correlations ($p < 0.0001$) were also observed for all items except for items 6, 8 and 9. The KMO test reported a value of 0.781, and was above the commonly recommended value of 0.6. Bartlett's Test of Sphericity was equal to 825.386 (df 55) at the significance level of 0.0001, both tests in the acceptable value range. The anti-image matrix diagonal showed normality with all values higher than 0.5 and ranging from 0.715 to 0.965. The item communalities were all above 0.3 confirming that the items shared some common variance with other items, except for items 8 with an item communality of 0.229. A three factor solution which explained a total variance of 46.152% was obtained. The leveling off of the eigen values on the scree plot occurred after the third factor, obtaining the following values 2.484, 1.915 and 1.484. Item loadings on each of the three factors were the same as those observed on the EFA performed for all participants (Table 4).

Table 4. Item factor loadings for the TG (n=642)

	Factor 1	Factor 2	Factor 3
Items	1, 2, 3, 4 & 11	7 &10	5, 6, 8 & 9

EFA for No Treatment Group

For the NTG (n=231) low but significant ($p < 0.0001$) correlations were observed for all items except for items 5 to 10. The KMO test showed a value of 0.735 and Bartlett's Test of Sphericity was equal to 316.694 (df 55) at a significance level of 0.0001, both being in the acceptable value range. The anti-image matrix diagonal showed normality with all values higher than 0.5. Item communalities were all above 0.3, obtaining a four factor solution (Table 5), which explained a total variance of 55.760%. The leveling off of the eigen values on the scree plot occurred after the fourth factor with the following values 2.712, 1.302, 1.107 and 1.012.

Table 5. Item factor loadings for the No-Treatment Group (n=231)

	Factor 1	Factor 2	Factor 3	Factor 4
Items	1, 2, 3, 4 & 11	7 & 10	2 & 8	5, 6 & 9

Table 6 shows information on EFA for the three different analysis (T/NT, TG and NTG) data set which obtained 3 factors. Items 1 through 5 and 11 loading on factor 1; items 7 & 10 loading in factor 2; and factor 3 with loadings of items 6, 8 & 9. The TG EFA showed 3 factors: items 1 through 5 and 11 loading on factor 1; items 7 & 8 loading on factor 2; and items 5, 6, 8 & 9 loading on factor 3. The NTG there were 5 factors. Item 5 having cross-loadings of 0.356 and 0.615 in factors 1 and 5, respectively. Among the three groups item 5 showed the most variability, loading on different factors on different analysis. The observed discrepancies in the number of factors obtained in each of the EFAs and the variability in the item-loading for item 5 hindered the determination and naming each of the factors. The number of factors obtained and the difficulty in defining factors 3 and 4 suggested further analysis should be performed by removing those items that were not contributing to a simple solution.

Table 6. Pattern Matrix with Factor Loadings for each EFA.

Item	All participants (T/NT)			Treatment (T) Group			No-Treatment (NT) group				
	Factor 1	Factor 2	Factor 3	Factor 1	Factor 2	Factor 3	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
1	0.568	0.293	-0.085	0.540	0.112	-0.104	0.682	0.175	-0.113	-0.303	-0.025
2	0.332	0.269	-0.003	0.353	0.258	0.097	0.091	0.155	0.678	0.206	-0.139
3	0.698	-0.040	-0.037	0.679	-0.007	-0.050	0.623	-0.149	0.234	0.058	-0.008
4	0.775	-0.117	0.018	0.790	-0.130	2.26x10 ⁻⁵	0.741	-0.133	-0.034	0.168	0.016
5	0.386	0.106	-0.221	0.350	0.113	-0.344	0.356	-0.051	0.054	0.615	0.084
6	0.111	-0.059	0.731	0.074	0.016	0.743	-0.007	0.032	-0.041	0.038	0.974
7	0.067	0.767	0.012	0.050	0.783	0.004	0.018	0.747	0.158	0.063	0.198
8	-0.020	-0.074	0.478	0.053	-0.124	0.461	0.150	-0.020	-0.810	0.303	-0.061
9	-0.112	0.170	0.616	-0.044	0.135	0.619	-0.279	0.166	-0.183	0.693	-0.021
10	-0.054	0.844	0.000	-0.068	0.855	-0.008	0.002	0.809	-0.002	0.072	-0.134
11	0.660	0.031	0.190	0.675	-0.024	0.199	0.737	0.199	-0.142	-0.085	-0.010

Based on the previous results, further a priori analysis were performed as it was necessary to remove those items that did not contribute to a simple factor structure and that failed to meet the minimum criteria of having a primary factor loading of 0.4 or above, and no cross-loading of 0.3 or above.

A total of four items were removed: item 5: “People with undetectable viral load do not need to worry so much about infecting others with HIV.”; item 6: “Until there is a complete cure for HIV/AIDS, prevention is still the best practice.”; item 8: “It's never safe to have sex without a condom, regardless of viral load.”; item 9: “It is just as important to practice safe sex now, than it was before the treatments”. These items had cross-loadings above 0.3, loaded on different factors and when removed from the analysis allowed for a greater interpretability of the factors obtained as well as for more correlation between the remaining items.

Once EFA was deemed suitable, the procedure was performed on the remaining 7 items. Item correlations were observed for each group. For the first analysis performed on the whole sample, TG/NTG, the correlation matrix showed a low but highly significant correlation

($p < 0.0001$) for all the items. For TG/NTG, KMO was 0.777 and Bartlett's test of sphericity was 884.849 df (21) $p < 0.0001$. The anti-image matrix diagonal showed normality with all the values been higher than 0.5 with values ranging from 0.737 to 0.854. Item communalities were all above 0.3 confirming that the items shared some common variance with each other, with values ranging from 0.312 to 0.716. Variables were rotated obtaining a two factors solution which explained a total variance of 51.603%. The leveling off of the eigen values on the scree plot occurred after the second factor, with values of 2.542 and 1.070.

Analysis of the TG showed a KMO equal to 0.782 and Bartlett's Test of Sphericity of 655.326 df (21) $p < 0.0001$. The anti-image matrix diagonal values were all higher than 0.5 ranging from 0.748 to 0.849. Item communalities were all higher than 0.3 with item 2 reporting the lowest value with 0.319 and highest for item 10 with 0.736. Total variance of 51.16% was explained by two factors with eigen values of 2.325 and 1.824.

For the NTG KMO was 0.750 and Bartlett's Test of Sphericity was 254.975 df (21) $p < 0.0001$. The anti-image matrix diagonal values were all higher than 0.5 ranging from 0.674 (item 11) to 0.857 (item10). Item communalities ranged from 0.297, considered acceptable given its proximity to 0.3, to 0.655. Total variance of 53.10% was explained by two factors with eigen values of 2.386 and 1.611.

Table 7 shows factor item loadings for all three EFAs performed. KMO, Bartlett and total variance explained by the two factors are also shown as well as scale reliability for each of the groups.

Table 7. Factor Loadings, KMO and Bartlett, alpha for 7 item-scale

	All Participants (TG/NTG)		Treatment (TG) group		No-Treatment (NTG) group	
	Factor 1	Factor 2	Factor 1	Factor 2	Factor 1	Factor 2
Item 1	0.642	0.011	0.621	0.024	0.666	0.021
Item 2	0.409	0.261	0.438	0.224	0.380	0.301
Item 3	0.703	-0.002	0.678	0.039	0.737	-0.089
Item 4	0.775	-0.075	0.776	-0.080	0.786	-0.086
Item 7	0.039	0.804	0.041	0.807	0.031	0.800
Item 10	-0.061	0.866	-0.054	0.878	-0.080	0.825
Item 11	0.665	-0.007	0.657	-0.054	0.717	0.091
KMO	0.777		0.782		0.750	
Bartlett Test	884.849 df (21) p<0.0001		655.326 df (21) p<0.0001		254.975 df (21) p<0.0001	
Total variance explained	51.603% (2 factors)		51.16% (2 factors)		53.1% (2 factors)	
Scale reliability (alpha)	0.696		0.702		0.678	

Results showed a two factor solution with factor 1 representing HIV treatment optimism and composed of a total of 5 items (1, 2, 3, 4 & 11) and factor 2 related to risk and severity of HIV/AIDS and represented by items 7 and 10. Internal consistency for this seven item scale was examined using Cronbach's alpha. The alpha for the scale on attitudes and beliefs about HIV Treatment (7 items) 0.696 on the analysis performed on all participants (TG/NTG). Internal consistency for the scale on the TG was 0.702 and 0.678 for the NTG. Overall, these analyses indicated that two factors, representing treatment optimism and risk and severity of HIV/AIDS in the studied population, was underlying the HIV attitudes and beliefs scale responses and that these factors had moderate internal consistency.

After performing FA, the original 11 item scale and the obtained 7-item scale were individually summated to observe and compare participants' total optimism scores. Table 8 shows the obtained results. Results of both summated scales for the TG show that 57.4% (11-item) and 56.1% (7-item scale) or participants scored low in the optimism scale. For the NTG 53.3%, in both summated, scales scored in the lower optimism range. Overall participants were

not optimistic in the light of HIV treatment, just as it was observed during the individual items analysis.

Table 8. Optimism score by group and Scale. 11-item ranges: 14-26 Low Optimism and 27-44 High Optimism. 7-item scale ranges: 7-13 Low Optimism, 14-28 High Optimism.

TG	11-item scale	7-item scale
Lower optimism	378 (57.4%)	369 (56.1%)
Higher optimism	264 (40.1%)	286 (43.5%)
Missing	16(2.4%)	3 (0.5%)
Total	658	658
NTG		
Lower optimism	129 (53.3%)	129 (53.3%)
Higher optimism	102 (42.1%)	106 (43.8%)
Missing	11 (4.5%)	7 (2.9%)
Total	242	242

The observed results suggest that the 7-item scale seems more appropriate for this population, with the final scale containing the following statements: HIV treatments take the worry out of sex (statement 1); If every HIV positive person took the treatments, the AIDS epidemic would be over (2); An HIV person on treatments is unlikely to transmit HIV (3); Treatments for HIV/AIDS make safe sex less important than it was (4); HIV/AIDS is a less serious threat because of the treatments (7); I am less worried about HIV now that treatment has improved (10); Treatments have made me more willing to take risks with my partner (11).

AIM 2 RESULTS

Syphilis and Chlamydia vs Optimism score

The 7-item scale was then compared with STD prevalence. Among the TG (n=658) there were a total of 44 cases (6.7%) of syphilis, 24 (54.5%) of these cases scoring Low range of the Optimism ($p=0.811$). For the NTG (n=242) 15 (6.2%) cases of syphilis were observed with 10 (66.6%) of them scoring in the Higher range of the optimism scale ($p=0.083$). A total of 4 cases of chlamydia were observed among the TG, 2 of these scoring in the Low Optimism range ($p=1.0$); and the single case of chlamydia amongst the NTG scoring in the High Optimism range ($p=0.451$). No significant correlation was observed between prevalence of chlamydia and syphilis and Optimism score among the TG or the NTG.

Condom frequency in the last 6 months vs Optimism Score

Analysis of the 7-item scale score and condom frequency use in the last 6 months showed that out of those in the TG who also scored in the Lower Optimism range (n=350): 216 (61.7%) reported always using condoms; 30 (4.8%) reported not using condoms in the last 6 months with 21 (70%) of them scoring in the High Optimism range. This finding showed that those who never used condoms in the last 6 months and were in the TG had significantly higher Optimism scores ($p=0.003$).

Out of a total of 103 (42.2%) participants in the NTG who also obtained a Low Optimism score, 65 (63.1%) reported always using a condom in the last 6 months. A total of 38 participants reported never using condoms in the last 6 months with half of these participants scoring in the Low Optimism Range (50%) No significant differences between Low or High optimism were observed according to frequency of condom use for the NTG ($p=0.487$).

Adherence and Optimism score

Finally, analysis of Optimism score and HAART adherence in the last 4 days was evaluated. Participants in the TG were asked on how many days they took all their antiretroviral doses: 542 (83.4%) took their medications the last four days with 307 (56.6%) scoring in the

Low Optimism range and 235 (43.4%) in the High Optimism range. No statistical significance was observed between Optimism score and adherence in the last 4 days ($p=0.173$).

V. DISCUSSION

Based on the preliminary exploratory analysis the 7-item scale seems to be more adequate for the population that was studied. Items 5 and 8 which included the concept of viral load and items 6 and 9 related to the importance of prevention, before as well as after the advent of HAART, seem to not discriminate the construct of optimism. This was particularly the case for the group that was not in treatment (NTG).

This could be explained in part by a lack of information or access to information among those who were not in treatment, reflecting the knowledge and education of the group that was under treatment or a combination of both factors. Those who were under treatment belonged to a different social-support network and therefore might have had more information about HAART therapy compared to those participants who were not under treatment. This might explain the observed differences in the obtained factor solutions while conducting exploratory factor analysis and the consequent need to remove the above mentioned items.

No association was observed between optimism and adherence to treatment. Overall, the analysis of Optimism score, prevalence of chlamydia and syphilis, unsafe sex and treatment adherence did not show any statistically significant relationship between optimism score and being under HAART or not. The observed results showed that a majority of participants that had safe behaviors scored lower in the optimism scale, while a small minority who did participate in high risk behaviors scored higher on the scale.

The fact that no significant relationship was found between Treatment Optimism and being under HAART treatment could imply that this construct only represents a perceived risk and not a real one. There is also a possibility that Treatment Optimism, in fact, represents a real (positive) optimism that is beneficial to those under treatment and promotes safe behaviors such as not using drugs or alcohol and practicing safe sex. Having a low viral load together with the possibility of living a better quality of life for longer (as a consequence of HAART treatment) might also be a contributing factor to maintaining safe behaviors and having a high optimism.

This study's results show that the association between optimism and risk behavior is not a simple one. It seems that optimism might be more related to factors related to sexual behavior than to adherence or to being under treatment, but to better determine this relationship further research will be necessary.

These results are consistent with other findings (143, 146, 151). Although some studies have found significantly higher optimism among sexually active individuals who had unprotected sexual intercourse compared to those who practiced protected sexual intercourse (144), other researchers have proposed that treatment optimism might be the result of previous high risk sexual behaviors and not necessarily the cause of high risk behaviors (152).

Crepaz et al. found that the prevalence of unprotected sex was not higher among PLWHA under HAART, when compared to those not under HAART or PLWHA with undetectable viral load compared to those with detectable viral load (153). A study conducted by Elford et al. was also not able to explain increases in high-risk sexual behavior among gay men in London (154), while in Glasgow researchers found that optimistic men were more likely to report high-risk behavior than men who were not optimistic (155) a pattern that was also observed among a minority of participants in this study.

As has been suggested by Kerrigan et. al (143), to better understand the consequences of optimism in the light of anti-retroviral treatment it is necessary to understand other underlying factors at the core of these beliefs and attitudes that might contribute to high risk behaviors. With PLWHA living longer and healthier lives, it is increasingly important to recognize the complexity of factors that determine the quality of life they experienced and study how these changes in beliefs, attitudes and behavior are maintained or changed with time to be able to develop interventions for later stages in the life of PLWHA that sustain appropriate changes in their behavior that promote and ensure their quality of life.

If Treatment Optimism only represents a perceived (potential risk) and given that only a minority of participants who were optimistic had high risk behaviors it is possible that HAART treatment might in fact promote a beneficial change in the patient's behavior. This could be

explained in part by an increase access to knowledge and education about HAART therapy and participation in social and support networks.

Based on these findings, should Treatment Optimism be promoted or prevented? Should Treatment Optimism be considered something positive or negative? In order to answer such questions further research will be necessary, but one thing is certain that there will always be optimistic or pessimistic people and that being in one group or the other does not necessarily influence treatment adherence neither safer sex behaviors, as there are many other factors that come in to play when making a decision.

Treatment Optimism does bring important issues to light, such as the role of education, information, social support networks and other resources, as well as the mental health well-being of PLWH and the important role that health providers can play in ensuring that PLWHA have adequate information and ability to take proper steps to care for their health.

VI. CONCLUSION AND RECOMMENDATIONS

As previously mentioned, at the beginning of the epidemic when little was known about HIV/AIDS, aside from the fact that it was an acute disease, people who were diagnosed with HIV/AIDS were faced with a radical change in their view and conception of life. Without a doubt, the consequences of having HIV/AIDS in the early 1980's were much more serious and severe than today thanks to the availability of antiretroviral treatment and greater knowledge about HIV/AIDS.

Like with any other chronic disease, those diagnosed with HIV/AIDS are expected to make drastic and permanent behavioral changes in their life in order to survive. The contrast created between the old and new lifestyle living with HIV/AIDS might affect the mental health well-being and physical health of the individual.

As each culture has different beliefs and conceptions of health and disease that shape our attitudes and behaviors, the reality that we experience and how we cope with health, it is necessary to ensure that PLWHA have access to a multidisciplinary approach that targets not only medical aspects, but also mental health and social issues underlying the experience of being living with HIV/AIDS. This approach should also include culturally sensitive educational strategies that will allow PLWHA to make informed and educated decisions that will promote and ensure their quality of life.

Other issues that must also be addressed include the role of stigma, discrimination and exclusion and access to information and education. Interventions and educational programs that address such issues, promote awareness, diversity and inclusion as well as interventions and campaigns that ensure the rights' of PLWHA including the right to disclose or not HIV/AIDS status should also be part of these combined efforts.

Without a doubt the changes in conception of HIV/AIDS, from an acute to a chronic disease have triggered a decrease perception of the severity and risk of transmission of HIV/AIDS among a small group of the population. As access to HIV treatment is scaled up in other

lower and middle income countries, programs and interventions that deal with social support, stigma, discrimination and exclusion and that promote mental health well-being and behavioral therapy are essential to ensure the well-being of PLWHA.

PLWHA require institutional and social support to have their needs met not only at the individual, but at the socio-cultural level. A holistic approach to adherence, that monitors and takes into consideration the impact of the experience with HAART on patients' daily lives, will be useful to improve care and ensure the uptake of beneficial behaviors and the quality of life for those living with HIV/AIDS.

VII. STUDY LIMITATIONS

As in most observational studies, this study is limited by key selection biases. All participants were referred by health care workers and no PLWHA out of clinical settings were recruited – therefore a highly selected population was recruited. Findings cannot be extrapolated to any other population of PLWHA, such as those who are not under clinical treatment or those who are infected, but are unaware of their serostatus and/or out-of-reach of clinical care in a given period and context.

Another shortcoming is the validity and reliability of self-reports. Research member in charge of data collection had extensive experience in conducting surveys and cohort studies among vulnerable and disenfranchised populations. In order to minimize possible biases interviewers were thoroughly trained and supervised. The assessment was exclusively based on validated questionnaires. Notwithstanding, comparison between self-reported adherence and adherence measured with more objective measures (e.g. pill counts, MEMS caps and pharmacy reports) have shown that PLWHA may overestimate their adherence and underestimate their risk behaviors (156). To minimize those biases, HAART adherence using pharmacy refill information was evaluated and compared to sexual risky behavior reports with STI result tests.

Finally, the study population may not be typical of other areas of Brazil, a country with deep social and regional heterogeneities. Much probably in the second largest metropolitan area of the country, better quality care is available vis-à-vis remote municipalities and the countryside. Despite the above mentioned limitations, the evaluation of HAART treatment optimism and the possibility of high risk behaviors among PLWHA in Brazil will represent a major achievement in the field.

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Appendix

**I. Research Proposal as submitted to the
Fiocruz Institutional Review Board**

Psychosocial Factors Associated with the Sexual Health and Well-Being of People Living with HIV/AIDS Receiving Treatment From Public Health Clinics in Rio de Janeiro, Brazil

L. BACKGROUND AND SIGNIFICANCE

HIV/AIDS is now the largest pandemic ever faced by humankind, with over 40 million people living with HIV/AIDS (PLWHA), worldwide. Over 95% of new infections since 2003 have been reported in the developing world, making the prevention, management and care of PLWHA in those settings a key priority (UNAIDS, 2006). While access to highly active antiretroviral therapy (HAART) has been of critical importance to the health and well being of PLWHA, its introduction into clinical care has not occurred without the creation of a series of public health challenges. Perhaps the two most commonly discussed in recent years and critical to curbing the continued transmission of HIV/STI are protective sexual behavior and adherence to HAART among PLWHA.

HIV/AIDS treatment roll-out has become a top priority in many developing countries. International donors such as the Global Fund and the United States President's Emergency Plan for AIDS Relief (PEPFAR) have assisted in creating access to HIV treatment. HIV-related treatment has also now been included as one of the goals of the millennium defined by the United Nations and its agencies, such as the World Health Organization (WHO) and the UNAIDS. However, Brazil is still one of the few developing countries to have developed and sustained its own system of universal access to anti-retroviral therapies (ARV) for PLWHA.

Despite the undeniable difficulties associated with launching and maintaining a reliable system of anti-retroviral procurement, distribution and monitoring of long-term and complex therapies, there is in parallel the pressing need to integrate ARV distribution in the context of the other health care activities and to move beyond the sole biomedical approach. While Brazil has been internationally recognized for its model actions in the realm of creating access to HIV medications, significantly less attention has been paid and resources provided to the comprehensive care needs of PLWHA in the Brazilian setting.

As recently reported by Sweat and colleagues (2007), the provision of HIV-related psychosocial support in developing countries pales in comparison with the growing needs of a persons living with the virus in impoverished and underserved communities. As HIV treatment roll-outs in different developing countries, there is an urgent need to formulate and test innovative management and preventive strategies aiming to minimize loss to follow-up, improve adherence to ARV treatment and help individuals and their partners to live healthier and safer lives, including the adoption and/or maintenance of protective sexual behaviors.

In an effort to begin to respond to this lack of information and the programmatic needs of PLWHA in lower and middle income settings, we propose to conduct a formative study to assess key behavioral aspects of PLWHA and the social context surrounding the

provision of ongoing HIV treatment and care to PLWHA in Rio de Janeiro, Brazil. The project will be carried out in a network of public health facilities with a high caseload and facing the usual difficulties of facilities operating out of the “protected” environment of sophisticated research units and universities. In this sense, those units document Brazil’s program of universal access, operating under “real-life conditions”.

In specific we will assess patterns of sexual behavior and adherence to HAART and their psychosocial and socio-economic correlates among PLWHA receiving treatment at Municipal public health units. This 18 months study will inform a subsequent project aiming to develop, implement and test an intervention aiming to improve psycho-social support initiatives currently available for PLWHA within those public facilities, aiming to improve both safer sexual behaviors and adherence to HAART.

La Protective Sexual Behavior among PLWHA

Since the beginning of the AIDS epidemic, 25 years ago, the development of innovative and effective HIV/STI (sexually transmitted infections) prevention approaches has evolved as an international priority. However, only recently have the specialized prevention concerns and needs of PLWHA begun to be addressed (Crepaz & Marks, 2002; Brewer et al., 2002; Schlitz & Sandfort, 2000). Researchers have hypothesized that the lack of focus on HIV/STI-related protective behavior among PLWHA may have been the result of two issues: 1) initially, diagnosis with HIV appeared to imply a limited survival time and 2) many feared that focusing prevention efforts on PLWHA could facilitate and/or further increase their potential stigmatization (Schiltz & Sandfort, 2000). However with the introduction of HAART, more and more PLWHA are living longer and healthier lives and in turn need to be assessed by prevention efforts that are both culturally appropriate and seek to reduce the potential stigma associated with living with HIV/AIDS. Such initiatives are a matter of prime public health importance in order to both reduce the vulnerability of PLWHA to sexually transmitted infections and/or reinfection with HIV, and to reduce the possibility of HIV/STI transmission to non-infected individuals (Brewer et al., 2002; Schlitz & Sandfort, 2000).

The majority of PLWHA report that they are sexually active after learning that they are infected with HIV. However, while following notification of their HIV-positive serostatus many PLWHA adopt safer sexual practices, an important percent report engaging in unprotected sexual behavior after receiving their diagnosis (Crepaz et al., 2002). A recent meta-analysis of eleven studies on the sexual risk behavior of PLWHA from the United States found the rates of unprotected anal or vaginal intercourse among PLWHA aware of their serostatus to be between 13-40 percent, depending on population group and partner type (Crepaz et al., 2004). Additionally, a study which examined the sexual behavior of PLWHA as compared to HIV negative controls, matched per socio-demographic similarities, found that while consistent condom use was higher among those living with HIV, PLWHA in this same study had higher rates of STI than the HIV negative controls. Study authors offer the hypotheses that either HIV-positive individuals over-reported

condom use and/or were engaged in higher-risk sexual networks, where the prevalence of STI was simply higher, than their HIV-negative counterparts (Brewer et al., 2002), indicating the increased vulnerability of PLWHA.

Research into the factors influencing safe sexual behavior among PLWHA has revealed that several similar factors influence the sexual behavior of both HIV-positive and negative individuals. Those include individual cognitive factors such as knowledge, attitudes and beliefs related to HIV/AIDS as well as relational factors such as perceived intimacy and power dynamics with regular sexual partners (Schlitz & Sandford, 2000). However, in addition to factors that might equally influence all individuals, regardless of HIV serostatus, there appears to be a specific set of critical psychosocial issues that PLWHA confront in their efforts to protective themselves and others. Some of these issues include: internalized anger, anxiety, depression and/or substance use related to HIV diagnosis, difficulty in disclosing of HIV status, perceived stigma and discrimination and associated fears of rejection and/or abandonment (Schlitz & Sandford, 2000; Marks & Crepaz, 2001; Kerrigan et al., 2006).

With regard to protective behaviors among PLWHA in Brazil, Guimarães et al. (2001) conducted a study with female partners of HIV-positive men in Rio de Janeiro, in order to identify predictors of safer sexual behavior. The authors found that nearly 40% of the 328 couples participating in the study practiced unsafe sex at baseline, despite the fact that in 39% of these couples, the woman was seronegative at the time of study recruitment. The study also found that compared to women who had known of their male partners HIV positive status for over twelve months, women who only found out in the last one to two months were eleven times more likely to practice safe sex. As time from disclosure increased, women were continually less likely to report safe sex behaviors. Similarly, in a study of women living with HIV in São Paulo, Paiva et al (2002) found that sixty-three percent of whom reported always using condoms with that partner since becoming aware of their diagnosis. However, more half of participants with a regular partner reported that their regular partner was HIV-negative or of unknown HIV status. Additionally, a recent qualitative study conducted among low-income PLWHA from Rio de Janeiro identified that unsafe sexual behavior appeared largely to be a product of psychosocial factors related to PLWHA's desire for social validation and linked to feelings of shame and denial, including but not limited to HIV. Participants expressed a considerable amount of fear and/or anxiety regarding behaviors such as disclosure of HIV status and condom use as a result of the conflict between implementing these behaviors and maintaining their ongoing romantic relationships (Kerrigan et al., 2006).

1.b Adherence to HAART

The introduction of antiretrovirals has been credited with extending the life span of PLWHA (Hogg et al., 1997). However, treatment efficacy relies on access to treatment and excellent adherence, which has proven to be a serious challenge to those receiving HAART (Mannheimer et al., 2005; Altice et al., 2001). The regimens are often complicated and can

include varying dosing schedules, dietary restrictions, and may lead to adverse effects (Ferguson et al., 2002). Consistently high levels of adherence are necessary for reliable viral suppression (Paterson et al., 2000; Bangsberg et al., 2000) and prevention of resistance (Bangsberg et al., 2003), disease progression (Bangsberg et al., 2001), and death among individuals living with HIV (Wood et al., 2003). At a population level, the lack of adherence to HAART may also lead to increased rates of infectivity among PLWHA and potentially increased rates HIV transmission – including increasing of HIV resistant strains transmission (de Ronde et al., 2001). Additionally, non-adherence may lead to escalating costs of care, of particular importance in resource-constrained settings, including the possible need for complex salvage therapies, intensive and sophisticated diagnostic procedures, and increased frequency of hospitalizations (Valenti, 2001).

Rates of non-adherence to antiretroviral therapy in adult populations have been shown to range from 33%–88%, depending on how adherence is defined and evaluated (Mills et al., 2006). Recent studies conducted in Brazil have also identified a range of adherence patterns. For example, according to a study by Bonolo et al. (2005), 36.9% of patients reported less than 95 percent adherence. Similarly, a study conducted by Pinheiro and colleagues (2002) found that 56.9% of patients were at least 95% adherent to their ARV regimens. However, a more comprehensive study conducted with 27 outpatient clinics and 1,141 patients in Sao Paulo, identified a slight higher rate of adherence to HAART (69%), although using a lower adherence threshold – adherence \geq 80% (Nemes, 2000; Laurence, 2001).

Based on the existing literature, researchers have begun to try and classify the types of factors that are closely associated with adherence to HAART. Ickovics & Meade, for example, have classified these factors into five key areas: patient variables, treatment regimen, disease characteristics, patient-provider relationship and clinical setting (Ickovics & Meade, 2002). While distinct and inconsistent socio-demographic characteristics have been found to be associated with adherence across the published studies a more consistent set of psychosocial factors has emerged as being key predictors of adherence across a variety of studies (Ickovics & Meade, 2002, Gordillo et al., 1999). These factors include: depression, social support, socio-economic stability, knowledge and beliefs related to adherence and medication resistance, and self-efficacy about taking the medications (Ickovics & Meade, 2002). Additionally, the complexity of the drug regimens and adverse side effects has been associated with lower levels of adherence (Chesney et al., 2000). Several aspects of the clinical setting have also been shown to be associated with adherence including communication and relationship dynamics with physicians and other service providers (Malta et al., 2005), as well as issues of clinic access e.g. transportation and childcare (van Servellen et al., 2002; Altice et al., 2001). An additional factor of concern has been the role of alcohol and drug use in lower rates of adherence to HAART (Lucas, 2002).

While a limited amount of information is currently available in the peer-reviewed literature on the psychosocial and structural factors influencing adherence to HAART in Brazil, the available research does indicate the importance of several related variables. For example, the main reasons reported by patients for non-adherence in a study conducted by

Brigido and colleagues in Sao Paulo included: forgetfulness, alcohol use, misunderstanding of the prescription, and intolerance of drugs (Brigido et al., 2001). Pinheiro et al. found that patients' perceived ability to take HAART in a variety of psychosocial and material circumstances was significantly correlated to adherence in Southern Brazil, including contexts such as: depression, discrimination, unemployment, and changes in regimen and provider (Pinheiro et al., 2002). The large multi-state study of adherence in Brazil conducted by Nemes et al. (2004) found that patient literacy levels, complexity of treatment regimens, and number of missed appointments were important predictors of adherence to HAART. Additionally, the number of patients attending the clinic and the number of providers allocated to attend them was a significant factor, indicating that underfunded and understaffed government clinics may also be affecting the rates of HAART-related adherence in Brazil.

II. SPECIFIC AIMS

When examining the factors that may be associated with both protective sexual behavior and adherence to HAART among PLWHA, based on the research available to date, several consistent and coherent themes begin to emerge. Factors of overlapping importance include: knowledge, attitudes and beliefs regarding HAART and its efficacy, acceptance of one's HIV status and similarly issues of internalized stigma or shame, relationship dynamics with sexual partners, social support from family and friends, communication and trust with clinical providers and socio-economic stability. In turn, the specific aims of this study to be conducted among PLWHA engaged in public clinical care in Rio de Janeiro, Brazil, are:

1. **To assess the statistical associations between psychosocial and structural factors and the adoption of protective sexual behavior and adherence to HAART among PLWHA.** We propose that the following factors will be significantly related to both behavioral outcomes: (a) HIV/HAART-related knowledge, attitudes and beliefs, (b) HIV-related acceptance and stigma; (c) social support within and outside of the clinic setting, and (d) socio-economic stability.
2. **To assess sexual behaviors and relational factors which may be associated with STIs among PLWHA.** We will first assess sexual behaviors including number and concurrency of sexual partnerships as well as condom use per partner type. We will then explore the relationship between length of sexual partnerships, disclosure of HIV status, partner HIV status and partner concurrency in relationship to STIs. Additionally, here we seek to establish a baseline STI prevalence to help guide intervention priorities and power calculations for a future intervention trial.
3. **To qualitatively explore psychosocial and structural issues which may influence both protective sexual behavior and adherence to HAART among PLWHA in order to inform intervention development.** We will examine: a) the ways in

which PLWHA's acceptance of their HIV diagnosis evolves over time; b) to document the psychosocial experiences and material resources which may influence shifts in HIV acceptance; c) the perceived links between HIV acceptance and HIV-related health behaviors.

Key socio-demographics to be considered in the analysis will include: age, education, gender, sexual orientation, and alcohol and drug use.

III. RESEARCH DESIGN AND METHODS

Using a cross-sectional design, we propose to use an integrated set of quantitative and qualitative data collection methods. The primary purpose of the survey component of our study is to determine the relative importance of psychosocial and structural factors which we hypothesize to be associated with protected sex and adherence to HAART, based on both the literature and our initial work with PLWHA in Brazil. We will also collect biological specimens from survey participants related to STIs and access routine CD4 and viral load tests conducted within participating clinics.

The assessment of the prevalence of STIs in this population has an exploratory character since these data are virtually absent from the Brazilian literature on HIV/AIDS. STIs may permit also to validate the behavioral measures in this particular setting for use in future intervention studies.

The qualitative component will help to explore the impact of HIV-serostatus and HAART use on PLWHA sexual behavior, and participants' perceptions about HIV/AIDS & HAART, and might also be used to clarify/explore survey findings. Findings from the study will inform a targeted intervention, to be further implemented and evaluated in a subsequent project.

Study setting: Participants will be recruited from 6 key facilities (concentrating around 60% of over 13,000 patients living with HIV/AIDS under follow-up), from a larger pool of 29 public health centers, managed by the Rio de Janeiro Health Secretariat.

The health centers are municipal primary care units and act as the reference site for primary care in their respective catchments areas. A local medical director and leadership team manages each clinic, but disease-specific treatment protocols are determined by the Health Department based on guidelines issued by the Brazilian Ministry of Health. In general, the health centers have five to ten private examination rooms, in addition to a reception area, waiting area, administrative office, storage room, specimen collection room, and pharmacy. Antiretroviral drugs are dispensed in the pharmacies at the same units where patients receive their medical care.

A team of health care workers involved in HIV/AIDS program exist in each clinic. The number and structure of the teams varies among the units and may include just one or two physicians, one nurse and one pharmacist in small units, to five or more physicians, nurses, auxiliary nurses, educators, outreach workers, pharmacists and other health professionals in larger ones.

Study population: The proposed study will interview a sample of 900 PLWHA, aged 18 to 50, currently under treatment in 6 public health facilities in Rio de Janeiro, Brazil, as follows.

The Municipal network of health facilities currently follow-up 13,855 patients, over 10,000 of them under HAART and over 3,000 under regular follow-up, but not eligible yet to receive anti-retrovirals, according to the guidelines regularly updated by the Brazilian Ministry of Health (BMoH).

Most of these patients concentrate in relatively large units, with a high caseload. We present in Table 1 a summary of the data from a set of 6 (six) health units concentrating approximately 47.4% of the overall clientele. We defined such set using a combination of units with high and middle caseloads and a diversity of geographic locations, scattered all over the municipality of Rio de Janeiro. The geographic criteria consider both the physical geography of Rio (e.g. North, South or West zones), as well as its divisions in Administrative macro-units called APs (e.g. AP1, AP3.1).

Table 1: Selected information on the 6 health units chosen for the study, with their respective caseloads, geographic and administrative location. Rio de Janeiro, July 2007

Unit	Caseload	Zone	APs
H. São Francisco de Assis	823	Center (Downtown)	AP 1
PAM XIII de Maio	1,524	Center (Downtown)	AP 1
PAM de Copacabana	978	South	AP 2.1
PAM da Penha	656	North	AP 3.2
PAM de C. Grande	645	West	AP 5.2
PAM de Santa Cruz	1,108	West	AP 5.3

We intend to select a sample composed by 900 PLWHA, 300 of them currently not under HAART (subsample B) and 600 PLWHA under HAART (subsample A), representative of the clientele of these 6 health centers. For this sake, we will use a two-stage sampling strategy, compensating for the heterogeneous nature of the different clinics, with different caseloads, i.e. considering both the size of each one of the health centers and the individual clients attending each one of them.

Recruitment and selection criteria for the survey component:

Participants will be referred to the study by their health providers. One specific health worker, e.g. a nurse or social worker will be trained to perform this task on a regular basis and will be a member of the study team. Participants will be eligible for the proposed study if they meet the following criteria:

- 1) Between 18-50 years old;
- 2) Have a confirmed HIV-positive status;

- 3) Are receiving HIV treatment and care from any of the 29 outpatient units managed by the Rio de Janeiro Health Secretariat (i.e. NOT including those visiting the health care unit with the sole purpose to get free ART and under follow-up with a private doctor);
- 4) Are currently receiving HAART once eligible (subsample A) or under regular follow-up, whether not eligible to receive HAART under the BMoH Guidelines (subsample B)
- 5) Are willing to participate in interviews, to sign and informed consent form, and to provide urine samples for STI testing.

Recruitment and selection criteria for the qualitative component:

One focus group per unit will be carried out in the three largest units before the surveys in order to help to define the contents of specific questions of the survey.

After completing the survey, a subsample of the larger survey of PLWHA will be recruited, and will include 50 PLWHA (35 from survey subsample A and 15 from survey subsample B).

Data collection procedures and measures

Survey: The questionnaire will be administered face-to-face by trained interviewers in private rooms, taking about 50 minutes to be completed. This instrument will seek to obtain data on: (a) sexual activity and relational factors, such as numbers and types of sexual partners, condom use per partner type, knowledge, as well as alcohol and drug use; (b) attitudes and beliefs related to HIV and HAART; (c) HAART experiences (adherence, side-effects, therapeutic regimen switch); (d) psychosocial and structural factors surrounding HIV treatment, including HIV-acceptance, stigma, socio-economic stability (e.g. monthly income, distance from home to clinic), and overall quality of life; and (e) available social support, both related to the public unit where s/he receives HIV treatment and related to social network outside the clinic (NGOs, friends, family).

A brief standard questionnaire on the daily activities will be applied as well, in order to compare the activities of people living with AIDS with the general population without HIV/AIDS, as documented by a large dataset representative of the population of the municipality of Rio de Janeiro, currently housed at FIOCRUZ scientific computing department (PROCC).

The following already developed and validated instruments will be included in our questionnaire:

Knowledge, attitudes, and beliefs related to HIV and HAART: (A) HAART-related knowledge will be assessed utilizing an assessment tool developed in Brazil by Ceccato et al (2004). The tool assesses patient-provider/clinic agreement regarding the specifics of the individual patient's HAART regimen including: name of medication, dosing, frequency of administration, dietary indications or other precautions and potential adverse reactions. (B) Treatment Optimism will be assessed utilizing an aggregate measure developed by Van de Ven et al. (2000). The overall scale had internal consistency reliability or Cronbach's Alpha of .79. After reviewing the results of their factor analysis of the forty original items, we have selected 10-items which loaded highest on the treatment optimism factor which include questions such as: 'New HIV treatments take the worry out of sex'; 'An HIV positive person on new treatments is unlikely to transmit HIV'; 'It's never safe to have sex without a condom, regardless of viral load'; 'Until there is a complete cure for HIV/AIDS, prevention is still the best practice'. We will use two measures developed by The Measurement Group related to condoms and HAART from the literature including a measure of (C) Condom-related expectations and beliefs (6 items): 'Using condoms will keep me healthy'; 'I could become re-infected with HIV if I don't use a condom'; 'Using condoms helps keeps my partner(s) safe'; 'Condoms block limit my ability to enjoy sex. (D) HAART-related expectations and beliefs (6 items): 'HIV medications will help me get better'; 'HIV medications will keep me alive longer'; 'If I don't take my medications everyday, my body may become resistant to the drugs'. Additionally, we will allow for open-ended responses to follow-up questions regarding why condoms were not used or why adherence to did not occur among those for which these inquiries are relevant. (D) ARV adherence: This scale was developed by the AIDS Clinical Trial Group's (ACTG) and asks patients how many medication doses they missed during the previous day, 2 days, 3 days, and 4 days (Chesney et al., 2000). The scale also queries the patient to find out if they disregard special dosing instructions by, for example, taking medicine on an empty stomach, being late with a dose, and missing weekend doses.

Sense of self and associated expressions of relationship to self: (A) Sense of self specifically related to HIV will be measured using the internalized self-image component of the HIV-stigma scale developed by Berger and colleagues (2001). Examples of the eight questions contained in this sub-scale include: 'I feel guilty because I have HIV'; 'I feel I am not as good as others because I have HIV; I never feel ashamed of having HIV'; 'I work hard to keep my HIV a secret'. The reliability (Cronbach's Alpha of this measure is .90. (B) Also related to HIV and sense of self, we will utilize a 10-item Illness acceptance measure adapted to HIV by our study team from the work of Huba et al (1996), which includes questions such as: 'I feel at peace with my HIV diagnosis'; 'I feel very angry about having HIV'; 'When I think about having HIV, I feel overwhelmed'. (C) Overall sense of self, not limited to HIV, will be measured by using the Unconditional Self-Acceptance (USA) 20-item measure developed by Chamberlain and Haaga (2001). Examples of items from this measure include: 'I feel that some people have more value than others'; 'Making mistakes may be disappointing but it doesn't change how I feel about myself overall'; 'My sense of

self-worth depends a lot on how I compare with other people'; 'I feel valuable as a person even when other people disapprove of me'. The reliability (Cronbach's Alpha) of the measure is .72. (D) Psychological well-being: We will use the Hospital Anxiety and Depression Scale (HAD) to assess psychological well-being among participating PLWHA. Examples of HADS questions regarding mind-states and experiences over the past month include: 'I felt tense or wound-up'; 'I enjoyed the things I use to'; 'I had worrying thoughts go through my mind'; 'I felt cheerful'; and 'I could sit at ease and relax'.

Socio-economic context: (A) Social support: The quality of social relationships in the personal lives of PLWHA will be measured using the Social Relationship Scale developed by Kerth O'Brien and colleagues (1993) which has been utilized for people at risk for and living with HIV. The measure involves 5 sub-components including: perceived availability of support (Alpha=.87); perceived sense of social validation (Alpha=.78); social conflict (Alpha=.82); and objective and subjective social integration (Alphas of .89 and .82, respectively). (B) Socio-economic status and social stability: We will assess average monthly income over the last three months, income-to-dependents ratio, employment status and type, housing status and type, whether has ever or recently been homeless, and food security based on prior work with PLWHA from the public health literature (Cunningham et al., 2005). (C) Relationship with clinical care providers: We will utilize the 15-item Patient Reactions Assessment developed by Galassi et al. (1992) which examines three sub-domains: Patient Information Index (Alpha=.87), Patient Communication Index (Alpha=.91), and Patient Affective Index (Alpha=.90); Overall satisfaction with the clinic will be assessed using a measure developed by The Measurement Group (1997), which explores how patients are generally treated and respected by other clinic staff, beyond their primary clinical care provider. (D) Discrimination: Past experiences of discrimination related to HIV, such as whether participants have ever been: verbally insulted, physically assaulted, lost friends, lost a sexual partner, rejected by family members or lost a job due to their status (Bouhnik et al 2002). (E) Form developed by the Municipal Authority to assess the daily activities of people living in Rio: This brief questionnaire has been used for both administrative (e.g. planning the optimal allocation of public transportation) and scientific purposes (by colleagues from PROCC-FIOCRUZ, to model the spread of major infectious diseases such as dengue fever).

Health service information: The instrument developed by the QualiAIDS team, from the University of São Paulo, and applied in a representative sample of health care units all over the country will be used. The form was originally applied to a network of health units from São Paulo, and is composed by a 31 items questionnaire on infra-structure and operations answered by top managers and a 20 items questionnaire on working conditions and daily operations answered by the local team of health workers (Nemes, 2000). In larger units, one representative by category (e.g. one nurse, one social worker) will be designated by the local team in order to avert inchoate/contradictory answers by many different professionals, as mentioned by Nemes (2000) as a key limitation of her original study.

Clinical information: Data on CD4 counts and viral load will be regularly abstracted from patient's case report forms and entered on a specific form, without any personal identification, exception made to a standard code.

Laboratory testing: Each patient will be invited to perform a rapid test for syphilis, after informed consent and counseling, according to the guidelines issues by the BMoH, used as a routine in the congenital syphilis control program. According to the Brazilian guidelines, patients with a positive result will be referred to their respective physicians, for further evaluation using VDRL and FTABS, and eventual treatment. All patients will be invited to donate a sample of urine, to be screened for gonorrhea and Chlamydia.

Qualitative component:

1. In the beginning of the study, three focus groups will be conducted with PLWHA from the largest units, in order to explore what are the major perceived risks for their lives (e.g. violence...) and the major health perceived risks. Those answers will be compiled and used to organize a ranking list, to be incorporated into the survey.

2. After completing the survey, we will conduct in-depth interviews with PLWHA. These interviews will gather information on the impact of HIV-serostatus and HAART use on PLWHA sexual behavior, and participants' perceptions about HIV/AIDS & HAART. In-depth interviews might also be used to clarify/explore survey findings. Such 50 PLWHA will be recruited from both subsamples (35 from survey subsample A and 15 from survey subsample B).

3. As of the end of the study, one focus group with 8-10 patients and one with health providers (5-8) from each unit will be conducted. The overall objective of those groups will be to further explore findings from the survey and the in-depth interviews, in order to triangulate findings and inform the drafting of an intervention model to be developed and tested by a further study.

Outcomes:

Behavioral Outcomes: We will collect information on behavioral risks for STI acquisition which are themselves important epidemiological outcomes, mainly related to unsafe sexual behaviors. Sexual practices include number and types of partners (gender and relationships), type(s) of sexual acts (oral, vaginal and anal intercourse), condom use, "survival" sex (sex for money, drugs, shelter, food and protection), and STI incidence.

Clinical Outcomes: We will abstract data on CD4 counts and viral loads performed in an interval 2 months before or after the day the questionnaire was applied. We will also asses self-reported signs and symptoms of disease, as well as a recent history of medical

diagnoses and health care utilization from medical charts. Specified diagnoses will be recorded using ICD-10 codes, by date and type of diagnosis, symptoms at presentation, date of symptom onset, and supporting clinical and laboratory findings.

STIs: We will evaluate the presence of syphilis using a standard rapid test, in all patients who agree to be tested and sign the informed consent form. We will ask participants to donate a small amount of urine, to be tested for gonorrhea and chlamydia. All participants testing positive for any STI will be provided with free, confidential treatment as well as pre/post test counseling by the clinic staff where they are diagnosed.

Data Analysis

Preliminary analyses. For all datasets, preliminary analyses will include checks for missing values, data range, and outliers. Normality will be examined using Q-Q plots and continuous data will be assessed for transformations or categorizations. Bivariate analyses will include Chi-square and Fisher's Exact tests to compare categorical variables, and t-tests or Wilcoxon tests for continuous variables.

Multivariate analyses: Log-linear models (logistic and Poisson) will be used for dichotomous and count outcome variables, and ordinary least squares to model continuous variables, in order to evaluate the effect of independent variables on each of the major outcomes: adherence to HAART and unsafe sex behavior (e.g. less than 100% condom use over the previous month).

For both outcomes (adherence to HAART and condom use), we will have a large number of candidate predictor variables (ordinal, categorical, or continuous), and a dichotomous outcome variable. We will begin with exploratory bivariate analyses of predictor variables that have been identified in previous studies, categorizing them as has been done previously.

Secondly, we will use logistic regression (or equivalent modeling strategies, such as Poisson regression with robust variance, see Barros & Hirakata, 2003) to select predictive models, estimate the odds ratios (or prevalence rates) for predictor variables, and generate likelihood ratios from the multivariate model for each outcome variable. If the logistic model fits poorly, we will dichotomize continuous predictor variables or replace them with indicator variables for different categories. The goodness of fit of overall logistic models will be evaluated using the Hosmer-Lemeshow method.

Finally, we will use multilevel modeling (Goldstein, 1995), since our study will include several health facilities with different characteristics. This analytic strategy will allow us to include in our modeling health service variables as they impact and interact with individual

level behaviors and developmental processes over and above that of individual level data (Blalock, 1984) and to explore variance between and within health units.

Qualitative analyses will adopt an ‘inductive’ approach where the emergence of key categories and findings throughout inform the focus of further investigation and analysis, including comparisons between different contexts of decision-making, study groups and sites. Hypotheses will be generated in relation to the social contextual factors influencing adherence to HAART, risk behaviors, HIV-related stigma and social support. The initial qualitative component will help developing the survey questionnaire and latter might also clarify initial findings from the survey. The final qualitative component will explore among health professionals and PLWHA the acceptability and feasibility of a proposed intervention model, to be implemented and tested in a subsequent study.

First, tape recorded interviews will be transcribed for use in conjunction with the computer software Atlas.ti® (Muhr, 1997). Second, ‘descriptive’ or ‘first-level’ coding will be undertaken, leading to the ongoing refinement of interview topic guides. Third, ‘interpretive’ or ‘second-level’ coding is undertaken, leading to the identification of emergent patterns across accounts.

The content of analyses will give priority to: (a) depicting the ‘situated rationality’ of unsafe sex behaviors; (b) teasing out the perceived contribution of HAART, and beliefs associated with HAART (including in relation to HIV transmissibility), alongside the contribution of other (non-intervention) factors, including social contextual factors, decision-making related to both HAART adherence and unsafe behavior; (c) generating hypotheses on the potential contribution and role of social contextual factors in shaping sexual and adherence behaviors among PLWHA, thereby informing the direction of ongoing study and future interventions; and (d) informing survey measures of outcome as well as assisting the interpretation of survey findings, including between-sites differences.

Sample Size estimation

During this 18 months project, we will carry out a survey in a sample of 900 patients, selected by a two-step sampling strategy, taking in consideration the different sizes of each health unit and their specific caseloads, as well as the specific characteristics of their clientele, such as its stratification by social strata, ethnicity, gender, place of residence and exposure category. Preliminary data were obtained from the Municipal Health Secretariat and will be used in the calculation of the quotas for each health unit, using a two-step (health unit and individual) sampling strategy.

The Municipal Secretariat of Health coordinates a large network composed by 29 health centers, with a global caseload of 13,855 patients, the vast majority of them (over 10,000) currently under HAART and more than 3,000 not yet eligible to enter ARV treatment. Of course, these figures are dynamic, as new patients found to be positive are

followed-up and some of them progress from HIV-infection to AIDS, and become eligible to receive HAART.

There is no underlying null hypothesis to be specifically assessed, but rather the aim to carry out an exploratory study. In this sense, the main challenge is to have enough statistical power to carry out statistical analyses.

Preliminary data made available by Municipal Health Secretariat points to a slightly predominance of men over women, especially among long-term patients (reflecting the characteristics of the AIDS epidemic in Brazil and the fact gay and bisexual men were hardly affected by the epidemic in its beginnings). Among younger patients, especially those not yet under HAART, the proportion of females increase, corresponding to approximately 45-47% of patients currently being followed-up.

Ethnic background and social strata of the clientele roughly corresponds to the reference general population and varies from one neighborhood to another. The inclusion of facilities with high and middle-sized caseloads and located all over the municipality of Rio has the explicit purpose to include as many diverse people as possible.

The minimum number of 300 patients not yet under HAART (the smallest sample under analysis) will provide enough statistical power, as shown as follows. Let us consider a p-value set at .05, a set of four covariates (for instance, age, gender, ethnicity, and recruitment site) and a single predictor variable (have an occasional partner in the previous month) and a single outcome (used condoms consistently in the previous month). If we assume that the covariates are able to account for 5% of the variance, we will have a power of .85 to detect this effect. In addition, we will have a statistical power higher than .85 to detect an r-square change of .04 for the single predictor variable.

There is no available data about the prevalence of the selected STI (syphilis, gonorrhea and Chlamydia) among PLWHA under treatment and care outside reference centers. Since there is no baseline data, and trying to assure enough statistical power to run our analysis, we will offer STI testing for all participants.

Data Management and Quality Control

Interview responses will be recorded on Teleform® scanable data forms and be reviewed by the interviewer for completeness and consistency prior to the departure of the participant. When needed, clarifications will be elicited. Following the interview, data forms will be reviewed by the Field coordinator and returned to the interviewer to rectify missing or incomplete data. The coordinator will scan forms for computer entry. Scanned data will be reviewed by the Project coordinator. The Teleform® program flags missing data and other problems with the data forms. The Field coordinator will rectify data forms (and, if necessary, designate missing data). Scanned data will be reviewed and prepared for analysis by the Principal investigator.

Timetable

Phase	Months	Research Activity
Staff hiring/training	1-2	Advertise, hire, integrate and train staff
Finalization of instrument	3-5	Develop, translate, pilot test, and finalize instrument.
Focus groups (3)	5	To help in the final development of the survey
Survey	6-11	Interviews and bioassay, pre- post-test counseling, provision of test findings, referral as needed for health and related services.
Qualitative Interviews	11-12	Open-ended interviews with nested subsample.
Focus groups (6 + 6)	12	Triangulation of findings, resources for future intervention development
Data Analysis	12-15	Data analysis, preparation and manuscript development.
Final Report writing	16-18	Writing the final report for the Ford Foundation
Intervention drafting	17-18	Drafting of a culturally appropriate intervention based on study findings. Elaboration of further project aiming to evaluate the feasibility, acceptability and effectiveness of each intervention model

Key variable definition

The main variables to be collected are described below:

Key variable definition	
Measure	Definition
Qualitative interview	50 participants will be selected for in-depth interview and 9 focus groups (3 + 6) will be conducted. These interviews will gather information on the impact of HIV-serostatus and HAART use on PLWHA sexual behavior, and participants' perceptions about HIV/AIDS & HAART. A subsample of health professionals will be selected for 6 focus groups as of the end of the study. These groups will help drafting the intervention model.
Demographics	Participant age, gender, ethnicity, educational level, job or occupation, employment status, income, religion, marital/partnership status, sexual orientation, number of household members, and number of children.

Sexual Behavior	<p>Numbers of male and female sex partners in the previous 6 months</p> <p>Types of sexual practices in the previous 6 months: insertive and receptive oral-genital, genital-genital and rectal-genital</p> <p>Frequency of condom use in the previous 6 months and main reasons for use (or not) condom.</p> <p>Exchange of sex for money, drugs, goods or shelter in the previous 6 months.</p>
HAART optimism	22-item HIV optimism scale developed and validated among gay men in Australia. Other items will be added that are specific to heterosexual male.
AIDS Knowledge	Statements about possible ways of transmitting the AIDS virus (e.g. through saliva, social kiss, blood, unsafe sex)
HAART adherence	<p>Missed HAART doses on previous day, 2 days, 3 days, and 4 days</p> <p>Major reasons for missing doses: forgetfulness, food requirement, weekends, routine changes...</p>

Study Limitations:

As in most observational studies, this study is limited by key selection biases. All participants will be referred by health care workers and no PLWHA out of clinical settings will be recruited – therefore we will recruit a highly selected population. Our findings should not be extrapolated to any other population of PLWHA, such as those who are not under clinical treatment or those who are infected, but are unaware of their serostatus and/or out-of-reach of clinical care in a given period and context.

Another shortcoming is the validity and reliability of self-reports. We have extensive experience in conducting surveys and cohort studies among vulnerable and disenfranchised populations. In order to minimize possible biases interviewers will be thoroughly trained and supervised. The assessment will be exclusively based on validated questionnaires. Notwithstanding, comparison between self-reported adherence and adherence measured with more objective measures (e.g. pill counts, MEMS caps and pharmacy reports) have shown that PLWHA may overestimate their adherence and underestimate their risk behaviors (Berg & Arnsten, 2006). Trying to minimize those biases, we will also evaluate HAART adherence using pharmacy refill information and compare sexual risky behavior reports with STI result tests.

Finally, our study population may not be typical of other areas of Brazil, a country with deep social and regional heterogeneities. Much probably in the second largest metropolitan area of the country, better quality care is available vis-à-vis remote municipalities and the countryside.

Despite the abovementioned limitations, we firmly believe that the full implementation of the first study evaluating both adherence and the possibility of safe sex burnout among PLWHA in Brazil will represent a major achievement in the field. Most importantly, this formative assessment will inform a targeted intervention, to be conducted and thoroughly evaluated in a subsequent project.

V. ETHICAL CONSIDERATIONS

Risks/Benefits

PLWHA from disenfranchised communities will participate in the study, all currently receiving treatment and care in public health facilities. Oswaldo Cruz staff has been specifically trained to work with vulnerable populations such as disenfranchised populations and drug users, among others. Hence we believe that the risks of participation in the study are minimal, due to the following: a) no identifying information such as names or addresses will be collected from participants; b) no participants will ever be recruited or interviewed in front of any health professional or clinic staff; and c) absolutely no information will be provided to health professionals about the information shared with research staff. Some of the possible risks that may occur include for either population group involve negative reactions to sensitive questions involving participants' sexual behavior and/or history of risk activities. These risks will be minimized by maintaining participant anonymity, prioritizing privacy in interview settings, providing full disclosure about the types of questions to be asked in the initial informed consent statement, and emphasizing that participants may not answer any questions considered uncomfortable. Benefits of the research include the use of research results to assist in the development of more effective and culturally-sensitive HIV/AIDS prevention and care interventions to better serve these disenfranchised populations.

Lab results will be given to patients confidentially, and appropriate counseling will be provided. For those who test positive for STDs free treatment and clinical follow-up will be provided at the same clinics where they already receive their HIV care

Patients who don't agree to participate at any time during the process will continue to receive their standard care at the health unit.

The project will be submitted to the IRBs of both institutions participating of the project: The Municipal Health Secretariat (on behalf of its network of health centers) and the Oswaldo Cruz Foundation.

Disclosure/consent processes: Culturally appropriate informed consent forms have been developed for participants, informing them of potential risks and benefits of participation. Informed consent statements will be read to each of the participants in their native language, Portuguese, prior to each of the data collection activities (in-depth interviews, surveys and/or focus groups). Participants will be asked to sign the informed consent form if they wish to indicate their agreement to participate in the study. Please see attached consent forms for in-depth interview, survey and focus group participants in both English and Portuguese.

Confidentiality Assurances: Informed consent and any data collection will be conducted in a private room within the clinics. With the exception of their signature on the informed consent form, no other identifying information such as names or addresses will be collected from the participants. All data collected will be kept under lock and key in the offices of Dr. Bastos at the Oswaldo Cruz Foundation. Additionally, study participants will be asked to avoid the use of proper names when participating in in-depth interviews or focus groups, which will be recorded. Any proper names used in those contexts will be changed to pseudonyms in transcriptions. Both the transcription company and the research assistants will be asked to sign a statement of confidentiality regarding any confidential information to which they will have access during the research process. All audiotapes will be kept under lock and key in the offices of Dr. Bastos at the Oswaldo Cruz Foundation, in order to follow Brazilian regulations. After this period, the audiotapes will be destroyed.

Consultive Committee: Every three months, a committee composed by representatives from health professionals, PLWHA, public health managers and the community will meet, in order to discuss the study findings and to bring new insights and information to inform the drafting of an intervention model.

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II. Institutional review Board approval

Parecer nº 241A/2007

Rio de Janeiro, 17 de dezembro de 2007.

Sr(a) Pesquisador(a),

Informamos a V.Sa. que o Comitê de Ética em Pesquisa da Secretaria Municipal de Saúde - CEP SMS-RJ -, constituído nos Termos da Resolução CNS nº 196/96 e, devidamente registrado na Comissão Nacional de Ética em Pesquisa, recebeu, analisou e emitiu parecer sobre a documentação referente ao Protocolo de Pesquisa, conforme abaixo discriminado:

PROCOLO DE PESQUISA Nº 202/07

TÍTULO: Aspectos psicossociais relacionados à saúde reprodutiva e bem estar de pessoas vivendo com HIV/AIDS em tratamento para o HIV/AIDS em serviços públicos do Rio de Janeiro, Brasil.

PESQUISADOR RESPONSÁVEL: Francisco Inácio Pinkusfeld Monteiro Basto.


UNIDADE ONDE SE REALIZARÁ A PESQUISA: Gerência do Programa de Doenças Transmissíveis.

DATA DA APRECIÇÃO: 17/12/2007.

PARECER: APROVADO

Ressaltamos que o pesquisador responsável por este Protocolo de Pesquisa deverá apresentar a este Comitê de Ética um relatório das atividades desenvolvidas no período de 12 meses a contar da data de sua aprovação (*item VII. 13.d., da Resolução CNS/MS Nº 196/96*).

Esclarecemos, ainda, com relação aos Protocolos, que o CEP/SMS deverá ser informado de fatos relevantes que alterem o curso normal do estudo, devendo o pesquisador apresentar justificativa, caso o projeto venha a ser interrompido e/ou os resultados não sejam publicados.


Salésia Felipe de Oliveira
Vice-Coordenadora
Comitê de Ética em Pesquisa

Parecer Consubstanciado de Projeto de Pesquisa

Título do Projeto: Aspectos psicossociais relacionadas à saúde reprodutiva e bem estar de pessoas vivendo com HIV/Aids em tratamento para o HIV/AIDS em serviços públicos do Rio de Janeiro, Brasil.

Pesquisador Responsável Francisco Inácio Bastos

Data da Versão 11/09/2007

Cadastro 417/07

Data do Parecer 15/10/2007

Grupo e Área Temática III - Projeto fora das áreas temáticas especiais

Objetivos do Projeto

1. Avaliar a associação estatística entre aspectos psicossociais e estruturais e a adoção de comportamentos sexuais mais seguros e aderência à terapia retroviral (HAART).
2. Avaliar os comportamentos sexuais e aspectos correlatos potencialmente associados às infecções sexualmente transmissíveis (IST) entre pessoas vivendo com HIV/AIDS (PLWHA).
3. Avaliar de forma qualitativa aspectos psicossociais e estruturais que possam influenciar tanto a adoção de comportamentos sexuais mais seguros, como a aderência à HAART entre PLWHA, objetivando com isso informar o desenvolvimento de futuras intervenções.

Sumário do Projeto

Estudo descritivo, qualitativo e quantitativo, que visa avaliar aspectos comportamentais sexual, psicossociais e econômicos de PLWHA e questões relacionadas a oferta de tratamento continuado para pacientes HIV/AIDS, na rede municipal de saúde da Cidade do Rio de Janeiro. Os sujeitos de pesquisas serão submetidos a entrevistas e exames de diagnóstico para duas IST, para sífilis e clamídia, com o objetivo de identificar a prevalência dessas IST nesses pacientes, objetivando informar o desenvolvimento de futuras intervenções.

Itens Metodológicos e Éticos	Situação
Título	Adequado
Autores	Adequados
Local de Origem na Instituição	Adequado
Projeto elaborado por patrocinador	Não
Aprovação no país de origem	Não necessita
Local de Realização	Própria instituição
Outras instituições envolvidas	Sim
Condições para realização	Adequadas

Comentários sobre os itens de Identificação

Secretaria Municipal de Saúde da Cidade do Rio de Janeiro . Coordenação Municipal de DST/AIDS

Introdução	Adequada
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Comentários sobre a Introdução

Objetivos	Adequados
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Comentários sobre os Objetivos

Pacientes e Métodos	
Delineamento	Adequado
Tamanho de amostra	Total 900 Local 06
Cálculo do tamanho da amostra	Adequado
Participantes pertencentes a grupos especiais	Não
Seleção equitativa dos indivíduos participantes	Adequada
Crítérios de inclusão e exclusão	Adequados
Relação risco- benefício	Adequada
Uso de placebo	Não utiliza
Período de suspensão de uso de drogas (wash out)	Não utiliza
Monitoramento da segurança e dados	Não necessário
Avaliação dos dados	Comentário

Privacidade e confidencialidade	Adequada
Termo de Consentimento	Adequado
Adequação às Normas e Diretrizes	Sim

Comentários sobre os itens de Pacientes e Métodos

Pesquisa qualitativa e quantitativa: Ambas as avaliações são adequadas.

Cronograma	Adequado
Data de início prevista	Out/Nov 2007
Data de término prevista	Jan/Mar/09
Orçamento	Adequado
Fonte de financiamento externa	Outras fontes

Comentários sobre o Cronograma e o Orçamento

FINANCIADORA: Fundação FORD

Referências Bibliográficas	Adequadas
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Comentários sobre as Referências Bibliográficas

Recomendação

Aprovar

Comentários Gerais sobre o Projeto

Após análise por este colegiado, tendo por referência as normas e diretrizes da Resolução 196/96, foi decidido pela APROVAÇÃO do referido protocolo.

Solicitamos apenas a adequação de valores expressos no orçamento.

Informamos, outrossim, que deverão ser apresentados relatórios parciais/anuais e relatório final do projeto de pesquisa.

Além disso, qualquer modificação ou emenda ao protocolo original deverá ser submetida para apreciação do CEP/Fiocruz.

Marlene Braz

pt/ Marlene Braz
 Coordenadora do Comitê de Ética em Pesquisa
 Em Seres Humanos da Fundação Oswaldo Cruz

**III. Health Professionals Focus Group
Informed Consent Form**

FORMULÁRIO DE CONSENTIMENTO INFORMADO

Participantes de Grupo Focal – Profissionais de Saúde

PESQUISA: Aspectos psicossociais relacionados à saúde reprodutiva e bem estar de pessoas vivendo com HIV/AIDS em tratamento para o HIV/AIDS em serviços públicos do Rio de Janeiro. Brasil.

PESQUISADORES: Francisco Inácio Bastos & Mônica Malta, FIOCRUZ
Betina Durovni & Rosa Domingues, Secretaria Municipal de Saúde do RJ

INTRODUÇÃO

Este é um projeto de pesquisa. Gostaríamos de lhe explicar o que pretendemos fazer nesta pesquisa, para que você possa decidir se gostaria de participar. Este documento contém informações sobre uma pesquisa. Eu gostaria de ler para você esse documento, que tem informações sobre a pesquisa que estamos fazendo, para depois você decidir se gostaria de participar deste estudo ou não. Você pode me interromper para fazer perguntas a qualquer momento, e se não entender alguma coisa que eu disser você pode pedir para que eu pare e explique melhor a parte que você não tiver entendido. Quando eu terminar de ler estas informações, e se você ainda desejar participar, eu pedirei a você que assine esse formulário para indicar que você deseja participar.

1. JUSTIFICATIVA E OBJETIVO DO ESTUDO

Eu faço parte de um grupo de pesquisadores que está trabalhando em um projeto de pesquisa de colaboração entre a Fundação Oswaldo Cruz e a Secretaria Municipal de Saúde, as duas do Rio de Janeiro. O objetivo deste estudo é conhecer melhor **as experiências das pessoas vivendo com HIV/AIDS sobre o tratamento para o HIV, a aderência ao tratamento, e também conhecer melhor as crenças e atitudes relacionadas a sua vida sexual**. Você foi selecionado(a) para participar da pesquisa e conversar conosco sobre suas idéias e experiências sobre assunto por trabalhar como profissional de saúde em um ambulatório que oferece tratamento para o HIV/AIDS. A sua decisão de participar desse estudo não vai influenciar de maneira nenhuma seu trabalho, nem seus superiores ou outras pessoas que não estejam participando deste grupo terão acesso ao que nós conversarmos durante a pesquisa.

2. PROCEDIMENTOS DA PESQUISA

Nessa pesquisa nós iremos coletar dados de diferentes maneiras. A forma como nós gostaríamos de obter informações de você é chamada de grupo focal. Estes grupos envolvem uma conversa informal com você e um grupo de profissionais do mesmo ambulatório no qual você trabalha, contando com aproximadamente 5-8 profissionais responsáveis pelo atendimento de pessoas vivendo com HIV/AIDS, e a conversa vai durar aproximadamente 1 hora. Caso você decida participar desse grupo focal, iremos fazer a você e aos outros participantes do grupo algumas perguntas sobre as suas experiências relacionadas ao tratamento de pessoas vivendo com HIV/

AIDS, principalmente com relação ao manejo da aderência desses pacientes ao tratamento anti-retroviral e os comportamentos sexuais e aderência destes pacientes ao tratamento. Vamos também perguntar se têm sido observadas modificações no comportamento destes pacientes ao longo do tempo, e quais as dificuldades mais frequentemente enfrentadas pela equipe de saúde no manejo destes pacientes. Para compreender e lembrar melhor de todas as informações que vocês vão dividir conosco, eu gostaria de gravar a conversa. Caso você prefira que a conversa não seja gravada, não há problema. Neste caso, eu irei tomar notas em papéis apenas durante a entrevista, para poder me lembrar dos detalhes da conversa.

Manipulação das fitas cassetes

Caso você aceite ter a conversa gravada, a fita cassete será utilizada da seguinte maneira. A fita cassete não terá seu nome, nem o nome de nenhum outro participante anotados em qualquer local. Após a conversa, a fita cassete será levada para o escritório na Fundação Oswaldo Cruz, aonde será guardada em um arquivo trancado. Após isso, um participante de nosso grupo irá transcrever (escrever) no computador o que nós falamos durante a nossa conversa, para que nós possamos entender melhor as respostas dos participantes – mas todos os nomes próprios serão retirados da transcrição, pra evitar que alguém possa identificar vocês ou as pessoas que vocês mencionarem durante nossa conversa. As únicas pessoas que irão ter acesso a esta fita cassete e às transcrições serão **Francisco Bastos** e **Mônica Malta**, os pesquisadores responsáveis pelo estudo no Brasil, além da pessoa que transcrever a fita. Nenhuma outra pessoa ou instituição irá escutar essa fita cassete. A fita gravada vai ser arquivada em um arquivo trancado, em nosso escritório na Fundação Oswaldo Cruz, durante um período de 5 anos, para atender às normas para pesquisas no Brasil. Após este período, as fitas serão destruídas.

3. DESCONFORTOS E RISCOS POSSÍVEIS E OS BENEFÍCIOS ESPERADOS

A sua participação nesse estudo não vai lhe trazer nenhum benefício direto, mas a nossa intenção é utilizar as informações que você nos dará para organizar serviços que atendam melhor as necessidades e dificuldades de pessoas vivendo com HIV/AIDS na comunidade. Algumas das questões que irei lhe perguntar podem ser embaraçosas, especialmente as perguntas relacionadas sobre suas dificuldades pessoais em atender estes pacientes. Caso alguma pergunta seja embaraçosa, você não precisa respondê-la. Em qualquer momento você pode terminar sua participação nesta entrevista, sem precisar nos dar qualquer explicação. Se você quiser obter maiores informações sobre o manejo de pacientes vivendo com HIV/AIDS, ou sobre qualquer outro assunto que nós tenhamos conversado durante este grupo, nós poderemos lhe encaminhar manuais e documentos especializados ou lhe encaminhar para cursos e treinamentos na área.

4. GARANTIA DE SIGILO

A sua participação nesta entrevista é totalmente confidencial e voluntária. Para assegurar o sigilo das informações que você nos der, as seguintes medidas serão tomadas: nenhum nome próprio, endereço ou informações pessoais serão coletados; ninguém além do grupo de pesquisadores terá acesso ao que você disser aqui e seu verdadeiro nome não será escrito ou publicado em nenhum local. Nenhuma informação que você vier a nos dar, durante sua participação na pesquisa, serão divulgadas para qualquer outra pessoa que não faça parte do nosso grupo de pesquisa.

Todos os textos, fitas e documentos da pesquisa serão guardados em um escritório trancado e os arquivos serão protegidos por senhas. As fitas cassetes serão guardadas durante um período de 5 anos, para atender às normas para pesquisas no Brasil. Se os resultados forem publicados, seu nome será mantido em sigilo.

5. GARANTIA DE ESCLARECIMENTO

Você poderá nos fazer qualquer pergunta ou tirar qualquer dúvida que você tenha sobre essa pesquisa a qualquer momento, quer dizer, você pode nos perguntar qualquer coisa da pesquisa antes de ter participado desse grupo ou enquanto você estiver participando do grupo. Nós lhe daremos telefones e endereços de contato para que você possa tirar qualquer dúvida também depois que terminar este grupo, se você decidir que quer participar dele.

6. SUA PARTICIPAÇÃO E SAÍDA DO ESTUDO

Caso você tenha qualquer pergunta sobre essa pesquisa, você pode entrar em contato com Francisco Bastos ou Mônica Malta, da Fundação Oswaldo Cruz. O telefone dos dois está em um cartão de contato que iremos lhe dar. Eles poderão esclarecer qualquer pergunta ou preocupação que você possa ter sobre esse projeto, ou registrar qualquer reclamação que você possa ter sobre o tratamento que recebeu durante essa pesquisa. Se você tiver qualquer interesse em conhecer os resultados deste estudo quando este terminar, os pesquisadores poderão lhe dar uma cópia.

Lembre-se que você pode se recusar a responder qualquer pergunta, ou parar de participar da pesquisa no meio do grupo, sem problema algum. Se você decidir não participar da pesquisa, ou quiser parar a qualquer momento, você não irá sofrer nenhum prejuízo, nem o atendimento que você recebe atualmente neste serviço de saúde, ou em qualquer outro serviço será prejudicado. A sua participação é totalmente voluntária e não existe problema algum se você não quiser participar.

Você gostaria de perguntar alguma coisa a mais? Você gostaria de participar?

VERIFICAÇÃO DO CONSENTIMENTO

Se você concorda em participar desse estudo por favor assinie seu nome abaixo

NÃO É VÁLIDO SEM PAPEL
TIMBRADO DA FIOCRUZ E
NÚMEROS DE REGISTRO DO
PROTOCOLO

POR FAVOR, ASSINE ABAIXO SE VOCÊ GOSTARIA DE PARTICIPAR DESSE ESTUDO.

____/____/____

Assinatura do participante

Data

Espaço para impressão digital do participante, no caso deste ser incapaz de assinar o consentimento

DECLARAÇÃO DO PESQUISADOR

Eu declaro que o participante teve o tempo necessário para ler e compreender o estudo e que todas suas dúvidas foram sanadas. É minha opinião que o participante compreendeu os objetivos, riscos, benefícios e procedimentos que irão ser seguidos neste estudo e que concordou em participar de forma voluntária.

____/____/____

(Assinatura de pessoa que obteve o consentimento informado)

Data

Nota: Cópias assinadas desse formulário de consentimento devem ser
a) mantidas arquivadas pelo Pesquisador Principal e b) dada para o participante

CARTÃO DE CONTATO PARA O PARTICIPANTE

PARA FALAR COM MÔNICA MALTA, PESQUISADORA RESPONSÁVEL PELO ESTUDO, VOCÊ PODE TELEFONAR PARA: (21) 2598-2715, OU ENCONTRÁ-LA EM SEU ESCRITÓRIO NA FUNDAÇÃO OSWALDO CRUZ, RUA LEOPOLDO BULHÕES Nº 1480, ESCOLA NACIONAL DE SAÚDE PÚBLICA SÉRGIO AROUCA (ENSP), SALA 905, MANGUINHOS, RIO DE JANEIRO/RJ, CEP: 21041-210..

VOCÊ PODE TAMBÉM TIRAR SUAS DÚVIDAS SOBRE A PESQUISA COM DR. FRANCISCO BASTOS, SUPERVISOR DO ESTUDO, ATRAVÉS DO TELEFONE: (21) 3865-3231. VOCÊ PODE TAMBÉM ENCONTRÁ-LO EM SEU ESCRITÓRIO NA FUNDAÇÃO OSWALDO CRUZ, AVENIDA BRASIL Nº 4365 BIBLIOTECA DE MANGUINHOS SALA 229, MANGUINHOS, RIO DE JANEIRO/RJ, CEP 21045-900.

SE VOCÊ TIVER OUTRAS PERGUNTAS SOBRE SEUS DIREITOS COMO PARTICIPANTE DA PESQUISA, VOCÊ PODE ENTRAR EM CONTATO COM O COMITÊ DE ÉTICA EM PESQUISA DA FUNDAÇÃO OSWALDO CRUZ (CEP/FIOCRUZ). O CEP/FIOCRUZ É UM COMITÊ QUE REVISAR E APROVA ESTUDOS ENVOLVENDO SERES HUMANOS QUE TENHAM SIDO COORDENADOS POR PESSOAS LIGADAS À FIOCRUZ.

**PARA FALAR COM ESTE COMITÊ, VOCÊ PODE TELEFONAR PARA: (21) 3882-9000 –
RAMAL 9011, OU VIR PESSOALMENTE AO SEGUINTE ENDEREÇO: AVENIDA
BRASIL, Nº. 4036 SALA 705, MANGUINHOS, RIO DE JANEIRO, RJ, CEP: 21040-360.**

IV. Focus Groups Informed Consent Form

FORMULÁRIO DE CONSENTIMENTO INFORMADO

Participantes de Grupo Focal

PESQUISA: Aspectos psicossociais relacionados à saúde reprodutiva e bem estar de pessoas vivendo com HIV/AIDS em tratamento para o HIV/AIDS em serviços públicos do Rio de Janeiro. Brasil.

PESQUISADORES: Francisco Inácio Bastos & Mônica Malta, FIOCRUZ
Betina Durovni & Rosa Domingues, Secretaria Municipal de Saúde do RJ

INTRODUÇÃO

Este é um projeto de pesquisa. Gostaríamos de lhe explicar o que pretendemos fazer nesta pesquisa, para que você possa decidir se gostaria de participar. Este documento contém informações sobre uma pesquisa. Eu gostaria de ler para você esse documento, que tem informações sobre a pesquisa que estamos fazendo, para depois você decidir se gostaria de participar deste estudo ou não. Você pode me interromper para fazer perguntas a qualquer momento, e se não entender alguma coisa que eu disser você pode pedir para que eu pare e explique melhor a parte que você não tiver entendido. Quando eu terminar de ler estas informações, e se você ainda desejar participar, eu pedirei a você que assine esse formulário para indicar que você deseja participar.

1. JUSTIFICATIVA E OBJETIVO DO ESTUDO

Eu faço parte de um grupo de pesquisadores que está trabalhando em um projeto de pesquisa de colaboração entre a Fundação Oswaldo Cruz e a Secretaria Municipal de Saúde, as duas do Rio de Janeiro. O objetivo deste estudo é conhecer melhor **as experiências das pessoas vivendo com HIV/AIDS sobre o tratamento para o HIV, a aderência ao tratamento, e também conhecer melhor as crenças e atitudes relacionadas a sua vida sexual**. Você foi selecionado(a) para participar da pesquisa e conversar conosco sobre suas idéias e experiências sobre assunto por estar em tratamento para o HIV/AIDS nesse ambulatório. A sua decisão de participar desse estudo não vai influenciar de maneira nenhuma a qualidade do serviço de saúde que você está recebendo aqui, nem os médicos e outros profissionais de saúde que lhe atendem aqui terão acesso ao que nós conversarmos durante a pesquisa.

2. PROCEDIMENTOS DA PESQUISA

Nessa pesquisa nós iremos coletar dados de diferentes maneiras. A forma como nós gostaríamos de obter informações de você é chamada de grupo focal. Estes grupos envolvem uma conversa informal com você e um grupo de aproximadamente 6-8 outras pessoas também vivendo com HIV/AIDS em tratamento neste ambulatório, e a conversa vai durar aproximadamente 1 hora. Caso você decida participar desse grupo focal, iremos fazer a você e aos outros participantes do grupo algumas perguntas sobre as suas experiências relacionadas à infecção pelo HIV, o uso dos medicamentos para tratar a infecção pelo HIV e seus comportamentos sexuais. Vamos também perguntar se o fato

de vocês terem HIV mudou alguma coisa nas suas idéias e comportamentos sexuais. Se vocês tiverem mudado algum dos seus comportamentos sexuais, vamos também perguntar se isso mudou depois que vocês souberam que tinham HIV ou depois que vocês começaram a tomar os medicamentos para tratar essa infecção. Para compreender e lembrar melhor de todas as informações que vocês vão dividir conosco, eu gostaria de gravar a conversa. Caso você prefira que a conversa não seja gravada, não há problema. Neste caso, eu irei tomar notas em papéis apenas durante a entrevista, para poder me lembrar dos detalhes da conversa.

Manipulação das fitas cassetes

Caso você aceite ter a conversa gravada, a fita cassete será utilizada da seguinte maneira. A fita cassete não terá seu nome, nem o nome de nenhum outro participante anotados em qualquer local. Após a conversa, a fita cassete será levada para o escritório na Fundação Oswaldo Cruz, aonde será guardada em um arquivo trancado. Após isso, um participante de nosso grupo irá transcrever (escrever) no computador o que nós falamos durante a nossa conversa, para que nós possamos entender melhor as respostas dos participantes – mas todos os nomes próprios serão retirados da transcrição, pra evitar que alguém possa identificar vocês ou as pessoas que vocês mencionarem durante nossa conversa. As únicas pessoas que irão ter acesso a esta fita cassete e às transcrições serão **Francisco Bastos** e **Mônica Malta**, os pesquisadores responsáveis pelo estudo no Brasil, além da pessoa que transcrever a fita. Nenhuma outra pessoa ou instituição irá escutar essa fita cassete. A fita gravada vai ser arquivada em um arquivo trancado, em nosso escritório na Fundação Oswaldo Cruz, durante um período de 5 anos, para atender às normas para pesquisas no Brasil. Após este período, as fitas serão destruídas.

3. DESCONFORTOS E RISCOS POSSÍVEIS E OS BENEFÍCIOS ESPERADOS

A sua participação nesse estudo não vai lhe trazer nenhum benefício direto, mas a nossa intenção é utilizar as informações que você nos dará para organizar serviços que atendam melhor as necessidades e dificuldades de pessoas vivendo com HIV/AIDS na comunidade. Algumas das questões que irei lhe perguntar são bastante pessoais, especialmente as perguntas sobre a influência de ter HIV/AIDS na sua qualidade de vida e na sua vida sexual. Caso alguma pergunta seja embaraçosa, você não precisa respondê-la. Em qualquer momento você pode terminar sua participação nesta entrevista, sem precisar nos dar qualquer explicação. Se você precisar de maiores informações sobre a infecção pelo HIV, os medicamentos que você toma, ou qualquer outro assunto que nós tenhamos conversado durante a entrevista, nós poderemos lhe encaminhar para os profissionais de saúde ou organizações que possam lhe ajudar.

4. GARANTIA DE SIGILO

A sua participação nesta entrevista é totalmente confidencial e voluntária. Para assegurar o sigilo das informações que você nos der, as seguintes medidas serão tomadas: nenhum nome próprio, endereço ou informações pessoais serão coletados; ninguém além do grupo de pesquisadores terá acesso ao que você disser aqui e seu verdadeiro nome não será escrito ou publicado em nenhum local. Nenhuma informação que você vier a nos dar, durante sua participação na pesquisa, serão divulgadas para qualquer outra pessoa que não faça parte do nosso grupo de pesquisa.

Todos os textos, fitas e documentos da pesquisa serão guardados em um escritório trancado e os arquivos serão protegidos por senhas. As fitas cassetes serão guardadas durante um período de 5 anos, para atender às normas para pesquisas no Brasil. Se os resultados forem publicados, seu nome será mantido em sigilo.

5. GARANTIA DE ESCLARECIMENTO

Você poderá nos fazer qualquer pergunta ou tirar qualquer dúvida que você tenha sobre essa pesquisa a qualquer momento, quer dizer, você pode nos perguntar qualquer coisa da pesquisa antes de ter participado desse grupo ou enquanto você estiver participando do grupo. Nós lhe daremos telefones e endereços de contato para que você possa tirar qualquer dúvida também depois que terminar este grupo, se você decidir que quer participar dele.

6. COMPENSAÇÃO

Nós lhe daremos 10 Reais para lhe ajudar com suas despesas de transporte e lanche, gastos que você teve para participar da pesquisa. Com esse dinheiro nós não estamos pagando pelo seu tempo, apesar de sabermos que sua colaboração é muito importante para nós. Nós lhe daremos essa pequena ajuda financeira imediatamente após o término da entrevista.

7. SUA PARTICIPAÇÃO E SAÍDA DO ESTUDO

Caso você tenha qualquer pergunta sobre essa pesquisa, você pode entrar em contato com Francisco Bastos ou Mônica Malta, da Fundação Oswaldo Cruz. O telefone dos dois está em um cartão de contato que iremos lhe dar. Eles poderão esclarecer qualquer pergunta ou preocupação que você possa ter sobre esse projeto, ou registrar qualquer reclamação que você possa ter sobre o tratamento que recebeu durante essa pesquisa. Se você tiver qualquer interesse em conhecer os resultados deste estudo quando este terminar, os pesquisadores poderão lhe dar uma cópia.

Lembre-se que você pode se recusar a responder qualquer pergunta, ou parar de participar da pesquisa no meio do grupo, sem problema algum. Se você decidir não participar da pesquisa, ou quiser parar a qualquer momento, você não irá sofrer nenhum prejuízo, nem o atendimento que você recebe atualmente neste serviço de saúde, ou em qualquer outro serviço será prejudicado. A sua participação é totalmente voluntária e não existe problema algum se você não quiser participar.

Você gostaria de perguntar alguma coisa a mais? Você gostaria de participar?

VERIFICAÇÃO DO CONSENTIMENTO

Se você concorda em participar desse estudo por favor assine seu nome abaixo

NÃO É VÁLIDO SEM PAPEL
TIMBRADO DA FIOCRUZ E
NÚMEROS DE REGISTRO DO
PROTOCOLO

POR FAVOR, ASSINE ABAIXO SE VOCÊ GOSTARIA DE PARTICIPAR DESSE ESTUDO.

____/____/____

Assinatura do participante

Data

Espaço para impressão digital do participante, no caso deste ser incapaz de assinar o consentimento

DECLARAÇÃO DO PESQUISADOR

Eu declaro que o participante teve o tempo necessário para ler e compreender o estudo e que todas suas dúvidas foram sanadas. É minha opinião que o participante compreendeu os objetivos, riscos, benefícios e procedimentos que irão ser seguidos neste estudo e que concordou em participar de forma voluntária.

____/____/____

(Assinatura de pessoa que obteve o consentimento informado)

Data

Nota: Cópias assinadas desse formulário de consentimento devem ser
a) mantidas arquivadas pelo Pesquisador Principal e b) dada para o participante

CARTÃO DE CONTATO PARA O PARTICIPANTE

PARA FALAR COM MÔNICA MALTA, PESQUISADORA RESPONSÁVEL PELO ESTUDO, VOCÊ PODE TELEFONAR PARA: (21) 2598-2715, OU ENCONTRÁ-LA EM SEU ESCRITÓRIO NA FUNDAÇÃO OSWALDO CRUZ, RUA LEOPOLDO BULHÕES Nº 1480, ESCOLA NACIONAL DE SAÚDE PÚBLICA SÉRGIO AROUCA (ENSP), SALA 905, MANGUINHOS, RIO DE JANEIRO/RJ, CEP: 21041-210..

VOCÊ PODE TAMBÉM TIRAR SUAS DÚVIDAS SOBRE A PESQUISA COM DR. FRANCISCO BASTOS, SUPERVISOR DO ESTUDO, ATRAVÉS DO TELEFONE: (21) 3865-3231. VOCÊ PODE TAMBÉM ENCONTRÁ-LO EM SEU ESCRITÓRIO NA FUNDAÇÃO OSWALDO CRUZ, AVENIDA BRASIL Nº 4365 BIBLIOTECA DE MANGUINHOS SALA 229, MANGUINHOS, RIO DE JANEIRO/RJ, CEP 21045-900.

SE VOCÊ TIVER OUTRAS PERGUNTAS SOBRE SEUS DIREITOS COMO PARTICIPANTE DA PESQUISA, VOCÊ PODE ENTRAR EM CONTATO COM O COMITÊ DE ÉTICA EM PESQUISA DA FUNDAÇÃO OSWALDO CRUZ (CEP/FIOCRUZ). O CEP/FIOCRUZ É UM COMITÊ QUE REvisa E APROVA ESTUDOS ENVOLVENDO SERES HUMANOS QUE TENHAM SIDO COORDENADOS POR PESSOAS LIGADAS À FIOCRUZ.

**PARA FALAR COM ESTE COMITÊ, VOCÊ PODE TELEFONAR PARA: (21) 3882-9000 –
RAMAL 9011, OU VIR PESSOALMENTE AO SEGUINTE ENDEREÇO: AVENIDA
BRASIL, Nº. 4036 SALA 705, MANGUINHOS, RIO DE JANEIRO, RJ, CEP: 21040-360.**

V. Participant In-Depth Interview Consent Form

FORMULÁRIO DE CONSENTIMENTO INFORMADO

Participantes de Entrevista em Profundidade

PESQUISA: Aspectos psicossociais relacionados à saúde reprodutiva e bem estar de pessoas vivendo com HIV/AIDS em tratamento para o HIV/AIDS em serviços públicos do Rio de Janeiro. Brasil.

PESQUISADORES: Francisco Inácio Bastos & Mônica Malta, FIOCRUZ
Betina Durovni & Rosa Domingues, Secretaria Municipal de Saúde do RJ

INTRODUÇÃO

Este é um projeto de pesquisa. Gostaríamos de lhe explicar o que pretendemos fazer nesta pesquisa, para que você possa decidir se gostaria de participar. Este documento contém informações sobre uma pesquisa. Eu gostaria de ler para você esse documento, que tem informações sobre a pesquisa que estamos fazendo, para depois você decidir se gostaria de participar deste estudo ou não. Você pode me interromper para fazer perguntas a qualquer momento, e se não entender alguma coisa que eu disser você pode pedir para que eu pare e explique melhor a parte que você não tiver entendido. Quando eu terminar de ler estas informações, e se você ainda desejar participar, eu pedirei a você que assine esse formulário para indicar que você deseja participar.

1. JUSTIFICATIVA E OBJETIVO DO ESTUDO

Eu faço parte de um grupo de pesquisadores que está trabalhando em um projeto de pesquisa de colaboração entre a Fundação Oswaldo Cruz e a Secretaria Municipal de Saúde, as duas do Rio de Janeiro. O objetivo deste estudo é conhecer melhor **as experiências das pessoas vivendo com HIV/AIDS sobre o tratamento para o HIV, a aderência ao tratamento, e também conhecer melhor as crenças e atitudes relacionadas a sua vida sexual**. Você foi selecionado(a) para participar da pesquisa e conversar conosco sobre suas idéias e experiências sobre assunto por estar em tratamento para o HIV/AIDS nesse ambulatório. A sua decisão de participar desse estudo não vai influenciar de maneira nenhuma a qualidade do serviço de saúde que você está recebendo aqui, nem os médicos e outros profissionais de saúde que lhe atendem aqui terão acesso ao que nós conversarmos durante a pesquisa.

2. PROCEDIMENTOS DA PESQUISA

Nessa pesquisa nós iremos coletar dados de diferentes maneiras. A forma como nós gostaríamos de obter informações de você é chamada de entrevista em profundidade. Esta entrevista envolve uma conversa informal com você que vai durar aproximadamente 1 hora. Caso você decida participar desta entrevista, iremos lhe fazer algumas perguntas sobre suas experiências relacionadas à infecção pelo HIV, o uso dos medicamentos para tratar a infecção pelo HIV e seus comportamentos sexuais. Vamos também perguntar se o fato de você ter HIV mudou alguma coisa nas suas idéias e comportamentos sexuais. Se você mudou algum dos seus comportamentos sexuais, vamos também

lhe perguntar se isso mudou depois que soube que tinha HIV ou depois que começou a tomar os medicamentos para tratar essa infecção.

Para compreender e lembrar melhor de todas as informações que você vai dividir conosco, eu gostaria de gravar a conversa. Caso você prefira que a conversa não seja gravada, não há problema. Neste caso, eu irei tomar notas em papéis apenas durante a entrevista, para poder me lembrar dos detalhes da conversa.

Manipulação das fitas cassetes

Caso você aceite ter a conversa gravada, a fita cassete será utilizada da seguinte maneira. A fita cassete não terá seu nome anotado em qualquer local dela. Após a conversa, a fita cassete será levada para o escritório na Fundação Oswaldo Cruz, aonde será guardada em um arquivo trancado. Após isso, um participante de nosso grupo irá transcrever (escrever) no computador o que nós falamos durante a nossa conversa, para que nós possamos entender melhor as suas respostas – mas todos os nomes próprios serão retirados da transcrição, pra evitar que alguém possa identificar você ou as pessoas que você mencionar durante nossa conversa. As únicas pessoas que irão ter acesso a esta fita cassete e às transcrições serão **Francisco Bastos** e **Mônica Malta**, os pesquisadores responsáveis pelo estudo no Brasil, além da pessoa que transcrever a fita. Nenhuma outra pessoa ou instituição irá escutar essa fita cassete. A fita gravada vai ser arquivada em um arquivo trancado, em nosso escritório na Fundação Oswaldo Cruz, durante um período de 5 anos, para atender às normas para pesquisas no Brasil. Após este período, as fitas serão destruídas.

3. DESCONFORTOS E RISCOS POSSÍVEIS E OS BENEFÍCIOS ESPERADOS

A sua participação nesse estudo não vai lhe trazer nenhum benefício direto, mas a nossa intenção é utilizar as informações que você nos dará para organizar serviços que atendam melhor as necessidades e dificuldades de pessoas vivendo com HIV/AIDS na comunidade. Algumas das questões que irei lhe perguntar são bastante pessoais, especialmente as perguntas sobre a influência de ter HIV/AIDS na sua qualidade de vida e na sua vida sexual. Caso alguma pergunta seja embaraçosa, você não precisa respondê-la. Em qualquer momento você pode terminar sua participação nesta entrevista, sem precisar nos dar qualquer explicação. Se você precisar de maiores informações sobre a infecção pelo HIV, os medicamentos que você toma, ou qualquer outro assunto que nós tenhamos conversado durante a entrevista, nós poderemos lhe encaminhar para os profissionais de saúde ou organizações que possam lhe ajudar.

4. GARANTIA DE SIGILO

A sua participação nesta entrevista é totalmente confidencial e voluntária. Para assegurar o sigilo das informações que você nos der, as seguintes medidas serão tomadas: nenhum nome próprio, endereço ou informações pessoais serão coletados; ninguém além do grupo de pesquisadores terá acesso ao que você disser aqui e seu verdadeiro nome não será escrito ou publicado em nenhum local. Nenhuma informação que você vier a nos dar, durante sua participação na pesquisa, serão divulgadas para qualquer outra pessoa que não faça parte do nosso grupo de pesquisa.

Todos os textos, fitas e documentos da pesquisa serão guardados em um escritório trancado e os arquivos serão protegidos por senhas. As fitas cassetes serão guardadas durante um período de 5 anos, para atender às normas para pesquisas no Brasil. Se os resultados forem publicados, seu nome será mantido em sigilo.

5. GARANTIA DE ESCLARECIMENTO

Você poderá nos fazer qualquer pergunta ou tirar qualquer dúvida que você tenha sobre essa pesquisa a qualquer momento, quer dizer, você pode nos perguntar qualquer coisa da pesquisa antes de ter começado a participar da entrevista ou enquanto você estiver participando da entrevista. Nós lhe daremos telefones e endereços de contato para que você possa tirar qualquer dúvida também depois que terminar este grupo, se você decidir que quer participar dele.

6. COMPENSAÇÃO

Nós lhe daremos 10 Reais para lhe ajudar com suas despesas de transporte e lanche, gastos que você teve para participar da pesquisa. Com esse dinheiro nós não estamos pagando pelo seu tempo, apesar de sabermos que sua colaboração é muito importante para nós. Nós lhe daremos essa pequena ajuda financeira imediatamente após o término da entrevista.

7. SUA PARTICIPAÇÃO E SAÍDA DO ESTUDO

Caso você tenha qualquer pergunta sobre essa pesquisa, você pode entrar em contato com Francisco Bastos ou Mônica Malta, da Fundação Oswaldo Cruz. O telefone dos dois está em um cartão de contato que iremos lhe dar. Eles poderão esclarecer qualquer pergunta ou preocupação que você possa ter sobre esse projeto, ou registrar qualquer reclamação que você possa ter sobre o tratamento que recebeu durante essa pesquisa. Se você tiver qualquer interesse em conhecer os resultados deste estudo quando este terminar, os pesquisadores poderão lhe dar uma cópia.

Lembre-se que você pode se recusar a responder qualquer pergunta, ou parar de participar da pesquisa no meio do grupo, sem problema algum. Se você decidir não participar da pesquisa, ou quiser parar a qualquer momento, você não irá sofrer nenhum prejuízo, nem o atendimento que você recebe atualmente neste serviço de saúde, ou em qualquer outro serviço será prejudicado. A sua participação é totalmente voluntária e não existe problema algum se você não quiser participar.

Você gostaria de perguntar alguma coisa a mais? Você gostaria de participar?

VERIFICAÇÃO DO CONSENTIMENTO

Se você concorda em participar desse estudo por favor assinie seu nome abaixo

NÃO É VÁLIDO SEM PAPEL
TIMBRADO DA FIOCRUZ E
NÚMEROS DE REGISTRO DO
PROTOCOLO

POR FAVOR, ASSINE ABAIXO SE VOCÊ GOSTARIA DE PARTICIPAR DESSE ESTUDO.

____/____/____

Assinatura do participante

Data

Espaço para impressão digital do participante, no caso deste ser incapaz de assinar o consentimento

DECLARAÇÃO DO PESQUISADOR

Eu declaro que o participante teve o tempo necessário para ler e compreender o estudo e que todas suas dúvidas foram sanadas. É minha opinião que o participante compreendeu os objetivos, riscos, benefícios e procedimentos que irão ser seguidos neste estudo e que concordou em participar de forma voluntária.

____/____/____

(Assinatura de pessoa que obteve o consentimento informado)

Data

Nota: Cópias assinadas desse formulário de consentimento devem ser
a) mantidas arquivadas pelo Pesquisador Principal e b) dada para o participante

CARTÃO DE CONTATO PARA O PARTICIPANTE

PARA FALAR COM MÔNICA MALTA, PESQUISADORA RESPONSÁVEL PELO ESTUDO, VOCÊ PODE TELEFONAR PARA: (21) 2598-2715, OU ENCONTRÁ-LA EM SEU ESCRITÓRIO NA FUNDAÇÃO OSWALDO CRUZ, RUA LEOPOLDO BULHÕES Nº 1480, ESCOLA NACIONAL DE SAÚDE PÚBLICA SÉRGIO AROUCA (ENSP), SALA 905, MANGUINHOS, RIO DE JANEIRO/RJ, CEP: 21041-210..

VOCÊ PODE TAMBÉM TIRAR SUAS DÚVIDAS SOBRE A PESQUISA COM DR. FRANCISCO BASTOS, SUPERVISOR DO ESTUDO, ATRAVÉS DO TELEFONE: (21) 3865-3231. VOCÊ PODE TAMBÉM ENCONTRÁ-LO EM SEU ESCRITÓRIO NA FUNDAÇÃO OSWALDO CRUZ, AVENIDA BRASIL Nº 4365 BIBLIOTECA DE MANGUINHOS SALA 229, MANGUINHOS, RIO DE JANEIRO/RJ, CEP 21045-900.

SE VOCÊ TIVER OUTRAS PERGUNTAS SOBRE SEUS DIREITOS COMO PARTICIPANTE DA PESQUISA, VOCÊ PODE ENTRAR EM CONTATO COM O COMITÊ DE ÉTICA EM PESQUISA DA FUNDAÇÃO OSWALDO CRUZ (CEP/FIOCRUZ). O CEP/FIOCRUZ É UM COMITÊ QUE REVISAR E APROVA ESTUDOS ENVOLVENDO SERES HUMANOS QUE TENHAM SIDO COORDENADOS POR PESSOAS LIGADAS À FIOCRUZ.

**PARA FALAR COM ESTE COMITÊ, VOCÊ PODE TELEFONAR PARA: (21) 3882-9000 –
RAMAL 9011, OU VIR PESSOALMENTE AO SEGUINTE ENDEREÇO: AVENIDA
BRASIL, Nº. 4036 SALA 705, MANGUINHOS, RIO DE JANEIRO, RJ, CEP: 21040-360.**

VI. Participant Survey Consent Form

FORMULÁRIO DE CONSENTIMENTO INFORMADO

Participantes de Questionário

PESQUISA: Aspectos psicossociais relacionados à saúde reprodutiva e bem estar de pessoas vivendo com HIV/AIDS em tratamento para o HIV/AIDS em serviços públicos do Rio de Janeiro. Brasil.

PESQUISADORES: Francisco Inácio Bastos & Mônica Malta, FIOCRUZ
Betina Durovni & Rosa Domingues, Secretaria Municipal de Saúde do RJ

INTRODUÇÃO

Este é um projeto de pesquisa. Gostaríamos de lhe explicar o que pretendemos fazer nesta pesquisa, para que você possa decidir se gostaria de participar. Este documento contém informações sobre uma pesquisa. Eu gostaria de ler para você esse documento, que tem informações sobre a pesquisa que estamos fazendo, para depois você decidir se gostaria de participar deste estudo ou não. Você pode me interromper para fazer perguntas a qualquer momento, e se não entender alguma coisa que eu disser você pode pedir para que eu pare e explique melhor a parte que você não tiver entendido. Quando eu terminar de ler estas informações, e se você ainda desejar participar, eu pedirei a você que assine esse formulário para indicar que você deseja participar.

1. JUSTIFICATIVA E OBJETIVO DO ESTUDO

Eu faço parte de um grupo de pesquisadores que está trabalhando em um projeto de pesquisa de colaboração entre a Fundação Oswaldo Cruz e a Secretaria Municipal de Saúde, as duas do Rio de Janeiro. O objetivo deste estudo é conhecer melhor **as experiências das pessoas vivendo com HIV/AIDS sobre o tratamento para o HIV, a aderência ao tratamento, e também conhecer melhor as crenças e atitudes relacionadas a sua vida sexual**. Você foi selecionado(a) para participar da pesquisa e conversar conosco sobre suas idéias e experiências sobre assunto por estar em tratamento para o HIV/AIDS nesse ambulatório. A sua decisão de participar desse estudo não vai influenciar de maneira nenhuma a qualidade do serviço de saúde que você está recebendo aqui, nem os médicos e outros profissionais de saúde que lhe atendem aqui terão acesso ao que nós conversarmos durante a pesquisa.

2. PROCEDIMENTOS DA PESQUISA

Nessa pesquisa nós iremos coletar dados de diferentes maneiras. O método para o qual você foi recrutado(a) é chamado questionário (ou entrevista quantitativa). Envolve uma quantidade de perguntas objetivas que eu farei apenas para você. Levará aproximadamente 30 minutos. Se você decidir participar dessa pesquisa, eu irei perguntar sobre seu passado, suas experiências relacionadas à infecção pelo HIV, o uso dos medicamentos para tratar a infecção pelo HIV e seus comportamentos sexuais antes e depois do diagnóstico positivo para HIV. Irei também lhe fazer

algumas perguntas específicas sobre as suas atitudes e crenças sobre o tratamento para o HIV/AIDS e sua experiência em tomar estes medicamentos.

Ao final do questionário, nós gostaríamos de fazer dois exames com você. O primeiro é um exame de sangue que poderá identificar se você tem sífilis, uma doença que é transmitida através do sexo. Se você concordar em fazer este exame, um profissional de enfermagem treinado irá coletar um tubo de sangue seu, usando materiais descartáveis. O segundo teste é um exame de urina, que poderá identificar se você tem clamídia, outra doença transmitida através do sexo. Para este segundo exame, nós iremos lhe dar um tubo no qual você deverá coletar sua urina e depois nos devolver. Nós iremos pedir que você volte para pegar seu resultado quando você puder. Você pode pular qualquer pergunta que você não queira ou não se sinta à vontade para responder.

Nós não iremos anotar seu nome nem no questionário nem nos exames, você vai ser identificado por um código específico. O questionário e este documento serão levados para o escritório na Fundação Oswaldo Cruz, aonde será guardado em um arquivo trancado. Após isso, um participante de nosso grupo irá digitar (escrever no computador) as suas respostas, para que nós possamos depois analisar melhor as respostas suas e dos outros participantes.

Os seus exames de sangue serão levados para um laboratório que irá fazer os testes e enviar os seus resultados para este mesmo ambulatório aonde você recebe acompanhamento para a infecção pelo HIV.

3. DESCONFORTOS E RISCOS POSSÍVEIS E OS BENEFÍCIOS ESPERADOS

A sua participação nesse estudo não vai lhe trazer nenhum benefício direto, mas a nossa intenção é utilizar as informações que você nos dará para organizar serviços que atendam melhor as necessidades e dificuldades de pessoas vivendo com HIV/AIDS na comunidade. Algumas das questões que irei lhe perguntar são bastante pessoais, especialmente as perguntas sobre a influência de ter HIV/AIDS na sua qualidade de vida e na sua vida sexual. Caso alguma pergunta seja embaraçosa, você não precisa respondê-la. Em qualquer momento você pode terminar sua participação nesta entrevista, sem precisar nos dar qualquer explicação. Se você precisar de maiores informações sobre a infecção pelo HIV, os medicamentos que você toma, ou qualquer outro assunto que nós tenhamos conversado durante a entrevista, nós poderemos lhe encaminhar para os profissionais de saúde ou organizações que possam lhe ajudar.

Com relação ao exame de sangue, é possível que você sinta um leve desconforto no momento que o profissional de saúde for coletar seu sangue. No entanto este profissional foi treinado e tem bastante experiência em colher sangue de forma rápida e buscando evitar ao máximo qualquer desconforto para os pacientes. O material a ser usado será todo descartável e não haverá nenhum risco de infecção. Com relação ao exame de urina, acreditamos que não exista nenhum tipo de desconforto para que você possa realizar este exame. O tubo para coleta da urina também é feito de material descartável.

4. GARANTIA DE SIGILO

A sua participação neste questionário é totalmente confidencial e voluntária. Para assegurar o sigilo das informações que você nos der, as seguintes medidas serão tomadas: nenhum nome próprio,

endereço ou informações pessoais serão coletados; ninguém além do grupo de pesquisadores terá acesso ao que você disser aqui e seu verdadeiro nome não será escrito ou publicado em nenhum local. Nenhuma informação que você vier a nos dar, durante sua participação na pesquisa, serão divulgadas para qualquer outra pessoa que não faça parte do nosso grupo de pesquisa.

Todos os documentos da pesquisa serão guardados em um escritório trancado e os arquivos serão protegidos por senhas. Se os resultados da pesquisa forem publicados, seu nome será mantido em sigilo.

5. GARANTIA DE ESCLARECIMENTO

Você poderá nos fazer qualquer pergunta ou tirar qualquer dúvida que você tenha sobre essa pesquisa a qualquer momento, quer dizer, você pode nos perguntar qualquer coisa da pesquisa antes de ter começado a responder o questionário ou enquanto você estiver respondendo o questionário. Nós lhe daremos telefones e endereços de contato para que você possa tirar qualquer dúvida também depois que terminar este grupo, se você decidir que quer participar dele.

6. COMPENSAÇÃO

Nós lhe daremos 15 Reais para lhe ajudar com suas despesas de transporte e lanche, gastos que você teve para participar da pesquisa. Com esse dinheiro nós não estamos pagando pelo seu tempo, apesar de sabermos que sua colaboração é muito importante para nós. Nós lhe daremos essa pequena ajuda financeira imediatamente após o término da entrevista.

7. SUA PARTICIPAÇÃO E SAÍDA DO ESTUDO

Caso você tenha qualquer pergunta sobre essa pesquisa, você pode entrar em contato com Francisco Bastos ou Mônica Malta, da Fundação Oswaldo Cruz. O telefone dos dois está em um cartão de contato que iremos lhe dar. Eles poderão esclarecer qualquer pergunta ou preocupação que você possa ter sobre esse projeto, ou registrar qualquer reclamação que você possa ter sobre o tratamento que recebeu durante essa pesquisa. Se você tiver qualquer interesse em conhecer os resultados deste estudo quando este terminar, os pesquisadores poderão lhe dar uma cópia.

Lembre-se que você pode se recusar a responder qualquer pergunta, ou parar de participar da pesquisa no meio do grupo, sem problema algum. Se você decidir não participar da pesquisa, ou quiser parar a qualquer momento, você não irá sofrer nenhum prejuízo, nem o atendimento que você recebe atualmente neste serviço de saúde, ou em qualquer outro serviço será prejudicado. A sua participação é totalmente voluntária e não existe problema algum se você não quiser participar.

Você gostaria de perguntar alguma coisa a mais? Você gostaria de participar?

VERIFICAÇÃO DO CONSENTIMENTO

Se você concorda em participar desse estudo por favor assinie seu nome abaixo

NÃO É VÁLIDO SEM PAPEL
TIMBRADO DA FIOCRUZ E
NÚMEROS DE REGISTRO DO
PROTOCOLO

POR FAVOR, ASSINE ABAIXO SE VOCÊ GOSTARIA DE PARTICIPAR DESSE ESTUDO.

____/____/____

Assinatura do participante

Data

Espaço para impressão digital do participante, no caso deste ser incapaz de assinar o consentimento

DECLARAÇÃO DO PESQUISADOR

Eu declaro que o participante teve o tempo necessário para ler e compreender o estudo e que todas suas dúvidas foram sanadas. É minha opinião que o participante compreendeu os objetivos, riscos, benefícios e procedimentos que irão ser seguidos neste estudo e que concordou em participar de forma voluntária.

____/____/____

(Assinatura de pessoa que obteve o consentimento informado)

Data

Nota: Cópias assinadas desse formulário de consentimento devem ser
a) mantidas arquivadas pelo Pesquisador Principal e b) dada para o participante

CARTÃO DE CONTATO PARA O PARTICIPANTE

PARA FALAR COM MÔNICA MALTA, PESQUISADORA RESPONSÁVEL PELO ESTUDO, VOCÊ PODE TELEFONAR PARA: (21) 2598-2715, OU ENCONTRÁ-LA EM SEU ESCRITÓRIO NA FUNDAÇÃO OSWALDO CRUZ, RUA LEOPOLDO BULHÕES Nº 1480, ESCOLA NACIONAL DE SAÚDE PÚBLICA SÉRGIO AROUCA (ENSP), SALA 905, MANGUINHOS, RIO DE JANEIRO/RJ, CEP: 21041-210..

VOCÊ PODE TAMBÉM TIRAR SUAS DÚVIDAS SOBRE A PESQUISA COM DR. FRANCISCO BASTOS, SUPERVISOR DO ESTUDO, ATRAVÉS DO TELEFONE: (21) 3865-3231. VOCÊ PODE TAMBÉM ENCONTRÁ-LO EM SEU ESCRITÓRIO NA FUNDAÇÃO OSWALDO CRUZ, AVENIDA BRASIL Nº 4365 BIBLIOTECA DE MANGUINHOS SALA 229, MANGUINHOS, RIO DE JANEIRO/RJ, CEP 21045-900.

SE VOCÊ TIVER OUTRAS PERGUNTAS SOBRE SEUS DIREITOS COMO PARTICIPANTE DA PESQUISA, VOCÊ PODE ENTRAR EM CONTATO COM O COMITÊ DE ÉTICA EM PESQUISA DA FUNDAÇÃO OSWALDO CRUZ (CEP/FIOCRUZ). O CEP/FIOCRUZ É UM COMITÊ QUE REVISAR E APROVA ESTUDOS ENVOLVENDO SERES HUMANOS QUE TENHAM SIDO COORDENADOS POR PESSOAS LIGADAS À FIOCRUZ.

**PARA FALAR COM ESTE COMITÊ, VOCÊ PODE TELEFONAR PARA: (21) 3882-9000 –
RAMAL 9011, OU VIR PESSOALMENTE AO SEGUINTE ENDEREÇO: AVENIDA
BRASIL, Nº. 4036 SALA 705, MANGUINHOS, RIO DE JANEIRO, RJ, CEP: 21040-360.**

VII. Baseline Questionnaire



Draft

ID:



Ministério da Saúde
FIOCRUZ
Fundação Oswaldo Cruz



Baseline Questionnaire

"Psychosocial and Structural Factors Associated with the Sexual Health and Well-Being of People Living with HIV/AIDS Attending Public Health Clinics in Rio de Janeiro, Brazil"

Interviewer-First letters:

Signature

Reviewed by Field Supervisor

Signature/Date

Date of interview / /

Time began: :

- Clinical Setting
- Site 1
 - Site 2
 - Site 3
 - Site 4
 - Site 5
 - Site 6
 - Pilot Questionnaire

Read out loud: Thank you for your participation in this study. We would like to get the most accurate information possible. For this reason if you don't understand a question or need more information, please just let me know. If you are unsure of a response, try and pick the response closest to how you think and feel. Remember, everything you say here is just between you and I, so please be as direct and honest as possible with your answers.



Draft

ID: [][][][][]

SECTION 1: Socio-demographic information

1.1 - Interviewee gender: Male Female Transgender

1.2 - How old are you? [][] years old

1.3 - What's your date of birth? (Interviewer: Fill with 88 if don't remember the day, 88 if don't remember the month and 8888 if don't remember the year)

[][] / [][] / [][][][]

1.4 - What is the highest level of school you completed?

- Illiterate Junior High School
- PreSchool Senior High School
- Basic (1° - 3° grade) College
- Basic (4° - 7° grade) Degree
- Basic (completed)

1.5 - How many years of school do you completed? (Include repeted years) [][] years

1.6 - Are you attending school right now? Sim Não

1.7 - How do you consider yourself related to your race/ethnicity?

- White Black Yellow Mixed Indigenous

1.8 - What is your marital status?

- Single WITHOUT steady partner Married or live with partner
- Single WITH steady partner (but don't live together) Separated/Divorced Widowed

1.9 - Where do you currently live or spend most of your nights?

- Own house or apartment Room granted by friend or job
- Rent house or apartment Shelter
- Rent room Hospital
- Hotel/motel Street

1.10 - How many people currently live with you? [][]

1.11 - How many sleep rooms (or rooms that work as sleep rooms) there are in the place you live? [][]

1.12 - With whom do you currently live? (Tick all that apply)

- Partner Brother/Sister Live alone
- Children Relatives Other
- Mother and/or father Friends

1.13 - How many (biological) children do you have?

[][] Don't have children -> If "don't have children", go to 1.17 (Tick NA on 1.14 - 1.16)

1.14 - How many of your (biological) children live with you? [][] NA

1.15 - How old are your children? 1 - [][] 2 - [][] 3 - [][] 4 - [][] 5 - [][] NA

Others: _____, _____, _____, _____, _____, _____, _____, _____, _____, _____

1.16 - Do you have anyone/anywhere to take care of your children if you need?

- Always Almost never
- Almost always Never
- Sometimes NA



1.17 - For how many people are you the primary caretaker? (children or adults)

children (aged 18 or younger) adults (older than 18)

1.18 - What is your current address? (District and/or community):

1.19 - How long, on the average, takes you to come from your home to this facility? (escolha o meio de transporte que você habitualmente utiliza - SINGLE ANSWER - If the interviewee uses more than one mean of transportation, fill the time of each of them)

INTERVIEWER : IF THE INTERVIEWEE RELATE THE TIME AS HOUR, PLEASE CONVERT TO MINUTES. EXAMPLE: ONE HOUR AND A HALF = 90 MINUTES.

Bus: minutes Particular vehicle: minutes
(car/motorcycle)
Train: minutes Bicycle: minutes
Subway: minutes Walking: minutes
Van: minutes
(Alternative transportation)

1.20 - How long have you lived at your current residence?

years Less than one year

1.21 - In how many different places have you lived over the past year?

If the interviewee hadn't move over the past year, fill with 01

1.22 - What type of income did you earn/receive in the last 6 months? (Tick all that apply)

- Regular employment (with contract)
- Regular employment (without contract)
- Occasional work
- Income from husband/wife, sexual partner, family members, and/or friends
- Begging, borrowing and/or donations
- Public Assistance/ Welfare
- Social Security

1.23 - What was your average monthly income during the last 6 months?

R\$. (ex: R\$1.000)

1.24 - What was the total household income on average during the last 6 months?

R\$. (ex: R\$1.000)

1.25 - How many people contributed to this income?

1.26 - How long have you been in your current job? (Interviewer: Single answer)

years or months NA (For those who are not current working)

1.27 - How many times have you changed jobs in the last 2 year?

times NA (For those who didn't work in the last 2 years)

1.28 - Do you have any savings?

- Yes
- No



1.29 - During the last 6 months, how often did you find yourself without enough money for basic necessities as housing, food, medical care?

- Constantly
- Sometimes
- Almost never
- Never

1.30 - During the last 6 months, how often were you unsure where the money would come from for such basic necessities as housing, food, medical care?

- Constantly
- Sometimes
- Almost never
- Never

1.31 - How many of each of the items below do you have at your residence? (Mark all apply)

TV:	<input type="text"/> <input type="text"/>	Maid:	<input type="text"/> <input type="text"/>
VCR/DVD:	<input type="text"/> <input type="text"/>	Vacuum:	<input type="text"/> <input type="text"/>
Radio:	<input type="text"/> <input type="text"/>	Washing machine:	<input type="text"/> <input type="text"/>
Bathroom:	<input type="text"/> <input type="text"/>	Refrigerator:	<input type="text"/> <input type="text"/>
Car:	<input type="text"/> <input type="text"/>	Freezer :	<input type="text"/> <input type="text"/>

1.32 - Currently, what is your religion?

- Catholicism
- Spiritism
- Evangelical (tradicional)
- Afro-Brazilian (Camdomble)
- Evangelical (pentecostal)
- Other
- None

1.33 - Have you ever been incarcerated?

- Yes No -> *If "not", go to 1.34 (Tick NA on 1.33)*

1.34 - Quantas vezes? Quanto tempo?

Times: Duration: Months (if more than one time, report longer sentence)

- NA

1.35 - Where were you born?

- Municipal District of Rio de Janeiro
- State of Rio de Janeiro, but in another municipal district
- Other state
- Other country

1.36 - Where did you grow up (until 18 years old)?

- Municipal District of Rio de Janeiro
- State of Rio de Janeiro, but in another municipal district
- Other state
- Other country

1.37 - How long have you lived in Rio de Janeiro (Municipal District)? (If less than one year, fill with 00)

year



Draft

ID:

SECTION 2: SEXUAL BEHAVIOR

Now, I would like to ask you some questions about your recent sexual relationships and behavior.

2.1 - Do you think of yourself as:

- Heterosexual Bisexual Homosexual Transexual

2.2 - In the past 6 months, how many different partners have you had sex with? (By 'have sex', I mean vaginal or anal sex)

- None 2 - 4 partners More than 10 partners
 Only one partner 5 - 10 partners

2.3 - Was the past 6 months typical for you in terms of the quantity of partners you had sex with?

- Yes - > If "yes" on 2.3 and "None" on 2.2, go to 2.9 (Tick NA on 2.4 - 2.8)
- > If "yes" on 2.3 and different of "none" on 2.2, go to 2.5 (Tick NA on 2.4)
 No

2.4 - If it was not a typical period, how many partners do you usually have sex with over a 6 months period?

- None 2 - 4 partners More than 10 partners
 Only one partner 5 - 10 partners NA

2.5 - How frequently did you have sexual intercourse onver the last 6 months?

- Daily Once or twice a month
 Almost daily Less than once a month
 Several times a week NA
 About once a week

2.6 - In the last 6 months, did you ever have sex, at least once, without using a condom?

- Yes No NA

2.7 - How frequently did you use condom in the last 6 months?

- Always- > If "always", go to 2.9 (Tick NA on 2.8)
 In the majority of the times
 In half of the times
 Sometimes
 Never
 NA

2.8 - Which were the reasons that you didn't use condom during the last 6 months? (Tick all that apply)

Interviewer: Read all the options below.

- Because condom compromise romanticism
 Because condom awaken suspicion of partner sexual behavior
 Because condom awaken suspicion about partner health
 Because condom can compromise men's pleasure
 Because condom can compromise women's pleasure
 Because condom can burst, so it's not reliable
 Because condom let AIDS virus pass through it, so it's not reliable
 Because I was desiring to be pregnant / Partner was desiring to have a child
 Because I didn't have enough money to buy it
 Religious reason
 NA



Draft

ID:

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2.9 - Since you were diagnosed with HIV, have you had any STDs (Sexual Transmitted Diseases like gonorrhea or syphilis) diagnosed by a doctor?

- Yes
- No - > *If "no", go to 2.12 (Tick NA on 2.10 - 2.11)*

2.10 - If yes, when was the last time you had an STD diagnosed by a doctor?

- Over the last 6 months
- Between 6 and 12 months
- More than one year ago
- NA

2.11 - If yes, which type was the last type of STD you had?

- Trichomoniasis
- Candidiasis
- Chlamydia
- Syphilis
- Gonorrhea
- Genital Herpes
- Genital warts/HPV
- Venereal lymphogranuloma
- Chancroid
- Hepatitis B
- Don't know
- NA

2.12 - Have you ever exchange sex for money, drug or other gifts?

- Yes
- No - > *If "no", go to next section (Tick NA on 2.13)*

2.13 - How often have you exchanged sex for money, drug or other gifts in the past 6 months?

- Daily
- Few times a week
- Few times a month
- Once a month
- Less than once a month
- Just a few times
- More than 6 months ago
- NA



Draft

ID:

SECTION 3: PARTNER GRID

Hadn't have steady partner over the last 6 months -> *Go to next section*

Interviewer: This section must be only answered by people who have/had STEADY PARTNER. If the interviewee hadn't have a steady partner over the last 6 months, go to next section.

(By Steady Partner I mean: person who you have a relationship as courtship, engagement, marriage or affair implying compromise.

Now I would like to ask you some questions about your most recent steady partner, during the last 6 months.

3.1 - How long had/have you been together? (Interviewer: Fill only one option)

years or months Less than one month

3.2 - What sex is this partner? Male Female

3.3 - How old is this partner? years

3.4 - Is this partner HIV positive?

- Yes
- No -> *If "no", go to 3.6 (Tick NA on 3.5)*
- Don't know -> *If "don't know", go to 3.6 (Tick NA on 3.5)*

3.5 - Is this partner taking HAART?

- Yes No Don't know NA

3.6 - Does this partner know you are HIV positive?

- Yes
- No -> *If "no", go to 3.8 (Tick NA on 3.7)*
- Don't know -> *If "don't know", go to 3.8 (Tick NA on 3.7)*

3.7 - When did you disclose your HIV status to this partner?

- Prior to first sexual contact
- After first sexual contact
- I was already with this person when I discovered I had HIV
- NA

3.8 - How often have you and your partner had sex (vaginal or anal sex) during the last 6 months?

- Every day Few times a week Few times a month
- Once a month Less than once a month Just once / few times
- During the last 6 months, I didn't have sex with my partner

3.9 - How often have you and your partner used condom when having sex (vaginal or anal sex) during the last 6 months?

- Always Almost always Sometimes Almost never Never

3.10 - When was the last time you and your partner had sex (vaginal or anal sex)? (Interviewer: Fill only one option)

days ago or months ago

3.11 - Did you and your partner use condom in this last sexual relation?

- Yes No I don't remember



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3.12 - Do you think your partner had other partner during this 6 months you were together? (OBS: For those who are less than 6 months with the partner, report the time they're together)

- Yes No Don't know

3.13 - Have you had other partner during this 6 months you were with this current partner? OBS: For those who are less than 6 months with the partner, report the time they're together)

- Yes No

3.14 - How often you and your partner drink before having sex?

- Very often Somewhat often Not very often Never

3.15 - How often you and your partner use drugs (not alcohol and tobacco) before having sex?

- Very often Somewhat often Not very often Never

3.16 - How often do you and your partner get high (under alcohol or drugs effect) before having sex?

- Very often Somewhat often Not very often Never

3.17 - How oftendo you and your partner have arguments (without physical hurt)?

- Very often Somewhat often Not very often Never

3.18 -Have you and your partner ever had an argument where he/she hit, slapped or physically hurt you?

- Many times Several times Just a few times Never

3.19 - Have you and your partner ever had an argument where he/she called you terrible names or made you feel really bad about yourself?

- Many times Several times Just a few times Never

3.20 - Do/did you want to use condom with your partner:

- Many times Several times Just a few times Never

3.21 - Does/did your partner want to use a condom with you:

- Many times Several times Just a few times Never

3.22 - How comfortable do you feel negotiating condom use with your partner?

- Very comfortable Somewhat comfortable Not very comfortable Very uncomfortable

3.23 - During the time you and your partner have been together, has he/she had an STD that you are aware of?

- Yes
 No - > If "No", go to next section (Tick NA on 3.24)

3.24 - If yes, when was the last time? (Interviewer: Fill only one option)

days ago or months ago or years ago

- NA



SECTION 4: FERTILITY AND CONTRACEPTIVE METHODS

Male homosexual couple (MSM) -> *If "MSM", go to the next section*

Now, I would like to ask you a few questions about your desire to have children and about contraceptive methods do you use.

ONLY FOR WOMAN

4.1 - How many times have you been pregnant in your lifetime? (When I say "pregnant" I mean miscarriage or termination of pregnancy (TOP), stillbirth and born alive) Interviewer: please, include current pregnancy.

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 times (Include miscarriage and TOP)

4.2 - How many times have you given birth to a live baby in your lifetime?

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 times

4.3 - How many times have you become pregnant since you were diagnosed with HIV? (When I say "pregnant" I mean any pregnancy that the result was miscarriage or termination of pregnancy (TOP), stillbirth and born alive) Interviewer: please, include current pregnancy, even if the she was diagnosed with HIV in the course of pregnancy.

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 times (include miscarriage and TOP)

4.4 - How many times, since you were diagnosed with HIV, have you given birth to a live baby

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 times

FOR ALL

Now I would like to ask you some questions about your desire to have children.

4.5 - Are you (or your partner) currently pregnant?

- Yes -> *If "yes", go to 4.9 (Tick NA on 4.6, 4.7 and 4.8)*
- No
- Not sure / Don't know

4.6 - Would you (or your partner) like to get pregnant now?

- Yes
- No -> *If "no", go to 4.8 (Tick NA on 4.7)*
- NA

4.7 - Are you (or your partner) currently trying to get pregnant?

- Sim -> *If "yes", go to 4.9 (Tick NA on 4.8)*
- Não
- NA

4.8 - Why aren't you (or your partner) currently trying to get pregnant?

- Because I'm HIV+
- Because I fell sick
- Other reason
- NA



4.9.1 - Would you like to have (more) children in the future?

- Yes
- No -> *If "no", go to 4.9.2 (Tick NA on 4.9.1A)*
- I'm not sure -> *If "no" or "I'm not sure", go to 4.9.2 (Tick NA on 4.9.1A)*

4.9.1A - How many (more) children would you like to have?

[][] children NA

Sometimes what a person wants and what they expect to happen are different and sometimes they are the same. You told me about you would like. Now I would like you to tell me what you expect to happen in terms of having more children in the future.

4.9.2 - Do you expect to have (more) children in the future?

- Yes
- No -> *If "no", go to 4.10 (Tick NA on 4.9.2A)*
- I'm not sure -> *If "I'm not sure", go to 4.10 (Tick NA on 4.9.2A)*

4.9.2A - How many (more) children do you expect to have?

[][] children NA

4.10 - Have any health care worker ever told you that you or your partner shouldn't get pregnant?

- Yes
- No

4.11 - Have you ever talked with your steady partner about having (more) children in the future?

- Yes
- No
- I don't have a steady partner -> *Se "nãõ", ir para a questão 4.16 (MARCAR NA EM 4.12 a 4.15)*

4.12 - In the last 6 months, have you and your partner used anything to prevent becoming pregnant, such as condom, pills, injectables, loop, hysterectomy, vasectomy or other method?

- Yes
- No -> *If "no", go to 4.15 (Tick NA on 4.13 and 4.14)*
- NA

ONLY FOR HETEROSEXUAL COUPLE

4.13 - What type of prevention methods have you and your partner used in the last 6 months? (Select all that apply)

Interviewer: If hysterectomy or sterilization, please note date. Fill if 88 if don't remember the day, 88 if don't remember the month and 8888 if don't remember the year.

Interviewer: DON'T READ THE OPTIONS. Tick the closest option to the interviewee answer)

- Pill (Oral contraceptive)
- Injectables (Depo-Provera or Nuristerate)
- Loop or IUD
- Implant
- Diaphragm
- Condom (male)
- Condom (female)
- Hysterectomy (removal of the uterus) → [][] / [][] / [][][][]
- Female sterilization (tubal ligation) → [][] / [][] / [][][][]
- Male sterilization (vasectomy) → [][] / [][] / [][][][]
- Other, specify: _____
- NA



Only for heterosexual couple

4.14 - What is the main reason you chose the method of prevention you and your partner use most consistently in the last 6 months? (SINGLE ANSWER) Interviewer: DON'T READ THE OPTIONS. Mark the closest option to the interviewee's answer.

Specify method _____

- It is easy to use
- It is convenient / more convenient
- It does not interfere with sexual activity
- It protects against transmission of sexual transmitted diseases and HIV/Aids
- It is good at preventing pregnancy
- My partner won't find out I'm using prevention
- My partner won't use birth control himself/herself
- I can use it only when needed
- It is cheap
- It has few or no side effect
- A doctor or nurse recommended it
- My friends use it
- My partner wants me to use this type of prevention
- I can decide when to use it an when not to
- Other, specify: _____
- NA

4.15 - Why haven't you used any prevention methods in the last 6 months? (Tick NA for those who answered "yes" on 4.12) Interviewer: DON'T READ THE OPTIONS. Mark the closest option to the interviewee's answer.

- I'm (my partner is) pregnant
- I'm (my partner is) trying to become pregnant
- I can get an abortion if I (my partner) become pregnant
- I'm not having sex
- I don't mind if I (my partner) become pregnant
- Health related side effects of prevention methods
- I don't believe in using prevention
- I don't know why / No reason
- I (my partner) cannot become pregnant (I'm infertile)
- My partner will not use and/or will not let me use prevention
- Other, specify: _____
- NA

For all

4.16 - How much do you agree with the sentence: If an HIV positive woman wants to have a baby, it is okay for her to try and get pregnant"?

- Strongly agree
- Somewhat agree
- Somewhat disagree
- Strongly disagree

4.17 - Have you and your doctor ever talked about the possibility of future pregnancy?

- Yes No



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SECTION 5: SAFE SEX BURN-OUT

Please, tell me how much do you agree or disagree with the following statements about condom use and HIV/STDs prevention.

5.1 - I feel tired of using condoms.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree
5.2 - I have given up worrying about whether I use condoms or not.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree
5.3 - I feel as though I've been using condoms forever.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree
5.4 - I often wish for a day when I don't have to worry about condoms anymore.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree
5.5 - Using condoms is become exhausting.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree
5.6 - I'm tired of worrying about HIV/STDs.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree
5.7 - I often feel like I don't have the energy to worry about condoms anymore.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree
5.8 - I have given up on worrying about HIV/STDs.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree



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SECTION 6: SOCIAL SUPPORT

People often look to others for companionship, assistance, or other types of support. In the last month, how often were each of the following kinds of support available to you if you needed...

6.1 -Someone to take you to the doctor if you needed?	<input type="checkbox"/> All of the time (Always) <input type="checkbox"/> Most of the time (Almost always) <input type="checkbox"/> Some of the time (Sometimes) <input type="checkbox"/> Almost none of the time (Rarely) <input type="checkbox"/> None of the time (Never)
6.2 -Someone to help you get your medicines?	<input type="checkbox"/> All of the time (Always) <input type="checkbox"/> Most of the time (Almost always) <input type="checkbox"/> Some of the time (Sometimes) <input type="checkbox"/> Almost none of the time (Rarely) <input type="checkbox"/> None of the time (Never)
6.3 - Someone to help with daily chores is you were sick?	<input type="checkbox"/> All of the time (Always) <input type="checkbox"/> Most of the time (Almost always) <input type="checkbox"/> Some of the time (Sometimes) <input type="checkbox"/> Almost none of the time (Rarely) <input type="checkbox"/> None of the time (Never)
6.4 - Someone to give you a place to stay?	<input type="checkbox"/> All of the time (Always) <input type="checkbox"/> Most of the time (Almost always) <input type="checkbox"/> Some of the time (Sometimes) <input type="checkbox"/> Almost none of the time (Rarely) <input type="checkbox"/> None of the time (Never)
6.5 - Someone to prepare your meals if you weren't able?	<input type="checkbox"/> All of the time (Always) <input type="checkbox"/> Most of the time (Almost always) <input type="checkbox"/> Some of the time (Sometimes) <input type="checkbox"/> Almost none of the time (Rarely) <input type="checkbox"/> None of the time (Never)
6.6 - Someone to give you money?	<input type="checkbox"/> All of the time (Always) <input type="checkbox"/> Most of the time (Almost always) <input type="checkbox"/> Some of the time (Sometimes) <input type="checkbox"/> Almost none of the time (Rarely) <input type="checkbox"/> None of the time (Never)
6.7 - Someone to help you if you were confined to bed?	<input type="checkbox"/> All of the time (Always) <input type="checkbox"/> Most of the time (Almost always) <input type="checkbox"/> Some of the time (Sometimes) <input type="checkbox"/> Almost none of the time (Rarely) <input type="checkbox"/> None of the time (Never)
6.8 - Someone to confide in or talk to about yourself or your problems?	<input type="checkbox"/> All of the time (Always) <input type="checkbox"/> Most of the time (Almost always) <input type="checkbox"/> Some of the time (Sometimes) <input type="checkbox"/> Almost none of the time (Rarely) <input type="checkbox"/> None of the time (Never)



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6.9 - Someone to shows you love and affection?	<input type="checkbox"/> O tempo todo (Sempre) <input type="checkbox"/> A maior parte do tempo (Quase sempre) <input type="checkbox"/> Raramente (Às vezes) <input type="checkbox"/> Quase nunca (Muito raramente) <input type="checkbox"/> Não teria ajuda (Nunca)
6.10 - Someone to make you feel wanted?	<input type="checkbox"/> O tempo todo (Sempre) <input type="checkbox"/> A maior parte do tempo (Quase sempre) <input type="checkbox"/> Raramente (Às vezes) <input type="checkbox"/> Quase nunca (Muito raramente) <input type="checkbox"/> Não teria ajuda (Nunca)
6.11 - Someone to have a good time with?	<input type="checkbox"/> O tempo todo (Sempre) <input type="checkbox"/> A maior parte do tempo (Quase sempre) <input type="checkbox"/> Raramente (Às vezes) <input type="checkbox"/> Quase nunca (Muito raramente) <input type="checkbox"/> Não teria ajuda (Nunca)
6.12 - Someone to get together with for relaxation?	<input type="checkbox"/> O tempo todo (Sempre) <input type="checkbox"/> A maior parte do tempo (Quase sempre) <input type="checkbox"/> Raramente (Às vezes) <input type="checkbox"/> Quase nunca (Muito raramente) <input type="checkbox"/> Não teria ajuda (Nunca)
6.13 - In general, how satisfied are you with the overall support you get from your friends and family members?	<input type="checkbox"/> O tempo todo (Sempre) <input type="checkbox"/> A maior parte do tempo (Quase sempre) <input type="checkbox"/> Raramente (Às vezes) <input type="checkbox"/> Quase nunca (Muito raramente) <input type="checkbox"/> Não teria ajuda (Nunca)

6.14 - About how many adults do you recognize or know by sight in this neighborhood?

- No adults
- A few
- Many
- Most of the adults in my neighborhood

6.15 - In the past 30 days, how many of your neighbors have you talked with for 10 min or more?

- None
- Just one neighbor
- 2 - 5 neighbors
- 6 or more neighbors

6.16 - Think about the neighbor you are friendliest with, how close do you feel you are to this neighbor?

- Don't know neighbors / Don't have any contact
- Not Close
- Acquaintances
- Friends
- Very close

6.17 - How many of your friends live in the neighborhood?

- None
- Few
- Some
- Most or all



SECTION 7: DISCLOSURE

People have different thoughts and experiences regarding disclosure of their HIV status. I would like to ask you a few questions about this issue now. Tell me how strongly do you agree or disagree with the following:

7.1 - I feel that it is important that close friends know that I am HIV positive.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree
7.2 - I feel that it is important that people I have sex with know that I am HIV positive.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree
7.3 - I feel comfortable talking to others about my HIV status.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree
7.4 - I am afraid that others will not accept me if I tell them that I am HIV positive.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree
7.5 - I prefer not to have romantic relationships to avoid having to tell people that I am HIV positive.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree
7.6 - I feel that it is important that my family members know that I am HIV positive.	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Strongly disagree

7.7 - Do your family members know your HIV status?

Yes

No, nobody knows -> If "no, nobody knows", go to 7.8 (Tick NA on 7.7A)

7.7A - If yes, who? (Multiple answer are allowed)

My partner

My children

My parents

Brother/Sister

My cousin/ uncle/aunt/grandparents

Others

NA

7.8 - Do your neighbors know your HIV status?

No, nobody knows

Yes, but just few neighbors

Yes, everybody I have contact



SECTION 8: ALCOHOL AND DRUG USE

8.1 - The following questions are about your experience with drugs (excluding prescribed medicines). Please tell me whether you have ever used any of the following drugs, whether they are injected and which ones you are currently using (by "currently" I mean in the past 3 months)

<i>If the interviewee answer "no" on "Ever used", go to next item (drug)</i>	<i>If the interviewee answer "no" on "Current use" go to next item (drug)</i>	Frequency of currently use: (past 3 months)
Cocaine Ever used? <input type="checkbox"/> Yes <input type="checkbox"/> No Injected? <input type="checkbox"/> Yes <input type="checkbox"/> No Snorted? <input type="checkbox"/> Yes <input type="checkbox"/> No	Current use? <input type="checkbox"/> Yes <input type="checkbox"/> No Injected? <input type="checkbox"/> Yes <input type="checkbox"/> No Snorted? <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Less than once a week <input type="checkbox"/> At least once a week <input type="checkbox"/> Daily
Crack Ever used? <input type="checkbox"/> Yes <input type="checkbox"/> No Injected? <input type="checkbox"/> Yes <input type="checkbox"/> No Smoked? <input type="checkbox"/> Yes <input type="checkbox"/> No	Current use? <input type="checkbox"/> Yes <input type="checkbox"/> No Injected? <input type="checkbox"/> Yes <input type="checkbox"/> No Smoked? <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Less than once a week <input type="checkbox"/> At least once a week <input type="checkbox"/> Daily
Heroin Ever used? <input type="checkbox"/> Yes <input type="checkbox"/> No Injected? <input type="checkbox"/> Yes <input type="checkbox"/> No Snorted? <input type="checkbox"/> Yes <input type="checkbox"/> No	Current use? <input type="checkbox"/> Yes <input type="checkbox"/> No Injected? <input type="checkbox"/> Yes <input type="checkbox"/> No Snorted? <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Less than once a week <input type="checkbox"/> At least once a week <input type="checkbox"/> Daily
Amphetamine Ever used? <input type="checkbox"/> Yes <input type="checkbox"/> No Injected? <input type="checkbox"/> Yes <input type="checkbox"/> No Oral? <input type="checkbox"/> Yes <input type="checkbox"/> No	Current use? <input type="checkbox"/> Yes <input type="checkbox"/> No Injected? <input type="checkbox"/> Yes <input type="checkbox"/> No Oral? <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Less than once a week <input type="checkbox"/> At least once a week <input type="checkbox"/> Daily
Anabolic Steroids (not prescribed by physician) Ever used? <input type="checkbox"/> Yes <input type="checkbox"/> No Injected? <input type="checkbox"/> Yes <input type="checkbox"/> No Oral? <input type="checkbox"/> Yes <input type="checkbox"/> No	Current use? <input type="checkbox"/> Yes <input type="checkbox"/> No Injected? <input type="checkbox"/> Yes <input type="checkbox"/> No Oral? <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Less than once a week <input type="checkbox"/> At least once a week <input type="checkbox"/> Daily

8.2 - Next are the non-injection drugs:

<i>If the interviewee answer "no" on "Ever used", go to next item (drug)</i>	<i>If the interviewee answer "no" on "Current use" go to next item (drug)</i>	Frequency of currently use: (past 3 months)
Ecstasy Ever used? <input type="checkbox"/> Yes <input type="checkbox"/> No	Current use? <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Less than once a week <input type="checkbox"/> At least once a week <input type="checkbox"/> Daily
Hallucinogens (LSD, acid,...) Ever used? <input type="checkbox"/> Yes <input type="checkbox"/> No	Current use? <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Less than once a week <input type="checkbox"/> At least once a week <input type="checkbox"/> Daily
Sniffing (glue, ether, solvents...) Ever used? <input type="checkbox"/> Yes <input type="checkbox"/> No	Current use? <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Less than once a week <input type="checkbox"/> At least once a week <input type="checkbox"/> Daily



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Only for MEN:		
<i>If the interviewee answer "no" on "Ever used", go to 8.3</i>	<i>If the interviewee answer "no" on "current use", go to 8.3</i>	Frequency of currently use: (past 3 months)
Viagra/Cialis/Levitra Ever used? <input type="checkbox"/> Yes <input type="checkbox"/> No	Current use? <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Less than once a week <input type="checkbox"/> At least once a week <input type="checkbox"/> Daily

8.3 - Alcohol use

<i>If the interviewee answer "no" on "Ever used", go to next section</i>	<i>If the interviewee answer "no" on "current use", go to 8.5</i>	Frequency of currently use: (past 3 months)
Alcohol Ever used? <input type="checkbox"/> Yes <input type="checkbox"/> No	Current use? <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Less than once a week <input type="checkbox"/> At least once a week <input type="checkbox"/> Daily

8.4 - Have you ever drunk regularly (more than 4 times a week)?

- Yes
- No -> *If "no", go to 8.6 (Fill in with 00 on 8.4A)*

8.4A - How old were you when you first started to drink alcohol on a weekly basis?

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years

8.5 - In the last 6 months, have you binged on alcohol (5 drinks or more on one occasion)?

- Yes
- No

8.6 - Have you ever felt you should cut down on your drinking?

- Yes
- No

8.7 - Have people annoyed you by criticizing your drinking?

- Yes
- No

8.8 - Have you ever felt bad or guilty about drinking?

- Yes
- No

8.9 - Have you ever had a drink first thing in the morning (as an "eye opener") to steady your nerves or get rid of a hangover?

- Yes
- No

8.10 - Do you drink less because you're taking antiretroviral medications?

- Yes, I'm drinking less than before
- No, I'm not drinking less than before
- I'm not taking antiretroviral medications
- I quit drinking before start taking antiretroviral medications

8.11 - Have you ever been in any kind of alcohol and/or drug treatment program?

- Yes
- No -> *If "no", go to next section (Tick NA on 8.11A)*

8.11A - When was it?

- More than 6 months ago
- Less than 6 months ago
- NA



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SECTION 9: ATTITUDES AND BELIEFS ABOUT HIV TREATMENT

Now I'd like to ask you some questions about HAART or the medications that are now available to treat HIV. Tell me how much do you agree with the statements below.

9.1 - HIV treatments take the worry out of sex.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
9.2 - If every HIV positive person took the treatments, the AIDS epidemic would be over.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
9.3 - An HIV person on treatments is unlikely to transmit HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
9.4 - Treatments for HIV/AIDS make safe sex less important than it was.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
9.5 - People with undetectable viral load do not need to worry so much about infecting others with HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
9.6 - Until there is a complete cure for HIV/AIDS, prevention is still the best practice.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
9.7 - HIV/AIDS is a less serious threat because of the treatments.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
9.8 - It's never safe to have sex without a condom, regardless of viral load.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
9.9 - It is just as important to practice safe sex now, than it was before the treatments.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
9.10 - I am less worried about HIV now that treatment has improved.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
9.11 - Treatments have made me more willing to take risks with my partner.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree



SECTION 10: EXPERIENCE WITH HIV/AIDS

The following questions are about your experience living with HIV. Please first tell me..

10.1 - When were you diagnosed with HIV? Interviewer: Fill with 88 if doesn't remember the month and with 8888 if doesn't remember the year.

[][] / [][][][] (month/year)

10.2 - Where/by who were you diagnosed with HIV?

- HIV Anonymous C&T clinic
- STD Clinic
- Antenatal clinic
- Private physician
- Hospital
- Outro _____

10.3 - What is the most likely way that you were infected with HIV?

- Sex with an HIV+ man
- Sex with an HIV+ woman
- Sharing needles with HIV+ person
- Blood transfusion
- Don't know
- Other: _____

10.4 - When did you begin taking HAART? Interviewer: Fill with 88 if doesn't remember the month and with 8888 with doesn't remember the year.

[][] / [][][][] (month/year)

Not in HAART

10.5 - have you ever been hospitalized for HIV related symptoms?

- Yes
- No -> If "no", go to 10.8 (Tick NA on 10.6 and 10.7)

10.6 - How many times? [][] times NA

10.7 - When was the last time you were hospitalized for HIV related symptoms? Interviewer: Fill with 88 if doesn't remember the month and with 8888 if doesn't remember the year.

[][] / [][][][] (month/year) NA

10.8 - What is your current viral load? [] . [][][] . [][][] Indetectable Don't know

10.9 - What is your current CD4 count? [] . [][][] Don't know

10.10 - Are any of your family members infected with HIV?

- Yes
- No -> If "no", go to 10.13 (Tick NA on 10.10a and 10.12b)



10.10a - How many people?

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 NA

10.10b - Whom?

Partner

Son/daughter →

--	--

 (Number of infected children)

Other _____

NA

10.11 - Are any of your family members currently taking HAART?

Yes

No → *If "no", go to 10.12 (Tick NA on 10.11a and 10.11b)*

NA

10.11a - How many people?

--	--

 NA

10.11b - Whom?

Partner

Son/daughter →

--	--

 (Number of infected children)

Other _____

NA

10.12 - Are you the primary caretaker for any family members living with HIV?

Yes

No → *If "no", go to 10.13 (Tick NA on 10.12a and 10.12b)*

NA

10.12a - How many people?

--	--

 NA

10.12b - Quem são?

Partner

Son/daughter →

--	--

 (Number of infected children)

Other _____

NA

10.13 - Over the past 6 months, how would you rate your physical health?

Poor

Fair

Good

Very good

Excellent

10.14 - Thinking about the next 5 years, how would you predict your physical health?

Poor

Fair

Good

Very good

Excellent



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SECTION 11: ADHERENCE TO HAART

Not in HAART -> If "not in HAART", go to next section

Now I'd like to ask you a few more questions about how you're doing taking your HIV related medications. We want to better understand how people with HIV are really doing with their medications. So please tell us what you are actually doing. Don't worry about telling us if you don't take all of your pills all of the time. We need to know what is really happening, not what you think we want to hear.

11.1 - During the past 4 days, on how many days did you TAKE all of your doses of all your HIV medications?

- None Three days
- One day Four days
- Two days

11.2 - During the past 4 days, on how many days did you MISS all of your doses of all your HIV medications?

- None Three days
- One day Four days
- Two days

11.3 - Most HIV medications need to be taken on a schedule, such as "2 times a day" or "3 times a day" or "every 8 hours". How closely did you follow your specific schedule for all of the medications you are taking over the last 4 days?

- Never
- Some of the time
- About half of the time
- Most of the time
- All of the time

11.4 - Do any of your HIV medications have instructions such as "take with food" or "on an empty stomach" or "with plenty of fluid"?

- Yes
- No -> If "no", go to 11.5 (Tick NA on 11.4a)

11.4a - How often did you follow those special instructions over the last 4 days?

- Never
- Some of the time
- About half of the time
- Most of the time
- All the time
- NA

11.5 - Some people find it hard to take pills on the weekend days. Did you miss any of your HIV medications last weekend (Saturday or Sunday)?

- Yes No

11.6 - When was the last time you missed taking any of your medications?

- Within the past week —————> How many days ago? days (1-7)
- 1-2 weeks ago (8-13 days)
- 2-4 weeks ago (14 - 28 ago)
- More than 3 months ago
- Never skip medications
- 1-3 months ago



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SECTION 12: APPOINTMENT ADHERENCE

12.1 - Have you missed any HIV medical appointments in the past 6 months?

Yes

No -> If "no", go to next section (Tick NA on 12.2a - 12.2k)

12.2 - Did you miss your medical appointment because:

a. You had family responsibilities (i.e had to care for a child or an adult)?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA
b. Had work responsibilities?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA
c. Weren't feeling well physically (i.e tired, sick or ill, asleep)?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA
d. Weren't feeling well emotionally (i.e depressed, embarrassed, afraid, reminds you of your HIV status)?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA
e. You don't feel like you're treated well by your doctor or clinic staff?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA
f. You forgot?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA
g. You were using/under effect of alcohol or drugs?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA
h. You didn't think your treatment was working?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA
i. You couldn't afford to go?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA
j. You had transportation problems?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA
k. You don't feel comfortable coming to the clinic?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA



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SECTION 13 - RELATED STIGMA AND DISCRIMINATION

How strongly do you agree with the following statements?

13.1 - Having HIV makes me feel like a bad person.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
13.2 - I feel like I'm not as good as others because I have HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
13.3 - Having HIV makes me feel unclean.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
13.4 - Having HIV in my body is disgusting to me.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
13.5 - People's attitudes about HIV makes me feel worse about myself.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
13.6 - I feel guilty because I have HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
13.7 - I never feel ashamed of having HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
13.8 - Its easy to avoid friendships than worry about telling others I have HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree



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DISCRIMINATION

13.9 - I have lost friends by telling them I have HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
13.10 - People I care about stopped speaking to me after learning I had HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
13.11 - I have lost a job because of having HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
13.12 - I have lost a romantic partner because of having HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
13.13 - I have been denied health care because of having HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree

13.14 - I have experienced discrimination because of having HIV.

- Many times
- Some times
- Rarely
- Never

13.15 - I have experienced verbal abuse because of having HIV.

- Many times
- Some times
- Rarely
- Never

13.16 - I have experienced physical violence related to having HIV.

- Many times
- Some times
- Rarely
- Never



SECTION 14 - PROVIDER RELATIONSHIP

The following questions have to do with your experience here at the clinic and clinic's staff. Remember that all the information you provide here is confidential. I'd ask you to be as open as possible in your responses. I'm going to start by asking you a few questions about your relationship with your doctor. Please, tell me how much you agree with the following statements.

14.1 - I doubt that my doctor(s) really cares about me as a person.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
14.2 - My doctor(s) is/are considerate of my needs and concerns.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
14.3 - My doctor takes the time to explain my treatment plan slowly and clearly.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
14.4 - I feel comfortable asking my doctor questions about my care.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
14.5 - I trust my doctor's judgments about my medical care.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree



□ □ □ □ □

<p>14.6 - I feel my doctor does not do everything he/she could about my medical care.</p>	<p><input type="checkbox"/> Totally agree</p> <p><input type="checkbox"/> Somewhat agree</p> <p><input type="checkbox"/> Somewhat disagree</p> <p><input type="checkbox"/> Totally disagree</p>
<p>14.7 - My doctor often seems very distracted when I meet with him/her.</p>	<p><input type="checkbox"/> Totally agree</p> <p><input type="checkbox"/> Somewhat agree</p> <p><input type="checkbox"/> Somewhat disagree</p> <p><input type="checkbox"/> Totally disagree</p>
<p>14.8 - My doctor is well qualified to manage medical problems like mine.</p>	<p><input type="checkbox"/> Totally agree</p> <p><input type="checkbox"/> Somewhat agree</p> <p><input type="checkbox"/> Somewhat disagree</p> <p><input type="checkbox"/> Totally disagree</p>
<p>14.9 - When my doctor gives me information about my treatment, I often come away feeling confused.</p>	<p><input type="checkbox"/> Totally agree</p> <p><input type="checkbox"/> Somewhat agree</p> <p><input type="checkbox"/> Somewhat disagree</p> <p><input type="checkbox"/> Totally disagree</p>
<p>14.10 - I feel respected by my doctor.</p>	<p><input type="checkbox"/> Totally agree</p> <p><input type="checkbox"/> Somewhat agree</p> <p><input type="checkbox"/> Somewhat disagree</p> <p><input type="checkbox"/> Totally disagree</p>
<p>14.11 - my doctor takes the time to ask me how I'm feeling.</p>	<p><input type="checkbox"/> Totally agree</p> <p><input type="checkbox"/> Somewhat agree</p> <p><input type="checkbox"/> Somewhat disagree</p> <p><input type="checkbox"/> Totally disagree</p>
<p>14.12 - I sometimes worry that my doctor may not keep the information we discuss totally private.</p>	<p><input type="checkbox"/> Totally agree</p> <p><input type="checkbox"/> Somewhat agree</p> <p><input type="checkbox"/> Somewhat disagree</p> <p><input type="checkbox"/> Totally disagree</p>



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SECTION 15 - CLINIC STAFF

Now I'd like to ask you a few questions about your interaction with the other staff here in the clinic:

15.1 - The staff here is available to help me.

- Always
- Most of the time
- Some times
- Rarely or never

15.2 - The staff here treats me with respect.

- Always
- Most of the time
- Some times
- Rarely or never

15.3 - Overall, I think the services here are:

- Excellent
- Very good
- Good
- Adequate
- Weak

15.4 - How often do you come to this clinic to be seen by a doctor?

- More than once a month
- At least once a month
- Every 2 months, approximately
- A cada 3 meses aproximadamente
- Intervals greater than 3 months

15.5 - How often do you come to this clinic to get your medicines?

- At least once a month
- Every 2 months, approximately
- Every 3 months, approximately
- Interval greater than 3 months
- I don't get medicines

15.6 - Do you also see another doctor for your HIV treatment?

- Yes
- No -> If "no", go to 15.8 (Tick NA on 15.7)

15.7 - Is this doctor a private physician outside SUS (public system)?

- Yes
- No
- NA

15.8 - Do you have private health insurance?

- Yes
- No



SECTION 16 - EXPOSURE TO INTERVENTION AND OTHER SOCIAL ACTIVITIES

16.1 - Do you participate in any type of individual counseling or case management at the present time (i.e psychologist , social assistent)?

- Yes
- No -> *If "no", go to 16.2 (Tick NA on 16.1A and 16.1B)*

16.1A - Where?

- At this clinic
- At another public clinic
- At private clinic
- NGOs (Pela Vidda, Abia, etc)
- NA

16.1B - How often?

- Daily
- Almost everyday
- Many times a week
- Once or twice a month
- Less than once a month
- NA

16.2 - Do you participate in any type of support groups or group activities related to HIV/AIDS?

- Yes
- No -> *Se "não", ir para a questão 16.3 (MARCAR NA EM 16.2A, 16.2B e 16.2 C)*

16.2A - Where?

- At this clinic
- At another public clinic
- At private clinic
- NGOs (Pela Vidda, Abia, etc)
- NA

16.2B - How often?

- Daily
- Almost everyday
- Many times a week
- Once or twice a month
- Less than once a month
- NA

16.2C - What type of activity?

- AA/ NA
- Therapeutic community
- Group therapy with phychologist/physician
- Mutual support group of PLWHA
- Other
- NA



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16.3 - Thinking more broadly about all the different types of group activities you maybe involved in, such as church, clubs, associations etc., can you tell me if you have participated in any of the following activities in the last 6 months?

- Church/Religious groups
- Neighborhood association
- Social clubs
- Voluntary organization (i.e. NGOs)
- Other _____
- I don't participate of any group activities

16.4 - How many different goup activities in total have you been involved in over the last 6 months?

--	--

16.5 - Do you help out a local group as a volunteer?

- Yes
- No

16.6 - Do you go outside your local community to visit your family?

- Yes
- No

16.7 - Over the weekend do you have lunch/dinner with other people outside your household?

- Yes
- No



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SECTION 17 - DEPRESSION AND ANXIETY

I'd like you to think about how you felt over this past week as you respond to the following questions. During the past week, would you say...

17.1 - I felt tense or "wound up":

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

17.2 - I enjoyed the things I used to enjoy:

- Definitely as much
- Not quite as much
- Only a little
- Hardly at all

17.3 - I got a frightened feeling as if something awful was about to happen:

- Very definitely and quite badly
- Yes, but not too badly
- A little but it doesn't worry me
- Not at all

17.4 - I was able to laugh and see the funny side of things:

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

17.5 - I had worrying thoughts go through your mind:

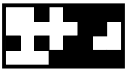
- A great deal of the time
- A lot of the time
- From time to time, but not too often
- Only occasionally

17.6 - I felt cheerful:

- Not at all
- Not often
- Sometimes
- Most of the time

17.7 - I could sit at ease and feel relaxed:

- Definitely
- Usually
- Not often
- Not at all



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17.8 - I felt slowed down:

- Nearly all the time
- Very often
- Sometimes
- Not at all

17.9 - I had a frightened feeling like "butterflies" in your stomach:

- Not at all
- Ocasionalmente
- Quite often
- Very often

17.10 - I lost interest in my appearance:

- Definitely lost interest
- I don't take as much care as I should
- I may not take quite as much care
- I take just as much care as ever

17.11 - I felt restless as if I had to be on the move:

- Very much indeed
- Quite a lot
- Not very much
- Not at all

17.12 - I looked forward with enjoyment to things:

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

17.13 - I got sudden feelings of panic:

- Very often indeed
- Quite often
- Not very often
- Not at all

17.14 - I could enjoy a good book, radio or TV program:

- Often
- Sometimes
- Not often
- Very seldom



Four empty boxes for ID number

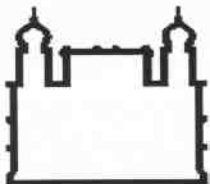
SECTION 18 - HIV ACCEPTANCE

The next questions are about how you currently feel regarding your HIV diagnosis. Tell me how strongly do you agree with the following statements.

18.1 - I have accepted the fact that I have HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
18.2 - I feel at peace with my HIV diagnosis.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
18.3 - I worry about the illness getting worse.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
18.4 - I see HIV as a part of my life now.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
18.5 - I spend a lot of time hoping that they'll find a cure for HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
18.6 - I feel very angry about having HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
18.7 - I really don't believe my HIV test result.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
18.8 - When I think about having HIV, I feel overwhelmed.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
18.9 - I suffer great anxiety about having HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree
18.10 - I keep thinking about what I could have done differently so that I wouldn't have gotten HIV.	<input type="checkbox"/> Totally agree <input type="checkbox"/> Somewhat agree <input type="checkbox"/> Somewhat disagree <input type="checkbox"/> Totally disagree

Time ended: :

VIII. Fiocruz Ethics Committee Approval from Present Study



Ministério da Saúde

FIOCRUZ

Fundação Oswaldo Cruz
Escola Nacional de Saúde Pública Sergio Arouca
Comitê de Ética em Pesquisa



Rio de Janeiro, 16 de agosto de 2011.

O Comitê de Ética em Pesquisa da Escola Nacional de Saúde Pública Sergio Arouca – CEP/ENSP, constituído nos Termos da Resolução CNS nº 196/96 e, devidamente registrado na Comissão Nacional de Ética em Pesquisa - CONEP, recebeu, analisou e emitiu parecer sobre a documentação referente ao Protocolo de Pesquisa, conforme abaixo, discriminado:

PROTOCOLO DE PESQUISA CEP/ENSP - Nº 172/11
CAAE: 0183.0.031.000-11

Título do Projeto: “ Otimismo relacionado ao tratamento e comportamentos de risco entre pessoas vivendo com HIV/AIDS em acompanhamento em serviços públicos do Rio de Janeiro. ”

Classificação no Fluxograma: Grupo III

Será encaminhado à Conep (áreas temáticas especiais) e, portanto, deve aguardar a apreciação final desta para início da execução? Não

Pesquisadora Responsável: Iliana Alexandra Angulo Arreola

Orientadores: Monica Malta e Angela Esher

Instituição onde se realizará: Escola Nacional de Saúde Pública Sergio Arouca – ENSP/FIOCRUZ

Data de recebimento no CEP-ENSP: 07 / 07 / 2011

Data de apreciação: 10 / 08 / 2011

Parecer do CEP/ENSP: Aprovado.

Ressaltamos que a pesquisadora responsável por este Protocolo de Pesquisa deverá apresentar a este Comitê de Ética um relatório das atividades desenvolvidas no período de 12 meses a contar da data de sua aprovação (*item VII.13.d., da resolução CNS/MS Nº 196/96*) de acordo com o modelo disponível na página do CEP/ENSP na internet.

Esclarecemos, que o CEP/ENSP deverá ser informado de quaisquer fatos relevantes (incluindo mudanças de método) que alterem o curso normal do estudo, devendo a pesquisadora justificar caso o mesmo venha a ser interrompido.


Prof. Angela Esher
Coordenadora
Comitê de Ética em Pesquisa
CEP/ENSP

CEP/ENSP
HORA: 12:06
DATA: 22/08/2011
RECEBI: Iliana Alexandra