Title
Barriers to Anti-Retroviral Therapy among Men who have sex with men in West Bengal, India

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Barriers to Anti-Retroviral Therapy among Men who have sex with men in West Bengal, India

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of Philosophy in Epidemiology

by

Debottam Pal

2017
ABSTRACT OF THE DISSERTATION

Barriers to Anti-Retroviral Therapy among Men who have sex with men in West Bengal, India

by

Debottam Pal

Doctor of Philosophy in Epidemiology

University of California, Los Angeles, 2017

Professor Roger Detels, Chair

OBJECTIVES

To explore the challenges and barriers to the continuum of HIV care and services of Men who have sex with men (MSM) living with HIV through qualitative inquiries and to measure adherence to Anti-Retroviral Therapy (ART), and barriers that hinder ART access.

METHODOLOGY

The study was conducted in Kolkata, India. During the qualitative phase, we conducted one Focus Group Discussion (FGD) with a MSM community-based organization (CBO) and 6 in-depth interviews (IDI) with MSM assigned to ART. In the quantitative phase, we recruited 104 seropositive MSM, who had been assigned to ART. We conducted a baseline Audio Computer-Assisted Self-Interview (ACASI) with the participants. A follow-up ACASI was conducted after 3 months. We employed the Aids Clinical Trial Group questionnaire and Homosexuality Stigma Scale for collection of relevant information.
RESULTS

The FGD and IDIs with seropositive MSM’s, identified several barriers they have to overcome in order to access free HIV care services in India. Social discrimination and barriers to HIV testing as well as of ART adherence. Poor health system responsiveness emerged as a major theme. The baseline ACASI revealed that 36% (95%CI: 26%, 45%) of the MSM’s were depressed. Depression was significantly associated with increased internalized stigma. An increase by 5 units in the stigma scale was associated with an increment of 1 unit on the depression scale (adjβ: 0.2, 95%CI: 0.1, 0.3). Self-reported adherence to ART reveals MSM’s were similarly adherent 67% (95%CI: 57%, 77%) as the general adult population. Among those who missed ART pills (n=41), 44% of the MSM’s just had forgot to take their medications. Fearing stigma, 24% did not want it to be know he takes ART medications and thus skipped medications. Linear multivariate analysis revealed that depression among MSM’s lowered adherence score (adjβ: -3.2, 95%CI: -4.9, -1.5). Alcoholics had a significantly lower score of adherence as compared to non-alcoholics (adjβ: -14.6, 95%CI: -25.0, -4.2), after controlling for other variables. Being less confident to be able to take medications at baseline significantly decreased the adherence score by 26 units when compared to those who were confident at baseline. (adjβ: -27.1, 95%CI: -39.2, -14.9), after controlling for other variables.

CONCLUSION

Our study findings will help fill some of the existing knowledge gaps regarding mental health status of MSM’s living with HIV in India and barriers of ART adherence among these socially marginalized population. We expect the findings to inform design and
implementation of suitable and effective intervention strategies targeted to improve the quality of life of HIV infected MSM living in India.
This dissertation of Debottam Pal is approved.

Li Li

Ronald S. Brookmeyer

Dallas T. Swendeman

Roger Detels, Committee Chair

University of California, Los Angeles

2017
Dedicated to

Mrs Shila Pal and Dr. Tapas Kumar Pal, my parents

Soma and Swapnil, my family
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<tr>
<td>ACASI</td>
<td>Audio Computer-Assisted Self-Interview</td>
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<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
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<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
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<tr>
<td>CBO</td>
<td>Community based organization</td>
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<tr>
<td>CDC</td>
<td>The Centers for Disease Control and Prevention</td>
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<td>FGD</td>
<td>Focus Group discussion</td>
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<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>ICMR</td>
<td>The Indian Council of Medical Research, India</td>
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<tr>
<td>IDI</td>
<td>In-depth interviews</td>
</tr>
<tr>
<td>IEC</td>
<td>Institutional Ethics Committee</td>
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<tr>
<td>IPC</td>
<td>Indian Penal Code</td>
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<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
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<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
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<tr>
<td>NACO</td>
<td>National AIDS Control Organization, India</td>
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<tr>
<td>NACP</td>
<td>National AIDS Control Program, India</td>
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<tr>
<td>PLH</td>
<td>People living with HIV</td>
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<td>Acronym</td>
<td>Description</td>
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<td>PLWHA</td>
<td>People living with HIV/AIDS</td>
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<tr>
<td>PMCT</td>
<td>Prevention to Mother to Child Transmission</td>
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<tr>
<td>UNAIDS</td>
<td>The Joint United Nations Programme on HIV/AIDS</td>
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Chapter 1 Introduction

In 2012 an estimated 35.3 (32.2–38.8) million people were living with HIV globally. New infections with HIV totaled 2.3 million [1.9 million–2.7 million] people worldwide, in 2012 [1]. 9.7 million people living with HIV (PLH) had access to antiretroviral therapy in low- and middle-income countries according to UNAIDS 2013 report. The National AIDS Control Organization (NACO), estimated 2.31 (1.93 – 3.04) million PLH in India [2]. The HIV epidemic in India is presently showing a stable trend. The adult prevalence estimate for 2011 was 0.27%. The initial cases of AIDS were diagnosed among five active homosexual men with Pneumocystis Pneumonia infections between October 1980 and May 1981 in Los Angeles [3]. Male to male sexual contact remained to be the most common transmission category in United States [4] and most parts of the developed world throughout the course of the epidemic. Both new HIV infection diagnosis and AIDS diagnosis is highest among male to male sexual contact transmission category as estimated by CDC [4]. Men who have sex with men (MSM), also known as males who have sex with males, are male persons who engage in sexual activity with members of the same sex, regardless of how they identify themselves. The term was created in 1994 by epidemiologists in order to study the spread of HIV among men who have sex with men, regardless of identity or orientation [5]. The very first case of HIV was diagnosed among sex workers in Chennai, Tamil Nadu, India [6]. Heterosexual route remains the predominant mode of transmission in India. The initial phases of the National AIDS control program NACP- I, NACP-II in India have targeted the heterosexual transmission as the primary focus for interventions. This might have resulted in the present scenario that MSM remain as the only high risk behavior group of India among whom HIV prevalence has a clear increasing trend [7, 8].
As opposed to popular belief, same-sex behavior is not a rarity in India, but a high proportion of MSM are married and/or bisexual and they remain reluctant to admit their sexual orientation [8, 9]. In a survey carried out on male patients attending a hospital in Mangalore, Karnataka, 12% reported a sexual preference for a partner of the same sex [10]. A different study, on Homosexual/bisexual behavior of 6661 MSM at 62 urban-rural locations of various sizes in the Indian state of Andhra Pradesh reported 41.8% were currently married to women; and 50.4% had vaginal/anal sex with women in the past 3 months, of whom 84% did not use a condom [9]. The NACO estimates of MSM population is around 0.427 million in India by the end of Dec 2012 [2] with an HIV prevalence of 4.43.

West Bengal, one of the 29 states of India, located in the eastern part of the country, sharing an international border with Bangladesh, has 88,752 km2 area and 19 districts. According to the provisional reports of the 2011 census, the total population of West Bengal is 91,347,736 with 46,927,389 males, a sex ratio of 947 females per 1000 males and a population density of 1029 per km2 area [11]. Kolkata is the capital city of West Bengal and headquarter of Kolkata district. By the end of 2012, there were 201 targeted interventions targeting MSM and transgender all over India, but only four were operational in West Bengal [12]. The prevalence of HIV among MSM in West Bengal was 5% [13], with Kolkata having the highest prevalence of 9.24% [12] in 2008. According to West Bengal state aids control society there are 9 ART centers distributed all over the state. Sentinel sites for MSM in India scaled up from 3 in 2000 to 763 in 2012-2013 [2] of which 2 are located in West Bengal (1 in Kolkata).
1.1 Background Information

1.1.1 MSM in India

1.1.1.1 Ancient literature and mythical reference

Male homosexuality has been referenced, somewhat obscurely, in various religious, mythical and social treatises, and sculptures/paintings of ancient India [14]. Going back to the earliest of Hindu scriptures, we can find symbolical references to homosexuality in the Vedas and Puranas. Historians Ruth Vanita and Saleem Kidwai, in their comprehensive research work, "Same-Sex Love in India: Readings from Literature and History" have cited various fragments of writings from the Veda-Purana era that discuss homosexuality in a wide variety of connotations, ranging from disdain to non-judgmental neutrality [15-17].

Historian Devdutt Pattanaik summarizes the place of homosexuality in Hindu literature as follows: "though not part of the mainstream, its existence was acknowledged but not approved" [14]. The Sushruta Samhita, an ancient Hindu medical text from 600 BC categorizes male homosexuals to two categories: “Kumbhika” – men who take the passive role in anal sex; “Asekya” – men who perform fellatio/devour the semen of other men, as well as transgenders (“Sandha” – men with the qualities, behavior and speech of women).

1.1.1.2 Sexual orientation and sexual identity

MSM in India suffer from self-defined identity crisis. Some of them consider themselves as gay while others identify themselves as Kothi, Panthi, Double-Decker, Hijras. In some large cities like Kolkata and Mumbai some of them who sell sex to other male persons and /or female clients are called Male sex workers. These identities are not fixed and are subject to change depending upon the social circumstances and thus it is very difficult to identify them in society due to stigma and discrimination. Identifying and locating structural social
networks where MSM usually congregate is a major challenge for Targeted Intervention for HIV prevention program [18].

1.1.1.3 Prevalent MSM behaviors

For the purpose of referring to different types of sexual identification among the MSM population of India, several terminologies are commonly used which include Kothi, Panthi, Ali or Hijra and double-decker or Dupli. This categorization is also used for the purpose of targeted interventions. Each of these indicates groups of MSM with distinct behaviors but considerable overlap among these types of population is not unexpected.

Kothi

MSM who typically express varying degrees of femininity but are biologically male and predominantly act as the receptive partners during anal and oral sex are termed as Kothi. Their style of speech and mannerisms are distinctly feminine and they generally refer to selves or other Kothis using feminine pronouns. Many Kothis assume the gender identity of women. Kothis sometimes get married to women but continue to engage in sex with other men [18, 19].

Panthi

These masculine appearing men, are predominantly involve in the role of insertive partners when they have sex with other men. They do not necessarily identify themselves as homosexual men and typically engage in sex with either Hijra/Ali or Kothi. These men are generally either married or expected to get married to a woman but also continue to engage in sex with other men. Some equivalent terms used in different states of India to refer these masculine, predominantly insertive MSMs include “Gadio” in Gujarat, “Parikh” in West Bengal and “Girija” in Delhi [18, 19].
Double–Decker

MSM who serve in both insertive and receptive roles during anal and oral sex are termed as double-decker. These men also usually get married to a woman but also continue to engage in sex with other men. Equivalent terms used in different states include “Dupli-Kothi” in West Bengal and “Do-Paratha” in Maharashtra [18, 19].

Hijra or Ali (Eunuch)

Hijras belong to a culturally and socioeconomically distinct group. They are considered as a third gender other than male and female. They are born biologically male but they endorse a female gender role. Many of them undergo castration, hormone therapy. Many Hijras use feminine pronouns while referring to themselves and other Hijras, grow long hairs, dress and makeup like women (cross-dress/transvestite). They are organized under seven predominant “gharanas” or clans. Hijras include emasculated (castrated or “nirvan”) men, non-emasculated (not castrated or “akva”/“akka”) men and inter-sexed persons (hermaphrodites). In general, they belong to a very poor socio-economic class as they remain socially much marginalized. Some of the Hijras find selling sex being an easier option of earning living for them and thus many Hijras become commercial sex workers. This group is referred as transgenders in the targeted intervention programs of India [18, 19].

1.1.1.4 Legal Issues

Sexual acts with the same sex had long been an issue of legal debate and social stigma in India. The section 377 of Indian Penal Code [20, 21] enacted originally in India by the British colonial rulers in 1860, included a judicial provision of criminalization for anal intercourse, that by itself could also criminalize male homosexuality, was being considered as a violation
of the fundamental rights under Indian Constitution by many activists and organizations. The associated stigma still remains to be profound.

In Naz Foundation v. Govt. of NCT of Delhi, the Delhi High Court ruled Section 377 and other legal prohibitions against private, adult, consensual and non-commercial same-sex conduct to be in direct violation of fundamental rights provided by the Indian Constitution on the morning of 2nd July 2009 [22]. However, the Supreme Court of India overturned the decision of the lower court on 11 December 2013 and upheld the primacy of section 377 [23]. Most researchers consider the judicial step, an important factor in terms of conducting public health research and targeted intervention programs in the hard to reach population of MSM in India.

1.1.2 National AIDS Control Program

The first case was detected in Chennai, Tamil Nadu 1986 among female sex workers [6]. Pressure from international agencies forced the central government to set up National AIDS Committee in 1986 under the Ministry of Health and Family Welfare. This committee was later renamed as National AIDS Control Organization (NACO). In 1989 a Medium-Term Plan was launched with Targeted education, Awareness campaign, Surveillance with support of WHO and global fund.

The National AIDS Control Program (NACP-I) was established in 1992 as a comprehensive program with the objectives of prevention and control of HIV in India and raising awareness among people [24].

In 1999, NACP II was launched with objectives of lowering the sero-positivity among the high prevalent states below 5%, below 3% in moderate prevalent states and below 1 to 2% in states where HIV was still at a nascent stage. It also aimed at reducing the blood borne
infection to less than 1%, increasing the awareness level to more than 90% among youth and people in reproductive age groups as well as increasing the condom use to more than 90%.

The different components of programs were Blood safety, STD control, Condom promotion, Voluntary Testing and Counseling Centers (VCTC), Information, Education and Communication (IEC) with social mobilization, Targeted Interventions, Prevention to Mother to Child Transmission (PMCT) and Care and support to PLH/AIDS (PLWHA) [24].

NACP III was established in 2007 based on lessons learnt from NACP-II with objectives of reversing and halting the HIV epidemic in India through prevention, care, support and targeted interventions for high-risk groups. The strategies that are highlighted under NACP-III are

1. Prevention of new infections in high-risk groups and general population through
   a. Saturation of coverage of high-risk groups with targeted intervention (TI)
   b. Scaling up interventions in the general population

2. Providing greater care, support and treatment to a larger number of PLH/AIDS.

3. Strengthening the infrastructure, systems and human resources in prevention, care, support and treatment programs at the district, state and national levels.


Under NACP-III special emphasis was put on mapping of truckers, providing them free access to counseling, testing, treatment and education, improved access to condoms all along the highways, halt points and social marketing. NACP-III showed success in interrupting the HIV infection through expanded surveillance, targeted intervention, a Link Worker scheme addressing the HIV prevention among rural communities with special focus on high risk
group, providing services for prevention and harm reduction like condom promotion, access to safe blood, awareness raising, integrated counseling and testing centers (ICTC), management of STI/RTI, prevention of parent to child transmission (PPTCT), post-exposure prophylaxis. NACP-III has been integrated with other national health programs like National Rural Health Mission, Reproductive and Child Health, Revised National Tuberculosis Control Program for better control of HIV infection. [24]

NACP IV was rolled out in 2012, taking into account lessons learned from NACP-III. NACP IV is expected to continue to provide care, support and treatment to all eligible population along with focused prevention services for the high-risk groups and vulnerable populations. It was in this program me that much of the focus was given to high risk groups including MSM [24].

1.1.2.1 West Bengal State AIDS Prevention & Control Society (WBSAP&CS)

West Bengal State AIDS Prevention & Control Society was registered in 1998-99. According to the directives of the World Bank, NACO planned to launch its ongoing AIDS control programs through the registered societies for each state for quick decision making, smooth flow of funds and local need based approach. WBSAP&CS aims to provide the residents of West Bengal state with an innovative and interactive system of HIV/AIDS prevention, care and treatment program to make an informed decision about seeking HIV prevention care and support [24].

1.1.3 Anti-Retroviral Treatment in India

ART rolled out in April 2004 in India. As of December 2012, 0.6 million PHLIV are on first line ART and 380 functional centers all over the country. Assessment of eligibility for ART is based on clinical examination and CD4 count. NACO continues to follow the WHO
guideline of 350 CD4count/mm3 for initiating ART [25]. Different types of ART centers are used to cater the treatment services.

Link ART Centers: In rural and high prevalence areas, they are linked to a nodal ART center.

Community Care Centers: Set up by NGOs with the objective of providing psycho-social support, ensure drug adherence and provide home-based care [25].

ART Centers: Usually in the Medicine Departments of Medical colleges and District Hospitals in the Government Sector.

ART Plus Centers: provides easy access to second line ART. These centers were created by upgrading some of the ART centers. Currently, there are 24 ART Plus Centers functioning in the country [25].

Regional Pediatric Centers: Centers of excellence for pediatric care treating children infected with HV. There are 7 such centers across country.

Centers of Excellence (COE): Training and research besides providing high quality care and support. 10 such centers are operational across country [25].

1.1.4 Literature review on MSM and their barriers to ART services in India

Estimated MSM population is around 0.427 million in India. Very few studies have been done among MSM’s in India. So far from the literature we know that a majority of the MSM population is engaged in hetero sexual relationship [9], being the most vulnerable group for acquisition of HIV infection through multiple sexual partners, diverse sexual mixing, unprotected anal intercourse and other risk behavior. One study from Andhra Pradesh, India among MSM reported 41.8% were currently married to women; and 50.4% had vaginal/anal sex with women in the past 3 months, of whom 84% did not use a condom [9]. Another
community based study in Mumbai showed that most female sexual partners of MSM are their wives although 18% of the MSM had multiple female partners [26].

1.1.4.1 Social factors

Most of the research has been done in South India. As opposed to popular belief, same-sex behavior is not a rarity in India, but a high proportion of MSM are married and/or bisexual and they remain reluctant to admit their sexual orientation [8, 9]. In a survey carried out on male patients attending a hospital in Mangalore, Karnataka, 12% reported a sexual preference for a partner of the same sex [10]. A different study, on Homosexual/bisexual behavior of 6661 MSM at 62 urban-rural locations of various sizes in the Indian state of Andhra Pradesh reported 41.8% were currently married to women [9]. Another study among MSM in Bangalore [27], South India in 2006, to quantify differences in sexual behavior patterns among men having sex with both men and women compared with men having sex with men only revealed 41% of the study population having sex with both sexes in the past year and 14% being currently married. Non-disclosure of the sexual practice to their wives was reported by almost all married participants [27]. A study among MSM in Chennai reported that 26% of the participants participated in a previous HIV prevention program, proportion of MSM being ever tested for HIV were mostly less than 50%, more than 80% reported varying level of harassment from police and others, whereas less education, non-participation in previous HIV prevention program and having clinical depression were significant predictors of unprotected anal intercourse, increased number of male partners, not being married, not having a child, non-disclosure of sexual identity in family, Kothi and Panthi sexual identity, having been paid for sex and perception of being at risk for sex among MSM [28].

Significant predictors of HIV infection included less education and not currently living with parents [29].
1.1.4.2 MSM in Kolkata

There are only a handful of studies done among MSM’s of Kolkata. In a study among 108 MSM subjects to assess sexual practice and perception of HIV/AIDS Amongst Men who have Sex with Men in Kolkata reported that the mean age of the study population was only 22.1 years, most of them being in the age group 19 to 23 years [30]. The literacy status was varied with 13.9% being illiterate while 16.7% were educated up to higher secondary and above. A majority (25%) of the clients were students. Some students indulged in such practices while residing in mess and hostels. Almost one-third of the MSM were married. Besides, the per capita monthly income was also found to be quite varied with 8.3% having an income of more than INR 2500 ($42) while 25% had a monthly PCI of less than INR 500 ($8.5) [30].

A majority (44.2 %) of them had sexual debut in the age group 15-19 years and the mean age of first such act only 16.6 years. 51% had a male friend as the first sexual partner, while the rest had CSW, girlfriends, classmates, relatives and even spouse at times was the partner in their first sexual act. Sexual concurrency was at large with 58.2% having more than one partner in the last one month. Among 5.6% of the cases, the number of partners in the last one month was high in the order of six or more [30]. The most common sexual act was receptive anal sex followed by vaginal sex, oral sex and insertive anal sex. The use of condom was very poor with only 15.7% using the barrier method during vaginal intercourse and 6.5% during anal intercourse in the last one month. 74% of the MSM who visited the clinic were feminized males practicing receptive anal sex (traditionally called Kothis) followed by Parikh or Panthi 14% who considered themselves real males and practiced insertive anal sex, Dupli or Double-Decker and Eunuchs or the transsexuals traditionally called Hijras. Interestingly majority (40%) of the study population had sex with men for
pleasure, 28% felt it was because of increased sexual urge while 22% thought they couldn't resist their sexual urge. According to circumstances, 8.3% were forced into the act while 1.9% performed such acts for exchange of money. About 19% of the men did the act in an intoxicated state. The average knowledge score was low, but significantly increased with the literacy status [30].

### 1.1.4.3 The Avahan Initiative with MSM in India

Avahan initiated in 2003 sponsored by the Bill & Melinda Gates Foundation to reduce the spread of HIV in India. Six states of India with historically the highest prevalence of HIV: Andhra Pradesh, Tamil Nadu, Maharashtra, Karnataka, Manipur and Nagaland were included. The program aimed to reduce HIV transmission and the prevalence of STIs in vulnerable high-risk populations, notably female sex workers, MSM, IDU and transgenders, through prevention education and services such as condom promotion, STI management, behavior change communication, community mobilization, and advocacy. According to a published paper with the data generated so far 82,293 MSM’s have made it to the Avahan clinics till the end of 2009 [31]. 44% of them identified themselves as Kothi, 27% identified as Double-Decker and 15% as Panthi. Mean age of the participants were 28 years, 29 years, 29 years respectively for Panthi, Kothi and Double-Decker. Mean years of sex work was 0.03 years, 1.8 years, 2.3 years respectively for Panthi, Kothi and Double-Decker. Double-Deckers had the highest number of partners than others.

An increasing proportion of HRGs attended the clinics for regular STI check-ups during the period. The proportion of clinic attendees undergoing internal examination (i.e. vaginal speculum or proctoscopy) increased from 1% to 54% amongst MSM from the year 2005 to 2009. Treatment seeking behavior improved with an increasing proportion of HRGs coming to the clinics within two days of the onset of symptoms. There was a declining trend in the
proportion of all syndromes diagnosed amongst HRGs from 2005 to 2009. Retention to care among MSM’s ranged from 69% to 52% during the second year, 47% to 41% for the third year, 34% to 33% for fourth year and finally dropped to 25% by the end of the fifth year [31].

1.1.4.4 **Barriers to HIV services and ART among MSM in India**

One qualitative study was conducted in 2007 to assess the barriers to free antiretroviral treatment access among Kothi-identified men who have sex with men and Aravanis (transgender women) in Chennai, India [32]. The subjects were recruited using purposive sampling through four community-based organizations (CBOs) in Chennai. They conducted three focus groups among adult HIV-positive Kothis and three among adult HIV-positive Aravanis. The study also conducted four key informant interviews with community leaders of agencies that work with Kothis and Aravanis. Semi-structured in-depth interview guides in local language with scripted probes that focused on barriers to ART access and how to address these barriers were used. The Kothi participants had a mean age of 32 years. Half of them had completed high school. Two-fifths were married; one-third on ART; and half engaged in sex work. Aravani participants had a mean age of 34 years. Half of them had completed high school; one-fourth on ART; and two-thirds engaged in sex work [32].

Findings from the focus group discussion of the study are presented below. [32]

**Family/social-level barriers**

Lack of family support: Most of the Aravani participants reported being estranged or evicted from their home. Kothis who live with their families usually do not disclose their HIV status or their sexuality, fearing familial rejection. Such estrangement or lack of disclosure precludes family support to initiate ART. Some Kothis have disclosed their status to their family members and are motivated to take ART for sake of supporting the family.
Discrimination and lack of support within Aravani and Kothi communities: Participants living with peers feared labeling, social rejection, and loss of emotional and psychosocial support from their own community if they were seen taking medications.

Unmet basic needs: The struggle of many Aravanis and Kothis is to meet day-to-day needs of food and shelter that presented obstacles to initiating even free ART. Most of the participants were engaged in sex work for sustenance. They fear revelation of their sero-status to clients resulting in loss of income.

Structural barriers/ Health care system barriers to ART access [32]:

Negative experiences with health care providers: Participants and key informants indicated continuing discrimination in government ART centers. Both actual and anticipating discrimination discouraged some of the Kothis and Aravanis from accessing ART.

Judgmental attitudes, substandard treatment, perceived deliberate delays in services, outright verbal abuse and non-verbal cues, such as facial expressions and body language, from health care providers were reported by the subjects creating significant obstacles to accessing ART and health care generally.

Inadequate counseling services and lack of confidentiality: Lack of privacy and confidentiality, inadequate time for counseling were some issues reported by the participants.

Perceived lack of focus on ART in HIV/AIDS interventions: The participants reported that targeted prevention interventions are more focused. No such initiatives are there for receiving ART or public messages to create public awareness for treatment.

Individual-level barriers to ART access [32]

Delays in HIV testing: Low HIV risk perception and a preference not to know one’s status, intertwined with fears of stigma, discrimination, and rejection from community, presented
barriers to HIV testing among Kothis and Aravanis participants. Knowledge of one’s sero-status is an important step to get linked to treatment.

Alcohol addiction: Health care providers emphasize that patients on ART should not consume alcohol. Many delay treatment initiation as they do not want to quit alcohol.

Insufficient knowledge about ART and belief in alternative ‘cures’: Most of subject’s lack of proper knowledge of ART, when to initiate therapy and eligibility criteria. Many of the participants are misinformed that HIV is curable via alternative medicine.

Fatalism: Even after learning of their HIV diagnosis and medical eligibility for ART, fatalism among some Kothis and Aravanis fostered reluctance to initiate ART. Fatalism appeared to be related to lack of social support from (and non-disclosure to) family members and not having a steady male partner.

1.1.5 Literature review on adherence to anti-retroviral treatment and services

We searched PubMed and google scholar for relevant literature. The following search terms were used in PubMed and Google scholar in various combination: (“ART ADHERENCE” [MeSH Terms] AND “MSM”/ “gay”/ “bisexual”/ “transgender”/ “none specific” [All Fields]) AND (“India” [All Fields]) AND ("1980/1/1" [Date - Publication]: "2017/7/8" [Date - Publication]). The search returned 6 results in PubMed. Google scholar retrieved 136000 results. We also used search terms were used in PubMed in various combinations: (“HIV TREATMENT” [MeSH Terms] AND “MSM”/ “gay”/ “bisexual”/ “transgender”/ “none-specific” [All Fields]) AND (“India” [All Fields]) AND ("1980/1/1" [Date - Publication]: "2017/7/8" [Date - Publication]). The search returned 140 results in PubMed. Google scholar retrieved 15400 results. Of these published peer-reviewed articles none met our criteria. No
quantitative study to measure the adherence of seropositive MSM’s to ART, has been conducted in India according to our search.

Nonetheless we used following search terms in PubMed and Google scholar in combination: ("ART" [MeSH Terms] AND “MSM” [All Fields]). The search returned 247 results in PubMed. Google scholar retrieved 59600 results. We observed that ART patients have been mostly studied in United States and Europe. Research in the US has focused on domains such as stigma, social support, depression/mental health, substance abuse and quality of life. There is some handful studies from India among the general population.

We reviewed three large cohort studies conducted to study adherence to ART among MSM population in United States, to identify the domains assessed in these studies for potential inclusion in my dissertation research.

The first study conducted among MSM’s accessing care from public county HIV clinics in Los Angeles, had as a primary outcome, retention in care as defined by 2 or more primary care visits in 6 months before interview [33]. In the Seropositive Urban Men’s Study primary outcome was defined as missing scheduled doses of medication [34]. The third study from Multicenter AIDS cohort study (MACS) [35] defined primary outcome as adherence to medications. This was a dichotomized variable with adherence 100% or adherence <100%. Any deviations from the scheduled dosage like missing pill in a dosage, taking fewer pills than what was prescribed and atypical pattern of drug intake was categorized as adherence <100%. This definition was assessed for each prescribed drug.

1.1.5.1 Key variables measured for association with adherence

In the first study to predict the factors of retention among Latino and African American MSM measured the following variables/ domains [33]: Social support, stress, detailed network
information, HIV disclosure, HIV-related stigma MSM -related stigma, psychological distress, major life difficulties and HIV-related symptoms

The Seropositive Urban Men’s Study measured CD4 levels, viral load, medication regime and adherence, mental health, partner related variables like main partner sero-status and discomfort in talking with sex partners with HIV, substance abuse like alcohol and recreational drug usage history, social desirability and health care information.

Adherence study in MACS measured adherence assessment with recall was 4 days prior to the day of interview, depression, cognitive decline assessment, quality of life and staging of HIV infection with clinical examination and symptoms, CD4 count and viral load.

1.1.5.2 Factors and Barriers associated with Adherence to ART

Regimen complexity

ART regimens are complicated and need substantial life adjustments in addition to food restrictions to ensure efficacy [36-38]. One study showed that twice-daily dosing or less leads to better overall adherence (at least 80%) to anti-HIV medication compared with more frequent dosing [39]. Twice-daily dosing is associated with better adherence than three-times-a-day dosing [40]. One study in 2003 among MSM in New York and San Francisco reported the mean number of 2.93 HIV medications with a range of 1 to 6. 165 out of 322 individuals reported missing a dose of any one of their medications [34].

Side effects

Common treatment-limiting side effects following HAART are either transient (diarrhea, nausea) or longer lasting (lipodystrophy, dyslipidemia, neuropathy) with individual variations. Adherence declines with the emergence of side effects [36, 41-44]. HAART is quickly discontinued by patient or changed when side effects occur, [45] whether the side
effects are actual or perceived. One study of 860 treatment-naïve patients showed toxicity discontinuations to occur within the first year in about 25% of patients [38]. The patients’ subjective side effect experience within the first 4 months predicts long-term adherence more strongly than do than socio-behavioral and other medical causes [46].

Patient-related factors in HAART adherence

Advanced disease reduces deterrents to adherence such as pill burden, as symptomatic individuals perceive a higher risk for HIV complications as a result of nonadherence [47]. Forgetting is the most commonly cited reason for non-adherence [42, 48] which becomes more prevalent as individuals regain well-being, return to work, and resume other activities. The most commonly forgotten dose is the middle dose in a three-times-a-day regimen [49]. Results from the AIDS Clinical Trials Group indicated that 25% of participants admitted not understanding how to follow their regimens [48]. Adherence studies among 205 general population participants in Mumbai, India 2005 reported reasons for missing doses were “ran out of pills” (in 26.2% of participants), “traveling away from home” (in 15.4% of participants), “felt sick or ill” (in 11.5% of participants), “simply forgot” (in 9.3% of participants), and “busy with other things” (in 8.2% of participants) [41]. In a study from south India among general population, participants reported financial constraints as a significant barrier [42].

Psychosocial issues

Adherence was related to drinking or drug use several times a week [34]. Substance abuse predicts non-adherence [42, 43, 48, 49], but good adherence is still achievable if the provider addresses medication, regimen, and side effect concerns. Intravenous drug users are less likely to begin antiretroviral therapy [50]. Depression, stress, HIV related stigma, social
stigma, hopelessness and negative feelings predicts non-adherence [40, 42, 43, 48]. Adolescents having higher depression levels demonstrate lower adherence compared to their non-depressed peers [51]. Social support systems addressing psychosocial problems were positively predicts adherence to ART [40]. Non-adherent individuals had higher levels of avoidant coping and discomfort in talking to sex partners about HIV [34]. The 2008 study among MSM in Los Angeles reported the major predictor of retention in HIV care was disclosure of HIV status to more social network members OR 1.5 [33]. Lack of medication reminders from family or friends negatively influenced adherence [41]. Supportive friends and families, treatment buddies and peer counseling also play a role in facilitating HAART adherence. Lack of family care predicted nonadherence [42, 43].

Patient belief system

Greater adherence is observed in individuals who believe that HAART is effective, [52] whereas negative beliefs reduce adherence. Like nonadherent patients in a study poorly understood the relationship between viral load and adherence [48].

Patient–provider relationship

Supportive patient–provider relationships can help overcome adherence barriers as observed in some studies [53, 54]. Unfortunately, very few providers routinely offer adherence counseling according to the patients [54]. Patients became frustrated when miscommunication occurred [41], when treatment becomes complex, or when side effects go unmanaged.
1.2 Rationale for the study

Targeted intervention for MSM from the NACP4 is still evolving. The NACO targeted intervention reaches only 70% of the estimated MSM population. According to NACO annual report 1.7 million people were ever registered for ART in India. Only 0.6 million is retained in care i.e. only 35% is retained in care [2].

Despite the sincere effort by NACO to provide ART to all eligible PLWHA as per the National guidelines, lack of adherence thus precluded the success of the HIV treatment programs, especially among stigmatized and hidden population like MSM. The resultant public health concern called for an estimation of adherence among HIV positive urban MSM residing in the Metro city of Kolkata, detailed evaluation of the role of potential correlates of adherence and the cumulative effect of these correlates and adherence on the treatment response in this population.

1.2.1 Framework of barriers to access ART services

The literature review outlined factors potentially associated with adherence. These factors are summarized in a framework developed by The Global Forum on MSM & HIV as shown in Figure 1-1. Longstanding evidence indicates that MSM experience significant barriers to access quality health care due to widespread stigma against homosexuality in mainstream society and within health systems [55-59]. Social discrimination against MSM, or homophobia, has also been described as a key driver of poor health outcomes in this population across diverse settings [60].

Homosexuality and homophobia

Homosexuality is not a psychiatric illness. Decades of research has been done on this issue, which also indicates that lasting change one’s sexual orientation is unlikely [61].
Homosexuality is understood globally among the scientific community as a normal expression of human sexuality. In 1992, WHO removed homosexuality as a psychiatric disorder from its International Classification of Diseases, 10th revision [62]. Some widespread myths surrounding homosexuality and MSM: homosexuality can be cured, MSM are pedophiles, MSM like to be feminized etc. MSM In India who does not behave within the parameters of normative masculinity or are considered gender nonconforming, experience direct discrimination and stigma leading to social marginalization and exclusion, as well as sexual vulnerability [63].

Thus, higher rates of depression, anxiety, smoking, alcohol abuse, substance use, running away from family or estranged from family and suicide have been reported among MSM as a result of chronic stress and disconnection from a range of social services and support mechanisms [64-69]. In India PLH/AIDS, has to deal with HIV-related stigma which has been associated with poor mental health outcomes in both adults and young people [70, 71] as well as poor physical health and lower help-seeking behavior [72, 73]. Male sex workers are common subjects of harassment, violence, and rape as seen from reports from all over the world [28, 74-76]. MSM are already marginalized in nearly every country including India through punitive policies through laws criminalizing homosexual sex, [77] driving these individuals further underground, doubly stigmatizing them, and isolating them away from necessary health services.

All these factors complicate and cause inadequate access to HIV-related services and accompanying homophobia continue to be part of ground reality for both MSM who are sex workers and their clients. These individuals face discrimination and struggle on a daily basis for the realization of access to basic health information and care.
1.3 Study Objectives

1.3.1 Qualitative phase

1. To understand the typical treatment seeking behaviors among HIV positive MSM in Kolkata.

2. To understand the barriers in treatment seeking especially regarding HIV testing and ART.

3. To understand the knowledge, perception and practice of MSM regarding adherence to ART.

4. To explore factors that MSM think affect their adherence to ART
1.3.2 Quantitative phase

1. To measure the adherence to Anti-Retroviral Treatment among HIV positive urban MSM residing in the Metro city of Kolkata

2. To identify the correlates of adherence and to measure the strength of association of these factors with adherence HIV positive urban MSM residing in the Metro city of Kolkata.
1.4 References

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Chapter 2 Methodology

2.1 Study area

Figure 2-1: Location of Kolkata, India

The study was conducted in Kolkata, the capital city of the state of West Bengal. The city extends from 22°03′N to 22°03′N and 88°02′E to 88°01′E, and is located just below the tropic of Cancer in the eastern part of India, on the eastern banks of the river Hooghly and approximately 120 kilometers from the Bay of Bengal. The city area of Kolkata is 187.33 km\(^2\) and the metropolitan area is 1380.12 km\(^2\). According to the 2011 census the total population of Kolkata district is 4,486,679 with a population density of 24252/km\(^2\). The sex
ratio is 899 females per 1000 males. The city of Kolkata is the 8th largest urban agglomeration in India.

2.2 Study setup

2.2.1 Field assessment

There are three National AIDS Control Organization (NACO) operated ART centers in Kolkata, catering to HIV infected individuals living in Kolkata and its suburbs. Subjects who have been initiated to ART usually return back to the designated ART center after a month or two for refilling ART medication. All HIV positive subjects usually get the services from a clinic that is closest to their residential address. We collaborated with a community based MSM organization named People Like Us -Kolkata (PLUS). They provided resources and help for conducting the study.

2.2.2 People Like Us

PLUS represents the experiences, realities of marginalized and vulnerable adolescent young men in India. PLUS is a support group of young people working for the promotion, protection and advancement of adolescent and young men’s health and rights, especially their sexual and reproductive health and rights, toward ensuring their meaningful participation and perspectives at all levels of decision-making. The headquarters is located at 254, Bonomali Banerjee Road, Kolkata, West Bengal, India, 700082. A UN RED RIBBON Award Winning Organization PLUS was formed in 2001 as an informal support group in Kolkata providing safe space for vulnerable and marginalized adolescents and young boys who are selling sex, in the city. Later PLUS commissioned a community owned study “Prostituted boys in Kolkata city” which initiated the organizational backbone. In 2003 PLUS formally registered
under the West Bengal Society registration ACT (1961) and has a secretariat based in Kolkata city. PLUS has two Drop in centers (DIC) in Kolkata one in North Kolkata opened 24 hours a day seven day a week whereas the resource center is also used for DIC purpose in south Kolkata with specific days and timings. Every day almost 120 drop ins are gathered in the DIC on average. The services provided by these DIC’s are; Educational Assistance, Health assistance, Legal assistance, Counseling service, and recreational activities. Other than the two DIC, PLUS also manages a temporary transgender walk-in shelter home named Prothoma. Prothoma is multifaceted and encompasses the following: Health management, Case management, ART therapy and livelihood options and trainings.

The Health assistance program provides some basic needs for the MSM and transgender youth population: regular Doctor’s checkup, regular visits to medical practitioner, prolonged treatment and medication, STI, HIV and AIDS testing, management and treatment and referral if needed, post castration care (for eunuchs) and protection, providing medication, condoms and lubrication

### 2.3 Ethical approval

The study was approved by the institutional review board (IRB) of University of California, Los Angeles and the institutional ethics committee (IEC) of the National Institute of Cholera and Enteric Diseases (under the Indian Council of Medical Research), the collaborating research institute located in Kolkata, West Bengal.
2.4 Study Conduct

2.4.1 Study Design

The study was carried out in two main phases, Qualitative, and Quantitative. The Qualitative phase consisted of Focus group discussion (FGD) with organizational staffs of the CBO, PLUS, and peer workers and In-depth interviews (IDI) with HIV positive MSM’s. In the Quantitative phase, we administered a baseline questionnaire and a follow-up interview with the recruited subjects after 3 months.

2.4.1.1 Qualitative phase

Between September and December, 2015, we conducted one focus group discussion (FGD) and 6 in-depth interviews (IDI), by trained study staff. The FGD included 7 committee members of the Community Based Organization (CBO) PLUS. The IDI’s were conducted among 6 HIV positive MSM’s who attended ART clinics. These participants were referred by the peer workers of the CBO PLUS. All discussions/interviews were conducted in a private room at the PLUS office, ensuring adequate privacy so that the participants can express their views clearly. Verbal consent was taken prior to the initiation of the discussions. Permission for taking notes and voice recording of the conversations were also obtained. A semi-structured discussion guide with few probes was used for this purpose, that focused on our objectives and possible ways to address them. Open ended topics was sometimes introduced during the discussions, keeping in mind the strategies to generate codes for the analysis of the information collected from discussion to identify patterns related to the aforementioned aspects regarding the participants. All interactions were done in their preferred local language. The interviews were conducted in Bengali, except for one IDI which was done in Hindi. The discussion topics/issues included in the guide were formulated from the review of
relevant literature and possible themes that had emerged. FGD was conducted for 120 minutes; IDI’s ranged from 20 to 45 minutes. Each participant was provided a food packet and their travel expenses.

2.4.1.1 Data collection and Analyses

Voice recorder was used to record the discussions from the FGD’s. Two other study staffs wrote down notes of the discussion. Audio recordings of the interviews and discussion were transcribed verbatim into Bengali and Hindi. Notes taken during interviews facilitated the transcription and enhanced the transcripts by insertion of comments. The process of transcription of the proceedings was completed within 2 days of completion of the interview/discussion. The interview transcripts were imported into Atlas 7.5 for the purposes of coding and analysis. We explored data using framework analysis [1] and used the barrier framework developed by The Global Forum on MSM & HIV [2]. We established a priori categories and further used open and in vivo coding. At the time of initial readings, we employed the ‘open coding’ technique, followed by ‘thematic coding’ during re-readings.

2.4.1.2 Quantitative phase

There are three NACO ART centers operating in the city of Kolkata catering to HIV infected individuals living in Kolkata and its suburbs. ART initiated subjects return back to the designated ART centers after a month or two for refilling ART medication. CBO peer workers visited these three ART centers operating in Kolkata. They identified HIV positive MSM’s and approached them for participation in the study. Between November 2015 and December 2016, we shared information about the study with individuals. Subjects who were interested in participation were screened for eligibility for inclusion in the study. We used decision making capacity assessment tool to determine if the participant was capable of decision making. Further details of the study were shared with eligible MSM’s and thus
recruited for the study. Participants would schedule meeting with the peer worker at a convenient location, for the baseline Audio Computer-Assisted Self-Interview (ACASI).

After recruitment, each subject was assigned a unique identification number for the purposes of the study. MSM’s signed informed consent before the interview. A recruitment log was thus maintained to track participants and schedule follow-up of the subjects. Three months after the baseline interview we again contacted the subject for the follow-up interview.

Inclusion criteria were as follows (i) age 18 years or older (ii) self-identified MSM behavior as Kothi, Panthi or Dupli (iii) capable of consenting for the study (iv) tested positive for HIV and subsequently initiated to anti-retroviral treatment prior to the recruitment for the study.

After consenting we collected data using ACTG baseline and follow-up questionnaire [3]. The survey was developed in English, translated into Bengali and Hindi and back translated into English to ensure semantic equivalence. Surveys were administered in Bengali and Hindi by the CBO peer worker under the supervision of the research coordinator.

2.4.2 Audio Computer-Assisted Self-Interview

An appropriate, culturally acceptable ACASI was developed in the local languages Bengali and Hindi. ACASI was implemented to collect data both at baseline and during the follow-up visit. AIDS clinical trial group (ACTG) baseline questionnaire was used at baseline and ACTG follow-up questionnaire was used during follow-up. Detailed information about patient socio-demographic status, was collected. We also assessed stigma related to homosexuality using the 10-item Homosexuality Stigma Scale [4]. Adherence was assessed only during follow-up ACASI which was self-reported by participants using the 5-item questions of the ACTG follow-up questionnaire [3].
The baseline ACASI was approximately fifty minutes in duration and the follow-up ACASI needed thirty minutes to complete. ACASI was conducted using an android tablet with audio prompts so that participants could hear the questions and choose the answers guided by color coded answer keys. This was done for having a minimum reliance on the reading and writing capabilities of the participants. Informed consent was collected at baseline from the participants before administering ACASI. Participants were compensated INR 250 (approximately 4 USD) as part of wages lost for participation in one interview.

2.5 Sample size

The exact sample size calculation for a follow-up study among seropositive MSM population of Kolkata was not be feasible due to a lack of parameter information.

The median prevalence of HIV among MSM in Kolkata was 9.24% in 2008 as estimated in HIV Sentinel Surveillance [5]. The total number of MSM population in Kolkata remains unknown.

According to studies conducted among general population in different parts of India adherence to ART was as low as 70% and high as 95%.

MSM client population served by CBO PLUS was approximately around 1500, we will have a minimum of 138 HIV positive MSM in Kolkata.

I have assumed that the study sample will be a simple random sample and 85% of the sample to be adherent to ART. $p = 0.85$, $q=0.15$

In order to infer about the HIV positive MSM population of Kolkata I would tried to enroll all 138 subjects.
2.6 Data collection and Analyses

Thus, we sought to recruit 138 subjects for our study. Between November 2015 and March 2017, 130 HIV positive MSM’s were approached for participation in this study. Among them, we managed to conduct baseline interview for a total 104 HIV positive MSM, with 80% participation. The study incurred 20% lost to follow-up and finally 84 participants turned up for the follow up study.

We used 2 instruments for the baseline data collection i.e. ACTG baseline questionnaire and 10-item Homosexuality Stigma Scale, and collected demographic information. During follow-up, we used only the ACTG follow-up questionnaire. For details on questionnaire please refer to Appendix 2.7.1 and 2.7.2. Table 2-1 describes the time point when different instruments were used to collect data.

Simple descriptive analysis was carried out to determine the distribution of socio-demographic characteristics of the participants. The Perceived stress scale, CESD-D-SF, HIV symptom distress scale and the China MSM Stigma instruments used for the study were subjected to confirmatory factor analysis for the validity of latent variable constructs to be used further for analysis. Confirmatory factor analysis model fit for the constructs was assessed with model fit chi-square values with p-value more than 0.10, indicating a satisfactory model fit. The RMSEA value were close to 0.05, indicating a good model fit [6]. Other fit indices including goodness-of-fit index, Bentlar-Bonnet index, attaining values above 0.9. All statistical analyses were performed using SAS 9.4.

Table 2-1 Summary of study measures

<table>
<thead>
<tr>
<th>Concept</th>
<th>Measure</th>
<th>Time point</th>
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<tr>
<td>Socio-economic information</td>
<td>The Kuppuswamy modified socio-economic scale 2012</td>
<td>Baseline</td>
</tr>
<tr>
<td>Drug and Alcohol use</td>
<td>ACTG adherence questionnaire</td>
<td>Baseline</td>
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</tbody>
</table>

39
<table>
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<th>CESD-D-SF</th>
<th>Baseline</th>
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<tr>
<td>Quality of life</td>
<td>20-item HIV symptom Distress Scale</td>
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<tr>
<td>Homosexual Stigma</td>
<td>China MSM Stigma Scale</td>
<td>Baseline</td>
</tr>
<tr>
<td>Adherence to antiretroviral medications</td>
<td>ACTG adherence questionnaire</td>
<td>Follow-up</td>
</tr>
<tr>
<td>HIV Symptom distress</td>
<td>20-item HIV symptom Distress Scale</td>
<td>Follow-up</td>
</tr>
</tbody>
</table>
2.7  Appendix

2.7.1  Baseline questionnaire

Thank you for agreeing to participate in this survey. The answers you give in this survey will be used to plan ways to help other people who must take pills on a difficult schedule. Please answer the questions carefully and honestly. If you need any help, ask the study personnel to help. The responses are color coded. Thank you for helping in this important study.

1. Where were you recruited from for this research study?
   Referred from ART clinic
   Referred by peers from NGO’s
   Recruited from hot-spots
   Self-recruitment, information from friends, etc.

2. What is your age? (i) 18-24 years (ii) 25-34 years (iii) 35-44 years (iv) 45-54 years (v) >55 years

3. What is your source of income?
   Professional  Self-employed
   Jobless       Salaried
   Unskilled

4. What type of house do you live in?
   Concrete house  Mud walled house
   Apartment      No home and sleep in streets

5. What is your religion?
Hindu  Muslim  Buddhist

Christian  Other

6. Where do you live?
With your family  In a house within MSM community
Own rented

7. With whom do you live?
Parents  Wife  Male sexual partner
Alone (no one)  Female partner (other than wife)
Friend (not sex partner)  Other

8. How much do you earn per year (INR)?
<12,000
12,000 - 24,000
24,000 - 36,000
>36,000

9. Please circle one response for question.

<table>
<thead>
<tr>
<th>Not at</th>
<th>Somewhat</th>
<th>Very</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>All sure</td>
<td>Sure</td>
<td>Sure</td>
<td>Sure</td>
</tr>
</tbody>
</table>

1. You will be able to take all or most of your medications as directed?  

0  1  2  3
2. The medications will have a positive effect on your health?

3. If you do not take these medications exactly as instructed, the HIV in your body will become resistant to HIV medication?

10. The following questions are about your social support.

<table>
<thead>
<tr>
<th>Very Dissatisfied</th>
<th>Somewhat Dissatisfied</th>
<th>Somewhat Satisfied</th>
<th>Very Satisfied</th>
<th>Not Applicable</th>
</tr>
</thead>
</table>

1. In general, how satisfied are you with the overall support you get from your friends and family members?

2. To what extent do your friend’s members help you remember to take your medication?

11. If you have not taken any medications within the past month, please check this box □

12. In the past month, how often did you miss taking your medications because you:
<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Were away from home?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Were busy with other things?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Simply forgot?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Had too many pills to take?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Wanted to avoid side effects?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Did not want others to notice you taking medication?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Had a change in daily routine?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Felt like the drugs was toxic/ harmful?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. Feel asleep / slept through dose time?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. Felt sick or ill?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11. Felt depressed / overwhelmed?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12. Had problem taking pills at specified times (w/ milks or empty stomach)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13. Ran out of pills?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14. Felt good and medications seemed unnecessary?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

13. When was the last time you missed taking any of your medications?

   Within the past week
1 – 2 weeks ago

2-4 weeks ago

1-3 months ago

More than 3 months ago

Never skip medication or not applicable.

14. In the past week, how often did you:

<table>
<thead>
<tr>
<th>Question</th>
<th>Never/Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Mostly or Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feel like you couldn’t shake off the blues even with help from your</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>family or friends?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Have trouble keeping your mind on what you were doing?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Feel that everything you did was an effort?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Have trouble sleeping?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Feel lonely?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Feel sad?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Feel like you just couldn’t get going?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

15. In the past month how often have you:
People have various health habits. The following questions ask about your alcohol and drug use, past and current.
16. How often have you had a drink containing alcohol—a glass of beer, wine, a mixed drink, or any kind of alcoholic beverage— in the last 30 days? Check one

<table>
<thead>
<tr>
<th>Daily</th>
<th>Nearly</th>
<th>3 or 4</th>
<th>Once or</th>
<th>2 or 3</th>
<th>Once a</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

17. On days when you drank any alcoholic beverage in the last 30 days, how many drinks did you usually have altogether? By a drink we mean a can or glass of beer, a 4-ounce glass of wine, a 1-1/2 ounce shot of liquor, or a mixed drink with 1-1/2 ounces of liquor? Check one

<table>
<thead>
<tr>
<th>1 or 2 Drinks per Day</th>
<th>3 or 4 Drinks per Day</th>
<th>5 or 6 Drinks per Day</th>
<th>7 or 8 Drinks per Day</th>
<th>9-11 Drinks per Day</th>
<th>12 or more Drinks per Day</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

18. During the 30 days, how often have you had 5 or more drinks of alcohol in a row, that is, within a couple of hours (e.g. 2-4 hours) Check one

<table>
<thead>
<tr>
<th>Daily</th>
<th>Nearly</th>
<th>3 or 4</th>
<th>Once or</th>
<th>2 or 3</th>
<th>Once a</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

19. Please Check “Yes” or “No” for each question.

Have you ever used marijuana? 1 Yes 2 No
If you did, did you use it within the past 6 months?  1 Yes  2 No

Have you ever used cocaine (powder, crack, or freebase)? If you did, did you use it within the past 6 months?  1 Yes  2 No

Have you ever used heroin?  1 Yes  2 No

If you did, did you use it within the past 6 months?  1 Yes  2 No

Did you inject it?  1 Yes  2 No

Have you ever used amphetamines (speed)?  1 Yes  2 No

If you did, did you use it within the past 6 months?  1 Yes  2 No

Are you currently in methadone treatment?  1 Yes  2 No

If no, have you ever been in methadone treatment?  1 Yes  2 No

20. What is the highest level of education you have completed? (Check one)

11th grade or less

High school graduate or GED

2 years of college/AA degree/Technical school training

College graduate (BA or BSc)

Master’s degree

Doctorate/medical degree/law degree

21. What is/are the most likely way(s) that you became infected with HIV?

Sex with a man who was HIV + 1 Yes  2 No

Sex with a woman who was HIV + 1 Yes  2 No
Shared needle with a person who was HIV + 1 Yes 2 No

Blood transfusion or other medical procedures. 1 Yes 2 No

Don’t know. 1 Yes 2 No

Other (needle stick at work etc.) 1 Yes 2 No

22. Do you work for pay outside the home? 1 Yes 2 No

23. Do you have any children? 1 Yes 2 No

24. The following questions ask about symptoms you might have had during the past four weeks. Please check the box that describes how much you have been bothered by each symptom.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>I DO NOT HAVE THIS SYMPTOM</th>
<th>I HAVE THIS SYMPTOM</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I HAVE THIS SYMPTOM AND......</td>
<td></td>
</tr>
<tr>
<td></td>
<td>IT doesn’t bother me</td>
<td>IT bothers me a little</td>
</tr>
<tr>
<td></td>
<td>IT bothers me a lot</td>
<td>IT bothers me terribly</td>
</tr>
<tr>
<td>1. Fatigue or loss of energy?</td>
<td>0</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>2. Fevers, chills, or sweats?</td>
<td>0</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>3. Feeling dizzy or light headed?</td>
<td>0</td>
<td>1 2 3 4</td>
</tr>
</tbody>
</table>

49
4. Pain, numbness, or tingling in the hands or feet? 0 1 2 3 4

5. Trouble remembering? 0 1 2 3 4

6. Nausea or vomiting? 0 1 2 3 4

7. Diarrhea or loose bowel movements? 0 1 2 3 4

8. Felt sad or depressed? 0 1 2 3 4

9. Felt nervous or anxious? 0 1 2 3 4

10. Difficulty falling or staying asleep? 0 1 2 3 4

11. Skin problems such as rash, dryness or itching? 0 1 2 3 4

12. Coughing or trouble catching your breath? 0 1 2 3 4

13. Headache? 0 1 2 3 4

14. Loss of appetite or a change in the taste of food? 0 2 3 4

15. Bloating, pain or gas in your stomach? 0 1 2 3 4

16. Muscle aches or joint pain? 0 1 2 3 4
17. Problems with having sex, such as loss of interest or lack of function or satisfaction?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Once or twice</th>
<th>A few times</th>
<th>Many times</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

18. Changes in the way your body looks, such as fat deposits or weight gain?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Once or twice</th>
<th>A few times</th>
<th>Many times</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

19. Problems with weight loss or wasting?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Once or twice</th>
<th>A few times</th>
<th>Many times</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

20. Hair loss or changes in the way your hair looks?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Once or twice</th>
<th>A few times</th>
<th>Many times</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

25. Stigma

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Once or twice</th>
<th>A few times</th>
<th>Many times</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

1. How often have you heard that homosexuals are not normal?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Once or twice</th>
<th>A few times</th>
<th>Many times</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

2. How often have you felt that your sexuality hurt and embarrassed your family?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Once or twice</th>
<th>A few times</th>
<th>Many times</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

3. How often have you been made fun of or called names because of your sexuality?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Once or twice</th>
<th>A few times</th>
<th>Many times</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
4. How often have you been hit or beaten up because of your sexuality?  
1 2 3 4

5. How often have you had to hide your sexuality to be accepted?  
1 2 3 4

6. How often had your family not accepted you because of your sexuality?  
1 2 3 4

7. How often have you lost friends because of your sexuality?  
1 2 3 4

8. Have you ever been kicked out of school for your sexuality?  
1 2 3 4

9. How often have you lost a place to live because of your sexuality?  
1 2 3 4

10. How often have you lost job or career opportunity because of your sexuality?  
1 2 3 4

THANK YOU FOR TAKING PART IN THIS STUDY. YOUR INFORMATION IS VERY VALUABLE.
2.7.2 Follow-up questionnaire

The next section asks the anti-HIV medications that you took over the last four days. Most people with HIV have many pills to take at different times during the day. Many people find it hard to always remember their pills: Some people get busy and forget to carry their pills with them. Some people find it hard to take their pills according to all the instructions, such as “with meals,” or “on an empty stomach,” “every 8 hours,” “with plenty of fluids.” Some people decide to skip doses to avoid side effects or to just not be taking pills that day. We need to understand how people with HIV are really doing with their pills. Please tell us what you are actually doing. Don’t worry about telling us that you don’t take all your pills. We need to know what is really happening, not what you think we “want to hear.”

IF YOU TOOK ONLY PART OF A DOSE ON ONE OR MORE OF THESE DAYS, PLEASE REPORT THE DOSE(S) AS BEING MISSED.

If you took only part of a dose on one or more of these days, please report the dose(s) as being missed.

1. During the past 4 days, how many days did you miss taking all your doses?

None

One day

Two days

Three days

Four days

2. Most anti-HIV medications need to be taken on a schedule, such as 2 times or 3 times a day or every 8 hours. How closely did you follow your schedule over the last four days?
3. Do any of your anti-HIV medications have special instructions, such as “take with food” or “on an empty stomach” or “with plenty of fluids? 

1 Yes  
2 No

If yes, how often did you follow those special instructions over the last four days?

<table>
<thead>
<tr>
<th>Never</th>
<th>Some of The Time</th>
<th>About Half of The Time</th>
<th>Most of The Time</th>
<th>All of The Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

4. Some people forget to take their pills on the weekend days. Did you miss any of your anti-HIV medications last weekend (Saturday/Sunday)?

1 Yes  
2 No

5. When was the last time you missed taking any of your medications?

Within the past week

1 – 2 weeks ago

2-4 weeks ago

1-3 months ago

More than 3 months ago

Never skip medication or not applicable.
6. People may miss taking their medications for various reasons. Here is a list of possible reasons for missing medications. How often did you miss taking your medications because you: (Circle one response for each question.)

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Were away from home?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Were busy with other things?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Simply forgot?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Had too many pills to take?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Wanted to avoid side effects?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Did not want others to notice you taking medications?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Had a change in your daily routine?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Felt that the drugs were toxic/harmful?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. Fell asleep/slept through dose time?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. Felt sick or ill?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11. Felt depressed/overwhelmed?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12. Had problems taking pills at specified times (with milk or empty stomach)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13. Ran out of pills?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14. Felt good and that medications were unnecessary?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

7. The following questions are about symptoms you might have had during the past four weeks. Please check the box that describes how much you were bothered by each symptom.
<table>
<thead>
<tr>
<th>1. Fatigue or loss of energy?</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Fevers, chills, or sweats?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Feeling dizzy or light headed?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Pain, numbness, or tingling in the hands or feet?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Trouble remembering?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Nausea or vomiting?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Diarrhea or loose bowel movements?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Felt sad or depressed?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Felt nervous or anxious?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Difficulty falling or staying asleep?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Question</td>
<td>Score Options</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------------------------------------</td>
<td>---------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Skin problems such as rash, dryness or itching?</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>Coughing or trouble catching your breath?</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>Headache?</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Loss of appetite or a change in the taste of food?</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Bloating, pain or gas in your stomach?</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Muscle aches or joint pain?</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Problems with having sex, such as loss of interest or lack of function or satisfaction?</td>
<td>0 1 2 3 4</td>
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<td>18.</td>
<td>Changes in the way your body looks, such as fat deposits or weight gain?</td>
<td>0 1 2 3 4</td>
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<td>19.</td>
<td>Problems with weight loss or wasting?</td>
<td>0 1 2 3 4</td>
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<td>20.</td>
<td>Hair loss or changes in the way your hair looks?</td>
<td>0 1 2 3 4</td>
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2.8 References


Chapter 3 Social disadvantages, challenges and barriers around access to HIV services for Men who have sex with men – findings from a qualitative study in Kolkata, West Bengal India

3.1 Introduction

“End HIV and AIDS epidemic by 2030”, an agenda that has been argued to all member nations of the United Nation General Assembly in 2016 [1]. Fast track targets have also been set out for 2020 [1]. However, it will be difficult to control the HIV epidemic, if detailed information on neglected high-risk populations like Men who have Sex with Men (MSM) is not collected, collated and used appropriately to intervene. MSM are highly vulnerable group and have been affected disproportionately in all parts of the world [2, 3]. Globally HIV is on the rise among MSM [4]. In 2014, MSM accounted for 56% of the total persons living with HIV (PLHIV), and 70% of all the new infections in USA [5]. The HIV epidemic in India is predominantly driven by heterosexual transmission [6], and thus efforts have been concentrated to prevent heterosexual transmission [7]. The Government of India introduced a state sponsored National Aids Control Program (NACP) in 1992, and ART has been added to the agenda in 2004. The National Aids Control Organization (NACO) is responsible for the sponsored program, and has currently deployed NACP-IV all over the country. Over the decades India has undergone a drop in adult prevalence rates from 0.38% in 2001-03 to 0.26%, as estimated in 2015 [8]. According to the National Integrated Behavioral and Biological Surveillance (IBBS) MSM in India had a
prevalence of 4.3% (95%CI: 3.7 – 5.1) during 2014-2015, although geographic variations exist [9].

Homosexuals in India are cursed, due to the draconian Victorian law IPC 377, which criminalizes homosexual acts. Although male homosexuality was present in ancient times, is referenced obscurely in social treatises, presented in sculptures/paintings of ancient India [10], as well as in Vedic texts like the Veda-Purana, Sushruta Samhita [11-13]. The act of homosexuality leads to imprisonment, and thus MSM are technically invisible in India. Some MSM’s in India are married, but continue to engage in heterosexual activity [14], serving as a bridge population in fueling India’s HIV epidemic [15].

MSM’s are categorized into several categories, which include Kothi, Panthi and Dupli or Double-Decker. Kothi are MSM who express varying degrees of femininity, although they are biologically male and predominantly act as a receptive partner during anal or oral sex. Panthi are masculine appearing men, who are involved in insertive role during anal or oral sex. They are also known as Parikh or Gadiyo or Giriya. These men are generally married or expect to get married to a woman. Thus, they engage in heterosexual act, while they continue with homosexual activity. They usually deny their identity as homosexual and typically engage in sex with a Kothi or a woman preferably his wife. Double-Decker are MSM who serve in both receptive and insertive roles during anal or oral sex.

In seeking to understand the current situation of the HIV epidemic in India, assessment of different high-risk groups is necessary. Previous studies among MSM in southern India identified some barriers regarding access to HIV services and care [16, 17]. They elicited some family/social-level barriers, structural barriers and individual level barriers that have hindered access to the HIV care continuum. Barriers to ART access among seropositive
MSM’s have seldom been studied in India. Thus, in this study we endeavored to identify the barriers that prevent access of seropositive MSM to ART services.

3.2 Methods

We collaborated with a community based MSM organization named People Like Us -Kolkata (PLUS). This is a support group of MSM working for the promotion, protection and advancement of adolescent and young men’s health and rights, especially their sexual and reproductive health and rights, and toward ensuring their meaningful participation and perspectives at all levels of decision-making. A UN RED RIBBON Award Winning Organization PLUS was formed in 2001 as an informal support group in Kolkata providing safe space for vulnerable and marginalized adolescents and young boys who are into selling sex, in the city. Later PLUS commissioned a community owned study “Prostituted boys in Kolkata city” which initiated the organizational backbone. In 2003 PLUS formally registered under the West Bengal Society registration ACT (1961) and has a secretariat based in Kolkata city.

Between September and December, 2015, we conducted one focus group discussion (FGD) and 6 in-depth interviews (IDI), by trained study staff. FGD included 7 committee members of the Community Based Organization (CBO) PLUS. The IDI’s were conducted among 6 HIV positive MSM’s who attended ART clinics. These participants were referred by the peer workers of the CBO PLUS. All discussions/interviews were conducted in a private room at the PLUS office. Verbal consent was taken prior to the initiation of the discussions. Permission for taking notes and voice recording of the conversations were also obtained. The interviews were conducted in Bengali, except for one IDI which was done in Hindi. A semi-structured discussion guide with few probes was used for this purpose, that focused on
barriers to ART access and possible ways to address these barriers. The discussion
topics/issues included in the guide were formulated from the review of relevant literature and
possible themes that had emerged. The FGD was conducted for 120 minutes; IDI’s ranged
from 20 to 45 minutes. All participants received an honorarium of 250 Indian rupees
(∼$4USD). The study was approved from the University of California Los Angeles,
Institutional Review Board and National Institute of Cholera and Enteric Diseases,
Institutional Review Board.

3.3 Data management and analysis

Audio recordings of the interviews and discussion were transcribed verbatim into Bengali
and Hindi. Notes taken during interviews facilitated the transcription and enhanced the
transcripts by insertion of comments. The process of transcription of the proceedings was
completed within 2 days of completion of the interview/discussion. The interview transcripts
were imported into Atlas 7.5 for the purposes of coding and analysis. We explored data using
framework analysis [18] and used the barrier framework developed by The Global Forum on
MSM & HIV [19]. We established a priori categories and further used open and in vivo
coding. At the time of initial readings, we employed the ‘open coding’ technique, followed
by ‘thematic coding’ during re-readings.

3.4 Results

3.4.1 Participant characteristics

There were 13 participants in total. Six HIV positive self-identified MSM were interviewed.
Half of the interviewees were Kothi and the other half Panthi, according to the standard
classification of MSM’s in India. The majority of the participants (50%) were sex workers by
profession, 33% were peer outreach workers and 17% were unemployed. Almost all of the participants were single except for one, who was married (17%). The 7 FGD participants were committee members of the CBO PLUS. Four of the participants (57%) were CBO board members and the other three were CBO peer workers (43%). Of all the participants in the qualitative study, only 3 (23%) participants were aged less than 25 years, all others were aged between 25 years and 35 years.

3.4.2 Emerging themes

The broader themes that emerged from the content analysis of the IDIs and FGD transcripts were: a) Social discrimination, b) Challenges following disclosure of sero-status, c) Barriers to testing and associated Stigma of HIV, d) Barriers for initiation of ART, and e) Barriers to ART adherence.

3.4.2.1 Social Discrimination

Owing to institutionalized homosexual stigma, discrimination is rife. Instances of violence, are always a concern, for these sexually marginalized people. Kothi MSM are the common victims. Social discrimination has always been there for MSM as revealed from the following verbatim.

“Yes, many instances of harassment have occurred in the past, although it is less nowadays, but has not stopped entirely. I have no idea of what type of act is actually termed as harassment, but whenever I am travel few guys ogles at me constantly. I then feel harassed. This type of harassment has never stopped. A lady looking with contempt or a guy looking with lust, both harasses me.” Kothi MSM, peer outreach worker

“Recently there was an incident. A man in our locality used to beat us regularly. We were afraid of him. One day we gathered with our friends and protested against this man.
Immediately the offender surrendered to the police. We had in lodged a complaint with the police. But to our utter dismay his relatives had freed from the police station at around 11pm. So, you see we are not supported by the police. Political influence does a lot in here.” Kothi MSM, peer outreach worker

“I sometimes get mocked and taunted by names on the street. Previously I had to gather some friends and protest. Now I shout out slangs and they just stop, even if it is a policeman or a common man.” Kothi MSM, peer outreach worker

As observed, law and legal system have long abandoned justice to this population. Nevertheless, they still hope for a better tomorrow.

“I do not have to use slangs every time. I along with other community members have been trained to handle situations like this. We are mentally more mature /strong to deal with it. If a person tries to say something and I reply with slangs, then it is of no use, I cannot present myself. I have often counselled common people and most of them have understood. For some folks, I needed to use slangs, but people are well informed about us. They differentiate between a transgender and Kothi. Thanks to the news and cine media.” Kothi MSM, peer outreach worker

3.4.2.2 Challenges following disclosure of sero-status

Disclosure of HIV sero-status was like revealing a dark secret about life, and leads to social discrimination. Family members and friends tend to isolate and relegate positive individuals. Some MSM experience breakup with their partners on disclosure.

“I take him to testing center, if not getting report the same day, I have to convince him to manage some time and come back for the report. I say him come in time or you will not get the report…. Who is he going to tell! He will not tell it to his family neither he will be able to
disclose it his boyfriend if he has one. Immediately after knowing the sero-status, his boyfriend rejects him, even if his boyfriend is seropositive, he himself is to be blamed. His partner says you are bad, you have relationship with others, so you are bad.” Kothi MSM CBO Board member and peer outreach worker

“I do not want to reveal my sero-status to my friends and family members, all of them know me as a good boy. If I become open and say I am positive, I have HIV in my body they will never think the same about me, never have that same warmth and compassion for me after that. My revelation will hurt our relationship with them. They will lose respect and love for me. I don’t want to be deprived of my friends. As a result, I will remain careful, never to get detected or divulge my sero-status.” Kothi MSM

3.4.2.3 Barriers to testing and associated Stigma of HIV

HIV related stigma is common among the general population, MSM’s are no different. Family members, friends and sometimes even the employer lose faith on seropositive. They fear revealing of their HIV sero-status, as this might lead to his social isolation, even by MSM community members.

“There are some people who are engaged in sexual activity are not interested in testing for HIV. There are people like me who are peer workers, are also engaged in sex. Even with a lot of knowledge about HIV, they are not willing to test for HIV. These guys think that if they are noticed visiting ICTC, people will suspect that they are bad guys, infected with HIV.” Kothi MSM

“Yes, we must go to ICTC to take the HIV test. If people go to private center neighbors or friends may know about it, so it's better to go at the hospital ICTC center.” Panthi MSM
“Many of my friends do not want to know serostatus. Those who are MSM like me I tell them to get tested for HIV. They say what has happened to me? I am doing fine! Can I say this is confidential because of virus that can get inside your body when you do sex without condoms.” Panthi MSM

“I have known persons from the community who are not willing to test for HIV because they don’t have the idea, that this needs to be done for their own good. But if they had been counselled and convinced they will test willingly.” Panthi MSM, peer outreach worker

Retesting

“Once tested for HIV and know that they are negative, they do not have the idea that they need to come back and retest for HIV. Also, no guarantee that he will be using protection with condom during sexual activity, as he knows he is negative and thinks that his partners are also negative. It is very difficult to convince them to retest them after 3 or 6 or 9 months.” Panthi MSM, peer outreach worker

Thus, MSM’s neglect testing of HIV, even peer workers avoid it until necessary. Retesting for HIV, after 6 months among those HIV negatives is a rare occasion.

3.4.2.4 Barriers for initiation of ART

Some MSM’s have depressive thoughts, and they just do not initiate ART. After knowing serostatus MSM experience mental breakdown. Instances of runaways have also occurred. Some also have negative vibes and want to harm others by having unprotected sex.

“I had a mental breakdown and was not willing to start taking medications. My family members forced me to start medication. Did not do that willingly when I was first diagnosed I thought I would rather die for now, today than tomorrow. It is a kind of feeling that no one can understand unless he or she is infected. Many people think like me and do not want to
start medication. I feel people have similar thoughts and they do not want to live and start taking pills.” Kothi MSM

“Persons not only from our community, but also other people of our society, perceive that if a person is tested HIV positive, then he has done some bad things, irrespective of being a boy or girl. This is how our society thinks. Therefore, a HIV positive boy or girl have to face stigma, but for MSM’s this stigma is four times. This is more severe for TG’s or MSM (Kothi). After hearing test results, many just hide-out or get lost and cannot be traced about his whereabouts. They disappear just suddenly from his home, he just cannot bear it. In some cases, I have been successful, but in some cases I fail. But I have to keep trying.” CBO Board member and peer outreach worker

“Some of the MSM’s those who come here for counselling, think that since he is infected, so he will spread this to others. Few of them do think this way. He will not get any treatment, or do anything, but he will spread. Most of these people are TG’s or MSM who perceives these negative thoughts. Normal person tries to get treated after knowing status, but there are these few odd guys, who do the opposite. I have become positive, I will do sex and spread to him and make him positive too.” CBO Board member and peer outreach worker

3.4.2.5 Barriers of ART adherence

3.4.2.5.1 Personal barriers

Some MSM’s have skipped medication as they have been drinking alcohol. Some do not return to ART centers on schedule, to collect their medications. Few have skipped medications, as they were feeling healthy.

“I have seen myself in Medical College. They take pills and also drink alcohol. Few of them return back to the clinic after 2 months. I am sure they are not very interested to take
medications……. There is nothing to fear. I take HIV medication to get well, to remain healthy, but it will not get totally cured. But will remain healthy. But some people drink alcohol and do not take medications, takes other medication, so stopped taking HIV medications. Some have lost papers so do not take medications.” Married Panthi MSM

“When I go to refill my medications; I often hear the staff asking subjects why you did not take the pills and people saying sister, I was sick and so I was taking the other medications. But I take those pills even if I take other medications.” Married Panthi MSM

“People think that they are better now, and so they stop medication. But you see I want to continue medications as long as live.” Kothi MSM

3.4.2.5.2 Social Barriers: Fear of stigma if noticed taking ART

Social boycott of families and persons taking ART pills, has been a phenomenon in our society. Sero-positives are always careful, not to divulge their status to neighbors or other family members.

“MSM carry medications when they work outside of their home town. Sometimes it takes more time than it was anticipated to finish the program, and come back home. They carry medications for one month but after this finished up they do not come back home, only for the medications. They will also not visit the nearest government hospital with the documents to procure some of the medications. But by doing this people will get to know that he takes medication and will lose his job. So, he doesn't want to take the risk. They will again visit the center when they return home, after 2 or 3 months.” CBO Board member

“ART medication causes general weakness and subjects losses weight. If neighbors are able to detect the actual cause, they will get disgusted. They will boycott me; many families have been boycott following disclosure of their sero-status. Some MSM’s experience mental
breakdown after observing this social behavior.” Panthi MSM, and a peer outreach worker for MSM CBO

“People may know. I have started my medications, I live alone in my house or travelling alone, I will able to take the medications on schedule. But at family home when I try to maintain schedule and ready to take pills, they will ask what are you taking from your bag. What will I say then or show them? What will I do, I have not disclosed to anybody about my status. I will have to take the pills when I'm not being followed or nobody is there, so that no one notices. Only this way I will be able to take the medications regularly and keep myself healthy.” Kothi MSM

3.4.2.6 Poor Health System Responsiveness

Certain mal-practices exist among the health care staff in the government hospital. They charge money for free services, misbehaves with MSM’s. Staff may refuse service, or may discriminate in dispensing the pills. Also, staffs are rude in behavior. Verbal harassment of MSM (Kothi) at clinics occurs frequently, which may be due to a provider or other staffs.

“I take someone for Medicine where everything is free. The medicine person is made to wait for long time, then we enter and then they tell us medicine has finished, we will write it down for you to buy it over the counter. The person says I don’t have money to buy medicines. Each medicine is costly, and finally we returned that day. At last with the help of a counselor he gets the medicine after seven days! So, there's nothing I can say about it.” Panthi MSM, peer outreach worker

“Yes, at the beginning we had to face insults and felt shy. Now that we are more confidant, they can feel that these guys can go far if something happens here they can reach higher levels and these activities will get reported to higher levels and thus perform their due
diligence but they are not polite. They may pass on wrong information about some ART medications or other issues, so we are always there with the subjects. We have some experience and knowledge about these confidential information, so we accompany friends or whoever asks to accompany. If something is not right or not occurring as it should have, we ask them questions. The mere thought of having negative feedbacks to higher level make them perform their duties towards us, still this experience varies between staffs. Sometimes we shout loudly to hurry up, but those who are shy to speak up, often has to return later for medications or other rude instructions.” Panthi MSM, CBO Board member

“Yes, here maximum ICTC counselor working here including labtechs does not accept the facts. At ICTC only pretest counselling is done, post-test counselling is never done properly. Very little information is shared after testing, as post-test counselling. There are problems with the government infrastructure, where confidentiality is not maintained. Very little space. Counsellors are discriminatory, they bother if patients react. All of them are provided reports in a sealed envelope, but some are open. It’s obvious if two persons are there to collect the report, and the counselor comes up with two envelopes one enclosed and one opened, that is discrimination and more so towards transgenders and (Kothi) MSM. Some of the counsellor inquisitiveness, causes verbal harassment. Few of them even asks to show our genitalia. This is so absurd kind of behavior. I think they should be trained on this aspect.” Kothi MSM, CBO Board member

“In some hospitals, I find some transgender counsellors when I have accompanied someone for testing HIV. He is similar to me, a TG, but surprisingly he laughs and giggles at me and ask questions like ‘What did you do?’, that harasses me!” CBO Board member TG Peer worker
“I know people who work at the HIV testing centers. They ask for a lot of information, but the conversation is harassing. They just don’t think that they are harassing us. This is an awkward situation we are in.” Kothi MSM

“Yes, I got help at some places from persons whom I have known. In some like in _ Hospital, when I used to go for testing subjects then I have witnessed counselors asking How did it get to you? What did you do? What kind of sexual practice you do? then smiling. At some places like _ we had good relation with the counselor. I would talk frankly do some gossip. But some places are even worse. They don’t pay much attention to what I say, they just laugh. So how do I confide in him.” Kothi MSM CBO Board member and peer outreach worker

3.5 Discussion

Seropositive MSM’s in Kolkata face many challenges and multi-level barriers in order to access ART medications. Losing family support, losing livelihood, outright discrimination combined with bureaucratic challenges are some of the formidable challenges MSM must confront to gain access to HIV services. Limited knowledge of HIV and ART, hindered MSM to test for HIV. Although regular counselling of ART subjects has been a part of the program, MSM lacked the will to continue medication at all times. Many of them would skip medication when they feel better. Transactional sex is common among the Kothi MSM’s living in and around Kolkata. Fearing HIV related stigma and loss of job, many would skip medication, to avoid someone noticing. Barriers to ART adherence emerged at healthcare system, social and individual levels. Depressive thoughts and lack of knowledge often caused MSM to skip ART medications. Apart from perceived stigma, poor healthcare services are among the major barriers that inadvertently caused verbal harassment to the MSM.
Our study results are similar to previous findings among MSM in southern India [16, 20]. Kothi participants reported having boyfriends, who may be Panthi or a Double-Decker. They like to imagine themselves as females and dress accordingly. They rely on clandestine long-time romantic relationship with their partners for emotional and material support. Some of them may be married couples. Disclosure of HIV status, to partners, has resulted in termination of relationships for some and few were renounced by family members. The Kothi subgroup among all MSM face more social discrimination.

However, except for targeted intervention (TI) initiative of the NACP, government services targeting MSM were scarce. HIV Seropositive MSM participants, and MSM peer workers pointed to structural, social and individual level barriers. Participants reported negative and judgmental attitudes of hospital staff towards MSM, and discrimination of Kothi MSM’s in healthcare settings. As a result of these experience Kothi MSM’s feel reluctant to avail services at public hospitals including the ART centers.

Our findings provide valuable insights and identify some issues that needs to be addressed for better HIV-related outcomes for MSM. A multi-sectorial approach is needed to address the multi-level barriers that plague HIV/AIDS. Public campaigns must be undertaken to increase acceptance of HIV infected persons, complementing the recently passed Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) (Prevention and Control) Bill, 2017 [21]. Information, Education and Communication (IEC) about HIV is much needed to mobilize the general population. NACO needs to undertake promotion of acceptance of these socially marginalized high-risk core groups like MSM’s especially the Kothi and other sub-groups. Mobilization of their community and empowering them is recognized as an important aspect of structural approaches in HIV prevention [4, 22].
Despite being a core risk group in the HIV epidemic and transmission dynamics in India, not much effort has been outlined in NACO to study the possible barriers to the HIV care continuum. Targeted intervention (TI) approach has not been much successful, as evident from the low coverage of MSM in the program. TI services for MSM’s needs to be augmented and monitored, and eventually evolve into wide network of well-trained MSM peer workers. Healthcare provider and the supporting staff need to be trained at regular intervals with specific focus on: a) non-discriminatory rendering of health care services to all subjects irrespective of their appearance b) challenges perceived by MSM’s especially Kothi’s and their subgroups, while they access HIV care services c) tailored counselling for the sexual minority and high-risk populations like MSM and their subgroups. Counselling needs regular compassion to educate patients about HIV and its treatment. Thus, provision of mandatory counselling must be in place, at the time of each contact or refill. Counselling should be imparted by health staffs and caregivers, focusing on issues pertaining to alcohol abuse, mental health and disclosure of sero-status to friends and family. d) periodic training of TI MSM peer workers, and solicit subject counselling to help bridge in the knowledge gap of the seropositive MSM.

Poor infrastructure, low manpower and low healthcare expenditure has resulted in this poor health system responsiveness. Improvement of infrastructure and engaging more manpower for HIV services across the country is needed.

There are several limitations which might limit, the scope of interpretation of our study findings. We interviewed 6 MSM and 7 CBO members. This sample size is small enough to saturate the themes that have emerged. Double-decker MSM are underrepresented in our study. However, this is not unexpected, as this behavior is often not reported by MSM. Other
subpopulations of MSM, like bisexual-identified or gay-identified MSM’s may have different barriers to access ART [23].

In conclusion we identified barriers, that hinder MSM’s access to free HIV services and ART at the government clinics in the eastern region of India. We make recommendations to address the barriers to HIV services at personal, social and more importantly modifying the healthcare system for marginalized people.
3.6 References


Chapter 4 Depression and its correlates among seropositive Men who have sex with men- A study from eastern India

4.1 Introduction

Depression is a serious mental disorder that causes dysphoria and/or a loss of interest in activities [1]. A myriad of factors like biological, social, psychological stress, substance abuse or their complex interaction modulated with adverse life events are likely to cause depression. These can bring about specific changes in brain chemistry that may lead to symptoms of depression and related conditions [2]. Depression is a burdensome disease for the patient, relatives and society [3]. Despite being a treatable disease, mental illness is often associated with chronic medical conditions [4-6]. It is one of the most prevalent comorbidities among HIV-infected individuals [7-9]. Similar with other chronic diseases [10-12] depressive symptoms are associated with inadequate HIV treatment adherence [13, 14].

Globally 322 million people suffered depression in 2015, with nearly half of these depressed individuals living in South-East Asia region and Western Pacific region [15]. An estimated 56 million Indians were depressed during 2015, accruing a national prevalence around 4.5% with a DALY of 10 million [15].

Indian Penal Code section 377 criminalizes homosexuality, thus institutionalizing stigma towards LGBT in India. Thus, stigmatization of homosexuality, and associated discrimination is rife leading to limited access to health care including HIV-related services [16-19].

Moreover, MSM’s in India face a plethora of negative life experiences. Studies have identified elevated levels of psychological illness. These factors have been associated with
higher HIV-risk behavior, lower testing for HIV and thus reduced initiation to HIV treatment and the care continuum [16, 17, 19, 20].

Studies conducted among MSM’s across the country elicited diverse prevalence of depression, ranging from 5% to as high as 64% [16-23]. Our study aims to measure the prevalence of depression and its predictors among HIV positive MSM’s who have been initiated to Anti- Retroviral Therapy (ART).

4.2 Methods

We collaborated with a MSM community based organization (CBO) named. People Like Us - Kolkata (PLUS). PLUS is a support group of MSM’s working for the promotion, protection and advancement of adolescent and young men’s health and rights, especially their sexual and reproductive health and rights, toward ensuring their meaningful participation and perspectives at all levels of decision-making. A UN RED RIBBON Award Winning Organization PLUS was formed in 2001 as an informal support group in Kolkata providing safe space for vulnerable and marginalized adolescents and young boys who are into selling sex, in the city. Later PLUS commissioned a community owned study “Prostituted boys in Kolkata city” which initiated the organizational backbone. In 2003 PLUS formally registered under the West Bengal Society registration ACT (1961) and has a secretariat based in Kolkata city. Due to shortages of funds, PLUS now manages only a temporary transgender walking shelter home named Prothoma. Prothoma is multifaceted and encompasses the following: Health management, Case management, ART therapy and livelihood options and training. The Health assistance program provides some basic needs for the MSM and transgender youth population.
There are three National AIDS Control Organization (NACO), ART centers operating in the city of Kolkata catering to HIV infected individuals living in Kolkata and its suburbs. ART initiated subjects return back to the designated ART centers after a month or two for refilling ART medication. CBO peer workers visited these three ART centers operating in Kolkata. They identified HIV positive MSM’s and approached them for participation in the study. Information about the study was shared with individuals. Subjects who were interested in participation were screened for eligibility for inclusion in the study. We used decision making capacity assessment tool to determine if the participant was capable of decision making. Further details of the study were shared with eligible MSM’s and thus recruited for the study. Participants scheduled meeting with the peer worker at a convenient location, for the baseline Audio Computer-Assisted Self-Interview (ACASI). After recruitment, each subject was assigned a unique identification number for the purposes of the study. MSM’s signed informed consent before the interview. Thus, we implemented a cross-sectional survey among seropositive MSM on ART.

4.3 Data Collection

Between November 2015 and December 2016, 130 HIV positive MSM’s were approached for participation, of whom we managed to conduct survey of a total 104 (80%) HIV positive MSM. Inclusion criteria were as follows (i) age 18 years or older (ii) self-identified MSM behavior as Kothi (receptive partner), Panthi (insertive partner) or Dupli (both receptive and insertive partner) (iii) capable of consenting for the study (iv) tested positive for HIV and subsequently assigned to receive anti-retroviral treatment prior to the recruitment for the study. After consenting, we collected information on socio-demographic variables like age, occupation, income, marital status, education level, homosexual stigma, depression
symptoms, perceived stress, drug abuse history and HIV symptom distress. The survey was developed in English, translated into Bengali and Hindi and back translated into English to ensure semantic equivalence. Surveys were administered in Bengali and Hindi by the CBO peer worker under the supervision of the research coordinator.

4.3.1 Measures

4.3.1.1 Socio-Economic Status

The Kuppuswamy modified 2012 socio-economic scale [24] based on Indian standards was used to measure SES which included income, occupation and education of the participant. Respondents were asked if they were illiterate or read or write, and their highest level of education. We also inquired about their occupation with choices like student, unemployed, sex worker, labor, self-employed etc. They also responded to their monthly average income with choices to choose from monthly income less than 3000INR, less than 10,000 INR etc.

4.3.1.2 Stress

Stress was measured with a 10-item Perceived Stress Scale [25] in its original format. This scale is a modified version of the 14 item Stress Scale [26]. Respondents were asked to consider how they have felt over the last month. There are 10 questions in which people can choose how often they have felt a certain way: never, almost never, sometimes, fairly often and very often. For positive questions coding had to be reversed for analysis. Possible scores range from 0 to 40, higher the score the worse the stress. Reliability of the scale was assessed. Overall Cronbach’s alpha was 0.41; Psychological Stress subscale 0.79; Physical Stress subscale 0.48.
4.3.1.3 Homosexuality Stigma

Homosexuality Stigma Scale used in this study was based on the China MSM Stigma scale [27] in its original format, adapted from the Homophobia scale [28]. There are ten items which asks participants about certain homophobic incidents which they might have experienced. Each item had four response options: 0= “never”, 1= “once or twice”, 2= “a few times”, and 3= “many times.” Possible scores may range from 1 to 30, the higher the score more the stigma was internalized. This scale includes dimensions of enacted stigma and perceived stigma. Overall Cronbach’s alpha was 0.75; enacted subscale 0.79; perceived subscale 0.44.

4.3.1.4 Depression

Depression was measured using the 7-item CESD-D-SF [29] in its original format, which is a shorter version of the CES-D scale [30]. The seven-item scale asks participants how often they have felt a certain way, during the past week. The participants can choose from the following options 0= “rarely or never”, 1= “sometimes”, 2= “often”, and 3= “mostly or always.” Possible score may range from 0 to 21. The Higher the score, the worse the depression. Internal consistency was assessed. Cronbach’s alpha for this scale was 0.82.

4.3.1.5 Symptom Distress

Symptom Distress was assessed using the 20-item HIV Symptom Distress Scale [31]. The self-reported distress, in HIV infected population is characterized by phenomena such as fatigue/low energy, fevers, dizziness, tingling/hand/foot pain, memory loss, nausea/vomiting, diarrhea, depression, anxiety, sleep problems, skin problems, cough/shortness of breath, headache, appetite loss, bloating/gas, muscle/joint pain, sexual problems, weight gain, weight loss, and hair loss. Each item had five response options: 0= “no symptom”, 1= “does not bother”, 2= “bothers a little”, 3 = “bothers a lot” and 4 = “bothers terribly”. This scale
includes dimensions of physical and mental distress. Overall Cronbach’s alpha 0.91; physical distress subscale 0.89; mental distress subscale 0.78. For the purposes of the study we excluded the mental distress subscale from analysis, as depression was measured using the 7-item CESD-D-SF scale. Possible score may range from 1 to 68, higher the score, more the distress due to symptoms and lower the quality of life.

4.3.1.6 Social support, Alcohol and Drug use

The questions on social support, alcohol and drug use were adapted from the ACTG adherence baseline questionnaire [32]. We asked participants if they were satisfied with the overall support they get from their friends and family. Participants were asked if they used alcohol in past month and about the frequency of its use. Due to lower access and availability of amphetamine some questions related to drug abuse were modified.

4.4 Procedure and Analysis

The survey was approximately fifty minutes in duration and ACASI was conducted using an android tablet with audio prompts so that participants could hear the questions and choose the answers guided by color coded answer keys. This was done for having a minimum reliance on the reading and writing capabilities of the participants. Signed informed consent was collected from the participants before administering the survey. Participants were compensated INR 250 (approximately 4 USD) as part of wage lost for participation. Simple descriptive analysis was carried out to determine the distribution of socio-demographic characteristics of the participants. The instruments used for the study were subjected to confirmatory factor analysis for the validity of latent variable constructs to be used further for analysis. Confirmatory factor analysis model fit for the constructs was assessed with model fit chi-square values with p-value more than 0.10, indicating a
satisfactory model fit. The RMSEA value were close to 0.05, indicating a good model fit [33]. Other fit indices including goodness-of-fit index, Bentlar-Bonnet index, attaining values above 0.9. We employed simple and multiple linear regression to explore the association of depression and its predictors. We checked the data for outliers in variables and the normality checks for the scale scores using histogram, boxplots and scatter plots. The final linear multivariate model was subjected to influential points analysis using studentised residual, leverage, Cooks distance and DFFITS. We thus excluded 13 influential observations from the final multivariate analysis. Final model fit was assessed with $R^2$ and adjusted$R^2$, implying the proportion of variance of the dependent variable explained by the model. Normality Quantile-Quantile plot of the residuals, plot of residual vs predicted value and tests of collinearity was inducted on the final model. Analysis was done using SAS 9.4 © SAS Institute Inc., NC, USA.

4.5 Results

Table 4-1 describes the socio-demographics of participating MSM’s. About 47 % of the MSM participants were aged between 21-35 years and 33% were 35-49 years. Most of the MSM’s were sex workers by profession (39%), or unemployed 24%. Only 15% were laborers and merely 17% were skilled to run business or be employed. Thirty-five percent of the participants lived in mud walled house, whereas 55% lived in a concrete house. The Majority of the participants (78%) were Hindus by religion but 16% were Muslims. About 60% lived with their family whereas 34% lived in a rented house. Thirty three percent of the MSM were married to a female, 6% married to a male and 16% have married both a male and female sequentially. Some of the MSM’s never married (14%), and 32% got divorced/widowed. Monthly income was less than 3000 INR for majority of the participants (64%), whereas 32%
had incomes ranging between 3000 – 10,000 INR. A considerable portion (21%) of HIV positive MSM’s were illiterate, 55% attended middle school and only 23% had post High school education.

Subjects were assessed for the common symptoms of depression (Table 4-2). About 43% of the subjects were dysphoric sometimes, and 26% was always sad. Thirty four percent of the subjects had trouble sleeping sometimes and 20% always had trouble sleeping. Almost 23% of the respondents always felt tired and 31% sometimes felt tired. Fifty percent of the participants had trouble remembering. About 53% of participants experienced trouble thinking over the past week. Among the gravest of all the inquires, suicidal ideation had sometimes occurred to 30% of HIV positive MSM’s and 29% had suicidal thoughts.

The prevalence of depression among HIV positive MSM’s on ART was 36% (95%CI: 26%, 45%)\(^1\). The overall mean score on the CES-D-SF depression scale was 6.4 (Standard deviation ± 4.9), with scores ranging from 0 to 21 (Table 4-3). The mean score on the Perceived Stress scale was 19.0 (Standard deviation ± 5.3), while the scores ranged from 6 to 34. The internalized Homophobia mean score was 7.2 (Standard deviation ± 5.5), and the scores ranged from 0 to 29.

\(^1\) Using the score <8 on the depression scale as not having clinical depression [29].

Bivariate analysis revealed that higher depression score was associated with a significantly higher score in the Perceived stress scale (\(\beta:0.5, 95\%\text{CI}: 0.4, 0.6\)) (Table 4-4). Depression score was significantly associated with higher score on the Homosexuality stigma scale (\(\beta:0.5, 95\%\text{CI}: 0.3, 0.6\)). Increased HIV distress symptom score was associated significantly with higher score on the CES-D-SF scale (\(\beta:0.3, 95\%\text{CI}: 0.2, 0.4\)). Presence of social support significantly decreased the depression score among the participants (\(\beta: -2.4, 95\%\text{CI}: -4.8, -
0.8). Multiple linear regression analysis identified the adjusted parameter estimates, as shown in Table 4-4. Depression was significantly associated with an increase in perceived stress. An increase in score by 4 units on the stress scale was associated with an increase by 1 unit on the depression scale (adjβ:0.3, 95%CI: 0.1, 0.4), after controlling for other variables. Depression increased significantly with increased internalized stigma. An increase by 5 units in the stigma scale was associated with an increment of 1 unit on the depression scale (adjβ:0.2, 95%CI: 0.1, 0.3), after controlling for other variables. HIV symptom distress was associated with depression among HIV positive MSM’s. Increase in score by 5 units on the HIV distress scale was associated with an increase by 1 unit on the CES-D-SF depression scale (adjβ:0.2, 95%CI: 0.1, 0.3), after controlling for other variables.

4.6 Discussion

The current study aimed to investigate the prevalence of depression among HIV positive MSM and factors associated with depression. We hereby report the results amongst this sexual minority and hidden population living in eastern India. Prevalence of depression was 36% in our sample which is well above the national prevalence of depression (4.5%) during 2015 [15] among the general population. This finding was in accordance with previous studies that have revealed high prevalence of depression among MSM’s throughout India [16-22].

The impact of Homophobia, poverty and life stress have been associated with depression among MSM [34, 35]. Our study results indicate that homosexuality stigma and stress was associated with a greater level of depression among HIV positive MSM. The finding corroborates studies conducted among MSM’s in different parts of India [17, 22, 36].
The prevalence of drinking was 37% in our sample. Based on literature review, this variable was considered in the final model [17, 36]. Among the ART initiated HIV positive MSM’s, we found that alcohol intake was not associated with depression, interestingly our multivariate results show insignificant no correlation with depression among the subjects (adjβ: 0.04, 95%CI: -0.2, 0.1). This finding was in contrast to that reported from prior studies conducted in India [17, 36] among MSM’s. One reason may be due to lack of sample size. A correlation between depression and alcoholism among HIV positive MSM has not been reported in India.

Analysis of socio-demographic variables indicate that 6% belonged to middle/lower-middle SES strata, 80% of MSM’s belonged to lower/upper-lower SES strata and 14% belonged to lower SES strata respectively [24]. Majority were illiterate or did not finish middle school education and had low income as evident from distribution of the strata. A considerable proportion of the participants were male sex workers.

We were able to recruit 104 HIV positive MSM subjects, who had initiated to the continuum of care. Our results suffered several limitations owing to its observational nature. First, due to its cross-sectional design, lack of temporality prevented us from eliciting causal inferences. Second, we employed convenience sampling with the help of peer workers of the CBO. They may have approached only those likely candidates who are identified as MSM. Following institutionalized homosexual stigma, a portion of MSM remains undetected. Undisclosed MSM identity was not part of our sample. Third, as discussed before, almost all of the MSM’s belonged to lower socio-economic strata. Therefore, generalizability of our study findings is limited.
The NACO implemented HIV programs for high risk groups are primarily focused on coverage, clinical parameters for evaluation of ART and management of consequent side-effects due to ART medications. Depression is not queried at the ART clinic. From descriptive analysis of socio-demographic characteristics, we observed that a significant proportion of HIV positive MSM’s were sex-workers by occupation. Consistent use of condoms by MSM during anal-sex has been low in India, Manipur 57.6%, and 48.9% in Tamil Nadu [37]. BSS 2009 reports low condom usage among MSM’s in different parts of the country[38]. Marginalized by institutionalized stigma, discrimination and the associated secrecy all leading to low self-esteem, thus engaging in unprotected sex[39, 40]. Adverse health seeking behavior and other harmful behaviors like smoking and alcohol use may be indirectly influenced by depression [41, 42]. Meta-analytic review of ART adherence studies, has associated depression and treatment with non-adherence [14]. Thus, depression may contribute to accelerate HIV disease progression [43] and poses a major threat to health and health seeking behavior among its victims.

We also find participants sometimes married both male and female partner (Table 1), thus acting as a high-risk bridge population in fueling the HIV epidemic in the general population. It should be noted that the clients or partners of these sex workers are either already infected or will be in near future as practice of safe sex is low in the depressed psychological state. It is thus recommended to implement psychiatric screening and counselling at the ART clinics. Effective counselling is needed to mitigate the various negative factors associated with depression. Knowledge of factors associated with depression, may help determine appropriate management strategies. Need based counselling may be tailored based on individual cases. For MSM with clinical depression, health care providers must refer the individual to counsellors.
The prevalence of depression among MSM, must be considered within the context of the institutionalized homosexual stigma in India. IPC 377 not only criminalizes homosexuality, it also threatens ten years of imprisonment. This drives the MSM population underground, thwarting the efforts of combating HIV/ AIDS. Lawmakers in India should repeal the law to bolster the efforts of fighting HIV and stop AIDS.

In summary, our study high levels of depression among seropositive MSM’s. We report perceived stress, homosexual stigma and HIV symptom distress to be associated with depression. These modifiable factors need to be addressed at the national level, so that MSM’s in India are relieved of the curse of homosexuality and can live a normal livelihood.
Table 4-1. Socio-demographic characteristics of study participants (n=104)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Categories</th>
<th>frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>&lt;21 years</td>
<td>8</td>
<td>7.7</td>
</tr>
<tr>
<td></td>
<td>21-35 years</td>
<td>49</td>
<td>47.1</td>
</tr>
<tr>
<td></td>
<td>35-49 years</td>
<td>34</td>
<td>32.7</td>
</tr>
<tr>
<td></td>
<td>&gt;49 years</td>
<td>13</td>
<td>12.5</td>
</tr>
<tr>
<td>Occupation</td>
<td>Sex Worker</td>
<td>41</td>
<td>39.4</td>
</tr>
<tr>
<td></td>
<td>Student/ Unemployed</td>
<td>25</td>
<td>24.0</td>
</tr>
<tr>
<td></td>
<td>Laborer(Agriculture/Non-Agriculture)</td>
<td>16</td>
<td>15.4</td>
</tr>
<tr>
<td></td>
<td>Business/Salaried or Self employed</td>
<td>18</td>
<td>17.3</td>
</tr>
<tr>
<td></td>
<td>Others</td>
<td>4</td>
<td>3.8</td>
</tr>
<tr>
<td>Type of House</td>
<td>Concrete house</td>
<td>57</td>
<td>54.8</td>
</tr>
<tr>
<td></td>
<td>Mud walled house</td>
<td>36</td>
<td>34.6</td>
</tr>
<tr>
<td></td>
<td>Apartment</td>
<td>11</td>
<td>10.6</td>
</tr>
<tr>
<td>Religion</td>
<td>Hindu</td>
<td>81</td>
<td>77.9</td>
</tr>
<tr>
<td></td>
<td>Muslim</td>
<td>17</td>
<td>16.3</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>6</td>
<td>5.8</td>
</tr>
<tr>
<td>Living in</td>
<td>Family house</td>
<td>63</td>
<td>60.6</td>
</tr>
<tr>
<td></td>
<td>House within MSM community</td>
<td>6</td>
<td>5.8</td>
</tr>
<tr>
<td></td>
<td>Rented house</td>
<td>35</td>
<td>33.7</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Never married</td>
<td>15</td>
<td>14.4</td>
</tr>
<tr>
<td></td>
<td>Married to a female</td>
<td>34</td>
<td>32.7</td>
</tr>
<tr>
<td></td>
<td>Married to a male</td>
<td>6</td>
<td>5.8</td>
</tr>
<tr>
<td></td>
<td>Married both to a female and male</td>
<td>16</td>
<td>15.4</td>
</tr>
<tr>
<td></td>
<td>Divorced/Widowed</td>
<td>33</td>
<td>31.7</td>
</tr>
<tr>
<td>Monthly Income</td>
<td>&lt;3,000/month</td>
<td>67</td>
<td>64.4</td>
</tr>
<tr>
<td></td>
<td>≤3,000 - &lt;10,000/month</td>
<td>33</td>
<td>31.7</td>
</tr>
<tr>
<td></td>
<td>≥10,000/month</td>
<td>4</td>
<td>3.8</td>
</tr>
<tr>
<td>Education</td>
<td>Illiterate</td>
<td>22</td>
<td>21.2</td>
</tr>
<tr>
<td></td>
<td>Middle school or less</td>
<td>47</td>
<td>45.2</td>
</tr>
<tr>
<td></td>
<td>High School</td>
<td>15</td>
<td>14.4</td>
</tr>
</tbody>
</table>
Table 4-2. Analysis of CES-D-SF items, as how often the participants felt in a specific way during the past week (n=104)

<table>
<thead>
<tr>
<th>Item no.</th>
<th>Specific questions</th>
<th>Symptom evaluated</th>
<th>Sometimes</th>
<th>Often/Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Couldn’t shake off the blues even with help from your family/ friends</td>
<td>Troubled thinking</td>
<td>24</td>
<td>29</td>
</tr>
<tr>
<td>2</td>
<td>Trouble keeping your mind</td>
<td>Lack of Concentration</td>
<td>33</td>
<td>17</td>
</tr>
<tr>
<td>3</td>
<td>Felt that everything you did was an effort</td>
<td>Fatigued</td>
<td>31</td>
<td>23</td>
</tr>
<tr>
<td>4</td>
<td>How often did you have trouble sleeping</td>
<td>Troubled Sleep</td>
<td>34</td>
<td>20</td>
</tr>
<tr>
<td>5</td>
<td>How often did you feel lonely</td>
<td>Suicidal Ideation</td>
<td>30</td>
<td>29</td>
</tr>
<tr>
<td>6</td>
<td>How often did you feel sad</td>
<td>Dysphoria</td>
<td>43</td>
<td>26</td>
</tr>
<tr>
<td>7</td>
<td>How often did you feel like you couldn’t “get going”</td>
<td>Troubled thinking</td>
<td>36</td>
<td>18</td>
</tr>
</tbody>
</table>

1 percent of total participants felt the symptoms sometimes
2 percent of total participants felt the symptoms often or always

Table 4-3. Univariate analysis of the instrument scales used for measurement of health-related variables among HIV positive MSM's (n=104)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Median</th>
<th>Std Dev</th>
<th>Range</th>
<th>Minimu m</th>
<th>Maximu m</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homosexual Internalized Stigma</td>
<td>7.2</td>
<td>6</td>
<td>5.48</td>
<td>29</td>
<td>0</td>
<td>29</td>
</tr>
<tr>
<td>HIV symptom distress</td>
<td>12.8</td>
<td>9</td>
<td>12.16</td>
<td>61</td>
<td>0</td>
<td>61</td>
</tr>
<tr>
<td>Depression</td>
<td>6.4</td>
<td>6</td>
<td>4.87</td>
<td>21</td>
<td>0</td>
<td>21</td>
</tr>
<tr>
<td>Alcohol Use</td>
<td>2.2</td>
<td>0</td>
<td>3.75</td>
<td>16</td>
<td>0</td>
<td>16</td>
</tr>
<tr>
<td>Stress</td>
<td>19.0</td>
<td>19</td>
<td>5.28</td>
<td>28</td>
<td>6</td>
<td>34</td>
</tr>
</tbody>
</table>
Table 4-4. Parameter estimates from unadjusted and adjusted regression analysis to evaluate the association of Depression with predictor variables among ART initiated HIV positive MSM's (n=96) *

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unadjusted Analysis</th>
<th>Adjusted Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parameter Estimate</td>
<td>95% CI</td>
</tr>
<tr>
<td>Perceived Stress</td>
<td>0.5*</td>
<td>0.4, 0.6</td>
</tr>
<tr>
<td>Homosexual Stigma</td>
<td>0.5*</td>
<td>0.3, 0.6</td>
</tr>
<tr>
<td>HIV Symptom distress</td>
<td>0.3*</td>
<td>0.2, 0.4</td>
</tr>
<tr>
<td>Socio-economic Status</td>
<td>-0.3</td>
<td>-0.7, 0.1</td>
</tr>
<tr>
<td>Alcohol use</td>
<td>0.01</td>
<td>-0.3, 0.2</td>
</tr>
<tr>
<td>Age</td>
<td>-0.6</td>
<td>-1.8, 0.5</td>
</tr>
<tr>
<td>Social Support</td>
<td>-2.8*</td>
<td>-4.8, -0.8</td>
</tr>
</tbody>
</table>

# Influential observations were excluded. Adjusted R^2 0.63, F value 22.87, p <.0001
*Statistically significant (p≤ 0.05).
4.7 References


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Chapter 5 Barriers to ART Adherence among MSM’s of eastern India

5.1 Introduction

It was estimated that 66% (1.4 million) of the 2.1 million infected individuals knew their seropositive status [1] in India and 63.5% (1.3 million) of them received ART by the end of 2015 [2], whereas globally 46% (43%-50%) of the 36.7 million PLHIV received ART medication during 2015 [3].

The advent and rapid widespread availability of highly active antiretroviral therapy (HAART), has been an incredible achievement in the fight against HIV/AIDS, since its inception in 1996. The last two decades have witnessed a decline in AIDS-related mortality, with improved virological, immunological, clinical outcomes and subsequent longer life expectancy among HIV infected HAART initiated subjects [4-7]. However, HIV-infected patients have to take daily lifelong antiretroviral therapy and high levels of adherence are necessary, for reducing viral load, viral replication and lowering the likelihood of developing viral resistance [8, 9]. Studies have suggested that low adherence to therapy, can induce viral resistance [10-12]. The dynamic process of adherence to HAART, has been continued to be modulated with factors like sociodemographic, behavioral, stigma, treatment-related and quality of life associated with HIV patients [13-18]. Studies conducted among the general population in different parts of India report adherence to ART was as low as 60% and as high as 97% [19-24].
MSM’s in India are generally reluctant to admit their sexual orientation and a high proportion of MSM are married and/or bisexual [25, 26]. They are one of the high-risk groups in India with a HIV prevalence of 4.43% [27]. MSM’s with bisexual concurrency, are a bridge population for HIV transmission in India [28, 29]. With the need of higher adherence rates to combat the transmission of HIV, adherence to ART among high risk groups have been studied extensively in the developed world [30-32]. The Victorian Law Indian Penal Code section 377 criminalizes homosexuality and institutionalized homosexual stigma, it is expected that MSM’s will have experienced social, structural and individual level barriers to ART services [33].

The dearth of information pertaining to ART adherence among this important high-risk population, thus led us to measure the adherence rates among MSM’s and the factors influencing adherence.

5.2 Methods

We collaborated with a community based MSM organization named PLUS. (People Like Us -Kolkata) which is a support group of MSM’s working for the promotion, protection and advancement of adolescent and young men’s health and rights, especially their sexual and reproductive health and rights, toward ensuring their meaningful participation and perspectives at all levels of decision-making. A UN RED RIBBON Award Winning Organization PLUS was formed in 2001 as an informal support group in Kolkata providing a safe space for vulnerable and marginalized adolescents and young boys who are selling sex, in the city. Later PLUS commissioned a community owned study “Prostituted boys in Kolkata city” which initiated the organizational backbone. In 2003 PLUS formally registered
under the West Bengal Society registration ACT (1961) and has a secretariat based in Kolkata city.

There are three National AIDS Control Organization (NACO), ART centers operating in the city of Kolkata catering to HIV infected individuals living in Kolkata and its suburbs. ART initiated subjects return back to the designated ART centers after a month or two for refilling ART medication. CBO peer workers visited these three ART centers operating in Kolkata. They identified HIV positive MSM’s and approached them for participation in the study. Information about the study was shared with individuals. Subjects were also informed about the confidentiality of the study, and that we would collect name and contact details for the follow-up interview. Subjects who were interested in participation were screened for eligibility for inclusion in the study. We used decision making capacity assessment tool to determine if the participant was capable of decision making. Further details of the study were shared with eligible MSM’s and thus recruited for the study. Participants scheduled a meeting with the peer worker at a convenient location, for the baseline Audio Computer-Assisted Self-Interview (ACASI). After recruitment, each subject was assigned a unique identification number for the purposes of the study. MSM’s signed informed consent before the interview. A recruitment log was thus maintained to track participants and schedule follow-up of the subjects. Three months after the baseline interview we again contacted the subject for the follow-up ACASI interview.

5.3 Data Collection

Between November 2015 and March 2017, 130 HIV positive MSM’s were approached for participation, of whom we managed to conduct baseline ACASI interview for a total 104 HIV
(80%) positive MSM and finally 84 (81%) of the participants turned up for the follow-up ACASI interview.

Inclusion criteria were as follows (i) age 18 years or older (ii) self-identified MSM behavior as Kothi (receptive partner), Panthi (insertive partner) or Dupli (both receptive and insertive partner) (iii) capable of consenting for the study (iv) tested positive for HIV and subsequently assigned to receive anti-retroviral treatment prior to the recruitment for the study. After consenting we collected baseline data using the ACTG baseline questionnaire [13]. This questionnaire was complemented with other questions to have information on socio-demographic variables like age, occupation, income, marital status and perceived homosexual stigma. We used a modified ACTG follow-up questionnaire [13] for detailed self-reported adherence after 3 months from the baseline interview. We excluded questions asking name of the ART drug and the prescribed doses, as this information was available from their ART card. The survey was developed in English, translated into Bengali and Hindi and back translated into English to ensure semantic equivalence. Surveys were administered in Bengali and Hindi by the CBO peer worker under the supervision of the research coordinator.

5.3.1 Measures

5.3.1.1 Socio-Economic Status

The Kuppuswamy modified 2012 socio-economic scale [34] based on Indian standards was used to measure SES which included income, occupation and education of the participant. Respondents were asked if they were illiterate or could read or write, and their highest level of education. We also inquired about their occupation with choices like student, unemployed,
sex worker, labor, self-employed etc. They also responded to their monthly average income with choices to choose from monthly income less than 3000INR, less than 10,000 INR etc.

5.3.1.2 Stress
Stress was measured with 10-item Perceived Stress Scale [35] in its original format. This scale is a modified version of the 14 item Stress Scale [36]. Respondents were asked to consider how they have felt over the last month. There are 10 questions in which people can choose how often they have felt a certain way: never, almost never, sometimes, fairly often and very often. For positive questions coding had to be reversed for analysis. Possible scores range from 0 to 40, the higher the score the worse the stress. Reliability of the scale was assessed. Overall Cronbach’s alpha 0.41; Psychological Stress subscale 0.83; Physical Stress subscale 0.47.

5.3.1.3 Depression
Depression was measured using the 7-item CESD-D-SF [37] in its original format, which is a shorter version of the CES-D scale [38]. The seven-item scale asks participants how often they have felt a certain way, during the past week. The participants can choose from the following options 0= “rarely or never”, 1= “sometimes”, 2= “often”, and 3 = “mostly or always.” Possible score may range from 0 to 21. The higher the score, the worse the depression. Internal consistency was assessed. Cronbach’s alpha for this scale was 0.82.

5.3.1.4 Homosexuality Stigma
Homosexuality Stigma Scale used in this study was based on the China MSM Stigma scale [39] in its original format, adapted from the Homophobia scale [40]. There are 10 items which asks participants of certain homophobic incidents they might have experienced so far.
Each item had four response options: 0 = “never”, 1 = “once or twice”, 2 = “a few times”, and 3 = “many times.” Possible score may range from 1 to 30, the higher the score the more stigma internalized. This scale includes dimensions of enacted stigma and perceived stigma. Overall Cronbach’s alpha 0.77; enacted subscale 0.79; perceived subscale 0.53.

5.3.1.5 Alcohol and Drug use

The questions on alcohol and drug use were adapted from the ACTG adherence baseline questionnaire [13]. Participants were asked if they used alcohol in past month and about the frequency of its use. Due to lower access and availability of amphetamine some questions related to this drug abuse were modified.

5.3.1.6 Symptom Distress

Symptom Distress was assessed using the 20-item HIV Symptom Distress Scale [41]. The self-reported distress, in HIV infected population is characterized by phenomena such as fatigue/ low energy, fevers, dizziness, tingling/hand/foot pain, memory loss, nausea/vomiting, diarrhea, depression, anxiety, sleep problems, skin problems, cough/shortness of breath, headache, appetite loss, bloating/gas, muscle/joint pain, sexual problems, weight gain, weight loss, and hair loss. Each item had five response options: 0 = “no symptom”, 1 = “does not bother”, 2 = “bothers a little”, 3 = “bothers a lot” and 4 = “bothers terribly”. This scale includes dimensions of physical and mental distress. Overall Cronbach’s alpha 0.89; physical distress subscale 0.86; mental distress subscale 0.78. Depressive symptoms were measured with CESD-D-SF scale, so for the purposes of the study we excluded the mental distress subscale from analysis. Possible score may range from 1 to 68, the higher the score, the more the distress due to symptoms and lower the quality of life.
5.3.1.7 Baseline adherence self-efficacy/confidence

We asked subjects at baseline interview, about their confidence of taking ART pills using a four-point likert scale. They had responded about how confident they were, so that they were able to take most of their medications as directed. They had to choose from options if they were ‘extremely sure’, ‘very sure’, ‘somewhat sure’ and ‘not at all sure’. We categorized subjects choosing ‘extremely sure’ and ‘very sure’ as persons confident in taking their medications.

5.3.1.8 Adherence

Adherence was assessed during follow-up ACASI which was self-reported by participants using the 5-item questions of the ACTG follow-up questionnaire [13]. Participants were asked about very recent adherence, in the preceding four days before the interview. Interviewees recalled about past adherence: (1) skipping ART pills over the past weekend (Saturday, Sunday), and (2) identifying the last time they missed any of their medications with the following response options: 0 = “never skip medication”, 1 = “more than 3 months ago”, 2 = “1 – 3 months ago”, 3 = “2 – 4 weeks ago”, 4 = “1 – 2 weeks ago” and 5 = “within the past week”.

MSM’s also provided information on the dietary guidelines to be followed subsequently with pill intake, and how closely they were able to follow those guidelines over the last four days. We asked them if they have followed special instruction during pill intake over the last four days with the following response options: 0 = “never”, 1 = “some of the time”, 2 = “about half of the time”, 3 = “most of the time” and 4 = “all of the time”. The information gathered was transformed into an adherence index ranging from 0 to 100. Adherence index score
demonstrates statistically significant correlations with HIV viral load [42] using the formula suggested by Reynolds et.al [43] thus:

\[
\text{Adherence} = 100 \times \left( (0.65 + (2.15 \times \text{AdhDay1}) + (2.21 \times \text{AdhDay2}) + (2.07 \times \text{AdhDay3}) + (1.99 \times \text{AdhDay4}) +(0.37 \times \text{Followsch}) +(0.36 \times \text{Instrfu}) - (0.13 \times \text{Lastskip}) \right) / 11.99.
\]

### 5.4 Procedure and Analysis

The baseline ACASI was approximately fifty minutes in duration and the follow-up ACASI needed thirty minutes to complete. The ACASI was conducted using an android tablet with audio prompts so that participants could hear the questions and choose the answers guided by color coded answer keys. This was done for having a minimum reliance on the reading and writing capabilities of the participants. Informed consent was collected from the participants before administering ACASI. Participants were compensated INR 250 (approximately 4 USD) as part of wage lost for participation for each interview.

Simple descriptive analysis was carried out to determine the distribution of socio-demographic characteristics of the participants. The instruments used for the study were subjected to confirmatory factor analysis for the validity of latent variable constructs to be used further for analysis. Confirmatory factor analysis model fit for the constructs was assessed with model fit chi-square values with p-value more than 0.10, indicating a satisfactory model fit. The RMSEA value were close to 0.05, indicating a good model fit [44]. Other fit indices including goodness-of-fit index, Bentlar-Bonnet index, attaining values above 0.9.
We employed simple and multiple linear regression to explore the association of adherence index and its predictors. We checked the data for outliers in variables and the normality checks for the scale scores using histogram, boxplots and scatter plots. The final multivariate model was subjected to influential points analysis using studentised residual, leverage, Cooks distance and DFFITS. We thus excluded 8 influential observations from the final multivariate analysis. Final model fit was assessed with $R^2$ and adjusted$R^2$, implying the proportion of variance of the dependent variable explained by the model. Normality Quantile-Quantile plot of the residuals, plot of residual vs predicted value and tests of collinearity was inducted on the final model. Analysis was done using SAS 9.4 © SAS Institute Inc., NC, USA

5.5 Results

Table 5-1 describes the socio-demographics of participating MSM’s. About 45% of the MSM participants were aged between 21-35 years and 32% were 35-49 years. A considerable portion (21%) of HIV positive MSM’s were illiterate, 42% attended middle school and only 19% had post High school education. Most of the MSM’s were sex workers by profession (39%), unemployed 20%, only 18% were laborer and merely 18% were skilled to run business or be employed. Monthly income was less than 3000 INR for majority of the participants (67%), whereas 30% had income ranging between 3000 – 10,000 INR. The majority of the participants (77%) were Hindus, but 15% were Muslims. Thirty four percent of the MSM were married to a female, 5% married to a male and 14% married both a male and female sequentially. Some of the MSM’s never married (14%), and 32% were divorced/widowed. Thirty-four percent of the participants lived in a mud walled house,
whereas 55% lived in a concrete house. About 59% lived with their family whereas 34% lived in a rented house.

Alcohol and drug use

Baseline Alcohol and drug use information was available from the participants n=84, Table 5-2. Majority of the HIV positive MSM’s (63%) did not use any alcoholic beverage in the last 30 days. Only 11% were using alcohol on a daily basis and only 19% used it once or more during the last month. A minority of participants reported use of Marijuana, within the past 6 months (12%). Four percent ever used Cocaine/heroin or other drugs, whereas 4% of the respondents reported that they had been in methadone treatment.

MSM’s reported being prescribed one or two ART medications to be taken once daily. Non-adherence was common (Table 5-3): 13% skipped medicine one-day prior, and a total of 33% reported skipping medications during the prior four days. Almost half of the HIV positive MSM’s, 49%, reported ever missing medication. Twenty five percent said that they had missed pills on the last weekend. Half of the subjects 50% were following their schedule of ART pills over the last four days, whereas 21% tried to maintain schedule most of the times. A minority of the subjects 9% never followed their schedule. Based on four-day recall, 67% (95%CI: 57%, 77%) of the MSM’s were adherent to ART.

Reason for missed taking ART medications

Among subjects who reported missing any of the ART doses in the past (n= 41), majority of them slept through the dosing time 49% (Table 5-4). A considerable proportion, 44% just forgot to take the medications. Some were busy with other things and thus skipped medications 43%. Thirty-nine percent were not at home when they missed doses. Some of the
MSM’s were depressed or overwhelmed and did not take medication 37%. Some wanted to avoid side-effects (24%), whereas 22% ran out of pills. Fearing stigma, 24% did not want it to be known they take ART medications and thus skipped medications.

Knowledge about the likely ways the participants got infected was assessed (Table 5-5). Fifty-five percent of the total MSM’s reported that they got infected as a result of having sex with a seropositive man. Only 27% of the total subjects thought that they were infected as a result of sharing needles with a HIV positive. and 26% of the total participants stated that their infection was a result of sexual activity with seropositive woman. A considerable proportion (44%) of the total participants had no knowledge of the possible route they got infected.

Table 5-6 describes the univariate analysis of the instrument scores used in our final linear model. We employed simple and multiple regression analysis with the composite adherence index. Bivariate analysis revealed that higher depression score lead to a lower adherence score Table 5-7. With every 1-unit increase in depression score, there was a 2-unit decrease in the adherence index (β: -2.2, 95%CI: -3.5, -0.8). Being less confident to be able to take the medications, also lowered ART adherence. Less confident subjects had a significantly lower score on the adherence index (β: -26.3, 95%CI: -39.4, -13.3).

The multiple linear regression model for a causal model of adherence included seven predictor variables: Homosexual stigma, alcohol use, stress, HIV symptom distress, depression, socio-economic status and confidence of taking ART pills. Multiple linear regression analysis identified the adjusted parameter estimates, as shown in Table 5-7. An increment of 1-unit of depression score, resulted in a 3 unit decrease in the adherence score
(adjβ: -3.2, 95%Cl: -4.9, -1.5), after controlling for other variables. Adjusted analysis revealed that alcohol use lowered ART adherence. Use of alcohol caused a lower adherence index score. Alcoholics had a significantly lower score of adherence as compared to non-alcoholics (adjβ: -14.6, 95%Cl: -25.0, -4.2), after controlling for other variables. Being less confident to be able to take medications at baseline significantly decreased the adherence score by 26 units when compared to those who were confident at baseline. (adjβ: -27.1, 95%Cl: -39.2, -14.9), after controlling for other variables.

5.6 Discussion

The current study aimed to investigate the prevalence of proper adherence needed for the ART regimens [11, 12]. About 24% of the HIV positive MSM (Table 5-4), who had ever missed ART medication reported that they don’t want others to know about their medications. We had speculated this scenario and thus did not solicit to carry their medications so that we could count the pills. We hereby report adherence levels amongst this sexual minority and hidden population in eastern India. About 67% of the MSM’s self-reported to be adherent to ART. This reveals that reported adherence is similar among MSM’s and the general population in India, which ranges from 60% to 97% [19-24]. Although, 49% of the participants ever missed medication, only 33% self-reported recent non-adherence and half of the respondents 50% did not follow schedule during the last four days of the recall. A lack of funding prevented us from measuring the CD4 count of the participants, a definitive marker of adherence. None the less we were able to summarize the responses of all the 5-items of self-reported adherence measure. The adherence index is a composite score, combining and utilizing all the information that had been gathered on ART
adherence among MSM’s. This index used in published literature [45-47] has been significantly correlated with viral RNA levels [42], can be utilized in resource limited settings.

The study identified important causal barriers to ART adherence. One of these was alcohol use. The prevalence of drinking was 37% in our study population. Use of alcohol had a major impact on adherence to ART among MSM’s (adjβ: -14.6, 95%CI: -25.0, -4.2). A rich body of literature identifies alcohol as an important barrier to ART adherence [48-51]. This predictor is important given that alcohol is also associated with high risk behavior. Persons using alcohol may be more likely to miss a dose of medicine because of actively consuming alcohol or drugs, forgetting the dosage timing, or running out of medication. MSM’s consuming alcohol do not adhere to ART medication and may develop resistant mutations of HIV. They may be transmitting resistant strains to partners while engaging in high risk sexual activity. Many of the MSM’s are married and have a wife or engage in heterosexual activity. Thus, these resistant strains may be transmitted to the general population.

The study identified depression to be a barrier to ART adherence (adjβ: -3.2, 95%CI: -4.9, -1.5). The prevalence of depression was 37% (95%CI 26%, 48%) in our study population. Depression impacted adherence to ART among MSM’s. A rich body of literature identifies depression as an important barrier to ART adherence [52-55]. On receipt of anti-depressant treatment, adherence to ART have improved [56, 57]. Although it still remains grey, which aspects of depression leads to lower adherence. Diminished cognitive function probably hinders remembering, the need to take medications [55].
The study also revealed that subjects who were more confident of taking their ART pills as instructed, had significantly higher levels of adherence (adjβ: -27.1, 95%CI: -39.2, -14.9). Intuitively, subjects who had understood the regimen, and associated instructions of timing as well as food habit better, were more likely to remain adherent. This finding is consistent with published literature of self-efficacy and adherence to treatment [58-60]. Improving self-efficacy improves adherence to medications. Studies have also looked at the factors [61] that influences self-efficacy and improve adherence to ART pills.

Although non-significant, distress caused due to symptoms had an inverse relationship with adherence to ART. This finding is in contrast to that reported from prior studies that have been conducted among ART recipients [62, 63].

Analysis of socio-demographic variables indicate that 6% belonged to middle/lower-middle SES strata, 80% of MSM’s belonged to lower/upper-lower SES strata and 14% belonged to lower SES strata respectively [34]. Majority were illiterate or did not finish middle school education and had low income as evident from distribution of the strata. A considerable proportion of the participants were male sex workers. Our study did not achieve significance of association of lower socio-economic status and non-adherence. A meta-analysis of adherence literature, revealed mixed results for SES as a barrier to adherence [64].

We were able to recruit 104 HIV positive MSM subjects at baseline, who had initiated to ART. The study suffered 20% lost to follow-up, resulting in 84 participants considered for the final analysis. The remainder did not ever turn up at the designated ART centers. One possible explanation of this attrition may be due to migration out from the study area ART centers.
There are several limitations to our study that should be acknowledged. First, the sample size is low which may limit our ability to estimate the effect of the barriers to ART adherence. Due to the high variability in the sample we have wide confidence intervals for the estimates. Although it is powered enough for estimating the prevalence of adherence among the HIV positive MSM subjects. Second, we employed convenience sampling with the help of peer workers of the CBO. They may have approached only those likely candidates who are identified as MSM. Following institutionalized homosexual stigma, a portion of MSM remains undetected. Those with undisclosed MSM identity were not included in our sample. Third, as discussed before, almost all of the MSM’s belonged to a lower socio-economic stratum. Therefore, one should be cautious of generalizability of our study findings. Fourth, our adherence measures were self-reported. This could introduce information bias and misclassification of individuals.

Our study has some strengths as well. First, owing to the follow-up design, we were able to elicit causality of the predictors in our sample. Second, ACASI did have zero reliance on the participants reading and writing capabilities. Participants heard both the questions and the respective choices read out to them via audio headphone and answer the choices guided with color coded keys. Third, all of the data collection was electronic, thus eliminating key punch errors due to data entry.

Our study did not find any association of homosexual stigma and ART adherence among MSM’s. This is in contrast with findings from previous research conducted with homosexual or gay identified men and their reduced engagement towards ART [65-67].
Draconian IPC 377, which criminalize homosexuality in India. Ten years of imprisonment if caught red handed, structural violence and institutionalized stigma forces the MSM’s underground. As predicted in a previous study [68], this law itself has had an adverse impact on the fight against HIV and AIDS in India. They are less likely to present for testing, and prevention services. Although some of them do turn up for the HIV services and get engaged in the care continuum. Denial of homosexual activity also makes it difficult to work with the MSM’s. CBO/NGO working on HIV prevention among MSM in India have also been harassed and booked under Section 377 [69]. Amongst these hardships some CBO like PLUS, for the MSM and by the MSM, have been instrumental in its activities for uplifting their brethren.

In collaboration with WHO, India has adopted a treat all policy for HIV. These services will be rendered by NACO pan India, through its ART centers. But mere distribution of free ART pills does not complete the responsibility. The prevalence of adherence among general population varies with geographical location, but it ranges as low as 60% and high as 97% [19-24].

Our study findings have implications for improving adherence to ART. We propose assessment of risk factors of poor adherence in the ART clinics. Providers should assess and screen for harmful use of alcohol and alcohol use disorders among all HIV patients. Link alcohol use to potential adherence problems, and monitor outcomes in both alcohol consumption and medication adherence. Provision of on-site advice or brief counseling for those with harmful use of alcohol and referrals to more intensive alcohol treatment services for those with serious alcohol-related problems are indicated. Screening of depressive
symptoms at the ART clinics during regular refills and subsequent referral of subjects displaying higher levels of depressive symptoms, for further counselling by psychologist.

Positive provider interactions have affected adherence self-efficacy and medication adherence[59]. Promotion of such positive interactions is needed. This may require structural changes within ART clinics or provider training. Training of providers to increase collaborative negotiation in setting treatment goals and strategies to bolster adherence self-efficacy. Greater time per patient visit will provide opportunity of such positive interactions [70].

In summary, this study was among the few focused-on ART initiated HIV positive MSM’s in India. We reported similar levels of reported adherence to ART as that of general population, among MSM’s and have identified 3 important modifiable barriers to adherence, depression, self-efficacy and alcohol consumption. It is to be noted that sexual minorities like MSM’s use alcohol or other substance to cope with their internalized stigma, discrimination and prejudice. These modifiable factors need to be addressed at the national level, so that MSM’s in India can effectively fight the infection and prevent transmission and death.

Table 5-1. Socio-demographic characteristics of HIV positive MSM participants (n=84)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Categories</th>
<th>frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>&lt;21 years</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>21-35 years</td>
<td>38</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td>35-49 years</td>
<td>27</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td>&gt;49 years</td>
<td>12</td>
<td>15</td>
</tr>
<tr>
<td>Education</td>
<td>Illiterate</td>
<td>18</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Middle school or less</td>
<td>35</td>
<td>42</td>
</tr>
<tr>
<td>Occupation</td>
<td>%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------</td>
<td>----</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex Worker</td>
<td>33</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student/ Unemployed</td>
<td>17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Labor (Agriculture/Non-Agriculture)</td>
<td>15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Business/Salaried or Self employed</td>
<td>15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Monthly Income</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;3,000/month</td>
<td>56</td>
</tr>
<tr>
<td>≤3,000 - &lt;10,000/month</td>
<td>25</td>
</tr>
<tr>
<td>≥10,000/month</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religion</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hindu</td>
<td>65</td>
</tr>
<tr>
<td>Muslim</td>
<td>13</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never married</td>
<td>12</td>
</tr>
<tr>
<td>Married to a female</td>
<td>29</td>
</tr>
<tr>
<td>Married to a male</td>
<td>4</td>
</tr>
<tr>
<td>Married both to a female and male</td>
<td>12</td>
</tr>
<tr>
<td>Divorced/Widowed</td>
<td>27</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Type of House</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concrete house</td>
<td>46</td>
</tr>
<tr>
<td>Mud walled house</td>
<td>29</td>
</tr>
<tr>
<td>Apartment</td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Place of living</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family house</td>
<td>50</td>
</tr>
<tr>
<td>House within MSM community</td>
<td>5</td>
</tr>
<tr>
<td>Rented house</td>
<td>29</td>
</tr>
</tbody>
</table>

**Table 5-2. Alcohol use and substance use among the HIV positive MSM respondent’s (n=84)**

<table>
<thead>
<tr>
<th>Alcohol use in last 30 days</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>63</td>
</tr>
<tr>
<td>Once or more a Month</td>
<td>19</td>
</tr>
</tbody>
</table>
Once or Twice a Week      6
3 or 4 times a Week       1
Daily                     11

**Marijuana use**

Ever                      20
Past six months           13

**Cocaine /Heroin or other drug use**

Ever                      4
Past six months           4

**Methadone treatment**

Ever                      4
Currently                 4

**Table 5-3. Reported adherence to antiretroviral medications (n=84)**

<table>
<thead>
<tr>
<th>Reported adherence</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skipped taking some/all ART pill last four days</td>
<td>33</td>
</tr>
<tr>
<td>Taken all pills last four days</td>
<td>67</td>
</tr>
<tr>
<td>Followed ART schedule over the last four days</td>
<td></td>
</tr>
<tr>
<td>Most of The Time</td>
<td>21</td>
</tr>
<tr>
<td>Some of The Time</td>
<td>20</td>
</tr>
<tr>
<td>Never</td>
<td>9</td>
</tr>
<tr>
<td>Missed pill on the last weekend</td>
<td>25</td>
</tr>
<tr>
<td><strong>Ever missed medication</strong></td>
<td>49</td>
</tr>
</tbody>
</table>

**Table 5-4. Reasons missed ART medications by HIV positive MSM (n=41)**

<table>
<thead>
<tr>
<th>Reason</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slept through dose time</td>
<td>49</td>
</tr>
<tr>
<td>Simply forgot</td>
<td>44</td>
</tr>
<tr>
<td>Busy with other things</td>
<td>43</td>
</tr>
<tr>
<td>Away from home</td>
<td>39</td>
</tr>
<tr>
<td>Felt depressed / overwhelmed</td>
<td>37</td>
</tr>
</tbody>
</table>
Problems taking pills at specified times (with meals, on empty stomach, etc.) 34
Change in daily routine 29
Felt good 29
Too many pills to take 27
Felt sick or ill 27
Avoid side effects 24
Did not want others to notice you taking medication 24
Ran out of pills 22
Felt like the drug was toxic/harmful 12

Table 5-5. Perceived route of HIV infection among HIV positive MSM (n=84)

<table>
<thead>
<tr>
<th>Route</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex with HIV +ve man</td>
<td>46</td>
<td>55</td>
</tr>
<tr>
<td>Sex with HIV +ve woman</td>
<td>22</td>
<td>26</td>
</tr>
<tr>
<td>Needle sharing with HIV +ve</td>
<td>23</td>
<td>27</td>
</tr>
<tr>
<td>Blood transfusion</td>
<td>21</td>
<td>25</td>
</tr>
<tr>
<td>Needle stick at work</td>
<td>16</td>
<td>19</td>
</tr>
<tr>
<td>No Knowledge</td>
<td>37</td>
<td>44</td>
</tr>
</tbody>
</table>

Table 5-6. Univariate analysis of the instrument scores (n=84)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Median</th>
<th>25th Pctl</th>
<th>75th Pctl</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>6.3</td>
<td>6.0</td>
<td>3.0</td>
<td>8.5</td>
<td>0.0</td>
<td>21.0</td>
</tr>
<tr>
<td>Internalized Homosexual Stigma</td>
<td>7.3</td>
<td>6.0</td>
<td>3.0</td>
<td>10.0</td>
<td>0.0</td>
<td>29.0</td>
</tr>
<tr>
<td>HIV symptom distress</td>
<td>12.0</td>
<td>8.0</td>
<td>3.5</td>
<td>19.0</td>
<td>0.0</td>
<td>42.0</td>
</tr>
<tr>
<td>Adherence index</td>
<td>72.2</td>
<td>83.6</td>
<td>60.1</td>
<td>92.8</td>
<td>5.4</td>
<td>100.0</td>
</tr>
<tr>
<td>Perceived stress</td>
<td>18.9</td>
<td>19.0</td>
<td>16.0</td>
<td>22.0</td>
<td>6.0</td>
<td>31.0</td>
</tr>
</tbody>
</table>
Table 5-7 Parameter estimates from unadjusted and adjusted linear regression analysis to evaluate the predictors of adherence (n=76)\(^1\)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unadjusted Analysis</th>
<th>Adjusted Analysis#</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parameter Estimate</td>
<td>95% Cl</td>
</tr>
<tr>
<td>Internalized Homosexual Stigma</td>
<td>-0.8</td>
<td>-2.1, 0.6</td>
</tr>
<tr>
<td>Alcohol use</td>
<td>-10.5</td>
<td>-22.2, 1.2</td>
</tr>
<tr>
<td>Depression</td>
<td>-2.2^</td>
<td>-3.5, -0.8</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived Stress</td>
<td>-0.7</td>
<td>-1.9, 0.5</td>
</tr>
<tr>
<td>Socio-economic status</td>
<td>0.3</td>
<td>-2.6, 3.3</td>
</tr>
<tr>
<td>HIV symptom distress</td>
<td>-0.2</td>
<td>-0.7, 0.2</td>
</tr>
</tbody>
</table>

\(^1\) Influential observation were excluded. Adjusted \(r^2\) 0.32, F value 6.04, p <.0001.

# Adjusted for all the variables in the table.

^Statistically significant (p \(\leq\) 0.05). 

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5.7 Reference

1. WHO. India adopts policy to treat all people living with HIV 2017 [http://www.who.int/hiv/mediacentre/news/India-treat-all/en/].


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Chapter 6 Conclusion

MSM’s in India face challenges and have to overcome different barriers, in order to access HIV care services [1, 2]. In this context, we aimed to find out the challenges and barriers MSM would have to overcome, to access ART medications. Amidst institutionalized homosexual stigma, some of them were wise enough to get tested and being retained in the HIV care continuum. We assessed mental health, as well as adherence of ART among seropositive MSM’s in Kolkata, India. In order to achieve our goal, we started with qualitative inquires of challenges and barriers, they have faced. Further, we conducted investigation of ART adherence, mental health assessment of HIV positive MSM’s, assessment of self-efficacy, assessment of stress, and distress caused due to HIV symptoms. We incorporated two instruments from the ACTG baseline and follow-up questionnaire and the [3] China MSM Stigma scale [4], for the quantitative assessment.

We report the prevalence of depression among HIV positive MSM’s on ART was 36% (95%CI: 26%, 45%) and 67% (95%CI: 57%, 77%) of MSM’s self-reported to be adherent to ART medications. To the best of our knowledge there has not been any published studies that quantitatively explored adherence of ART among MSM’s assigned to receive ART in India. The qualitative interviews with HIV positive MSM’s and MSM CBO members, allowed us to gain perspective of the social disadvantages and barriers to HIV testing and access to HIV care.

Qualitative findings highlighted social discrimination, challenges following disclosure, barriers to HIV testing, barriers of ART adherence. The findings from quantitative phase reveals barriers to adherence and high levels of depression among seropositive MSM’s. A
multi-sectorial approach is needed to address the multi-level modifiable barriers, plaguing the HIV/AIDS initiative.

We would like to make recommendations for India’s national HIV program, based on the literature review and findings from the qualitative and quantitative phases of the current study:

1) Mandatory screening of risk factors known to lower adherence among high-risk groups like MSM’s with specific emphasis on
   a) psychiatric evaluation at the time of each contact or refill, should be done by a trained psychologist. Referrals for subjects with higher levels of depressive symptoms.
   b) Providers to assess and screen for harmful use of alcohol and alcohol use disorders. Provision of on-site advice or brief counseling for those with harmful use of alcohol and referrals to more intensive alcohol treatment services for those with serious alcohol-related problems are indicated.

2) Promotion of environment that will foster positive provider patient interactions.
   Allowance of greater time for each patient visit needs to be mandated.

The National AIDS control organization (NACO) has been instrumental in maintaining a stable adult prevalence in India. To achieve “fast track targets set for 2020” and the agenda of “End HIV and AIDS epidemic by 2030” in 2016 [5] NACO will need much more than the current standards of imparting sponsored HIV care. MSM’s in India had been identified as a bridge population in the context of HIV epidemic in India [6, 7]. NACO identifies MSM’s as a high-risk group, but is yet to acknowledge MSM’s as a bridge population.

In conclusion, our study findings will fill some of the existing knowledge gaps regarding mental health status of MSM’s living with HIV in India and barriers of ART adherence
among these socially marginalized population. We have highlighted relevant areas that requires further research among MSM in India. We expect the findings to inform design and implementation of suitable and effective intervention strategies targeted to improve the quality of life of HIV infected MSM living in India.

Finally, we would like to thank the MSMs for participation without which this study could not have been possible.

### 6.1 Reference


