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Missing in Action

**Loss of clients from
HIV testing, treatment,
care and support services:
Case studies of gay men
and other men who have sex
with men in Manila**

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MISSING IN ACTION

**Loss of clients from HIV testing, treatment,
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May 2017

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The purpose of the *Missing in Action: Loss of clients from HIV testing, treatment, care and support services: case studies of gay men and other men who have sex with men in Manila* study was to document why significant numbers of men who have sex with men based in Metropolitan Manila (also known as Greater Manila, Metro Manila and Manila) currently do not access HIV services at different levels of the HIV treatment cascade.

The initial findings of the study were presented at the dissemination meeting – Exploring Barriers Hampering Access to HIV Testing, Treatment, Care and Support Interventions among Men who have Sex with Men in Manila – held on 15 December 2015 in Pasig City. The final results of the study were reviewed at the Client-Centered HIV Case-Management Services Workshop held on 23 January 2017 in Quezon City.

The results of the study have informed the development of the Manual of Procedures for Client-Centered HIV Case Management adopted by Quezon City*, and the Manual of Procedures for Delivery of HIV Services for Men who have Sex with Men and Transgender People for the Quezon City Health Department**.

The primary investigator of this study was Jan Willem de Lind van Wijngaarden.

Additional technical inputs were provided by Dr Gerard Jose Belimac, National AIDS Programme Manager, Department of Health, and Andrew Desi Ching, independent consultant.

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* Quezon City Health Department & UNAIDS. (2016). Manual of Procedures for Client-Centered HIV Case Management. Quezon City: QCHD & UNAIDS. Unpublished document.

** Quezon City Health Department & UNAIDS. (2016). Manual of Procedures for Delivery of HIV Services for Men who have Sex with Men and Transgender People. Quezon City: QCHD & UNAIDS. Unpublished document.

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Abbreviations and acronyms

AIDS	Acquired Immunodeficiency Syndrome
ART	Anti-retroviral treatment
ARV	Anti-retroviral (treatment/medicine)
CMV	Cytomegalovirus retinitis
DOH	Department of Health
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
ISEAN	Islands of Southeast Asia Network on Male and Transgender Sexual Health
LGBT	Lesbian, Gay, Bisexual and Transgender
MSM	Men who have sex with men
NGO	Non-governmental organization
PCP	Pneumocystis pneumonia
PEPFAR	United States President's Emergency Plan for AIDS Relief
PLHIV	People/Person Living with HIV
RITM	Research Institute for Tropical Medicine
STI	Sexually Transmitted Infection
TB	Tuberculosis
TG	Transgender
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
USAID	United States Agency for International Development

Executive Summary

Qualitative interviews were conducted with 48 men who have sex with men from four cities in Metropolitan Manila to explore barriers they faced at four levels of the HIV service cascade: HIV testing; the follow-up of a reactive HIV test; enrolling on antiretroviral treatment (ART); and adhering to ART.

The reasons for all of these barriers are diverse. Some are at the social level in terms of stigma and discrimination, or economic hardship. Some are internal, based on the attitudes, beliefs or behaviour of the men. Other barriers are institutional, at the policy level or in the health care system.

Many participants initially did not see the need to get tested for HIV despite significant risk. Justifications for not getting tested included being in good shape and not feeling ill, having a boyfriend believed to be HIV negative, and perceiving oneself as not “the type of person that gets HIV”. Being monogamous was another reason why some participants felt no need to get tested; however, the lack of communication about sexuality between intimate partners in the Philippines’s sexual culture calls into question the promotion of faithfulness and monogamy as HIV prevention strategies. Other reasons not to test were: far distances to testing facilities, fear of what will happen after being infected with HIV, fear of side effects of ARVs and fear of high health care expenses.

Reasons why clients do not follow up an initial reactive result to HIV testing to get a confirmation test and CD4 testing included denial, and, again, fears about side effects of ARVs. Some worried about being stigmatized by family and friends. Several reported poor counselling practices, with problems with the empathy, attitudes and friendliness of counsellors. Others were the victims of bureaucracy: rules and regulations partly caused by the current algorithm for testing and related post-test counselling practices.

For those who had a positive confirmation test but did not enrol on ART afterwards, poor counselling and poor treatment by medical personnel were found as factors explaining why they postponed enrolment. Other factors included long waiting times and the long distance to treatment centres, system-related obstacles or events related to the transfer of client records between HIV service providers, and fears about side effects of ARV medicines, which led some to try to stay off ARVs for as long as possible. Beliefs about HIV as a punishment for homosexuality were not widespread and were usually temporary. Instances of stigma in the health care system or elsewhere were rarely reported because most participants kept their HIV status to themselves.

A recurring reason to interrupt or stop ART was depression. A number of participants mentioned unfriendly treatment by medical staff and poor or no pre-ART enrolment counselling. The occurrence of side effects was another key reason to interrupt ART. A few men thought they could treat themselves with good nutrition or with certain traditional medicine, such as black oil seed, and mentioned this as a reason to stop ART. Some reported trouble getting to and from their HIV treatment hub, and had not been told about other treatment options. Nearly all participants in this category of the study complained about a lack of privacy and long waiting times at their treatment hubs. Other reasons to drop out of ARV treatment were the costs – opportunity costs such as missing work, and considerable transportation costs – involved in getting to and from the treatment hubs, as well as costs for baseline tests. Some research participants mentioned their family as a factor in discontinuing or delaying the onset of their ARV treatment, related to the requirement to have a “treatment buddy”, treatment-related fears of disclosure to the family and a desire not to be a “burden” on their family.

The final section of this report summarizes the reasons for the loss of clients from HIV testing, treatment, care and support services and gives overall recommendations on making improvements in the HIV cascade to serve HIV positive men who have sex with men better, as well as specific recommendations to address loss of clients from HIV testing services, follow-up testing and ARV treatment, as well as to address the issue of challenges in adhering to ARV treatment.

Chapter 1: Introduction to the study and context

Background

The Philippines is in the middle of a rapidly expanding HIV epidemic among men who have sex with men (MSM), people who inject drugs and – very likely, but not yet confirmed by data – transgender (TG) people. A record 4,643 new HIV cases were reported to the Philippine Department of Health between January and June 2016, of which 4,446 (95.8%) were male. Of these men, 86 percent reported sex with men. 40 percent of all new HIV cases reported from January to June 2016 were in the Metropolitan Manila region (also known as Greater Manila, Metro Manila and Manila). In June alone, 841 new cases were reported, an all-time record; of these, 82 percent were among men who have sex with men, transgender women and bisexual men.¹ The official HIV prevalence in men who have sex with men and transgender women in greater Manila’s biggest city (Quezon) was 5.5 percent in 2015 (N=600, 95% confidence interval: 2.9–10.3%), slightly down from 6.6 percent in 2013 but sharply up from 0.4 percent in 2007 and 1.5 percent in 2009.²

Meanwhile, condom use remains low and large numbers of men who have sex with men have multiple sexual partners. This, combined with the growing epidemic among people who inject drugs, is the ‘perfect storm’, similar to the situation that preceded the HIV epidemic among men who have sex with men in Thailand, where prevalence is currently still around 30 percent.

In 2012, the Philippines National AIDS Council developed the National Comprehensive Strategic Plan on HIV and AIDS for Men having Sex with Men and Transgender Population that sets out a roadmap of interventions to respond to HIV among these populations. It sets as its core goal: “interrupting the transmission of HIV and STIs in MSM populations”. Achieving this goal requires that large numbers of men who have sex with men know their HIV status, have access to the means to prevent HIV infection, and can easily utilize services for the diagnosis and treatment of HIV and sexually transmitted infections (STIs).³

The cascade of HIV services

The ‘cascade of HIV services’ is a useful tool for monitoring or evaluating an HIV programme in a city. The tool can point to and prioritize ways for improvements.⁴ An HIV service cascade lists the levels of HIV services through which a person with HIV moves, starting with prevention and testing and, for those who test positive, enrolment in and adherence to antiretroviral treatment (ART) and care and support, followed by the final level, which is the achievement of viral suppression (meaning a person has obtained the maximum health benefits of their HIV treatment and is no longer likely to pass on HIV to other people).

1 Bureau of Epidemiology, DOH, Manila (2016). See: http://www.doh.gov.ph/sites/default/files/statistics/EB_HIV_June-AIDSreg2016_0.pdf

2 Bureau of Epidemiology, DOH, Manila (2015). pp. 77–80. See:

http://www.aidsdatahub.org/sites/default/files/highlight-reference/document/Philippines_2015_IHBSS_Factsheets.pdf

3 Philippine National AIDS Council (2012). The National HIV and AIDS Strategic Plan for MSM and TG Populations 2012–2016. Manila, PNAC.

4 Kilmarx, P.H. and Mutasa-Apollo, T. (2013). Patching a leaky pipe: the cascade of HIV care. *Curr Opin HIV AIDS*.8.1: pp. 59–64.

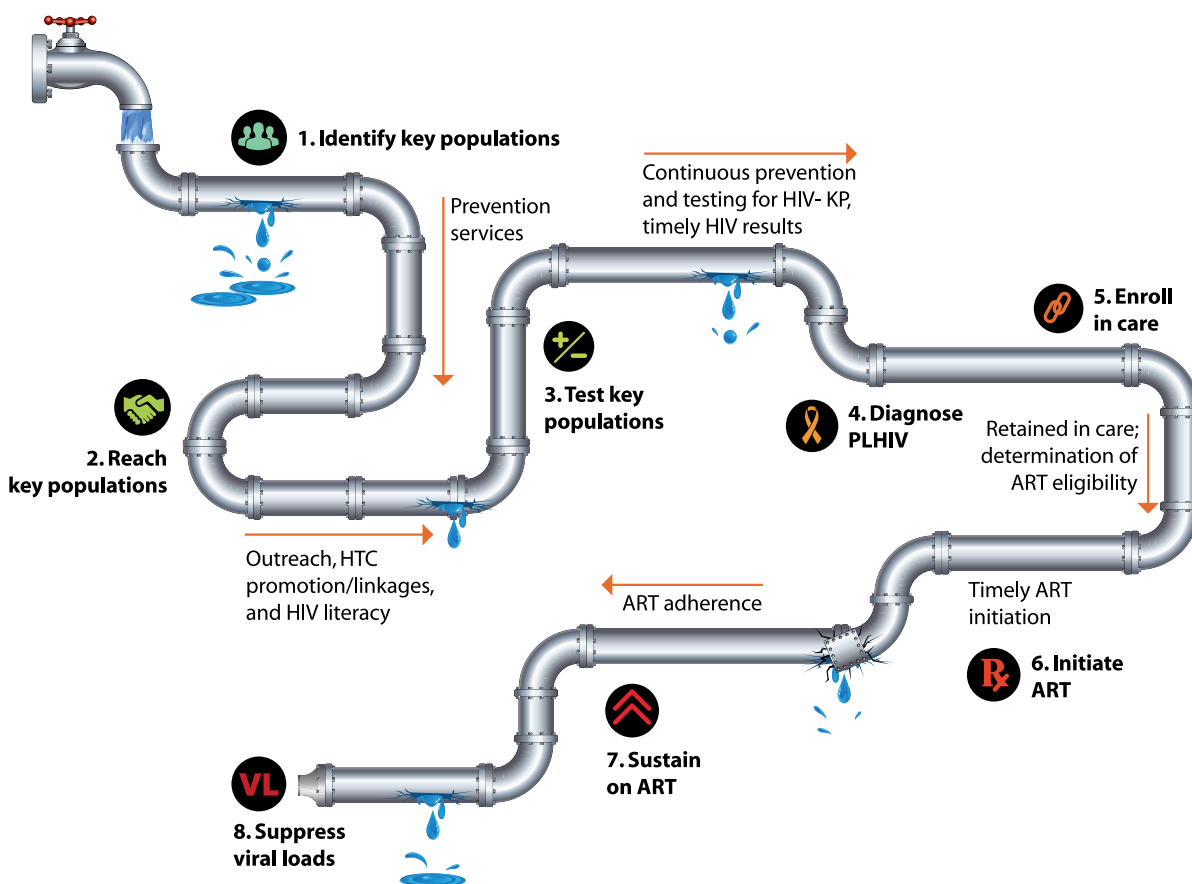
Figure 1.
HIV SERVICE CASCADE



Source: WHO (2015) Consolidated strategic information guidelines for HIV in the health sector. Geneva: WHO, May 2015 (www.who.int/hiv/pub/guidelines/strategic-information-guidelines/en/)

A visual depiction of the HIV service cascade helps show the extent to which men who have sex with men are being reached for testing and enter into treatment and care services after diagnosis with HIV. The cascade is often depicted as a pyramid or a flow, with bars of decreasing height to indicate the loss to follow-up HIV services from one level to the next. USAID, FHI 360, PEPFAR and the LINKAGES Project have helpfully depicted the HIV service cascade as a ‘leaking pipe’ where clients of services drop out at different levels, as shown in Figure 2.

Figure 2.
FLOW AND LOSS OF CLIENTS FROM IDENTIFICATION TO VIRAL SUPPRESSION



Note: **KPs**=key populations; **HTC**=HIV testing and counselling; **ART**=antiretroviral therapy; **PLHIV**=people living with HIV
Source: USAID, FHI 360, PEPFAR and the LINKAGES Project (2015). HIV cascade framework for key populations. Washington, DC: FHI 360.

Purpose and methodology of the study

The purpose of this research project was to explain why significant numbers of men who have sex with men based in Metropolitan Manila (also known as Greater Manila, Metro Manila and Manila) currently do not access HIV services at different levels of the HIV treatment cascade – or, as described according to the tool above, to examine the leaks in the pipe, i.e. the reasons why clients of HIV services are unable or unwilling to move to the next level of service, at four different levels of the HIV service cascade: testing, results, treatment, and adherence support.

One of the levels of the HIV service cascade is testing. Except perhaps in Quezon City, testing rates are still not high in comparison with the gravity of the HIV epidemic. Then there is a leak. Between the first and the confirmatory HIV test, 54 percent of those tested dropped out in 2015, according to the Quezon City Health Department. Considering the relatively high quality of HIV services available in Quezon City compared to other areas, this is probably one of the lowest dropout rates among the cities of Metro Manila. Why the dropout? It was assumed that an important factor is the prevalence of stigma and discrimination in health care settings, and related to this, self-stigma and low self-esteem among newly diagnosed men who have sex with men.

Once people receive their two test results and their CD4 and other baseline test results, the next hurdle is accessing antiretroviral treatment, another level of the HIV service cascade. However, a significant number of men who have sex with men do not access these services and keep postponing reporting to a treatment hub. Others report to a treatment hub, but then keep switching between HIV treatment services. It is not known exactly why. It was an important focus for the study to understand the reasons for not accessing services or switching them.

A key basis for the study was the belief that understanding and contextualising the problems men who have sex with men face in accessing HIV testing, treatment, care and support can lead to learning important lessons for improving HIV services, including in awareness raising and prevention, as well as for making HIV services better integrated, more efficient and effective, and more friendly to men who have sex with men. This, in turn, is expected to reduce the 'leakage' along the HIV service cascade that was shown in Figure 2.

The draft study protocol for the study was reviewed by a number of individuals and organizations (see page 2 for Acknowledgments) in a series of individual face-to-face meetings and discussions during the week of 4 May 2015. The draft research report was presented in a meeting to around 25 stakeholders for comments on 15 December 2015, and following this, the report was finalized.

Research question

The key research question of the study was:

- What are the key barriers for men who have sex with men in accessing HIV services in Manila along the HIV services cascade, and how are these barriers overcome?

In order to answer the research question, 48 qualitative in-depth individual interviews were conducted, focusing on men who have sex with men who failed to access four levels in the treatment cascade in a timely fashion: testing, results, treatment and support. The interviews were divided over 4 groups of 12 interviews each:

- Men who have sex with men who have accessed prevention services, i.e. had exposure to outreach workers but have (so far) refused to access HIV testing (data presented in Chapter 2).
- Men who have sex with men who have tested HIV positive during the HIV screening test, but have refused to conduct the confirmation test or to go and receive the result (data presented in Chapter 3).
- Men who have sex with men who have accessed CD4 and baseline testing, received the result, but have not started on ARV treatment despite their CD4 count being under 500 (data presented in Chapter 4).
- Men who have sex with men who have problems in adhering to ARV treatment, frequently switch treatment hubs, or switch to private care systems (data presented in Chapter 5).

The study was conducted in four cities that are part of Metro Manila: Quezon City, Manila, Pasay and Caloocan. The cities were selected to represent the diversity of the HIV response in Greater Manila, with the HIV services in some cities expected to function better than others.

In each of the 4 participating cities, 12 interviewees were recruited for a total of 48 in-depth interviews, as follows. The 12 interviewees in each city represent a purposive sampling, also known as subjective or selective sampling, chosen according to the purpose to the study and characteristics of the population:

- Three men who have sex with men who choose not to be tested with the first screening test were recruited from participating NGOs and peer workers and from the social hygiene clinics.
- Three men who have sex with men who had tested positive but were either continuously postponing going for the confirmation test or who had tested but were refusing to get the result were also recruited via outreach workers at participating facilities as well as social hygiene clinics.
- Three men who have sex with men who were not accessing ARV despite being medically assessed as needing treatment were recruited via participating support groups for people living with HIV.
- Three men who have sex with men who had been on ART but have now dropped out, often after switching service providers or after facing other difficulties in adhering to their treatment, were recruited via participating support groups for people living with HIV.

By the time of the interview, the situations for some of the men had changed but the substance of the interviews was still valid. For example, some of the men do not have problems currently with adherence to ARVs but did in the past and were able to describe the barriers to adherence.

Operational definitions

HIV service: An organization, business or individual person (i.e. a doctor or an outreach worker) that provides HIV prevention knowledge or goods, HIV counselling and testing, HIV treatment, HIV care and support to people who need it.

Men who have sex with men (MSM): Filipino men self-reporting anal or oral sex with another men in the past year, aged 18 years old or more, and living in the selected cities of Manila for at least one year. This definition includes bisexual men, heterosexual men engaged in male sex work and self-identified gay men.

Barrier: Something that stops or prevents a person from accessing a service. Barriers can be related to correct or incorrect knowledge about the need to access the service, attitudes towards the service or towards HIV disease, moral attitudes towards homosexuality, or previous experiences accessing or trying to access the service. They can also be related to distance, opening hours and the perceived quality or friendliness of the service, including the attitude of health care workers.

Ethical considerations

Participants entered into the qualitative component of the study via their contact with NGO or HIV service workers, out of their free choice and without any undue persuasion or pressure. All participants were approached in online venues or through referrals from partner organizations. Recruitment also occurred via the personal and professional networks of the local consultant and sole study interviewer, Andrew Ching, or via staff of partner organizations with whom he works. Potential participants who expressed an interest in being interviewed were given a brief information sheet that explained the purpose of the study.

After agreeing to participate in the study, an appointment for an interview was made at a time and location chosen by the participant. The interviews took place at public locations such as coffee shops or restaurants. The interviewer provided soft drinks or coffee or tea. In addition, each participant received 800 Philippine Pesos to cover transportation costs and in appreciation of the time spent with the research project.

Before each interview started, participants were asked to sign an informed consent form indicating they understood the purpose and process of the study, as well as their right to confidentiality; their right to refuse giving an answer to one, several or all questions; their right to change their mind about their participation and end the interview; and their right to request a copy of the interview transcripts or of the result of the study at a later stage. They were given contact details of the interviewer and they retained the right to withdraw from the study up to 30 days after the interview was completed (by written notice). None of the participants used this right.

After the interview was concluded, participants were given information about counselling and information providers, both online as well as offline, in case the discussions during the interview had triggered a demand for such services. Audio recordings and transcripts related to the interviews were stored on a password-protected computer in an encrypted folder to protect the confidentiality of participants. Only the local consultant had access to this information; only the international and the local consultants had access to interview transcripts and summaries. During analysis, names of participants and salient details that may identify them were changed in the translated summary transcripts to protect their confidentiality. After transcription was completed, the audio recordings were immediately destroyed.

The National Ethics Committee of the Philippine Council for Health Research and Development approved this research protocol after ethical review (NEC Code: 2015-010-vanWijingaarden-HIV/AIDS, see Annex 1).

General observations about the 48 men in the qualitative sample

Before moving to the findings, some general observations about the 48 men in the sample are presented below:

The sample of 48 men who have sex with men, mostly living with HIV, reported low levels of condom use over their lifetimes, especially before their diagnoses. There were only two or three men in the study who reported consistent high levels of condom use. The reasons for not using condoms included the belief that partners were 'clean' due to good physical appearance and/or a perceived high socio-economic status, and that they often found condom use to reduce sexual pleasure. Many men also had not believed in the need to use condoms in the past, and had perceived them to be a tool for family planning.

One finding among the study sample was a very high level of sexual activity by those under the age of 18, always with older partners, some much older. Many of these older partners were neighbours or family members such as uncles and cousins. While many participants noted they were raped or "molested", others said that these sexual contacts were consensual and not forced upon them, and were sometimes initiated by them, where they "seduced" partners. It should be noted that several studies have found links between the early onset of sexual activity, including abuse, and increased HIV vulnerability at a later age.⁵

A large majority of the men came from families that are not intact where usually the father had moved out or found a new partner. Family problems seemed to be more common among those who grew up in lower socio-economic contexts. Several participants in the study said they thought their unhappy childhoods were linked to their tendency to put themselves at risk at a later age: one was involved in sex work to support his family and likely became infected that way; some said they were looking for love and warmth from older men because of a missing father figure during their childhood; many more said they received no guidance on how to live their life properly, which made them 'bad' or naughty. Others said that they had left their family and moved to a life alone in the city, which increased their opportunity for casual sex and partying. The availability of social media dating apps was also mentioned as a factor that made having multiple sexual encounters much easier, and this was seen as increasing one's vulnerability to HIV.

Several of the interviewees were probably infected with HIV during 'bursts of sexual activity', meaning that they went through a brief period in which they went 'wild' sexually, often after breaking up with a long-term partner, or just after leaving their family and obtaining a space of their own, leading to more freedom. It is important to make gay men aware of the tendency to have periods of more frequent sexual activity and to provide the option of pre-exposure prophylaxis (PrEP) as an extra layer of protection during or after these periods. WHO recommends that PrEP be offered to people at substantial risk of HIV infection as an additional prevention choice, as part of comprehensive prevention, including condom use (see <http://www.who.int/hiv/topics/prep/en/>).

Another observation (and perhaps a limitation of the study) is the high number of men in the study who were open about their sexuality towards friends and family. The same can be said about the high proportion of men living with HIV who were open towards their family, at least to a certain extent, about their HIV status. Both these phenomena can be explained partly by selection bias, as a result of the way the men were recruited into the study.

⁵ See, for example, Boroughs MS and others (2015). Complexity of childhood sexual abuse: predictors of current post-traumatic stress disorder, mood disorders, substance use, and sexual risk behavior among adult men who have sex with men. *Archives of sexual behavior*. Oct 1;44(7): 1891–902 and Outlaw, Angulique Y and others (2011). Age of MSM sexual debut and risk factors: results from a multisite study of racial/ethnic minority YMSM living with HIV. *AIDS patient care and STDs* 25.S1: S23–S29.

Chapter 2: Men who have sex with men with barriers to accessing HIV testing services

Introduction

In 2014, 38 percent of the estimated population of men who have sex with men in Quezon City (estimated at slightly over 24,000) were tested.⁶ In the rest of Manila, it is estimated that less than 10 percent were tested in 2014, and in the rest of the country (with the possible exception of Cebu city) testing rates are likely to be under 5 percent.⁷

There are at least 14 HIV Counselling and Testing (HCT) facilities in the greater Manila area, with two NGO-operated clinics and one private clinic specifically targeting men who have sex with men, and at least two government-run social hygiene clinics also widely touted as ‘men who have sex with men-friendly’. There are outreach workers based at all HCT centres, who work to find clients and who sometimes accompany clients to these facilities for testing – but most commonly they just make potential clients aware of the availability of the testing service who are then referred and advised to go by themselves.

There are at least 17 social hygiene clinics across Metro Manila. The Research Institute for Tropical Medicine (RITM), two hours travel from central Manila, also provides testing services, with the added advantage that this is one of only a few places where a rapid confirmation test and, if both tests are positive, CD4 and other baseline tests are available immediately. In all other places with free services, the western blot confirmation test is required before baseline tests and enrolment in ART, which takes two to four weeks. However, RITM and the two MSM-friendly NGO-run clinics have started collaborating on a research project that makes rapid diagnosis also available at these clinics.

A 2014 evaluation of HIV behaviour change communication programmes commented on counselling practices observed in the Philippines.⁸ It found a widespread practice of counsellors and medical personnel handing clients an HIV test result in a sealed envelope, without the counsellor being aware of the result. This is because lab technicians mistakenly believe they would be breaking confidentiality laws if they informed counsellors of clients’ test results prior to informing the client. Hence, no post-test counselling takes place at all in these instances, and as a result the client has to interpret the contents of the envelope by himself, with potentially serious consequences:

“[T]he evaluation team felt that [this practice] might account for a considerable proportion of those having been diagnosed not presenting at treatment and care services. Counsellors and lab staff stated they had interpreted Article 2 Section 32 of Republic Act 8504, The Philippine AIDS Prevention and Control Act of 1998, to mean they were not allowed to open the results; only the clients could open their results, and that they did not have to share the results with the counsellor. Further, it was frequently stated that counsellors felt they could even ask [the client] for their test results.”

6 Belimac, Dr Gerard Jose (2016), personal communication.

7 Estimated by key informants consulted during a consultancy by the author of this document for UNAIDS in March 2015.

8 Casey, Kathleen, Dano, Ethel and Merilles Jr, Onofre Edwin A. (2014). Evaluation of the HIV and STI Programs and Strategies for Males having Sex with Males, Transgender and People Who Inject Drugs in Philippines. Commissioned by the Philippine Department of Health (DOH), 2 June 2014 (Unpublished), p. 15.

This interpretation of the AIDS Law and the resulting absence of any post-test counselling for those newly diagnosed with HIV is a serious situation that should be relatively easy to address, simply by issuing a clarifying guideline from the Department of Health to all HCT counsellors in the country.

For HIV testing, parental consent is required up to the age of 18. A recent study on men who have sex with men in Iloilo City found that 86.5 percent of the participants had their sexual debut before the age of 18, with the mean age being 15⁹ and 44 percent engaging in anal sex during their sexual debut. In other words, the great majority of men who have sex with men are already sexually active a number of years before they turn 18 years of age. However, the current age of consent law for HIV testing prevents them from accessing their right to know their HIV status and their right to access HIV treatment, care and support if they are HIV positive.

Epidemiological data from Quezon City shows that 38.5 percent of all new HIV infections among men who have sex with men in 2013 and 2014 were in the 15–24 age group.¹⁰ There is an effort by civil society organizations to lower the age of consent for testing to 15, but it is uncertain if the Senate will agree, and there seems to be no strong leadership in the government supporting this. A recent Supreme Court ruling was paradoxical: it stated that obtaining parental consent for testing was more important than the public health concerns of the minor related to underage sexual activity (or pregnancy), while at the same time stated that people providing reproductive health services (presumably including HIV testing) to minors should not be prosecuted.

In this chapter, data is presented from 12 men who have sex with men who were interviewed across the 4 cities of Caloocan, Manila, Pasay and Quezon who had been reached by peer educators or counsellors but refused HIV testing or decided to postpone getting tested. Men who had been tested more than one year ago were also included in this category, as were some men who had not been tested for several years before eventually testing positive for HIV; these men were asked about their reasons for not testing in the past.

The 12 men interviewed in this category were from 19 to 42 years old, with an average age of 25.75. Three worked in middle to senior office and corporate jobs; three worked in lower office jobs; three were teachers or trainers; two were students and the one oldest participant was an unemployed manager. Half were born in the Metro Manila area and the other half had migrated to Manila. All names have been changed to protect confidentiality.

9 Italia, William Fred P., and Ryan Michael F. Oducado (2014). Men Who Have Sex With Men in Iloilo City, Philippines: Profile, Sexual History, Level of Knowledge About HIV/AIDS and Sexual Risk-Taking Behaviors. *Asia Pacific Journal of Multidisciplinary Research*, Vol. 2, No. 6, December 2014.

10 Powerpoint presentation shared by Dr Rolly Cruz, Quezon Health Department (2014).

Case Studies

JOEY, 33 QUEZON CITY

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Joey (33, Quezon City) had been tested once, some five years ago. He had not much to say about the experience except that he had been worried during the post-test counselling. He describes himself as a “serial monogamist” but has never had a relationship that has lasted longer than a number of weeks. He said he did not like using condoms while being a top, and when he was a bottom, he left the decision to use condoms to his partner. He calls himself as “very high risk” and comments, “I may very well be positive at this time”, but he is still unwilling to get tested. Later in the interview, he said:

“It’s not that I never wanted to take the test, it’s just I never got around to taking the test [chuckles]. But seriously, it’s not a question of WANT. I know I need it, I know I want it, I really just never got around to it.”

Joey is friends with several outreach workers and counsellors, including the interviewer. When asked why this has not resulted in him getting an HIV test in the past five years, he responded:

“I guess there’s that part of me that just totally ignores the importance of testing. I mean I hardly see you or anyone of our friends in [the] HIV advocacy, things get really busy at work and when I’m not at work, I play [Laughs]. [Silence]. I know it frustrates you, and it worries you. I know that you cried over the deaths of our close friends who ended up not taking the test but were perceived to have died from AIDS, and I’m sorry, friend. It’s just I never get around to really taking the time off to take the test.”

Joey also said he had 12 or 13 friends with HIV “outside of those who died over the past years.” This situation had not led him to feel the need to get tested either: “No. Stubborn, right? I guess I’m apathetic when it comes to death or maybe I am just good in ignoring things I would prefer to ignore. I don’t know.” Joey never searched for information about HIV. Asked whether the Internet or social media played a role in his decision not to get tested for HIV over the last five years, he said: “The Internet or the social media would be the last place on earth to ever affect making my decisions.”

11 The partner who is penetrating the other during anal sex.

12 The partner who is being penetrated by the other during anal sex.

NJA, 42 PASAY



NJA (42, Pasay, unemployed) became infected with extra-pulmonary tuberculosis “via a colleague”; however, he did not feel the need to get tested for HIV. He said he was never told by a health care provider that an HIV test is recommended for all TB patients. NJA said he used condoms infrequently, and mentioned several instances of sexual risk-taking. Despite this, he said he never wanted to get tested since he said he was “physically okay”; he was a frequent gym fanatic, which he said was a typical characteristic of the gay lifestyle. Volunteers and outreach workers approached him for an HIV test several times over the past five years, but he said there was no need because “I knew I was healthy”. Later, it also became clear that NJA had several friends who were “sick with AIDS”; he strongly associated having HIV with signs of the physical deterioration typically associated with AIDS:

“I had five friends. The first one had boils all over his body. The other one we visited in [public hospital A], he was so thin and had so much weight loss. That’s how I knew I was okay. I was healthy and I didn’t have weight loss.”

NJA met outreach workers regularly in a gay bar in Quezon City. Even though there were sometimes mobile testing facilities present, he still did not want to get tested: “It’s a bar, you know. People, when they see you lined up for an HIV test, they will judge you.” He was also worried about confidentiality. He said that “in order to get rid of the outreach workers, I would get condoms and lube [from them], but I never got tested.” He seemed to suggest that the outreach workers were somehow not professional: “There’s this back area at the bar where you can cruise and have sex in the dark. And the outreach workers will be in the dark as well [laughs].” NJA was aware that oral sex, his preferred sexual behaviour, was less risky than anal penetrative sex and he used this knowledge to justify his decision not to get tested – despite him having engaged in anal sex occasionally and reporting other situations of risk for HIV.

Later in the interview, it appeared that NJA had been “accused” of having HIV while hospitalized for TB; he had a conflict with his health insurance company about it:

“When I had TB, I felt that whatever happens, I would just let it be. I only hoped it wouldn’t be HIV. Even when I was hospitalized, I never thought of HIV. Even the doctors, they never mentioned HIV to me. I was surprised that when I was about to be discharged, the health insurance refused to cover my hospitalization, accusing me of [having] HIV though I never got tested. [...] No one told me about HIV. There was one doctor who gave a pep talk about HIV, telling me it’s not a death sentence but it was very casual. It didn’t dawn on me that I need to take the test. [...] There’s a case now I filed against [the insurance company] and my former company. I can’t talk much about it since the case is ongoing. But all I know is that they shouldn’t have assumed that I’m HIV positive.”

NJA never looked for information on HIV via the Internet; he explained: “I did not have signs, symptoms or weight loss”. While he was younger he had gonorrhoea twice, and found out about how to treat it; he bought medicines via the Internet several times. He never saw a doctor for his symptoms. He also shared information about treatment via the Internet with friends. NJA was not aware that treatment for sexually transmitted infections (STIs) is available for free at the social hygiene clinics.

* The same lack of urgency was reported by Don (29), whose case is discussed in Chapter 3. Don said he was contacted by outreach workers and had discussed HIV with friends, but:

“There wasn’t really any urgency specific to HIV. It seemed then that it was impossible to happen to us.”

DRAKE, 33 QUEZON CITY

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Drake (33, Quezon City) found out he was HIV positive in September 2015. Since becoming sexually active in 2001, he had never been tested until then. He gave two reasons for finally doing the test: “[The] first reason is I could feel something that I couldn’t explain, but I knew that there was something wrong. And second, my best friend had herself tested and I accompanied her.” He said he had never gotten tested before because he always used condoms and usually did not engage in penetrative sex. He believes he was infected in July 2015 when he used the drug ice for the first (and only) time. He mentioned that he felt something was wrong with his health a few times after that.

Drake said that he was worried about the confidentiality of the HIV testing centre:

“They [other clients waiting to be tested] will know if the person is positive or not based on the reaction of the person when he got out of the post-counselling. And that’s the purpose of testing centres. It’s just other people give malice to the entire testing concept.”

When Drake tested positive, he told his best friend right away, but she did not believe him: “She said I was such a good actor.” Drake thinks his friend does not want to believe that he is positive; perhaps she would not know how to deal with it.

ROBERT, 26 MANILA

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Robert (26, Manila) wanted to be a woman and experimented with hormones while at high school, but then decided that life would be easier as a gay man. He was sexually abused from the age of 6 or 7. He described that he eventually would not have condoms used during anal sex, as he preferred the feeling of being penetrated without them. Robert did look for information about HIV online but this did not result in him getting an HIV test. He tested positive in July 2015, which was his first-ever HIV test after being convinced by his (gay) boss to take a test. He said before then, he did not want to be tested because he was worried he would be the only one who was positive in his group of friends; for that reason he preferred, for a long time, not to know. He said he felt sorry that he had not been tested earlier, and seemed to blame himself for it:

“I was self-centred before but I didn’t know that being positive can reverse your life, either for good or bad. [...] And because I was that self-centred, I always went for whatever made me happy.”

However, once Robert found out, he decided to tell his siblings, but not his parents “because they are already senile”. However, his sister then told his mother that he had AIDS: “My mother texted me to go to church, pray a lot, go to Cavite where there is a healing priest there. I told her not to worry.” Robert disclosed his HIV status to his friends and colleagues too, including his staff and his boss. His boss is also gay and was an important impetus for Robert to get tested, as his boss was worried about a persistent cough Robert had.

JUSTINE, 28 QUEZON CITY



Justine (28, Quezon City) found out he was HIV positive in March 2015 with a CD4 count of 6. He had been in a presumably monogamous relationship with his first boyfriend for a period of 11 years. Initially they used condoms, but in the past two years, according to Justine, they had stopped using them. He had had several symptoms of AIDS-related disease in the months before finally taking the test, including TB of the lymph nodes, and had been in contact with medical authorities to test for many different diseases, including TB, cardiovascular disease and cancer – but not HIV:

“[F]rom Infirmary we went to the Lung Centre to [Hospital A], to [Hospital B] for cardiovascular, all the results were negative. I felt there definitely was something wrong. [...] That’s the time I started to search online for common symptoms. [...] My EENT told me to have my lymph tested to know if it was cancerous [...]. That night I posted on my Facebook that I might die tonight. People were aware that all my lab tests were negative. Some friends were even texting me but never directly told me to get tested for HIV, but eventually one of them told me to do so. A very close friend of mine [...] told me, ‘Son, I love you but son of a bitch, get HIV tested as I don’t want you to join the [death] statistics.’”

Justine seemed totally convinced that he could not have HIV because of his boyfriend’s and his own family were doctors, which made him classify himself as “low-risk”:

“I was already aware of [a major NGO HIV service provider] and my friends in Malate, like [XX] and [YY], and they’re always telling me to be careful but since they know that my partner and I came from a family of doctors, they’re sure that we are safe. Also [in] my ex’s family, being a family of doctors, HIV is a common discussion or topic.”

He also thought that the healthy looks of his partner meant he could not have HIV:

“I am not that equipped with correct info and my partner seemed healthy based on his physical condition, and there is that trust that [my] partner is healthy, aside from the fact that he is a doctor. I had no reason to have doubts.”

When Justine finally went to get tested for HIV for the first time, it was so crowded at the clinic that Justine turned around and left. He came back later dressed in different clothes and wearing a cap out of fear of being recognized: “There were so many people and we left because I was afraid and intimidated. But we came back after I disguised [myself], [I] wore shades, cap and a mask.”

When he tested positive in March 2015, his boyfriend of 11 years admitted that he had known that he was HIV positive for the past 5 years. Despite this, Justine was willing to stay in a relationship with him, but to no avail: “Even when we were in our [HIV] training [two weeks before], I was crying and I was saying I felt bad, not because I acquired it [HIV], but I felt bad because after I acquired it from him, he left me.”

Justine considered himself a “victim of love”. However he agreed that his HIV infection was partly his own fault:

“But lately I realized and it’s funny, I think back now that I’m taking ARV and I’ve seen that same bottle before, with my ex. But admittedly, that was one of my mistakes, I never asked him anything that connected him to being positive, I didn’t even search online what are those bottles and pills I’ve seen before. All he said was that medical representatives gave him those pills for [a] trial.”

Justine received the test result in the company of a family member and also told his entire family about his HIV status the same day. They responded well:

“When I finally blurted out the news, there was that moment of silence and they were all just staring at me. My brother told my parents, ‘Why, dad? Can’t you give your favourite child a hug? Ma, Can’t you hug him? He’s your favourite, can’t you stand up and go over [to] his side and give him a hug?’ Then they stood up and gave me a hug and uttered, ‘We shall fight!’ The day after, my Mom accompanied me to [the hospital].”

Justine told his colleagues at the place he was teaching and was well supported; colleagues collected 10,000 pesos to help with his medical expenses and over the following months his weight went up from 42 to 56 kilograms: “The support I needed came and I never had to look for it.” Asked why this might be the case, he responded:

“I guess it’s because I have been a good person. That’s why I have been getting all the support, care and love that I need from them. They were all surprised to know, but they all managed to understand my status and looked at the things I am capable of rather than dwelling on the idea that I am sick and I am limited. My family has been very supportive ever since, and I don’t see a reason for them not to accept me [Smiles]. My friends and officemates normally entrust their secrets and stories with me, I kept them, didn’t judge them, I guess that’s why [I] am getting the same respect and acceptance I have given them.”

Note how Justin, by positioning himself as ‘good’ and, indirectly, as an innocent victim of HIV, managed to obtain strong support from family, colleagues and friends. By the way he presented himself and explained his HIV infection, he could navigate the tremendous societal stigma of having HIV, and of being gay. Justin ‘read’ his social environment well, and marshalled societal and family support to keep going in the face of the social and institutional stigma and discrimination that characterizes life for many Filipino men who have sex with men living with HIV.

VINCE, 26 MANILA

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Vince (26, Manila) had been involved in male sex work for short periods of time to make ends meet since he was 22, but was employed as an administrative assistant at the time of the interview. He had not been tested since 2014, despite having been at considerable risk for HIV; one of his ex-boyfriends had tested positive, as had a steady sex partner described as a client with whom Vince would not use protection. He said he was not “effective” when using condoms with his partners, meaning that he would lose his erection. Vince gave the distance to the testing clinic as a reason not to get tested, and also his work schedule, which he described as “toxic”. He also mentioned the long waiting times as a factor that might put people off. He seemed resigned to the fact that he might have HIV: “I guess I’ve long waited for and expected a positive test result”. Even so, he had not made plans to get tested at the time of the interview.

ZEN, 21 PASAY

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Zen (21, from Pasay, grew up in Manila, working as a fast-food crew member) started being sexually active from the age of 18 and would generally not use condoms. He found sex partners via Planet Romeo and WeChat. Commenting on what made him decide whether to use condoms or not, he said: “It depends on the looks of the person. If he looks healthy or when I have been exchanging texts with the person for some time, I would trust him and condom[s] would not play a role anymore.”

When he had a persistent sore in his mouth, a former boss who was a nurse told him he should have it checked out and be tested for HIV, after which he found out he was positive in November 2014. He said two factors explained why he had not taken an HIV test earlier: he had been “busy” and “the fact that I wasn’t feeling anything bad or odd about myself.” This suggests that the idea of HIV being linked to certain symptoms of disease is still prevalent, making it difficult to conceptualize or internalize the idea of a communicable disease without symptoms. Zen has not told anybody about his HIV status except the people he has met through HIV services. He believes his brother, to whom he is close, would understand, but he feels embarrassed and he seemed to judge himself in a moral sense: “because I didn’t think and took for granted my health and the risks that come with the action.”

KARL, 26

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Karl (26), a law student from Vigan who moved to Manila when he was 15, considered himself to be bisexual but was more sexually active with men. He was worried about being possibly infected “because I was promiscuous” and because he never used condoms. He was diagnosed with gonorrhoea twice, once infecting his then-boyfriend. Karl kept postponing taking the HIV test:

“I had a mindset that after taking the bar [lawyer’s exams, JWDLVW], I will go for an HIV test. I assumed then that by that time, I’ll be capable to support and provide for my own means in my treatment on the presumption that I’ll turn out reactive for HIV.”

He was influenced in the decision to postpone his HIV test by information he found on the Internet around 2011. This led him to believe that if he had to take HIV medicines, there would be severe side effects:

“I refused to get tested then regardless of my sexual activities, because I was still studying. [...] I based this decision on the things that I have read in several blogs, specifically those of the drug reactions. I was thinking

then that it will be taxing on my part much more that I'm still financially dependent [on] my mom. I have no source of income to provide for my medication if it turned out reactive. I also considered the possibility of getting through extreme depression.”

Note that Karl was worried about the cost of ARV treatment, and was not aware at the time that this treatment was available for free. Interestingly, Karl found information about how long it would take for him to show symptoms of infection, and used this information for a while to justify postponing the HIV test and starting treatment:

“[A]t that time, I was hoping that my immune system was still doing well. I knew then that complications can only appear within 7 to 10 years from infection. I did the math; since I became sexually active, complications would only become a problem come 2019. But I was wrong, as certain complications came in as early as 2014.”

Concern about his family played a role in postponing his HIV test in another way besides him possibly losing financial support for his studies, as he was worried about the impact of being a “disappointment” to his mother if he tested positive:

“As I started law school, I have also developed the hobby of becoming a constant disappointment to my mom with several subjects that I failed. I did not want to add more salt to the injury so I refused [to get] tested as the results may contribute to my infamous list of failures.”

A final factor that led him not to get tested was Karl’s worry that he would be unable to enter his planned profession of a lawyer if it became known that he was HIV positive. However, his plan to postpone his test until finalizing his law studies could not be carried through, as his health started to deteriorate rapidly:

“There were already several manifestations of possible HIV infection. I have shredded several pounds for a period of six months without even trying to reduce my weight. There were no conscious efforts to lose weight then but my weight was drastically going down.”

He also suffered from herpes zoster (also known as shingles) and hence decided to take the test in 2014 and tested positive.

* The influence of the Internet is not always negative: MC (21, advertising executive from Pasay) said that the information he obtained and found on the Internet actually encouraged him to get tested:

“The more I read those articles, the more encouraged I was to take the test.”

Observations

From the case studies, it can be observed that the reasons for not getting tested or delaying HIV testing can be categorized into four main sets of reasons: misconceptions about why it is necessary to get tested; moral issues (or conceptions of morality) that obstruct testing; the fear of discovering you are HIV positive; and problems with access to, or worries about the confidentiality of HIV counselling and testing centres.

> **Misconceptions that downplay the need to get tested**

A number of key reasons for not getting tested can be derived from the case studies. The most important reason was not seeing the need to get tested, despite often-significant episodes of risk for HIV.

Perceived justifications for not getting tested included being in good physical shape, having a healthy lifestyle, not feeling ill and not losing any weight – an oft-mentioned (mis)perceived sign of not having HIV infection.

‘Us’ versus ‘them’ thinking can be an impediment to HIV testing. Justine, for example, thought that because his boyfriend was a doctor, and he was a medical science teacher, that they were somehow superior to “the type of person that gets HIV”, which explains why he refused to get tested for HIV until a very late stage.

Often participants said they had “no time” or “never got around” to doing it – showing a lack of urgency or significance given to HIV testing, although it could also point to them having less equitable access to HIV testing services (see below).

Another reason not to get tested for HIV was a stated preference for oral sex. Though it is true that oral sex carries a much lower risk for HIV transmission than anal sex, few of the participants were having no anal sex at all and hence, they were downplaying their risk of HIV infection.

> **Morality as a factor to not test**

Being monogamous or feeling morally superior to “other gay men” was another reason why some participants felt no need to get tested. The rationale was that it is OK to have unsafe sex as long as it is in the context of a monogamous relationship. However, some of the participants were ‘serial monogamists’, i.e. they were monogamous but stayed with the same partner only for a limited period of time before moving on to the next boyfriend, resulting in multiple possibilities for HIV infection over a number of years. Also, it was not always clear whether both partners had actually tested negative for HIV before the decision was taken not to use condoms anymore.

The case of Justine illustrated the limitations of monogamy as a strategy to avoid HIV infection. In Asian settings, it seems difficult to conduct a ‘face-losing’ conversation with a partner in case one has breached such a monogamy agreement. Justine’s boyfriend was unable to tell Justine that he had slept with someone else and not used a condom. He continued his sexual relationship with Justine even after knowing he had been infected with HIV. It is possible that he felt unable to bring the issue up and was afraid the relationship might not survive it. Justine’s complete trust in monogamy and faithfulness as a strategy to keep him safe, in other words, in his own ‘goodness’ to protect himself, had nearly fatal consequences.

Monogamy, i.e. being ‘faithful’ and having sex only with one’s partner, is a popular strategy for HIV prevention, especially in conservative countries such as the Philippines. However, as a strategy for HIV prevention, it does not necessarily work. It requires both partners to be honest with each other, to be committed to the concept and to be able to have open and frank communication to be able to talk about challenges, failures of the agreement (sex with other people), and about how to make their monogamous sexual relationship work to the satisfaction of both partners.

But all of these provisos would seem especially difficult in the Philippines, where friends of the same gender may joke and boast about sex and sexuality, but communication about sexuality between intimate partners seems absent in the country’s sexual culture. This would also disqualify the promotion of ‘negotiated safety’ as a prevention strategy in the Philippines. This is where partners agree on an open relationship where they do not use condoms with each other but use condoms consistently with other sexual partners. This requires a similar level of honesty, commitment and openness as discussed above, and would be difficult in a culture where sexual relations and intimacy are not discussed.

The mere idea of being seen to be tested for HIV was for some participants embarrassing, as they thought it would reveal to their social circles that they might have a reason to be worried about HIV, i.e. they may have engaged in behaviour that some consider immoral, such as having multiple sexual partners. This explains why Justine ran away from the testing centre the first time he went there, and came back covered up with sunglasses and a cap. Another participant mentioned this as well: he had refused to stand in line to be tested by a mobile HIV testing van that had parked outside a gay entertainment venue, afraid to be spotted by his friends. One participant mentioned that he thought he was “not promiscuous enough” to get HIV, showing how HIV is still negatively linked to certain concepts of morality, and whether one is a “good” or “bad” person. Improving general knowledge about HIV and its transmission, as well as promoting HIV testing as an act of wisdom, responsibility and courage could help counter the ways in which morality obstructs HIV testing.

Participants were also asked whether they believed HIV should be seen as a punishment, and whether this could explain their delay in getting tested or seeking treatment. But this was not the case. NJA saw the HIV epidemic as a way to “strengthen” gay people:

“I don’t see it as a punishment. I see it as something to strengthen us. It may be something to reflect on. If you are weak, it’s going to be hard. I mean, you go to those places [gay entertainment venues] or do those things [gay sex]. So man up to it.”

Robert had a very positive view about HIV since being diagnosed a few months before:

“I didn’t take it as punishment, but I took it as a new challenge. There is nothing new in my life aside from [the] office, work and partying. But when the virus struck me, I saw this as a reason and as a challenge to live longer.”

› Fear of what happens when one tests positive

One participant was aware that he had been at risk for HIV for a long time, but was worried that he would end up being the only person with HIV in his circle of close friends. For that reason, he kept postponing and postponing the test. This shows how the HIV epidemic operates silently in the Philippines: most participants did not know another person with HIV personally, at least not before they became infected themselves. It is important to try to break the silence around HIV and make sure there is wide recognition and knowledge of the HIV epidemic in the Philippines and the risks of infection for men who have sex with men, for example that currently up to 22 men who have sex with men become infected with HIV every day in Manila alone.

Another participant was dependent on his parents while studying, and worried about losing their support if he tested positive; he kept postponing taking the test as he had read it would take 7 to 10 years before the first symptoms would develop.

The same participant and several others were overly fearful of side effects of HIV medications, having read horror stories about this in online blogs. They worried that if you have to be on HIV treatment while still depending on your family, the resulting side effects would lead your family to find out about your HIV status. However, most participants were not aware of the serious consequences of not being tested. Some people instead wait for a problem to occur. This could have serious health consequences, such as opportunistic infections, and, ironically, may also make the antiretroviral medicines more difficult to digest for the body and, hence, lead to more severe side effects.

› Factors related to HIV testing services

Some of the reasons for not getting tested were linked to the actual or perceived characteristics of HIV counselling and testing centres. The most important and most frequently mentioned factor was the worry about the large number of people who use and attend these centres, and hence whether there would be a lack of confidentiality and privacy of the test result because so many other people are around.

Other clients, especially those with low salaries and incomes, found the testing centres located too far away, found the waiting times too long, or found their opening hours conflicted with their work schedules. This points to the need to bring HIV testing closer to potential clients.

Easier and more private ways to be tested for HIV must be made available, for example through trained outreach workers, self-testing, extending the opening hours of HCT centres and by improving and institutionalizing online appointment systems.

It is obvious that HIV testing facilities are not equitable at the moment: poorer and working-class people have less access to it due to the way the system currently operates. The opportunity costs for HIV testing must be lowered to make access to HCT more equitable, meaning that the time or income lost from being tested should not be significant.

Chapter 3: Men who did not follow up after a reactive result of an initial HIV screening test

Introduction

When this study began, the Philippines was still using the western blot method as the confirmatory test for HIV, resulting in a waiting time of two to four weeks to receive a confirmation test result (see page 28 for further discussion on HIV confirmation tests). Since only 2 facilities are allowed to conduct this test in the entire country, people had to wait between 10 and 14 days when in Manila; for those from outside Manila, it could take up to 4 weeks to get a confirmatory test result. Unsurprisingly then, according to Dr Rolly Cruz of the Quezon City Health Department, in 2014, 206 people, or 49 percent of people who had been screened as positive for HIV in Quezon City in their first test, did not return for the result of the confirmation test. This was already a strong improvement on the 85 percent that disappeared in between the two tests in 2013 (N=255).

After receiving the confirmation result, newly diagnosed clients are required to undergo CD4 testing and further assessment needed for enrolment in ART. There are several locations where CD4 tests are available in Metropolitan Manila. Some of the clinics, such as [private clinic E], have started to arrange CD4 and other baseline tests for its clients, sometimes for a fee, but the great majority of newly diagnosed people are referred for further evaluation including viral load testing and have to go on their own, without a system in place for follow-up.

At the Quezon City Health Department, it was mentioned that a big gap in current services is psychological and social support for people who were recently diagnosed with HIV. An estimated 10 to 20 percent of people need such support to deal with issues related to disclosure and treatment adherence.

In this section, the findings are presented of interviews with men who got tested for HIV via a rapid test, received at least one positive screening test result, but then did not pick up the result of the confirmation test and/or did not proceed towards CD4 and baseline testing. The men were aged between 20 and 41 with the average age as 29.3. In this category, 3 out of the 12 men interviewed were born outside greater Manila. Two were students; the rest had a wide variety of professions, from banker to masseur to art designer to call centre employee.

Case Studies

CLYDEN, 28 MANILA

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Clyden is a 28-year-old man who works as a masseur. Born in Masbate, he came to Manila when he was 23 to find work. He said he had sex with men “only for the money”. His condom use was inconsistent and partly depended on the type of condom that was available; if they were the thick kind, he would sometimes not use them. Despite knowing that “HIV is not gauged on physical appearance”, Clyden said the way a person looks still influenced his decision whether to use a condom or not.

He was tested for HIV in September 2014 and tested positive, but did not go back to pick up the confirmation test result: “No time. Busy. No schedule [was] specifically set [for me to pick it up] so I guess I was lax. [The counsellor] also said he would call me, but no calls have come until now.” He mentioned that the cost of a CD4 test was another reason he did not want to go back. Despite being aware of the positive and life-extending effect of treatment, he was worried about possible side effects of the antiretroviral medicines and said he did not have enough money to afford treatment even if it was free, due to the cost of the laboratory tests and the transportation costs to get to and from the treatment hub.

DON, 29

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Don, a 29-year-old agent for a call centre, and from a poor family, was diagnosed during a hospitalization for pneumonia in May 2014. The positive confirmation test result was shared with him after his confinement had ended. When he came back for a follow-up visit, he was referred for a CD4 test and other baseline tests in [public hospital A], which happened to be prohibitively expensive:

“I was told to do some more lab tests. I think that was more than 10 [tests]. But I already did those in [public hospital C]. This had me worried because of the expenses. Gene expert alone was 1,900, RPR was 1,200... [...] I was the only [one] working in the family and I was not able to sustain and pay for all the cost[s] of the labs required by [public hospital B]. I was told by the infectious disease doctor as well in [public hospital B] that no ARVs will be issued unless lab tests are complete.”

He tried finding financial support for these tests, to no avail. He transferred from [public hospital B] to the RITM treatment hub where more than one month after the arrival of his confirmatory results, he finally did a CD4 test and was found to have a CD4 count of only 12. He was made (by public hospital B) to come back some days later to pick up a referral letter so he could complete his RITM transfer – something he found unnecessary:

“They told me to come back August 13 where I got the letter and other documents. I got there [again] and it was just a piece of paper with the heading ‘referral’. This made me wonder – why did it take two days from the time I initially said I was transferring when the letter was just a one-pager and essentially didn’t contain anything except that I was transferring to RITM from [public hospital B]? I was thinking there were going to be a lot of documents.”

A few days later, Don managed to start ARV – more than two months after his initial positive screening test – with assistance from the female doctor who treated him for pneumonia at the first hospital, who pushed for him to have treatment. He commented about the long time it took for him to finally access ARV: “It was partly because of financial challenges brought about by the unreasonable health system, and protocols of our treatment centres”.

Don expressed fear about the cost of second-line ARV treatment, which he had heard was about 18,000 pesos per month – something he would be unable to afford.

ADRIAN, 28

Adrian is 28 years old, an effeminate gay man from a wealthy family working as an art designer and living with a Caucasian boyfriend. He had sexual contact with an uncle at age 9, considering that he “seduced” him (“Not molested. I knew you were going to ask that!”). He grew up completely open about his sexuality. After high school, he became more sexually active but used condoms only about 30 percent of the time – only if his (mostly insertive) partners required it: “With a condom, I feel I am not satisfied”.

Adrian became very ill in 2012, when he had TB of the intestines and lymph node problems, leading to significant medical bills for his parents. A doctor suggested he could have HIV and proposed he be tested for HIV, which he was, but Adrian’s mother decided they would not go back to get the result because they were “afraid”. Adrian said that he felt that he “was going to die quicker if I knew about my status”.

A year later, Adrian was back in the hospital with severe pneumonia and neuropathy of the arms and legs, with medical bills of nearly 1.3 million pesos. Then his mother decided she would like to know the result of the HIV test, which was, not surprisingly, positive. He was referred to RITM immediately and his CD4 count was found to be 12. In hindsight, Adrian felt sorry that he had not immediately taken the HIV test result during his first hospitalization, as it would have prevented the suffering of his later opportunistic infections as well as the huge medical bills.

When Adrian knew about his HIV status, he immediately disclosed it to all his friends via Facebook. He said he lost some friends as a result, and his sister was afraid that her child would be infected. He said, “my cousins were also afraid of me as if I was a leper.” This situation gradually improved. Adrian suffers from bipolar disorder and depression, which he self-manages by “talking”: “I can easily avoid depression as long as I keep talking and talking, like non-stop talking. I text people if I am really depressed and I post something on my Facebook about me hating life.” He felt he “deserved” HIV because he “lived in promiscuity”.

JORDAN, 41 PASAY



Jordan, a 41-year-old manager from a wealthy family in Pasay, started being sexually active at the age of 15 by having sex with 18- to 21-year-old workers in his father's business. He became very sexually active from the age of 21, when he frequented various cruising places several times a week – he claimed to have had more than 2,300 sex partners between the ages of 18 and 33 (with whom less than 50 involved anal sex). Condoms were “generally not used at that time”, Jordan said.

In August 2007, he was invited to undergo a series of free blood tests via a person he knew at a laboratory. He was unaware that one of them was an HIV test, which turned out to be positive. They called Jordan back in October after the confirmatory test had been done, also without his knowledge, to tell him that he was HIV positive.

They then asked him to come back to “formalize” it, as the test had been “under the table”; Jordan was asked to fill out a blood donor form and make it look like he was diagnosed while donating blood. In November 2007, he was called again and referred to the Bureau of Epidemiology, who in turn referred him to [public hospital A] where he was scheduled to undergo a CD4 test in December 2007.

The process from test to confirmatory test to baseline took altogether four months. But it got worse: when he showed up at [public hospital A] for the scheduled CD4 test and other baseline lab tests, they could not find Jordan's medical files. After waiting for hours, he decided to walk away. He added that he was not told clearly what he was supposed to do at [public hospital A], what the CD4 test and the other lab tests were for, and why they were important – so he decided to just leave.

Two years later, in 2009, he had shingles and then returned finally to do his baseline in January 2010, accompanied by an outreach worker from a major HIV NGO. Jordan said he had not ignored or denied his HIV status between 2007 and 2010; he had told his partner, friends and colleagues about it. The reason he did not do his baseline was related to the experience when the hospital staff lost his file and somehow blamed Jordan for it:

“I definitely left [public hospital A] because of poor service. That lesbo doctor was raising her voice on me. She accused me that I didn't use my real name, ergo they could not find my records, but I used my real name! Let's be clear, I didn't fear bad treatment, but I hated and I refused to deal with poor service providers!”

His CD4 count turned out to be 247 and he enrolled in ART immediately, but says he has been lucky: “Imagine the more than two years of gap of no baseline – I could have died. [...] I was lucky I guess, considering my lifestyle and stress at work, I still had a CD4 [count] of more than 240 in 2010.” Perhaps part of Jordan's “luck”, or healthy condition, was that he had a positive attitude, was open about his HIV status, and received support from his family, partner and friends around him.

PABLO, 31 QUEZON CITY



Paolo is a 31-year-old bank manager from Quezon City. He started having sex with the brother of his grandmother at age 13, and this contact continued for a while. While in college, he sometimes had sex in cinemas. When he was 26, he started having anal sex; his first time was with a colleague. After this, he started to frequent [a well-known gay bathhouse] and [a well-known gay bar] up to five times a week, and did so for many years. He said he tried to use condoms “as much as possible” but often he had sex without them, usually while drunk. He was open about his sexual exploits: his friends jokingly referred to him as ‘*higad*’, a local term meaning caterpillar – caterpillars cause itchiness – and the term refers to being horny or hot all the time.

Paolo was tested for HIV the first and only time in 2011, when a mobile testing van showed up in front of the bathhouse. He said he had never thought about testing for HIV before then, and had no idea where else he could have had the test. When he tested positive, the doctor told him he should have a confirmatory test, but Paolo did not follow this up:

“The doctor talked to me and I didn’t know what to do. I was even with a partner then who was still inside the bar. It was like I was thinking about it for a few days and I made myself believe it was all a way for the government to drive fear into the hearts of others by telling they were [HIV] positive, [...] that it was a strategy to discourage the youth from being promiscuous.”

In shock and denial, Paolo tried to ignore his positive test result: “I was concerned about the family and I had a partner at the time. I couldn’t accept the fact, and I thought HIV [equalled] death”. He briefly searched online for information on HIV when he suffered from a throat infection. He had a friend who died from a lung illness and there was an air of secrecy around the cause of death.

Paolo’s health deteriorated gradually between 2011 and 2015. In 2014, he had gall bladder problems. Then he had amoebiasis, and then “atypical pneumonia” which he had the doctor change on the certificate to “community-acquired pneumonia” so that it would be covered by his health insurance. The same doctor suggested Paolo should do an HIV test and asked about his sexual history, “and she was asking if my mom can join the conversation”.

He finally agreed to do an HIV confirmation test at a treatment hub in Pasig, and he was tested there. His blood “was declined from confirmatory because the record already showed that I had a confirmatory [test] on file with the [social hygiene clinic A] in Quezon City.” Because of this, he was unable to get the confirmatory test result: “I haven’t been able to get it nor is Pasig [treatment hub] able to get it for me without an authorization letter [signed by me]. I am not sure if it’s in [the social hygiene clinic] or in [public hospital A].”

The doctor advised Paolo not to try to find information about HIV on the Internet “because it can cause depression”. Instead, Paolo listened to the stories of people who he met at the HIV treatment hub, and drew inspiration from them.

Meanwhile, Paolo was ill: he had a fever and the doctor at his treatment hub therefore decided to give him ARVs without the confirmatory test result. Later, his CD4 results came back with a count of 4. A month later, while on ARVs, he was confined in hospital with multi-drug-resistant TB: “I met patients there who weren’t able to take ARVs while confined. Good thing I was able to get mine even while I was confined.” He was released and enrolled on TB drugs, which he had to pick up every day from the hospital; this

appeared to be too taxing and time consuming, so he stopped. As a result, in August he was confined again with TB.

Paolo is now finally on ARVs and recovering his health and strength. He said he had been so depressed that he wanted to end his life if he had had a way. "It is a good thing that friends and family were supporting." He added: "Eventually I learned to accept my status and now I am even proud of myself. I want to show people that I can actually survive the series of confinements and all that – you can become stronger and you can actually fight." It should be noted that the doctor at the treatment hub almost certainly saved Paolo's life by prescribing ART drugs to him before his confirmation test was completed.

IAN, 20 QUEZON CITY



Ian is a 20-year-old student from Quezon City. When he was 5 years old he was raped several times by a teenage cousin – Ian never told his family about it. He is open about his sexuality towards his family. Only when he went to college at age 18 did he become sexually active again, with his new boyfriend. They broke up for a three-month period, during which Ian had two sex partners with whom he had unprotected sex. Ian blames one of these experiences for his becoming infected with HIV. Ian was diagnosed with HIV in December 2013, as part of a family health check-up, which was required when his mother applied for an Australian visa:

“After the medical at [private clinic B], they called my mom and we were referred to [private hospital A] where I was processed as an HIV patient. [Private hospital A] then gave me a list of baseline laboratories and I did everything. I did my viral load and everything, except the CD4 [count]. [...] I stopped going there because I didn't know what to do. There were too many expenses like vaccinations and we were told it will cost us around 10,000 pesos. As it is, we already spent thousands for the viral load and all the laboratory exams then. So I just stopped going to [private hospital A].”

Ian had not received any counselling before or after his HIV test at [private clinic B], but was counselled at [private hospital A]: "They also informed me about the expenses, so there, I ran!" Ian said he found more information about HIV online, but that information on the process of accessing treatment is missing: "All I saw on the net was basic HIV information, really."

Ten months later, in October 2014, his boyfriend brought him to the [main MSM/TG NGO] clinic for counselling. He brought all his medical records along with him, and a week later he was accompanied to RITM where he did a new baseline and was enrolled on ARVs immediately: "It was a smooth sail from thereon".

JASON, 29 CALOOCAN

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Jason is a banker, aged 29 from Caloocan. His first sex was at age 12, with a neighbour who tried to penetrate him, which did not work – they met for sex several more times after that. From his teenage years, he started going to bathhouses regularly, using condoms inconsistently. He came from a family with a very strict and protective mother, and after she died, when Jason was 22, he gained more freedom and started being more sexually active.

He tested for HIV once, and eight months after this in February 2014, he tested again – positive. Jason said he had not wanted to be tested at the [main MSM/TG NGO] clinic, as he was involved with their activities as a volunteer, and was worried about people talking about his status behind his back. He received his confirmatory test result around April 2014, but continued to do his baseline tests only in June 2015, 14 months later:

“I was thinking, honestly, since I already had it, I said I might as well let it be until I die. Eventually I realized I was too young to die.”

He said that at the back of his mind, he always knew he could do something about HIV, and eventually he did. He had his baseline tests done in RITM but his treatment hub is now one of the social hygiene clinics, partly because it is open during the evenings. His CD4 count was 77; he had suffered from herpes zoster and in 2012, he had had pneumonia. He had not disclosed his HIV status to anybody except the person he was dating at the time, who was very supportive and comforting. He was worried about the side effects of ARVs, and claimed that the doctor at the social hygiene clinic tried to frighten him about them.

HARRY, 26

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Harry is a 26-year-old businessman from the island of Isabela who spent part of his childhood in Singapore, where his mother worked. He came back to Manila for college. His mother knew and was supportive of his sexuality and all his friends were from the LGBT community. After coming back from Singapore, he gained a lot of freedom because of his living situation and his discovery of gay dating apps:

“When I got to Manila, my dad had me live in a condo near the campus where I studied college. I was alone there. Then I found out about various social apps and then, boom! I exploded like a bomb. I would have sex with someone almost every night.”

He used condoms every time and was “well-oriented” in condom use while in Singapore. One day in 2012, when he was 23, something very unfortunate happened:

“I went to a bar in Ortigas where I met this guy. [...] Then when the night went deeper, and the alcohol went over my head, he asked me to go over [to] his place with him. [...] We got to his condo and when I got there, there were three other guys doing drugs in the living room area. I said hi and we went to his room. He went out and came back with a glass of juice. After drinking it, I was so groggy that I couldn't control my body. I was numb. He started kissing me and I knew I was drugged. He tied me to the bedposts and I

wanted to shout but I couldn't. I wanted to struggle but I couldn't. He fucked me bareback and he came inside, I think. It felt like it was hours. I didn't [get to leave] until after two days. The next two days, he and his friends alternately fucked me bareback. Most of the time, I was barely conscious. [...] I just woke up in the hospital. My mom was there, my dad. I woke up around four or five days after the night we met. I don't know how I got to the hospital."

Two or three weeks after his ordeal, Harry had a bad fever. Since he was aware about the symptoms of sero-conversion for HIV, he knew something was wrong and he became afraid. A month after what happened, he tested positive for HIV at RITM Satellite. He did not tell the counsellor about what happened with him, just said he had "an unprotected orgy of some sort". He was not happy about the counsellor's attitude:

"After the results, he was apathetic. He was rushing and he said that in most of the cases, those who turned positive are not able to absorb the information so he won't bother spending time with me anymore. Instead, he gave me a referral for RITM and he told me I should take my baseline or else I will get worse. [...] I felt it was a bad counselling session. I was not assessed on whether I would just jump off a building when I leave the clinic. [...] I did ask him what baseline was, all he told me was that it's a required step I needed to do. I asked also why I needed to do the baseline when he said confirmatory will be done still – all he said it's protocol."

Nevertheless, Harry educated himself via the Internet and soon found out the details about what "baseline" was and the next steps he should take. He did not want to come back to RITM for baseline tests, and also did not want to go to a public hospital; he did not know where to go. He even considered going to Thailand to do his baseline tests there. In February 2014, he enrolled in a private clinic in Pasig, where he had his baseline tests and started ARV. He did not talk about his rape experience until he met a counsellor online, early in 2015. He never pursued legal action against his rapists, even after he met them again in a mall:

"I saw them around together at the mall a couple of months after and I didn't feel anything for or against them. I gave them a faint smile and turned my back. One added me on Facebook, that's how I still get to see them. The same guy who I met at the bar added me on Facebook, he also apologized. He was hospitalized in November 2014, that's the time he sent me a Facebook message to apologize. He died from some respiratory complication. The other guy died around March this year from pneumonia, I think. But no, I don't hate them."

AL, 28 CALOOCAN



Al is a 28-year-old IT professional from Aklan in Visayas Region who grew up in Northern Luzon and moved to Manila for college with his mother and siblings. He is quite open about his sexuality.

He tested negative for HIV around 2005 or 2006 after having engaged in risky casual sex. Since then, Al says he only had protected sex, except for oral sex: "I was thinking, I would have gotten it from oral sex since I have braces and I always had mouth sores."

In early 2014, Al had tuberculosis; on the suggestion of his pulmonologist, Al did an HIV test and tested positive. He received pre-test counselling but no post-test counselling; he never came back for the result of the confirmatory test and moved to Bataan with his brother, where he soon got ill with pneumocystis pneumonia (PCP) and was confined in the hospital. A few weeks later, just when he had decided to go back to Manila to seek treatment for his suspected HIV infection, he discovered a spot in one of his eyes, which appeared to be cytomegalovirus retinitis (CMV). He went to [private hospital F] in Manila, but was shocked at the cost of treatment, and he went to Twitter to find support.

He decided to do his baseline tests at RITM and had a CD4 count of 48. First he was treated intravenously for 21 days for CMV; 21 days after the CD4 count result he initiated ARVs in May 2014. When his CMV treatment was nearly completed, RITM experienced a stock-out of drugs, after which his blurry eyesight returned and he had to start treatment all over again.

When he repeated his CD4 count in November, it had dropped to 18, despite the antiretroviral drugs he was taking; as a result, he was moved to second-line treatment. He was very ill at the time with continuous gastrointestinal problems and severe weight loss. In December, he was confined to hospital again for a week, tied to his bed "because they said I lost my mind, I went crazy!" However, he was discharged a few days later and has gradually recovered since then.

Observations

> Denial, shock and depression

An important reason why clients disappear from medical care after a reactive test for the initial HIV screening test was denial. Several research participants did not want to let the news of their HIV infection sink in and decided to actively ignore reality for a while – in one instance, the mother of a participant contributed to this process. Shock and depression also played a role in clients' decisions not to pursue further medical care.

It is important to strengthen follow-up systems once a client tests positive for the screening test. Immediately linking a newly diagnosed client to a case manager who can provide online information and counselling, for example via social media apps, is likely to dramatically reduce dropout at this level.

Recurring opportunistic infections (and often very high hospitalization expenses) eventually led to several participants taking confirmation and CD4 tests, who often would finally enrol on ART.

> Poor counselling

A few participants mentioned that they had not received, or had received only very basic counselling while being tested. It is important that counselling includes providing clients with clear ideas about the pathways to care, even before and after the screening test, as well as clear and easily accessible pathways to social and psychological support groups. Better explanations should be given about what the CD4 test is, what baseline tests are done, what they cost and why they are important; again, this information should be provided in the context of the overall pathways to care.

The attitude and friendliness of counsellors and their capacity to be empathetic, comforting and supportive was shown to be less than optimal: there is a need to recruit the right type of personality in the role of counsellor, and ensure that counsellors receive training to ensure they are client-oriented, friendly and not judgmental. Importantly, counsellors also need to be regularly supervised and counselled themselves – some of them may experience burnout if faced with the emotional toil of a continuously high number of clients that are newly infected with HIV.

> Fears about side effects of ARV drugs

Another important barrier to HIV services were fears and misconceptions about the side effects of ART, similar to those held by research participants who postponed their screening test discussed in chapter 2. This is another issue that counsellors should bring up in pre-test counselling sessions. Currently, it seems that this form of counselling is deferred to when the confirmation test result is received. However, since a significant number of clients drop out after a positive screening test result, pre-test and post-test counselling around the rapid screening test needs to be improved.

> Fear of being stigmatized

Several participants mentioned being worried about being stigmatized by family and friends if they pursued their confirmation and baseline tests and instead decided to ignore their initial positive test result. One of the participants was a volunteer worker at [main MSM/TG NGO] and he felt not confident enough to disclose his HIV status to his colleagues and co-workers there; he even decided not to use the [main MSM/TG NGO] facilities for his screening test out of fear that his status would be disclosed. This shows how organizations working on HIV prevention in the Philippines are not yet able to accommodate the needs of people living with HIV. HIV service organizations need to expand their scope and become broader and more integrated, providing services and being a safe space for all clients and workers, including those living with HIV.

> Institutional barriers and mishaps

Several participants were the victim of bureaucratic rules and regulations and too many referrals and cross-referrals.

The main bottleneck in the treatment cascade of the Philippines seems to be the current algorithms for testing and related post-test counselling practices. It is imperative to bring testing guidelines in the Philippines in line with current WHO and US CDC guidelines.

The use of the western blot started in the 1990s and is a practice that has not been updated, despite progress made in HIV testing technology. The Department of Health should change the testing algorithm and abolish the use of the western blot as confirmatory test in favor of modern rapid tests. Anyone who tests positive after the screening test should have this confirmed by a second rapid test. In line with the latest WHO guidance, the two conditions of being a man who has sex with men and having confirmed HIV are sufficient conditions for enrolment on ARV treatment; there should be no unnecessary wait for CD4 tests or viral load test results.

If the Government decides to stick with the western blot as a confirmatory test, it should not be necessary to wait for its result to enrol people into HIV treatment. In fact, the RITM appears to already be doing this – they should issue guidelines to other HCT service providers to do the same.

For some reason, many people seem to believe that changing from the western blot to rapid testing can only be done as part of an amendment to the AIDS Law that is currently being debated. In fact, the AIDS Law only stipulates that the confirmation of a new case has to be done by a government facility in order for new cases to be properly recorded. It does not prescribe which test should be used for this – this is up to the Department of Health to decide.

› **The high costs of transportation and baseline tests, and high opportunity costs**

It was unclear why some participants in the study reported very high costs of baseline tests in private hospitals. It is important to make information about this widely available, so that people can compare different hospitals and treatment hubs and decide where to go for their baseline test. Participants also expressed worries about the purported cost of second-line treatment; this information should also be made available online.

Finally, for some participants, the opportunity cost of going to RITM to get their confirmation test was an issue. Some participants worked and could not take time off, or could not afford the cost of transportation to get there. It is important to make it easier and quicker to get an HIV confirmation test, preferably by changing the national HIV testing algorithm, so that access to confirmation testing, baseline tests and CD4 tests becomes more equitable.

Chapter 4: Men who are HIV positive with barriers to enrolling in ART

Introduction

The national health insurance, PhilHealth, has an 'outpatient HIV and AIDS treatment package' (OHAT) that enables its members enrolled in treatment hubs to access general benefits such as free CD4 testing, free viral load testing, and tests in other labs that the hub sees fit to include. Public hubs generally offer more services than private hubs as their lab rates are cheaper.

People pay out of pocket if they refuse to be PhilHealth members or refuse to be associated with OHAT. People also pay out-of-pocket individual contributions under Philhealth on top of what their company contributes when they are afraid their companies would ask why they are regularly requesting PhilHealth documents. This could be from fear of exposure as someone living with HIV, if benefits are not yet applicable in their hub, or if they are not yet officially enrolled yet and therefore do not qualify for treatment and care. This could be the case, for example, for newly diagnosed patients in hospitals for PCP in need of CD4 tests for whom the confirmatory test has yet to be released after three to four weeks, which is a requirement of OHAT.* Even with the release of the confirmatory test result, a newly diagnosed person cannot claim the cost of the CD4 test from OHAT since he has not yet enrolled on ART, which is a requirement. RITM is unique in allowing newly diagnosed people to have free CD4 tests.

There is no centralized system tracking the number of people diagnosed as HIV positive under regular monitoring of health services, let alone those who are men who have sex with men. What is known is that at [social hygiene clinic A] and some other clinics, around half of the people screened positive for HIV do not come back for their confirmation test result two weeks later, and are presumed to not want to enrol in ART. Key informants of REDx and other organizations mentioned that people sometimes turn up years later, when they are symptomatic and have a very low CD4 count. In other clinics, such as [private clinic E], the retention rate is better (86% to 99%), although some further 'leakage' occurs later in the treatment cascade.

The total number of men who have sex with men under monitoring is probably available, but would take a considerable amount of time to collect from each of the 7 treatment hubs (3 government hubs, 2 satellite hubs and 2 private hubs). It is known that the treatment hubs in Manila have 6,500 to 6,600 patients under their care; considering the characteristics of the HIV epidemic in the Philippines, it is likely that a majority of them are men who have sex with men. Not much is known about transgender people and their access to care and support services.

In this chapter, the situation is discussed of men who have sex with men who have been diagnosed with HIV (with both confirmation test and CD4 testing completed) but who have not accessed further care or enrolled in ART despite, though having a low enough CD4 count to do so. The average age of the 12 men in this category was slightly younger than 29 years old; 3 of them (25%) were born in provinces outside greater Manila, the rest were from greater Manila.

* PHILHEALTH CIRCULAR No. 19, s-2010.

Case Studies

ALLAN, 33 QUEZON CITY

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Allan is 33 years old, from Quezon City. He studied human resource management but is currently unemployed. He was “molested” by a teenage cousin for a period of time when he was seven years of age; Allan stopped this when the cousin started trying to anally penetrate him. After this, he became sexually active again when he was around 20 or 21 years-old with a colleague who worked in the same hotel. After working briefly in Japan, Allan came back and entered a “reckless period” in which he slept around with “everyone”. He was a bottom and never had condoms used during sex. He blamed this period of sexual activity on his inability to find work.

In 2007, he went for an HIV test at Remedios Foundation because a negative test result was needed to look for work abroad. There he found out he was HIV positive. He received his confirmation test result as well. However, nobody told him what to do next: “No instruction for me to go anywhere.” He said that at the time, he did not know what a CD4 test was and that he was unaware that treatment for HIV existed.

He told his sister about his HIV status, and his sister told his mother, who cried a lot. Both thought Allan would die soon. A counsellor at RITM talked to his mother and sister and educated them about HIV and the prognosis.

It was only in 2009 that a person from Remedios brought him to RITM to get his CD4 count, which was around 350. He was then given the choice to go on ARVs or not. Allan decided against it as he was worried he would be unable to adhere to the medicines and he was also worried about possible adverse reactions to the treatment.

In 2010, he was hospitalized with pneumonia for a month; it was during this confinement that he started on ARVs. In 2011, he was diagnosed with syphilis, which he had treated at a private hospital, and in 2013–2014, he spent around 75,000 pesos in a private clinic to treat anal warts. Allan was OK with the services at RITM but found the system was “bad” and time-consuming.

SAM, 36 CALOOCAN

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Sam is a 36-year-old nurse from Caloocan who was born in Albay and moved to Manila when he was 27, together with his siblings – his parents had both died. He started his sexual life at age 20, and his first anal sex was around the age of 22 or 23. His first experience was without condoms, but later he used condoms regularly.

In 2011, he tested for HIV during the gay pride march. He described the experience as “not comfortable because it was done around a huge crowd of people. The confidentiality was not good enough.” He tested positive. Post-test counselling was limited: “They merely suggested that we needed a confirmation test which should be done at RITM.” He went for confirmation, CD4 and baseline tests at RITM in mid-2011, where his CD4 count came out at around 100. He described himself as a “hypochondriac”. None of his family members knows about his HIV status except one cousin. He was supposed to return to RITM to start ART the week after his confirmation and baseline, but Sam decided not to:

“I tried to do things if I can still improve my CD4 [count]. A cousin told me also that when I start with my medications, I could no longer stop, as it is a lifelong commitment.”

He also said he was “considering the idea that the result [of the test] was a false positive”, because he could not recall any condomless sex during his previous sexual activities. He was unaware that treatment was available for free. Eventually, his cousin informed him of this fact. He also mentioned that the distance to RITM was a factor that explained the six-month delay between his confirmation test and baseline test results and the time he enrolled on ARV.

At the beginning of 2012, he went back to RITM to retest his CD4 count and it was 90. He then enrolled on ART, and when his CD4 count did not rise and when he had problems with side effects, he switched regimens. Nevertheless, his CD4 count is currently still only 118. Sam reported adherence problems, mostly because he experienced side effects during treatment. He was not aware of his current viral load. Sam has had frequent private consultations with a doctor at the National Kidney Transplant Institute.

KIAN, 19

Kian, at 19, is one of the youngest participants in the study. He was from a poor family with many family problems; his father drove a tricycle and his mother did not work. Eventually, both his parents found new partners with whom they had children. Kian wanted to be a woman when he was aged 12 to 14, and cross-dressed frequently. At age 12, a friend of his father anally penetrated him; later he had sex with a teacher at his school, and with “other strangers”. He said he had no knowledge or idea about HIV and would never use condoms. At age 17, Kian decided to become an escort, selling sex via Planet Romeo to support his family.

He found out he was HIV positive at [social hygiene clinic B] in August 2013 after his aunt and a peer educator had both suggested he should get a test, because he had jaundice/ Hepatitis A. His family found out soon after, and they did not respond well – despite the fact that Kian might have become infected while trying to help the family make money:

“After diagnosis, I was paranoid and I didn’t know what to do or where to go. All I know was that I drank and I was so drunk and my cousin said, ‘I know you, you have a problem... Do you have HIV?’ That’s when I cried and I told my cousin the truth and showed my confirmatory [test result]. My cousin was the one who told my aunt. So everyone knows except my father.”

When asked how they reacted, his response was:

“They were aloof. My things are separated from theirs – utensils and all. I wanted to educate them but I don’t know how to. For two years, I have felt the stigma in the family. I know that the discrimination is there. If ever I tell them I am not feeling well, they would tell me, ‘Isn’t that what you wanted, you brought that to yourself, you wanted that...”

He partly blames his parents for his predicament:

“I told my parents that if our family relationship was better, my life would have been better, I would not have been like this. I feel like crying. Sorry. We were okay before when my father used to work in a good company but he ended up with a mistress and my mom eventually found her own man. [Crying]. This is why I am saying that this greatly affected me. I told them that if they were better parents, I would have been a better person.”

Kian did his baseline test and his CD4 count was 430 in September 2013. The [social hygiene clinic B] counsellors were supportive and kind to him, but he decided not to enrol in ART: “I was afraid that people would find out. I was embarrassed since I was still very young.” He decided to stay off treatment, and his cousin helped him find information online about healthy nutrition options for people living with HIV. He said he was depressed and cried a lot. He also found support from a mobile app called ‘Simsimi’:

“I would talk to Simsimi and even if he answers back with all sorts of stupid things, I would try to divert my attention.”

Besides his parents, Kian said he blamed himself for having HIV:

“[T]his is my fault, I asked God, why me? [Crying]. I went through a lot with the family, and it already felt like the whole world, the heavens and hell all fell down on me [...]. I couldn’t accept it at the time. Actually, until now, I can’t accept it but I have to force myself to accept it. [Crying]. After the diagnosis when I worked and volunteered at the social hygiene [clinic], I still can’t take it and I even had myself retested. I wanted to make sure, as I was in denial. They still had post-test counselling because at the time, I was still depressed. Even if I were saying I already moved on, the trace of my past is always haunting me. [Crying]. They are saying, there’s life after HIV – but for me, it felt like I lost everything. I mean as it was, I didn’t have a family and I was just there at my aunt’s, no regular job, it felt like all hardships I had to go through.”

Two years later, in 2015, he went back for another CD4 test after being encouraged to do so by friends he had met via social media: “That’s when I came alive again and decided to take the meds, finally.” His CD4 count stood at 239. Since then, he has enrolled in ARV treatment. He has never been referred to any support group, but he has signed up as a peer educator for [social hygiene clinic B].

JAY, 31 CALOOCAN

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Jay is a 31-year-old IT worker from Caloocan. He found out he was HIV positive when in June 2013, he tried donating blood for a friend's mother who was in need of his blood type. His aunt and some close friends are the only ones who know about his HIV status: "It actually made me feel a lot better [disclosing]." He did not go to RITM to get his confirmation test done until October 2013:

"I was stuck with work and since I was informed that my confirmatory [test] would come out after two to three weeks, I sort of forgot about it until I received the confirmatory in July and so I talked to my friend to accompany me to go to RITM. Since he said his schedule to go there would be the first week of October, I decided to push back until then [...]."

In October, his blood was drawn for the CD4 test, but he did not wait around to get the result. He only went back to RITM to pick it up in April 2014, six months later:

"For my CD4 [count] – after the extraction, and all the baseline tests, there were no further instructions given. This was part of the reason why I left early and did not get my initial CD4 [count] until April 2014 – of course again coupled with the seemingly slow process in RITM."

Jay mentioned the support he had found online from [a PLHIV support group for men who have sex with men], which he described as his "extended family", as an important reason he did go back to RITM in April 2014 to get the result of his CD4 test:

"After the first CD4 [count], I began reading again my notes about HIV and also got involved in social media and found a community which I have considered an extended family. This became a major turnaround point for me to go back to the hub."

Then, a close friend, who also had HIV and whom Jay had accompanied a few times to RITM, advised him that he should take a new CD4 test since so much time had passed. In October, Jay's CD4 count was 344 and in April it had dropped to 300. He was then recommended to start ARVs immediately, which he did. In January 2015, he transferred from RITM to a private doctor, after a serious breach of his confidentiality by one of the RITM doctors:

"In 2014, I was actually thinking of already transferring since my aunt did say 'get a private doctor', but what prompted me to transfer finally was when a doctor [who works at the RITM hub] disclosed my status to his patient's partner. The patient's partner was a common friend of this doctor and mine, since I came from the medical field as well. [So] I felt that my privacy in that hub was compromised."

The interviewer asked Jay whether he complained, what he did, and what happened:

“I actually asked around what I can do about it, but opted not to do anything about it since I was also thinking of my privacy still if I made a legal case out of it.”

Interestingly, Jay said he considered the fact that RITM was far away as an advantage:

“One reason that made me consider RITM before was that it was far from where I lived. During that time, my aunt didn’t know what I was going through, so I needed my treatment done far from where I lived, so she would not find out.”

RAI, 27

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Rai is a 27-year-old architect from a family that is intact, close and happy (which is worth mentioning as this seems to be a rarity in the sample of men for this study). Rai has not disclosed his sexuality to his parents, colleagues and most friends; he does have some gay friends online. His first sex was oral, at age 16; at 17, he had his first anal sex with a 40-year-old man he met in a bookstore. He had several sexual contacts since, and only started using condoms from age 25, but inconsistently.

He tested for the first and only time at RITM in February 2014 after having been encouraged by a potential sexual partner since December 2013, who apparently wanted to have bareback sex with him. Another reason he wanted to get tested is that a friend of his died of AIDS during that time. He never got tested before because he thought being mainly insertive during anal intercourse, as well as not being very sexually active made him low risk. After testing positive, his CD4 count was done a week later and was 480. He decided to wait to enrol on ART: “RITM told me that [my CD4 count] might go up.” He said he weighed the pros and cons of starting ARV, among which was the news he had heard that a better treatment option, a three-in-one pill, was on the way. He decided he was not ready yet.

He tested his CD4 count again six months later in August 2014, and his CD4 count had indeed gone up to more than 780; another 6 months later, in February 2015, his CD4 count was back around over 400.

In August 2015, he missed his scheduled CD4 test: “I was too busy. I wanted to try [private clinic E]. I was procrastinating, I don’t know.” He also got a new job, which kept him distracted, and there was a bureaucratic hurdle if he wanted to transfer to [private clinic E]: “I never got around to finding the schedule to go to RITM to transfer my records.” As a result, Rai was still not on ARVs at the time of the interview. He would welcome a way to gain access to ARVs in a more convenient manner. A close female friend from high school, who works abroad, is the only one he has told about his HIV status, besides the counsellors and volunteers he met online.

RAD, 25 SAN FERNANDO, PAMPANGA

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Rad is a 25-year-old student from San Fernando, Pampanga from a broken family, who started his education in Manila when he was 16 or 17 while living at a boarding house. He is open about both his sexuality and his HIV status to his parents and siblings. He became sexually active around that age and his first anal sex was in college with a classmate. No condoms were used, and Rad was receptive. Since then he became more sexually active and uses condoms around 40 percent of the time.

In November 2012, he had Dengue fever. His doctor wondered why his fever did not subside, and suggested he be tested for HIV:

“A doctor approached me and I was counselled. I can’t remember much because I was too weak. All I remember was that the doctor insisted that my parents were there with me during counselling.”

After being discharged from the hospital, he got his confirmation test result at the end of November 2012. His CD4 count came in December 2012 and was more than 500. He had heard that he should take a CD4 test every six months, but “Dr L”, his doctor, “didn’t tell me to take the CD4 test... She gave me prophylaxis, no ARV because she was saying something like I was not qualified for ARV yet at the time”. He was given “liver supplements and Vitamin C, also omeprazole”, and sent away without further instructions.

He went online and discovered that “the practice of Dr L on CD4 monitoring was inconsistent to what I saw on the net.” Dr. L also seemed unaware about different treatment options for Rad, as he was living in Pangasinan at the time. While he found information online on what he could do to keep himself healthy, Rad’s mother suggested that he should also look for support groups for people living with HIV in the summer of 2014.

He met [a support group for HIV positive men who have sex with men] volunteers, including the interviewer, who suggested he take a CD4 test urgently. He did, and it came out at over 200. He asked to be transferred to [private clinic E] to be treated there; his mother and the interviewer (in his capacity as counsellor) were present with his intake at [private clinic E]: “My mother was in the consultation room with me, but she was asked to go out as the questions became more personal.” He enrolled on ARV treatment in October 2014.

Rad has now accepted his status as a person living with HIV but initially viewed his infection in moral terms:

“Growing up in a religious environment, I thought it was one form of punishment for my being gay... For the bad things I did. And for not listening to the guidance of my mom. I recall they were telling me ‘it is just a phase’ being gay when I came out to them. So I was thinking, maybe if I listened to them, I would not have been infected.”

Rad’s father, despite having paid for his lab tests and other items, seems to not accept his HIV status, threatening to withdraw his financial support: “He was saying that even if I graduated from college, I won’t be able to help the family and I will forever be a liability.” This made Rad feel upset and depressed.

AMEER, 24

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Ameer is 24 years old and unemployed. His dad disappeared when Ameer was 12 and his mom was working abroad. He is an only child and stayed with his aunt and his ex, who was recently invited to move in by his aunt. He is open about his sexuality with everybody, but only his aunt and his ex know his HIV status. His sexual life started at age 20 with someone he met via social media. He had a series of encounters after that, mostly unprotected: "I know I'm not a fan of condoms". His ex "looks sick and he lost a lot of weight. He hasn't gotten tested. He is afraid, he said. I have always encouraged him to take the test, but to no avail."

Ameer found out he had HIV in February 2015 when he was forced to undergo an HIV test while trying to apply for an overseas job via an employment agency. No counselling was provided: "They were apathetic. They just gave me my referral sheet [to] [public hospital A] and off I go. No counselling. No nothing." He went there three weeks later for his baseline test. His CD4 count was 401 but he opted out of starting treatment: "I just didn't feel like I needed it. I am healthy and in fact, over the past four months, I gained around 5 kilos."

Another reason to postpone starting his treatment was the requirement of [public hospital A] that he bring his aunt or his mother as a 'treatment buddy' to attend his first ARV counselling session: "I didn't want to because, well, my aunt is very busy and my mom's abroad." He also found the experience of getting his baseline test unpleasant:

"[Public hospital A] can be very chaotic, so many patients. And that doctor, I don't know if she's a lesbian or what, but she shouts a lot at people. She frightens me."

Asked if scheduling issues were a factor in his decision not to access treatment, he said:

"No. Or yes. Schedule plus the fact that I find it inconvenient to go out of my way to get treated. I understand the importance of treatment but I never found the effort, will and time to just pack myself up and go there."

He said he has not suffered from depression, and that he considers himself to be a strong person. The reason he has so far not accessed treatment is that he believes he does not need treatment at this point in time.

HARVEY, 25 SURIGAO DEL SUR

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Harvey is a 25-year-old teacher and student of law from Surigao del Sur who arrived to work in Manila in 2010. His parents separated when he was 15; he has "two legitimate siblings and two illegitimate siblings". Harvey is the eldest. Currently, he rents an apartment together with seven friends. He said he had a bad relationship with his parents and that he "rebelled" against them "by exposing my sexuality". He started being sexually active from the age of 15 and in between 15 and 20 years of age, he had a series of partners. Harvey was always the bottom but never used condoms. He said condom use was "totally not discussed" at that time, especially in the province. Since November 2014, he has been in a steady relationship in which he always uses condoms.

He tested positive for HIV at [social hygiene clinic A] in December 2011. He was unhappy about the post-test counselling he received, which he said lasted only two minutes and he referred to as "shortcut counselling". He said the counsellor said she would SMS the

confirmation test result, but did not tell him what to do next in terms of baseline tests and CD4 count. He went for another test in the countryside for a second opinion, where he had a bad experience of discrimination:

“Inside the hospital, I was with my aunt. [...] My auntie discreetly said we were going to have an HIV test. The nurse shouted to the medical technician at the lobby that we’re getting an HIV test and everyone there was looking at us. So we were so embarrassed and then they referred me to go to another hospital after the ELISA positive test, to go to a counsellor-doctor for counselling. In fact, for family counselling, I think we paid 2,000 pesos. [After paying this,] all the doctor said was that they, being in the province, can’t do anything about this and that I needed to go back to [public hospital A] in Manila to seek treatment. I was depressed since I planned then to settle down in the province but since there was no treatment in the province then, I had to go back to Manila.”

After returning to Manila, he searched for information online and found out about the need to do CD4 and other tests, and about RITM. As a result, he had his baseline tests at RITM in January 2012, where his CD4 count came out at 320. He had a “traumatic experience” at RITM, which made him decide against enrolling on ARVs at the time. The doctor advised him to take cotrimoxazole for six months, but after a few days he started to develop an allergy to it and went back to RITM:

“They just took my temperature since they said no doctor was on duty at that time, but it was already 10 or 11am that time. They told me go to the dermatology department and I walked up the stairs. Imagine from one end of RITM to the other end? And since the fever was so high, I got dizzy and I fell down outside the derma clinic. [Paused, cried] It wasn’t normal consciousness and [it was a] good thing there were plastic chairs outside the derma clinic; I laid down there. I thought someone would come to my rescue since I was very weak and my fever was bad but no one came. [...] When I finally got into the derma[-tology] clinic, I was told to go back to [where I started]. So I walked again back to the [AIDS Research Group]. You know the feeling of not getting any help, having taken the effort of traveling from Quezon City and when I got there, no one was helping me. No one even told me to buy this or that meds. So from that traumatic experience I felt anger against the treatment hub.”

He finally was given a shot of antihistamine at the emergency ward and slept there for 30 minutes, and was then asked to leave around 4pm: “I was like, that’s it? I felt like I lost trust in RITM”. He did not complain about this poor treatment, and did come back to RITM

every six months for his CD4 count until it had dropped to 24 in January 2015. Harvey said he never transferred to another point of care because he did not know there were other places he could go to.

After being confined with symptoms of pneumonia at RITM, he finally started on ARVs, four years after being diagnosed. He said one of the reasons for the delay was his fear of side effects, which was exacerbated by news he saw on TV and on social media. Still, he also credited social media for meeting people who convinced him to start on ARVs. He said he was often depressed, and would drink and/or talk to friends when this was the case. He would welcome new distribution mechanisms for ARV that would prevent him from having to go to RITM to pick up his drugs; he thinks he would have started ARV earlier if he had had easier access.

Harvey's family was informed about his HIV status. He also told his roommates back in 2011 and very recently told his professors and fellow students in law school. He did experience some discrimination from his roommates when he disclosed his status, and also experienced unwanted disclosure of his HIV status at his previous job. His family was supportive and he even mentioned he received positive discrimination: "They felt I need more attention this time. My parents, grandparents and aunties, they all felt that I will live shorter so they gave [me] so much attention this time."

His HIV infection and his negative experiences in the workplace and while accessing care have motivated Harvey to go to law school, where he plans on becoming a human rights lawyer.

NEO, 24

Neo is a 24-year-old make-up artist with a background in nursing. He grew up in a middle-class family. From the age of 5 until he was 10, a neighbour who was in his mid-twenties sexually abused him, which involved oral sex. Neo is open about his homosexuality towards his family, but his HIV status is a secret. From age 18, he became sexually active and would normally use condoms, with some exceptions.

He had his first HIV test in 2011, when he tested negative. A year later, in 2012, he tested positive at a testing booth that was set up near a gay bathhouse. Neo did not go to RITM for his confirmation test. Since he was studying as a nurse, he said he believed that he could take care of his health by himself. He had an attitude that he had "nothing to lose" and had unprotected sex several times during this period. From April to December 2013, he used [recreational] drugs regularly and it was after this period that he started showing symptoms of HIV infection. Since his confirmation test result was lost, he retested in September 2014 and was diagnosed with both HIV-1 and HIV-2.

In October 2014, he did his baseline test; his CD4 count was over 400. He was prescribed and took home ARVs in December 2014. However, he started taking his ARVs only four months later, in February 2015. Asked why he pushed back on the starting date of his ARV, he said:

"I was thinking [that] I had enough knowledge since I am a nurse. [...] I was thinking that the ARVs were [poisonous to the liver] and the ARVs are going to be [taken for a] lifetime. So I was thinking maybe I can push back a little more and see my next CD4 [count]. Maybe it might go up so I don't have to take my ARVs [yet]. Remember [...] in that birthday party last year?"

There were these partners who weren't on ARVs yet for so many years."

Neo seemed to equate using ARVs with being under treatment and, hence, being sick; not being on ARVs he seemed to interpret as a sign of good health and of strength. However, in January or February he was diagnosed with syphilis and had to go on treatment for this; it was then that he decided to also take ARVs. He was worried about side effects and noted that his skin felt warmer. His mental health was good and he never experienced depression. Similar to Jay above, Neo said he preferred to go to RITM or another place far away out of fear that he may meet people he knows.

MARCO, 37



Marco is a 37-year-old business process outsourcing (BPO) employee who grew up with his mom, a step-dad and three half-sisters. He was close to two half-sisters whom he had told about his HIV status, but his mother doesn't know; all of them are currently abroad, so he receives his half-sisters' support via online channels.

Marco was shocked when he tested positive for HIV in 2013. He was a consistent condom user and always propagated the use of condoms among his friends. The reason he tested for HIV was because he had gonorrhoea at the time, for which he blamed his then-partner with whom he later broke up. First he tested positive at [private hospital F], then had a false negative test result at RITM; his confirmatory test came back positive as well. In November 2013 he had his baseline; he did not enrol on ARVs as he was worried about side effects of the treatment:

"I have heard a lot about adverse reactions and I was afraid I might not be able to handle it. Also, considering my lifestyle and the nature of my work, I could not handle the side effects."

He also seemed to try to ignore his HIV status for a while out of fear of depression, but he did not believe that he was in denial about his status:

"No, I don't think I'm in denial. I just don't dwell on it. I'm emotional and if I dwell on it, I might go into depression. It's something I don't want to go to – depression. I know myself. Even [if] I know I am strong, I get depressed even when I see sick people. I'm not in denial, it's a topic I would not want to talk about always."

Even so, Marco said he went through a period of depression and "wanting to die", but eventually his faith carried him through:

"I prayed, I told myself that I'm not going to die, I have big dreams in life. I'm a survivor. For me, I've accomplished so much, having nothing before. This is just a cross given to me, but I have to continue."

When he got sick with shingles in November 2014, he realized that this was an effect of his weakened immune system, and then decided to start treatment: "[G]od was very good to me. I didn't experience any side effects when I finally took the ARVs." Marco, like

Neo, may have had the same idea about equating taking medicines with sickness and weakness:

“I’ve read stories of people who stopped taking ARVs, who took ARVs and what they are doing, they’re living healthy, they’re boosting their immune system through different supplements – although I don’t practise it.”

NICO, 25 QUEZON CITY



Nico is a 25-year-old IT professional from Quezon City from a broken family, who was raised by his aunt. He is completely open about his sexuality. He has lived together with his partner for the past seven years, since he was 18. He was infected with HIV due to infidelity, which he partly blamed on “the growing technology where there is Planet Romeo (a gay dating app)”. He used condoms inconsistently, basing it on the physical attributes of his partners and on whether the partner was known to him before. His current boyfriend was his fourth sex partner.

Nico tested negative for HIV in 2013 during a “mass testing”. Nico was not impressed with the confidentiality of this event: “It was obvious that a positive result would be called [in for counselling] last. I guess that somehow affected the confidentiality.” In November 2014, he tested again after having had sex outside his relationship, and tested positive. His counsellor at [major MSM/TG NGO] accompanied Nico to RITM for his confirmation and baseline tests, and his CD4 count was 309:

“I was told [someone with a CD4 [count] of 350 [and] below] needs to start ARV. But I wasn’t ready since Christmas was coming and I was going to be with my siblings. I didn’t want to go through the holidays possibly with side effects hitting me and my siblings might notice. I was afraid, admittedly, of the adverse reaction.”

He became very distressed and even considered suicide, but decided against it: “If I commit suicide, I won’t go to heaven”. Nico finally made it to RITM, but asked to be transferred to [private clinic E] due to fears about his confidentiality, as he found that there were too many patients in RITM.

He started ARVs in February 2014, two months later. Despite this, he still seemed unable to fully accept his HIV status. He seemed to find it unfair that he had HIV due to one misstep whereas other people who were more promiscuous than him had tested negative:

“Because I got it from a one-time activity [...] I thought it’s hard to accept. I told myself that if I were to have HIV, I should have done it with more men. I mean compared to others who fooled around a lot, mine was one case of infidelity and I was infected. I wasn’t that promiscuous like the others.”

The interviewer asked Nico if he believed he deserved it:

“[No], I don’t.”

And then Nico was asked, “Let me reverse my question, do you think other people deserve it?” The response:

“It’s hard without seemingly being judgmental. I don’t want to say they deserve it, but when you become promiscuous, the risks go up. Mine was a one-time thing...”

Fortunately for Nico, his long-term partner tested negative for HIV and seems accepting of the situation.

ALVIN, 25 MANILA

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Alvin is an unemployed 25-year old bisexual man from Manila from a broken family. He converted to Islam at the age of 12, following his father. He was “soft” as a boy. Perhaps because of this, at age 18, he was forced into an arranged marriage with a girl, which lasted for 6 months and which he did not want to talk about. He moved out of his family home at the age of 19; his uncle paid for his studies. Alvin dropped out in the second year and started working. He illegally worked in Malaysia for two years and came back home in 2013. Alvin usually did not use condoms:

“I got used to trusting people. I was aware of [contracting] HIV through sex but I didn’t really have that much clarity on the transmission. Mostly, if I don’t know the people, maybe people I met for the first time, I would use condoms. But when it’s not the first time with the same person, I don’t use condoms anymore.”

When Alvin was testing for HIV in the summer of 2015, he was subjected to an abusive situation. He texted a number for testing that a friend on Planet Romeo had given him. When he got there, there was only the counsellor present, and nobody else, even in the reception area. There was a small toilet where the counsellor asked Alvin to enter:

“He asked me to bring out my penis, he told me to make it hard. He knelt down and examined my part. He held it, examined my balls and also, he swabbed the tip of my dick’s head with a cotton swab. [...] I pulled my pants back up and waited inside the counselling room. The blood extraction followed, and the result came and I went home. The same counsellor also asked me to give him money if I wanted a faster processing of the CD4 [test].”

The counsellor did not discuss the test result other than telling Alvin to wait for the confirmatory test and not to lose the counsellor’s number as he would text the confirmatory test result. Both tests were positive. He found it strange because just weeks before testing positive he had tested negative for HIV. He had gone to get tested due to a recurring fever which lasted more than 10 days. He tested again since his fever would not subside. In July 2015, he met someone on Planet Romeo who referred him to a counsellor from an HIV support group; as a result, in July 2015 a friend accompanied him to [social hygiene clinic A] where he had his baseline test, with his CD4 count being a bit over 200.

Alvin went into a period of depression after testing positive and decided against enrolling in ARV treatment, despite his low CD4 count. He also harboured suicidal thoughts for a while:

“I wasn’t in my right mind and I was confused. I felt hopeless, fear, embarrassment, and I said I can live without meds, so I didn’t come back.”

At first, he was planning to enrol on ART; he went to [social hygiene clinic A] to submit his confirmation test result in September 2015:

“I went back again the next day and the doctor gave me a list of vaccines that he said I had to do first before starting my ARV. I was also ordered to do my Hepatitis tests. [...] But I didn’t come back anymore since I didn’t have money to do the vaccines yet.”

A counsellor at [a major MSM/TG NGO] told him he could go to RITM if he found the process to be too slow at [social hygiene clinic A] but he was still not sure what to do next: “I am really confused”. He often looks online for more information, but has still not currently enrolled on ARV treatment; Alvin seemed to not be fully confident that ARVs would be effective in treating HIV:

“For me, ARV is a way to extend life, but I am not certain whether it is effective. I still read articles about people who were on ARV but still they suffered from illnesses. Like one time, someone [had a] CD4 [count] of more than 200, on ARV, but he still died from pneumonia. So I thought ARVs are not assurance that I won’t die. That’s just my opinion. [...] I guess it’s effective. But I don’t think I am totally confident about ARVs. I know [they] can help me, but I know it won’t cure me.”

Observations

› Poor counselling as a reason for not pursuing treatment

Some of the men did not receive clear instructions after their diagnosis. The case of 'Dr L', who failed to administer further CD4 tests and did not ask her client to return for further check-ups, is a case in point; as was the example of the client who went to RITM but was ignored after showing up and decided to leave.

Two of the participants in this chapter (and one additional participant in the next chapter) complained about being treated in an unfriendly or unprofessional manner by a particular doctor at [public hospital A]. Others found the staff or counsellors indifferent or apathetic. Often, counsellors spent not enough time with their clients and did not provide information that was tailored to the client's specific situation.

› System-related obstacles to ART enrolment

A few system-related obstacles or events caused people to drop out of or delay accessing ARV treatment, similar to the situations reported in the previous chapter. Such instances of system failure related mainly to the transfer of client records between HIV service providers. It would be commendable if, in line with the situation in other countries, the Philippines would move to a system where medical files are kept online and can be accessed across facilities.

Some participants were asked to undergo a number of expensive tests and have very costly vaccinations, not related to HIV, which led them to leave the facility and delay the onset of treatment. This shows the importance of clients having access to information, be it via the Internet or via a counsellor, about different options for doing baseline tests or enrolling on ART. Anybody found positive after the screening test should be confirmed by a second rapid test. In line with the latest WHO guidance, being a man who has sex with men and having confirmed HIV are sufficient conditions for enrolment on ARV treatment; there should be no unnecessary wait for CD4 testing or viral load test results.

Many participants disliked RITM for being too far away and for being too busy, leading to fears about confidentiality. Long waiting times also played a role in people dropping out of the system. On the other hand, two participants who were less open about their HIV status preferred to access their treatment at a more distant location for fear of running into neighbours or family members at nearby facilities.

At [public hospital A], the requirement to bring a family member as a 'treatment buddy' was mentioned by one participant as a reason for him to postpone starting his treatment. Having a treatment buddy could be beneficial in terms of long-term adherence, and was therefore included as an option in WHO training modules on counselling. However, its applicability should be tailored to fit to each individual client; obviously, some may not want to involve family members in their HIV treatment, or family members are distant, for example in the provinces. Having a treatment buddy should be recommended but not a requirement without which no treatment is made available.

› Misconceptions about ARVs and fears about side effects

Other explanations for delaying the onset of treatment were related to misconceptions and attitudes about ARV medicines. The most prevalent misconception was that ARVs would cause severe and debilitating side effects, which would affect the ability to study or work, or to adhere to the treatment itself. Related to this was the fear of toxicity of the liver. The fact that ARVs have to be taken for a lifetime also scared some people off, and led them to try to stay off ARVs for as long as possible, in order to reduce the supposed negative effects on the body.

Providing clear and correct information about ARVs online, including about their benefits in terms of keeping the immune system strong and the body healthy, and most importantly, about the rare frequency of side effects, might help reduce the impact these fears have on postponing treatment.

One participant had read about new ARV medicines in development, and decided to wait until these better medicines would become available, rather than starting on the current regimen of treatment. One participant expressed distrust about the effectiveness and benefits of ARVs.

Two participants associated taking medicines as a sign of sickness or weakness and not taking ARVs while having HIV was seen as a sign of strength and health.

Other misconceptions leading to delays in accessing treatment were related to the biology of HIV infection; some participants were convinced they would not need to go on treatment and that they could, by living a healthy or healthier life, increase their CD4 count to a level at which treatment with ARVs would no longer be necessary.

Instances of social stigma were limited, mostly because participants kept their HIV status to themselves. One participant experienced severe stigma within his own family, and his HIV status was disclosed against his will in a work setting and in a rural health care setting.

Chapter 5: Men who enrolled in ART but have barriers to adherence

Introduction

This chapter presents the case studies of men who have sex with men who started antiretroviral treatment but had difficulties in adhering or dropped out of ART altogether.

Currently, there are three government treatment hubs in greater Manila: [public hospital A] with approximately 2,200 cases, [public hospital B] with approximately 900 HIV cases under treatment, and the Research Institute for Tropical Medicine (RITM) with 2,500 cases.

Because the number of people on ART is rising so quickly, especially the number of men who have sex with men, two ‘satellite treatment hubs’ were recently established for men who have sex with men: one in [social hygiene clinic A], providing treatment and monitoring for 48 men, and one in [social hygiene clinic B] covering 22 men as of March 2015. Since then, [social hygiene clinic C], [social hygiene clinic D] and [social hygiene clinic E] have also started functioning as satellite treatment hubs,* but this study did not determine the number of people they cover. Apart from that, there are two private hospitals: [private hospital M], covering an estimated 500 to 600 people, and [private hospital F] covering 300 to 400.

Satellite treatment hubs are meant to provide ART to men who have sex with men if they are asymptomatic; for men who are symptomatic who require treatment for opportunistic infections, the main treatment hubs are used. The fact that treatment hubs use paper files has resulted in the absence of a large, up-to-date database with information about patients and clients.

A number of groups exist that support people living with HIV. The oldest is Pinoy Plus; a newer group is REDx, which functions entirely online, knowing that many men who have sex with men with HIV are reluctant to meet others face to face. Key informants in these organizations have mentioned the tendency for some clients of treatment hubs to ‘shop around’ and to move between hubs, or even disappear from them, due to dissatisfaction with the care received.

The average age of the men in this category was 31.3 years old. Of the 12 men, 4 were born outside greater Manila. Three were employed as BPO professionals; two were unemployed; two were IT professionals, and the rest had other professions.

* Andrew Ching, REDx, personal communication.

Case Studies

JAY, 26 BAGUIO

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Jay is a 26-year-old BPO employee who was unemployed at the time of the interview. He was born in Ilocos Norte and grew up in Baguio; his parents separated in 1995. He completed a degree in nursing. Jay is open about his sexuality to everybody on both his father's and his mother's sides of the family. Jay started being sexually active at the age of 17 with his first partner, who was a medical doctor. He has had only two sexual partners so far: besides the medical doctor, with whom he used condoms consistently during their six-year relationship, he had one "fling" during which he did not use condoms. It therefore must have been via this person that he became infected.

He was first tested HIV positive in October 2014 in Ilocos Norte but was unable to return to receive his confirmatory test result. He then tested again in Manila in February 2015 where he again tested positive and was referred for confirmation and baseline tests and finally enrolled for treatment in RITM. It was unclear to him at the time that he had the option of transferring to another treatment hub:

"I went to RITM for baseline [tests]. Actually, the option was to either go to [the] Pasig treatment [hub] or RITM. I did go to Pasig but then, they were fairly new. They told me to take the baseline in RITM who my records are now with. But they did say that after the trial period of ARV, they will transfer my records over to Pasig."

He started ARV and was given a "trial bottle" with pills for 14 days, which he took successfully. However, he did not go back to get a refill:

"In view of my family and my partner, I am having difficulties [adhering] up until now. The only reason I stopped my medication was because of financial reasons. I opted to prioritize my daily needs more than my health condition."

Apparently, the transportation costs to and from RITM were too much for Jay to bear. He had still not figured out whether there was an option to pick up his treatment from a location closer to home; when asked if he would be on treatment if the drugs were delivered to his home, he replied:

"Yes. It's hard for me to understand that there's only one treatment centre that addresses our needs up to a certain extent that we even have to spend money for our travel expenses. Treatment will become difficult, most especially [for] those who are facing financial

constraints. We cannot force people to spend [money] if there's really nothing to be spent to fund their expenses in the first place."

Jay was involved in a legal battle with his former BPO employer; this also had repercussions for his PhilHealth status, which also remained to be resolved. Jay was frequently depressed and would seek to be isolated from others as a way to deal with this, although he knew this made things worse. This may have been another factor in Jay's decision to stop treatment.

ED, 35 CALOOCAN

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Ed is a 35-year-old BPO professional from Caloocan who still lives there with his dad and brother. His mother died when he was 22 and his dad remarried. He has been open about his sexuality since he was young. He started being sexually active, being penetrated during anal intercourse with a cousin when he was younger than 10 years old. From the age of 13 onwards, when he was in high school, he had regular sex with schoolmates and other friends. He never used condoms.

He was diagnosed with HIV in July 2010, at the age of 30. He had gonorrhoea a few times, for which he self-medicated; he had 'neuro-syphilis' for which he was still being diagnosed and he has had genital and anal warts. Ed said he was always aware of HIV; he had tested for HIV regularly since 2005. Ed said he had no counselling after receiving his first reactive test result at [public hospital A], but did not return to pick up his confirmatory test result. Instead, he ordered two different online test kits himself:

"No counselling but I was told I needed to forward the screening test result [...] for confirmatory myself. That's where I stopped. I also had two online-ordered screening kits in 2010. All were reactive. And [I was re-tested] somewhere in Cubao."

He did not act upon these positive test results. More than two years after this, Ed was in the hospital for the skin condition erythema multiforme. He found out online that this is an immune-related disease. He therefore suspected his CD4 count was already low, so he had his baseline test at [public hospital B]; his CD4 count was between 200 and 300.

Asked why he waited for so long before going on ART, he mentioned his depression at that time was untreated: "I know for a fact what non-treatment could lead me to, so they say it is a form of suicide."

Upon taking his baseline tests, he was enrolled on ARVs immediately, but experienced a lot of vomiting while taking the drugs. On the fourth day, he switched to a new combination. One reason he mentioned for switching was his "double depression" for which he was being medicated; these medicines interfered with one of the drugs he had been taking.

Ed said he adhered to the new drug regimen badly. He would stop for two to three days at a time when the side effects became too severe, but perhaps also because he felt depressed. He mentioned dizziness, a feeling of being hungover, hallucinations, hot flushes and vivid dreams as side effects. He estimated that he took only 30 percent of the medicines he was supposed to take. Eventually, he became resistant to the drugs.

In mid-2013, around six months after enrolling on ART, he started second-line treatment (Alluvia). It took nearly five years after his diagnosis until he told his brother about his HIV status. He is now being treated by a psychiatrist regularly, and is adhering well to his second-line treatment. He has also started working as an occasional HIV related volunteer at [public hospital A], [public hospital B] and RITM.

BUDZ, 39 PASIG

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Budz, from Pasig, is 39 years old and also works as a BPO professional. He is an only child and has lived alone in his own condo since he was 23. He was close to his mother but his dad was mostly out of the country for business. His family was well off and he says his “financial support” helped him access bars and alcohol, and also mentions “technology” as a factor that increased his vulnerability. He was totally open about his sexuality towards his family.

His first sexual experience was with a carpenter working on his family’s house around 1991, when he was 15 years old. He says he has had 1,500 to 2,000 sexual partners since then who he has met via mIRC (online chat rooms), cruising and at bars. He mainly engaged in oral sex. He changed his sexual behaviour from almost entirely a top up until the age of 31 or 32 and now he bottoms. He did not use condoms until 2010: “I never thought about it.”

He was diagnosed in 2009, more or less by chance, as a friend asked him for company to get an HIV test: “I said, what the hell. And so we both tested positive.” He said he was “pretty much open” about it; he told all his friends and his family during the same week. His mother cried a lot at first but this improved after Budz asked his counsellor to come over and talk to her: “She was fine about it ever since” although “she worried a lot, like if she sees me posting I have a cold or cough, she will be knocking on my door the next hour!”

He did his baseline test and got his CD4 count the next month, which was 325. He was offered ARVs at [public hospital A], but initially decided against it. “But they forced me, saying it was going to be dangerous for my health, so I did. I took the ARV home after a series of counselling sessions.” But Budz said he was not psychologically ready for it:

“So after around two weeks, I stopped. I never went to the clinic ever since [...] I didn’t see the urgency. I was thinking I was healthy, no symptoms. I was stubborn.”

He said he searched everything he could on the Internet about nutrition, hoping that he could stay healthy and off ARVs by eating well:

“I also saw AIDS cases and it frightened me. Then again, I’d end up telling myself I was healthy and I can do it without ARV.”

Around three years later, in 2012, he was hospitalized for meningococcal disease and nearly died. His mother spent 1.2 million pesos on his treatment. After being discharged, he went on ARVs at [private hospital A] on which he commented:

“I’m doing fine there. I mean I don’t really have a need for a close doctor–patient relationship right now. I get refills every so often and that’s it. I do my annual labs and that’s it. The secretary is nice. The doctor

is nice. But I won't say I have developed any form of friendship with them. It's mostly what it is: I'm their patient, and they're my clinic."

Currently, his CD4 count has roared back to 1100. Budz was never depressed: "I did get sad, I guess that is when I started telling my friends about it. It is sort of my outlet."

MIKE, 34 CALOOCAN

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Mike is 34 years old, unemployed, formerly a salesman, from Caloocan. He has three younger sisters. He knew he was "different" since he was a child. Even so, he had sex with girls in high school and did not start having sex with men until his thirties. Initially, he had only oral sex. Some of it was in exchange for money, as he tried to earn money in order to stay in his undergraduate course, which his parents could not afford. It was easy to meet "clients" as he worked in a fast-food outlet and other young men working there referred his first clients to him.

Later, he started having anal sex with men. At first, he was a top, but since then he has become a bottom during anal intercourse. He has not had sex with women since 2008. He had a relationship for five years from 2010. When they broke up, Mike became "down and feeling blank inside" and entered a wild period in his life:

"I broke down and I got depressed. What I did was I went absent without leave with my life, I did things like party every night, things I couldn't do when I was in the relationship. It wasn't like I was having sex every night. It started February 2015 until April. April, I got sick [with gonorrhea]. [...] When I got cured, I didn't stop with the adventures and come May, I had another illness. I went back to the same doctor. This time it was pharyngitis. I could not eat and I could not swallow. The doctor said something about the need for me to get HIV screening; he said the two illnesses are leading towards HIV. He gave me another two week's worth of antibiotics and I got cured again."

He said he never thought of protection and of his safety in this wild period, despite the fact that in his five-year relationship with his ex-partner they always used condoms. After his second STI, his doctor referred him to a private clinic for HIV testing. According to his doctor, this was "better for [his] confidentiality". Mike went to a private clinic where he handed over his referral letter from his doctor, and his blood was taken without any counselling provided:

"After blood extraction, I was told that they will just contact me about the test results. I went home and I got an SMS the next day asking me to call the clinic. I did call them and the girl told me to go back to the clinic for another blood extraction. I was confused why there was another blood extraction, and the girl told me, 'Sadly to say, you were reactive.' I didn't know

what reactive meant and I had to ask her, through [the] phone. All these were through [the] phone! She said, ‘Sir, you’re HIV positive.’ Then she explained the need for another blood extraction leading to a confirmatory test.”

Mike went back and had his blood taken again; a month later, he had still not heard back from them. When asked if he had not been told that it would take this long, he responded:

“That’s it. No one told me anything. I didn’t get proper counselling or what the test is about, or if I had enough knowledge. It’s like I had blood taken from me and was asked to go home and wait.”

Mike started to think that they had made a mistake about his HIV status:

“The day I was wondering about this was the same day they texted me asking me to go back to the clinic. I was told that the confirmatory [test] was already there. I was told to bring it to the doctor who referred me to the clinic for testing. So there, I gave the results to my doctor, it was in an envelope.”

So when he got the envelope, it said “antibody” and he was thinking that he was HIV positive. He went back to the doctor and handed him the envelope:

“I asked him to explain to me the result. He was the first one to finally give me counselling and he was the first one ever to tell me what to expect.”

He decided to tell his mother, who initially was the only person to know:

“At the time I was going through the illnesses, I always updated [my mother] of my health status. I also set her expectations that I could be HIV positive. She has always told me not to be afraid and things will happen if they will happen. And if it does happen, we have to accept it for what it is because in the first place, this is my own self, my own body. She said, ‘As your mother, I will lead the disclosure to the family.’ And that’s what happened, she led the disclosure to the family. [...] My mom was sad. I saw in her eyes the sadness but she never blamed me. She said they were going to support me.”

His father blamed himself for Mike’s HIV diagnosis after his mother had told him about it:

“My father cried only after his birthday celebration. He was saying, ‘I want to blame myself. Was I too

lenient as a father that you came to this point?’ But he said I am still young, and they were supportive. Eventually, my siblings found about it. They all cried.”

Mike searched online to learn more about his options for treatment; he was planning to go to [private hospital A] instead of [public hospital A], where his doctor had referred him to. But upon telling his doctor about his decision, he told Mike that although the treatment processes were the same between [private hospital A] and [public hospital A]:

“He warned me about the expenses that can be entailed in a private clinic. He did warn me that there may be privacy issues in a public treatment centre.”

In other words, the choice that his doctor proposed to Mike was privacy but high costs, or confidentiality concerns and low costs. In the end, the doctor advised Mike to go to [public hospital A] and get a feel for the situation there. He ended up liking it, the people were friendly and he was given good information about HIV and his treatment process. He needed a “treatment partner” and decided his mother could fulfil this role. They both underwent several sessions of counselling, and at the end he was given his meds (lami/zido and nevirapine). However, he did not take his meds as instructed:

“I didn’t take the meds but I took it home. Something happened and I admit it, I am not against HIV treatment and I knew it could help me. When I went to take my first ARVs, I met someone there in [public hospital A] who recommended an alternative herbal medicine that he was taking. It was [an] oil called black oil seed. I felt it was a coincidence that I met this person the day I got the ARVs. So I had second thoughts about taking my ARVs. Honestly, it took almost a month up until now I haven’t taken the ARV since I was hoping everything will be fine with the black oil seed.”

Later in the interview, Mike explained that he had worries about the side effects of the ARVs, which he hoped to prevent by taking the alternative medicine:

“I actually read a blog saying that most fatal cases of PLHIVs were from ARV-related reactions. So that made me think twice.”

Meanwhile, Mike had set up a support group for people with HIV, all related via his social networks. One of the members of this group, who had heard about Mike’s refusal to take ARVs and his involvement in the black oil seed treatment, mentioned it at the [public hospital A] treatment hub. As a result, when he went for a refill, he was confronted about it; the officer said he should return the ARVs he had collected if he had not taken them. First, he denied he was not taking the drugs, but then:

“After the talk with [the [public hospital A] officer], and when I got home, I decided to talk to the hub

about my secret and that I will take my ARVs [from now on]. So there, yesterday, I finally got to talk to the doctor. I was actually expecting her to shout at me or probably get mad at me. She was unexpectedly calm and she told me that I was not the first one to do what I did. They were saying that all these guys who didn't take their meds didn't succeed."

He mentioned that his mother had also discovered his untouched ARVs at the same time and was pushing him to come clean and to start taking them. He agreed, and just a day before the interview, Mike went back for some more lab tests and was expected to enrol on ARVs the day after the interview

CARLO, 26 MINDANAO

Carlo is a 26-year-old bisexual IT professional from Mindanao who also volunteered until recently with an organization promoting adolescent reproductive health. He moved from Mindanao to Manila when he was around 20 years old to pursue a Master's degree. Although he had relatives living in Manila, he preferred to stay by himself: "I always wanted to be independent, alone, and do things on my own". He had supportive parents who made him into the self-confident person that he has become. Only a few friends know about his sexual affairs with men. He thinks his family may know as well "but we haven't really talked about it."

His first sexual encounter was around the age of 19, with a neighbour, when he was still in Mindanao. After arriving in Manila, he started to date more guys, "I usually ended up in bed". He said he used condoms 60 percent of the time; he linked non-condom-use to alcohol, drugs (which he used for a while when he was 20 and 21) and "trust": "I trust them very well. I know their lifestyle. They are very close partners with whom I have intimate relationships".

He was tested for the first time in July 2012, and tested positive. There was no counselling at all. Carlo called it "ironic" that he had tested only there and then, as he had been promoting HIV testing as part of his youth volunteer work with an NGO: "I was advocating [for HIV testing] but I was not submitting myself to the test."

But after having been diagnosed for gonorrhoea in April 2012, he started to be suspicious. He tested HIV positive at a clinic near Pasig City, and then went with this friend to get a confirmation test at a private clinic in Ortigas. Since this clinic said they were unable to provide counselling, he was referred from there to [private clinic E], and then went to [public hospital B], where he finally received counselling. After his gonorrhoea was treated he was also referred to SAGIP, where his baseline and CD4 tests were done. His CD4 count was 394; since the rule in 2012 was to start ARV under 350, he was advised to wait. Six months later his CD4 count had dropped to below 200, and he started ARVs at SAGIP in February 2013.

He had a negative memory of his experience going to this treatment hub, fearing that his family would find out and his confidentiality compromised. When asked if he feared stigma, he responded:

"Yes. It's always there with the line of work, somehow with the [adolescent reproductive health] organization that I am affiliated with. The perception of people might change since I'm in an endeavor and I'm working

for youth leadership. I was looked [up to]. However, these are just fears. I didn't want to destroy the reputation that I have built."

He said that counselling at SAGIP was good, but he did not like how the clinic was set up, with many people waiting outside. However, he started the ARVs immediately. He experienced strong side effects:

"I still remember that on my very first day and very first dose, I had numbness and I was vomiting a few minutes after I woke up. And then I got worried, I called my doctor and I was told to observe. On my first night, I was groggy and dizzy with the meds. [...] Then on my third, I was working; I could no longer control the dizziness. That made me decide to stop without advising my doctor. So, I only took my meds for two days. I felt like I couldn't walk straight and think straight when I was on my meds. I also felt that I was still in control of my health and that my resistance was still strong. Since I stopped and up until 2014, I never communicated with my doctor."

Carlo suggested that he would have stayed on treatment if he had had someone to take care of him at home, but he had opted to not tell his family about his HIV status "because I did not want to add burden upon them". The issues of "pride and ego" related to his work with adolescents was also a consideration.

The doctor and staff at SAGIP tried calling him around March 2013 and sent e-mails to him, to warn him that a refill of his medicines was due. "But I was so stubborn that I ignored their efforts. I was in denial somehow." Carlo mentioned also that he was "being chased by depression" in those years, considering quitting work and blaming himself for his situation.

In 2014, Carlo became weak and then sick; he coughed a lot and had chest pains. In October 2014, he "admitted himself" to [private hospital A] and consulted a pulmonologist who prescribed cough medicine. His situation became worse, partly due to heavy travel for work and exercise preparing for a sports event. He was then diagnosed with pulmonary TB and stayed confined at [private hospital M]. The health care workers at [private hospital M] still had not thought of HIV until he, in his own words, "confessed" that he was diagnosed HIV positive more than two years earlier.

He did contact [private clinic E] at that time, and did a baseline test at RITM where his CD4 count came out at 3. He was tested positive for cytomegalovirus retinitis, and was treated. Meanwhile he was treated for pulmonary TB for six months and was cleared; 21 days after starting CMV treatment he started ARV, but he could not complete the full 6 months of CMV treatment due to the high cost of the treatment and stopped. He was also concerned about the large number of medicines he was taking, which was another factor in his decision: "I felt that my body was already intoxicated from different medicines that I had been taking since I had pulmonary TB. Aside from cotri[moxazole], I also had azitro[mycin] which is taken once a week. So I stopped that [as well as the CMV medicine] and informed my doctor about my decision."

Due to his adherence to ARVs taken via [private clinic A] in January 2015, his CD4 count had risen to 60 and in August 2015 it was 80. The Internet helped him to assure that what the doctors advised him was correct during his first-line and second-line ARV treatment. He also searched online for information about side effects, and read about the supposed superiority of branded ARV medicines over generic ones. He also read about alternative treatments rather than ARVs, but did not trust this information.

CHOI, 25 PASAY

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Choi is a 25-year-old IT professional from Pasay. He is supporting his three younger brothers, to whom he is not close, and his parents. He had his first anal sex when he was still in grade school when he was around 12 or 13; his partner was a relative who was in high school: “[It was] consensual! So not really abuse. It happened several times.” After this, “a lot of things happened when I was in high school”. He said he never used condoms: “All I knew about condoms was that they are for family planning to prevent pregnancy.” He only heard about HIV in 2011, when he was 21 years old. After that, he would sometimes use condoms, but it depended on his partner: “If the partner says we need it, fine.”

In August 2012, he had shingles, and read online that this could be sign that the immune system was compromised. He had never tested for HIV before as he thought he was “not promiscuous enough” to have HIV. Nevertheless, he tested positive for HIV that month at [social hygiene clinic B] and had his confirmatory test done in October. He said the counselling he received was very poor, and he did not understand much about HIV. His CD4 count was 405 so he did not enrol on ARVs. In January 2013, he tested his CD4 count again, this time at RITM instead of [public hospital A]. He was unhappy with the quality of the service at RITM and worried about confidentiality. His CD4 count had dropped to 300 and he started his ARVs but decided to do so at [private hospital A] “since I was financially stable at the time.” He took ARVs for five months but then his situation changed:

“I had to resign because of the night shift. I got depressed and I told myself, I am dying anyway, so I won’t take my meds.”

Choi also said that he experienced treatment side effects, which was another factor for him to decide to quit: “I actually felt I was dying because of my meds, not because of HIV!” He did consult his doctor at [private hospital M], but she said “it will be gone soon” and did not give him any further advice or support. Hence, he quit treatment.

In May 2014, he came across [major MSM CBO] via a friend. He realized, being HIV positive, that he could contribute something to the community and became a [major MSM CBO] volunteer: “I decided to look at it from the bright side. I told myself that if I were to be sad, I would have even bigger problems.” He found out that it was impossible to live with HIV openly within the [major MSM CBO] support group:

“They were not a support group. We never talked about anything but PREVENTION. And during the time I was scared, I was not empowered enough to let the whole world know that I was HIV positive.”

When asked what could have empowered him, Choi responded:

“Maybe if people practised what they preach! Some people are saying they are HIV advocates but they are

the ones discriminating against PLHIVs, especially when they found out fellow advocates are HIV positive and they discriminate, that hurts!”

In January 2015, he switched to [private clinic E] to get back on ARVs: “You can call me a hopper!” Since then he has had no problems with adherence. He was clearly of the opinion that for HIV services in Manila, you get what you pay for, and that the paid-for, private services were better than the free government ones.

**GEORGE, 31
MANILA**

George is a 31-year-old businessman from Manila, who stayed behind in his ancestral home by himself after his parents passed away. His siblings moved out of Manila, hence “I never got the chance to move out.” With his father dead since George was 19, he had to take the duties of “the man in the house”, and “whenever I got the chance to unwind and got out, I was like a loose cannon”. He drank a lot during weekends and started having sex with men while he was in his 20s. At first, he considered himself to be bisexual as he had sex with women as well, but “eventually, I discovered that I was not attracted to women anymore and emotionally, I was attracted to men.” His siblings and friends know about his sexuality and he feels comfortable being gay.

When he was 28 years old, he met a male partner, and they stayed together until the partner died of tuberculosis in January 2014. Following the principle of “negotiated safety”, after having safe sex for the first four months of their relationship, they both tested negative for HIV in 2013 and decided to stop using condoms. Getting sicker and sicker, George’s boyfriend went home:

“But then he eventually tested positive for HIV, two months after he went home. But it was too late, his TB was bad, he acquired pneumonia in the hospital as well. Then first few days of January 2014, his dad picked me up from Manila. Then he died the same day I got there. [Crying] [...] Anyways, [by] the time I got there, we got to talk but he was very weak. He confessed having one unprotected sex when we were six months in the relationship. He recently found out that same guy died from AIDS-related PCP. He was crying while apologizing to me.”

George was sad but never angry: “How do I get mad with the only person I have learned to love unconditionally?” Back in Manila, George tested positive at the RITM Satellite. After he received his confirmatory test result, he was counselled and given different options on how to access treatment. He enrolled for ARVs at [public hospital A]. He was unhappy with the treatment he received:

“[Public hospital A] was bad, chaotic and the staff were not friendly. There’s that *bunso* (youngest child) they call who once was shouting at the pharmacy area. There’s that butch doctor who would raise her voice to the patients. No. No. No. I don’t like it there. I don’t think it’s an excuse to say they’re public, ergo the bad service.”

He dropped out of treatment after his poor treatment was followed by a stock out of ARVs in 2014:

“Last year when they were giving out ARVs for a few days’ worth, there was a stock out at the time and people were being asked to come back every x number of days. It drove me crazy since I had a business to

run. So I decided to stop my meds for three months until the stocks stabilized again.”

He said he was aware about the risk of developing resistance, but “the stress of seeing people stressed out over the stock out was too much”. He had heard about the concept of a “treatment holiday” and hence decided to take one. He noted that nobody at [public hospital A] tried to contact him when he did not show up to get the next few days’ worth of medicines: “[P]eople can just disappear into thin air and they won’t even notice!”

After three months, he decided to transfer to a private clinic, but he did not want to go back to [public hospital A] to get his medical files. Hence, he brought a confirmatory test result that he had received a number of months ago to a clinic there and enrolled as if he were a new patient. Showing his excellent knowledge of HIV, he knew he was at risk for drug resistance and he paid from his own pocket to get a genotype test while on vacation in the USA. It appeared that he was not drug resistant yet and hence, enrolled on ARVs again, achieving an undetectable viral load as of this year. George said he was never depressed to have HIV “knowing I got it from the love of my life! [Laughs]”. He said “HIV is what keeps me stronger every day. Morbid, but it reminds me of my one great love.”

**BOSS, 21
MANILA**

Boss is a 21-year-old BPO agent from Manila. His parents broke up when he was seven. His father took his only other sibling when he packed his bags in the middle of the night after a fight with his mother, and walked off, never to return again. He blamed his “broken family” situation for the sexual contacts he had with a 25-year-old man in the neighbourhood when he was aged 8 to 10. During his college years he had lots of casual sex “since there was no one there to guide me.” He is open about his sexuality. He was only a top during anal intercourse, and never used condoms: “I lose my hard-on with the feeling of latex on my dick.” He said he successfully used this argument with partners who asked him to use condoms: “I would tell them I can’t fuck them with a condom because I would lose my hard-on, then they would give in. Perks of being good-looking! [laughs]”.

He tested for HIV at [major MSM CBO] clinic in August 2015. The reason he tested was that an old casual sex mate of his was rumored to have HIV on Facebook. After testing positive for HIV, he received “less than 10 minutes” of counselling from a counsellor who seemed “rushed”:

“Yes, looking back, I think he should have checked if at all I was interested to pursue treatment, or if there were people I can talk to, other [HIV] positives. Or what were my issues then.”

He was referred to RITM for his baseline test, an experience that he did not enjoy:

“Terrible! There were so many people, everybody could see everybody! It was as if the crowd’s noise eventually disappeared in my head and I was in my own corner, with no one to talk to, no one to ask. [...] The HIV clinic was beside the rabies clinic and HIV clients are waiting at the hallway. Someone I met there even told me that the clinic staff once lectured about ARV at the hallway! Are you kidding me?”

His CD4 count was 402; he was offered ARV and decided to take it. However, he took the medicines for just two and a half days, and decided to stop:

“I had [a] bad fever, and I had to stop according to the instructions given to me. But when the fever subsided, I didn’t know if I wanted to go back to RITM anymore. And I haven’t done so.”

His working schedule also was a factor, as he works night shifts. Since then, someone who Boss was dating told him about [private clinic A], and he had made an appointment to go there in a week’s time after the interview. He partly blamed the counsellor at [major MSM CBO]: “I only knew of RITM. I wish the counsellor had told me about the other options. [...] After counselling, I was so lost. I actually was hoping that the counsellor would clear things up during the post-test but he didn’t help much.” Instead, it was social media that helped him handle his situation.

JERIC, 22 BULACAN

Jeric is a 22-year-old bisexual man from Bulacan, who works in his family’s poultry business. Jeric found out he had HIV in March 2013, when he got tested as part of a procedure relating to employment abroad. In January or February 2015 he got his confirmation test results after support from a PLHIV support group for MSM. In April 2015, he got his baseline tests done at the Pasig hub, and then received his first batch of ARVs. He had one refill, but when his drugs were running out and he could not get back for a refill, he decided to take only one pill a day rather than the prescribed two to make the ARVs last longer. In September 2015, the ARVs were finished and he stopped taking them, although he was well aware of the risks of drug resistance:

“[The reason was] work related. There was even a point that there’s only me in the poultry [business], and since that’s my aunt’s business, I couldn’t really walk out. I was afraid she’d tell my mom that I left. Actually when I found out about my status, I lost hope. I studied culinary because I wanted to go abroad but when I was diagnosed, I couldn’t go to Japan anymore. I knew culinary was in-demand for cruise ships.”

Jeric had difficulty reaching the treatment centre in Pasig, which was far away from his workplace. Fortunately, the Pasig hub seems to have recently become more flexible in providing medicines to its clients, and Jeric was therefore planning to go back on treatment:

“[E]arlier today, Pasig told me they can actually freight in my meds, that I can just send the money [for freight costs] over to them. I didn’t know that was possible. I actually find it really difficult going to the treatment centre since it’s far. After the [planned] November visit [to Pasig treatment hub], I think I would go for the option of sending the ARVs by freight.”

Jeric said that for him, being on ARV treatment was a “big thing in terms of money, time and effort”.

JOSH, 30 MARIKINA

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Josh is a 30-year-old bisexual entertainer and singer from Marikina. He has six younger siblings whom Josh is partly supporting, as well as his parents, who are living together. Initially, he studied nursing but did not do the final exams. He has worked as a singer in Malaysia, Taiwan Province of China and Dubai. Josh said he always used condoms both with men and with women. However, he was lured into a hotel room by a guest after a singing performance, and had unprotected receptive anal sex. This was his first time bottoming, as usually he was top. He points to this instance as the cause for his HIV infection. After testing negative around 10 times during his 10-year career, in September 2014 he was found to be HIV positive as part of a routine check-up in Dubai:

“In September, I remembered having received a notice from the agency to go back to the hospital and they were requesting a blood retest. When I got there, I was already nervous and I had a hunch there was something wrong. Every station I went to, I was always escorted by a guard. And finally he escorted me to the last room that had bars and what I knew then was once you entered that room, you cannot go out anymore. Then they told me that I was diagnosed positive with HIV, and I stayed in that room for a week while waiting for my ticket [to be deported back to the Philippines], and it stressed me out terribly.”

After coming back from Dubai, Josh was confirmed positive and did his baseline tests, and enrolled in ARV treatment. He said that as a side effect, he experienced “feeling crazy sometimes.” However, after taking ARVs for six months he stopped. He was depressed:

“I was thinking that all my opportunities were banished because I could not go abroad anymore, so why should I take the medicines if I am going to die anyway?”

He saw his infection as a “punishment from God for the things I have done before”. But there was also a financial reason:

“I stopped taking medicines when I stopped working and I didn’t have even a peso in my pocket. And I didn’t even know how to tell it to my siblings, why I need money, why I need to go to hospital, why they need to accompany me [as a treatment buddy] and have myself checked because I know they will ask me why and I could not explain. I could not handle it.”

But after counselling, he decided to get back on treatment, after a six-month break: “Someone made me realize that everybody wants a second chance” and that “in life, we have to experience failures to learn from our mistakes”. During his depressions and dark thoughts, he turned to Facebook and other online channels for support; this is also how he became connected to [a PLHIV support group for MSM] and an online counsellor who finally convinced him to return to treatment. He also learned about the life stories of other people with HIV who went through “more complicated situations, but they survived.” Hence, the testimonies of others helped him realize his own situation was not so bad after all. He has, since going back on treatment, let his family know that he is HIV positive and they were supportive and even remind him occasionally when it is time to take his ARVs. Only his romantic life has not come back to normal. Since becoming HIV positive, Josh says he has become “paranoid to the point that I don’t want to have

sex anymore”; he has turned into a “porn addict” to satisfy his sexual needs. He would welcome it if his ARVs could be delivered or picked up somewhere nearer to his home.

ANTHONY, 30 MAKATI

Anthony is a 30-year-old advertising executive from Makati. He is an only child from a wealthy family. He is open about his sexuality to his family, friends and colleagues. His first sexual contact was when he seduced the 21-year-old family driver when Anthony was 16: “He bottomed me at first and when I couldn’t take the pain, he asked me to fuck him.” He has had many sexual encounters since then, describing himself as “a very physical person”. He did not use condoms regularly. When he went to college he rented a condo near the campus and “went astray”; he said the sense of freedom made him feel he could do “anything to everything”. After graduating, he had a job immediately and moved to another condo, near where he worked.

In 2013, Anthony received an anonymous SMS message from someone he had had sex with who had become HIV positive, suggesting he should get tested too: “I got so paranoid, I went to the clinic the same day.” He chose [private clinic B]. Asked how the counselling was, he said:

“Bad. No counselling whatsoever. They drew blood from me and then they texted me with the result. I was so clueless and I didn’t know what to [do]. I went back after two weeks finally but I didn’t had the courage to go inside so I left. I googled and found out about RITM satellite, I got there but there were too many people. I left.”

Finally he went to [private hospital A] to get his confirmatory test; it was here that he received “very informative” counselling. He followed “a long list of laboratory tests” that he needed to do; his CD4 count came back at 320. He was given ARVs and took them for two or three weeks; then he had to stop:

“The vomiting was bad. I was light-headed most of the time and the second week, I was hospitalized for anemia. I had to have [a] blood transfusion.”

Initially, he tried to contact the doctor at [private hospital A], but he was out of the country and Anthony did not feel confident to talk to anybody else about his problems. He went to [public hospital C] to be treated for anemia, as it was nearer to his condo; he never went back to [private hospital A] again:

“I felt they were going to kill me. They did not warn me about possible anemia. They did not tell me to monitor my CBC (complete blood count). I was texting them about my vomiting and lightheadedness but all they said was to observe myself.”

Later, he googled about side effects of his treatment and found out that some of these were quite common. He blamed the poor counselling he received for not warning him about side effects and saw this as an important reason behind his treatment interruption. He thought that if he had known, “I could have handled [the side effects] given proper

monitoring". In the meantime, he tried to ignore his HIV infection; he could not talk to anybody about it. "I drank a lot, it made me forget."

At the end of 2014, he met volunteers from [a PLHIV support group for MSM] online who persuaded him to get back on treatment. He went to a private clinic and pretended to be a new patient, bringing his confirmatory test result but not telling them about his ARV history. He started treatment again, with a different medicine, in January 2015.

JC, 41 QUEZON CITY

JC is a 41-year-old government employee from Quezon City from a poor family; his father was a jeepney driver and JC had to work to help make ends meet and take care of his three siblings. The situation of the family deteriorated when his mother became ill in 1995. JC managed to get a nursing assistant job in Singapore via a job placement agency; he worked in Singapore between 2001 and 2005. The financial situation of the family therefore improved. In 2004, JC had a relationship with a Malaysian air steward. A year later, his boyfriend disappeared suddenly, back to Malaysia. JC tracked him down and took three days leave to see him in Malaysia:

"The last encounter we had was I went to him to Malaysia, before my diagnosis. I felt like we were married, shouting at him why he disappeared. [...] That was the time he gave a hint [that I should not be] afraid to get sick. I said, 'No, because I like you.' Of course, after that, my medical turned positive afterwards."

Later, JC found out that his boyfriend was deported due to HIV seroconversion. JC also tested positive; the Singaporean doctor told JC that he had "only five or six more years to live" and JC considered killing himself by jumping from the balcony of his tenth floor apartment. JC knew what was coming and disclosed his own HIV status to his employer, rather than waiting for the process of his doctor reporting it to the authorities. He was almost deported within three days, but begged the authorities to be allowed to wait to collect his final salary. As soon as he received his last salary, he went back home. His mother was bedridden at the time, and his father had had his arm amputated after a traffic accident. JC did not want to burden his family with his own "bad news" and decided to keep quiet:

"That time my mom was bedridden, I was thinking I was ok physically. I was also afraid of rumours since I suddenly came back from abroad and I didn't know how to start things. I think that time, I forced myself to become busy."

Once he returned, he showed his Singaporean health records at [public hospital A], but they did not do his CD4 count. JC was "frightened" and did not want to enrol on ARVs. He was worried about the treatment costs as well. Ironically, he became involved in [a general PLHIV support group]:

"It was my choice [not to pursue baseline tests/treatment]. It was a family thingy as well. During that time, there wasn't anything like we were being obliged to take the meds so I didn't see the urgency. Also, I was enjoying my work at [a general PLHIV support group] and I totally just didn't get around to thinking about my own CD4."

Between 2006 and 2009, he went to [public hospital A] regularly, partly related to his work, but never did a CD4 count: “What the doctor had in the records was ‘lost to follow-up’, although they always saw me in and around the clinic. I never had a check-up.” Probably his work in [a general PLHIV support group] led to assumptions by others that he was taking care of his own health. In December 2009, he finally did his baseline test – his CD4 count was 280. At that time, there was the requirement to have a “treatment buddy” who had to undergo counselling together with the newly diagnosed client. JC had, by that time, finally mustered the courage to tell his youngest brother and sister that he had HIV, but both were not in Manila at that time:

“[I] had a hard time to adjust. ARV counselling was once a month for three sessions so it took three months. I disclosed to my nephews in June then, plus three months, so by October that was the only time I had my ARV.”

Hence, while diagnosed and qualifying for ARVs because of his CD4 count in December, the requirement for a treatment buddy and JC’s problems with telling his relatives delayed JC’s access to ARVs by 10 months. In October, he went on a drug trial; he had some issues with one of his drugs so they switched him after 25 days. He was on treatment continuously from November 2010 until August 2013, when he went to ICAAP in Bangkok. He said he stopped due to his “family situation” and lack of support:

“I was thinking of paying for the [public hospital A] viral load and CD4, so I was telling myself, if I die, then I die. That time, my siblings had their own issues and I didn’t want to be a burden to them.”

He also mentioned poverty as a “big factor”. When his nephew was hospitalized in February 2014 for dengue fever, JC changed his mind again and decided to go back on ARVs. He asked Dr A of [public hospital A] if he could continue treatment without bringing his treatment buddy, as both were unable to join him, but she refused.

JC had an “ill feeling” with [public hospital A] related to the costs they charged him, as he was convinced these were supposed to be covered by PhilHealth. JC went to see another doctor in NKTl, whom he knew from his time when he was working there, before going to Singapore, and she helped him get back on ARVs in March – with NKTl/PhilHealth paying for all the tests. After being off ARVs for nine months, he has now been on ARVs again since March 2015. Asked if he would stop again, he said “No, never again. I am afraid now.” He is completely open about his HIV status now, even in the neighbourhood where he lives:

“I guess I got used to things. In our neighbourhood here, it’s funny, they are interested in me. One even said, ‘I thought we should be afraid, but then you should be afraid of us if your immune system is compromised.’ Sometimes though, I don’t think it’s always good to be always open. Some relatives can be affected by the rumors – while I don’t get affected anymore.”

JC thinks it is important if new mechanisms are designed and introduced for the delivery of ARVs to people who may not have money for travel expenses or cannot get time off work easily.

Observations

A host of factors and reasons for people to interrupt or stop ART were identified in this chapter.

> Depression

An important and recurring reason was depression, or losing the will to live. This led to people no longer seeing the need for treatment and to get better. It shows the importance of strong and empathetic adherence counselling, as well as the importance of linking people to social support groups. Indeed, several of the interviewees were recruited into the study by the same channel by which they returned to HIV treatment after lengthy interruptions: the Internet, where they became in touch with online counsellors and support groups.

The importance of depression as a factor to interrupt or cease treatment needs to be emphasized, and clients who commence ARVs must be told that depressive symptoms are common and should not be ignored but should be reported to health care providers and actively addressed. It is important to see HIV as just one aspect of a whole range of interlinked health issues relevant to men who have sex with men. The link between depression and mental health and HIV treatment adherence serves as one of the clearest examples of why HIV care must be embedded in and linked to a wider set of health care and social support interventions.

> Side effects

A second important factor leading to men dropping out of ARV treatment was the occurrence of side effects – this factor was strongest if men had not been properly counselled about the possibility of these side effects occurring. Side effects can be severe, and may be a reason to switch regimens – but sometimes they are part of the temporary process of the body getting used to the treatment, and are normal in that sense. Whatever the case, patients need to know what to expect when they start treatment, and improving ARV treatment counselling is an important way to reduce the dropout of people on ARVs due to side effects. Misinformation about side effects and scary stories and pictures of people with HIV found online were also mentioned as a factor that led people to discontinue treatment with ARVs. It is important that counsellors and HIV advocates strongly counter sensationalist and incorrect information about HIV and its treatment in their activities.

> Misconceptions

Post-baseline, pre-ARV-treatment counselling should also address a number of prevalent misconceptions about HIV and how it can be treated. Men might hope to “self-treat” with good nutrition or with certain traditional medicines, such as black oil seed. It is important that counsellors not only provide correct information about HIV and ARV treatment, but also carefully explore pre-existing ideas and (mis)conceptions that a client may have which could influence his likelihood and ability to adhere to treatment.

> Accessibility

A number of study participants had trouble getting to and from the RITM treatment hub, and were not told during the post-test counselling that RITM was just one of several options to get treatment. It is important that counsellors tell clients all options for accessing treatment, including the recent possibility to have ARV medicines delivered to homes by three of the existing treatment hubs. Counsellors should not try to simplify or decide for the client what they think is best for them.

A number of participants mentioned unfriendly treatment, including being shouted at, by a senior doctor at [public hospital A]; two mentioned this as a reason to shift to a private clinic. This is serious, as at the stage of commencing ARV treatment, many clients have had to overcome severe mental barriers, and it is important that they are encouraged and supported during this vulnerable stage. It is therefore important that the doctors, nurses and counsellors working to serve people living with HIV have the right personality and attitudes for their jobs; they should be monitored and regularly evaluated. In this regard, the planned HIV service rating system by [NGO Z], where clients can give scores to different HIV services for friendliness, professionalism, cleanliness, confidentiality and other criteria, should be welcomed, and will hopefully lead to unsuitable staff being removed or relocated to a different position where they can do less harm.

› Financial constraints

A common reason to drop out of ARV treatment was financial constraints. Whereas ARV treatment is free, there are considerable opportunity costs involved in getting to – and from – the treatment hubs such as transportation costs or losing time from work. In addition, baseline tests are not always free, and these expenses can add up for people with a low income or those who are dependent on others for such expenses. Some clients dropped out of treatment after switching from a day shift to a night shift, making it impossible to refill their ARVs. It appears that Pasig treatment hub, following RITM and [private clinic E] has now started to provide a home delivery service for refilling ARV; this should be applauded. At the same time, it was found that access to HIV treatment was inequitable between people who were relatively poor and those who were middle or upper class; this is an issue that needs to be addressed as a matter of urgency.

› Family issues

Some research participants mentioned their family as a factor in discontinuing or delaying the onset of ARV treatment. First, there was the requirement of bringing a “treatment buddy” who is supposed to support the client in adhering to his ARV regimen and can keep an eye on him during the trial treatment period. However, for men who have sex with men who are not open about their HIV status (often but not always linked to being closeted about their sexuality), finding a treatment buddy was not easy. It forced them to disclose their status to people whom they would, under normal circumstances, perhaps not disclose to, and led to delays in accessing treatment that could, from a clinical perspective, be damaging. The idea of treatment buddies is excellent and should be continued, but not as a requirement for accessing ARVs, as seems to be the case at least at [public hospital A] and [social hygiene clinic A].

A second family-related reason for discontinuing treatment was side effects, which some participants feared would lead to their family finding out about their HIV status. Some participants also could not deal with having to find excuses to their family about why they had to go to the treatment hub and spend a lot of time there, and why they had to spend large amounts on laboratory tests. A third reason to drop out that is linked to the family had to do with the family situation: where there was an ill or disabled parent or if there were other problems in the family, participants chose not to be a “burden” on their family by requiring attention, financial support and care for their HIV treatment. Instead, they preferred to take a wait-and-see approach. All these factors need to be integrated into the training of counsellors for pre-treatment and post-HIV test counselling to ensure some of these issues can be resolved and the best way forward can be determined.

› Lack of counselling

Nearly all participants in this category of the study mentioned concerns about the huge number of people accessing the treatment hubs, especially RITM and [public hospital A]. They had concerns about their privacy and confidentiality and were concerned about the long waiting hours. It is imperative that these important treatment hubs design better systems to manage their patient flow in and out of the premises, for example by designing it in a way that the exit and entry points are on different sides of the building, reducing the chance that clients bump into each other. Another option is to create smaller and more private waiting rooms or areas for clients to wait, again reducing the chance of bumping into relatives, colleagues or friends.

Some clients interviewed in the study did not receive any counselling at all – two different people mentioned [private clinic B] in this regard. While both these people eventually enrolled on ARV treatment, it is likely that a large number of clients could disappear, at least for long periods of time, if they do not receive proper pre-test and post-test counselling. The government should consider forbidding private clinics to conduct HIV testing if they cannot guarantee that clients also receive appropriate counselling. This counselling should include a clear explanation of the next steps after testing HIV positive, different options to access HIV treatment, linkages to further HIV counselling and support groups, and explanations of how HIV treatment works and how under normal adherence circumstances can result in a normal life expectancy.

› Other issues

Interestingly, people working in HIV-related organizations may have extra hurdles to access ARV treatment. One of the participants was a volunteer at [major MSM CBO] and discussed discrimination towards people living with

HIV and that the sole focus on HIV prevention in their work made him feel unworthy. It is important that Philippine NGOs and CBOs stop seeing prevention and treatment/care as separate domains, and make sure that they become organizations where people with HIV can feel supported and at home. Another participant worked at [a general PLHIV support group] which apparently led people around him to assume he was fine (and had enough information and support), even though he failed to access treatment initially, and after a while dropped out of ARV treatment due to financial concerns and family issues. No assumptions are warranted in terms of HIV service needs, even if people work for HIV service organizations.

Another reason for dropout encountered in the study was the 2014 stock out of antiretroviral drugs at RITM; drugs were strictly rationed and patients were asked to come back every three to five days to get small supplies of drugs. This led one of the interviewees to drop out, as it was impossible for him to return regularly to the clinic while he was running a business by himself.

An interesting finding was that 2 out of the 12 men interviewed in this category had dropped out of treatment, but then re-enrolled by pretending to be a new patient; this allowed them to not have to go back to their old treatment hub to get their files.

Chapter 6: Discussion and recommendations

Discussion

■ Men who have sex with men with barriers to accessing HIV testing

The most important reason for not getting tested for HIV was not seeing the need to get tested, despite often-significant episodes of risk for HIV. Often participants said they had “no time” or “never got around” to doing the test, showing a lack of urgency or not feeling HIV testing is important for them, although it could also point to them having less equitable access to HIV testing services.

Perceived justifications for not getting tested also included being in good physical shape, having a healthy lifestyle, not feeling ill, and “not losing any weight” – an oft-mentioned (mis)perceived sign of not having an HIV infection. Another impediment to HIV testing among some participants was having a boyfriend perceived to be HIV negative.

Being monogamous was another reason why some participants felt no need to get tested. Perceiving oneself as being superior to “the type of person that gets HIV” was also cited as a reason why participants had believed testing for HIV was unnecessary. A sense of moral superiority to other gay men was an issue, as was the belief that HIV infection is linked to a certain level of sexual activity – one participant said that he felt he was “not promiscuous enough” to get HIV.

Monogamy or “being faithful” is a popular strategy for HIV prevention, especially in conservative countries such as the Philippines. However, as a strategy for prevention, monogamy should only be promoted in settings where open and frank communication is possible between partners about their sexual relationship and possible sexual contact outside of the relationship. This seems to be an issue that is often overlooked: whereas friends of the same gender like to joke and boast about sex and sexuality, communication about sexuality between intimate partners seems absent in the Philippines’s sexual culture. This would also disqualify the promotion of “negotiated safety” (where partners agree on an open relationship where they do not use condoms with each other but use condoms consistently with any additional casual partners they may have) as a prevention strategy in the Philippines.

Other reasons not to test were related to fear of what will happen after being infected with HIV. This was linked to relationships with family and loved ones, as well as an overly strong fear of side effects from ARV medicines. Some people also feared the cost of health care and HIV treatment that would be incurred relating to testing HIV positive. Another reason was practical: the poorer participants in the study found that the testing centres were located too far away from where they lived and worked; transportation costs were too expensive for them to get to the centres and some of them could not take time off their work duties

■ Men who didn’t follow up after a reactive result of an initial HIV screening test

An important reason why clients disappear from medical care after testing positive for the HIV screening test was denial. Several research participants did not want to believe they were HIV infected and decided to actively ignore reality for a while.

Several participants mentioned that they worried about being stigmatized by family and friends if they pursued their confirmation and baseline tests and instead decided to ignore their initial positive test result.

Both these factors could perhaps be overcome by good counselling. Unfortunately, several participants reported poor counselling and that the attitude and friendliness of counsellors and their capacity to be empathetic, comforting and supportive was found to be less than optimal. It is important that counselling includes providing clients with

clear ideas about the pathways to care, before and after the screening test, as well as clear and easily accessible pathways to social and psychological support groups. It is important to recruit the right type of personality in the role of counsellor, and ensure that counsellors receive training to ensure they are client-oriented, friendly and not judgemental.

Other participants were victims of bureaucracy: rules and regulations and too many referrals and cross-referrals, partly caused by the current algorithms of testing and related post-test counselling practices. For some participants, the opportunity cost of going to RITM to get their confirmation test was an issue. Some worked and could not take time off, or did not have the transportation costs. It is important to make it easier and quicker to get an HIV confirmation test, preferably by changing the national HIV testing algorithm (using a rapid test for confirmation, and stopping the use of western blot) so that access to confirmation testing and baseline and CD4 tests becomes more equitable.

Another important barrier for clients to pursue further HIV services were fears and misconceptions about the side effects of ART as well as the costs of second-line treatment. These are issues that counsellors should bring up in pre-test counselling sessions; this issue should not be deferred to pre-ART and adherence counselling.

It was unclear why some participants in the study reported very high costs of baseline tests in private hospitals, which led some to stop contact with health services. It is important that people can compare different hospitals and treatment hubs and decide where to go for their baseline tests. The planned rating system by the NGO B-Change, in which clients can share experiences and “rate” different HIV services, is important in this regard.

■ **Men who are HIV positive but had barriers to enrolling in ART**

Some of the men did not receive clear instructions after their diagnosis; others complained about being treated badly by doctors or found staff or counsellors indifferent or apathetic. Often, counsellors spent not enough time with their client and did not provide information that was tailored to the client’s specific situation.

A few system-related obstacles or events, related mainly to the transfer of client records between HIV service providers, caused men to drop out or delay accessing treatment, similar to the situation reported at the other levels of the HIV service cascade. Many participants felt negatively about RITM for being too far away and for being too busy, leading to fears about confidentiality. Long waiting times also played a role in some participants dropping out of the system.

Similar to the situation found at other levels of the HIV service cascade, another cluster of factors that explained delaying the onset of treatment were related to misconceptions and attitudes about ARV medicines, the most important of which was fear that ARVs would cause severe and debilitating side effects, which would affect the ability to study or work, or to adhere to the treatment itself. These fears led some people to try to stay off ARVs for as long as possible in order to postpone the supposed negative effects of treatment for HIV on the body. Some participants seemed to see the act of taking medicines as an act of weakness and disease; others were convinced they could, by living a healthy or healthier life, increase their CD4 count to a level at which treatment with ARVs would no longer be necessary.

A small number of participants reported signs of self-stigma or self-blaming, especially after their initial diagnosis. Moral convictions, often related to religion, included seeing HIV as a punishment for homosexuality. Hence, delaying access to ARV could be seen as accepting punishment for being gay. Fortunately, these ideas were not widespread and were usually temporary, likely linked to the process of coming to terms with one’s situation and with overcoming depression.

Instances of stigma were limited, mostly because participants kept their HIV status to themselves. One participant experienced severe stigma within his own family and another two had their HIV status disclosed against their will in a work setting and in a rural healthcare setting.

■ **Men who enrolled in ART but have adherence issues**

An important and recurring reason for having problems with adherence to ARVs was depression, or losing the will to live. This led to people no longer seeing the need to seek treatment and to get better. The link between depression

and mental health and HIV treatment adherence serves as one of the clearest examples of why HIV care must be embedded in and linked to a wider set of health care and social support interventions.

A number of participants mentioned being dealt with in an unfriendly manner, including being shouted at by a senior doctor at [public hospital A]; two mentioned this as a reason to shift to a private clinic. This is serious, as at the stage of commencing ARV treatment, many clients have had to overcome severe mental barriers, and it is important that they are encouraged and supported during this vulnerable stage.

Counselling is key in this regard, but some participants reported not receiving any counselling after their diagnosis or treatment onset. It is likely that a large number of clients could disappear, at least for long periods of time, if they do not receive proper pre-test and post-test and pre-ART-enrolment counselling. The government should consider forbidding private clinics to conduct HIV testing if they cannot guarantee that clients also receive appropriate counselling.

A second important factor leading to men dropping out of ARV treatment was the occurrence of side effects – this factor was strongest if men had not been properly counselled about the possibility of these side effects occurring, including the knowledge that side effects are often temporary. A few men thought they could “self-treat” with good nutrition or with certain traditional medicines, such as black oil seed, and mentioned this as a reason to stop ART – another issue that needs to be addressed in pre-ART counselling.

A number of study participants had trouble getting to and from the RITM treatment hub, around two hours travel from central Manila, and were not told during the post-test counselling that RITM was just one of several options to get treatment, including the recent possibility to have ARV medicines delivered to one’s home by three of the existing treatment hubs. Nearly all participants in this category of the study mentioned that they had concerns about the huge number of people accessing the treatment hubs, especially RITM and [public hospital A]. They had concerns about their privacy and confidentiality and were concerned about the long waiting hours.

A common reason to drop out of ARV treatment was financial constraints. Whereas ARV treatment is free, there are considerable opportunity costs involved in getting to and from the treatment hubs, whether transportation costs or getting time away from paid employment. In addition, baseline tests required during the pre-ART process were found to be not always free, and these expenses can add up for people with a low income or those who are dependent on others for such expenses. There was a reported case where the counsellor failed to mention additional options available in terms of HIV service locations and services offered; if the options given to a newly diagnosed client are limited, it could increase the chance of the client dropping out of treatment.

Some research participants mentioned their family as a factor in discontinuing or delaying the onset of ARV treatment. First, there was the requirement of bringing a “treatment buddy”. For men who have sex with men who are not open about their HIV status (often but not always linked to being closeted about their sexuality), this was a barrier to commence treatment. Other participants feared that their family might find out about their HIV status due to the side effects of the treatment they were expecting to face and therefore delayed treatment. A third reason to drop out that is related to the family had to do with the family situation: where there was an ill or disabled parent or if there were other problems in the family, participants chose not to be a “burden” on their family by requiring attention, financial support and care for their HIV treatment, instead preferring to take a wait-and-see approach. All these issues need to be properly discussed during post-diagnosis and pre-ARV-treatment counselling.

Overall recommendations

- A **client-centred case management approach** should be introduced in the Philippines. With this approach:
 - » Clients are given prevention information and condoms.
 - » For those who are at high risk of HIV infection and are HIV negative, they are given the option to access PrEP.
 - » Clients who have sero-converted are actively followed into the health care system in a way that suits them best and ensures their access to life-saving treatment and care.

- » This means that after testing positive, they are accompanied by a case worker for the confirmation test and CD4 test, accompanied by the same case worker for support services from one of the several PLHIV networks (if they so desire) and accompanied to the first contacts with the doctor and other medical personnel to ensure their enrolment in ART in any of the treatment centres.
 - » Clinic times are set so they are convenient for clients. For example, Quezon City has successfully modelled the 'Sundown' approach with opening hours from 6pm to 11pm.
 - » A client-centred case management approach has proven in other countries, such as Thailand, to radically reduce the number of men who have sex with men from dropping out of the health system and consequently disappearing.
- There is a need for **better-integrated HIV services** that overcome the gaps that still exist between HIV prevention and treatment. The gap is an artificial concept. NGOs and CBOs in the Philippines need to embrace this new concept, in which HIV prevention and treatment are two sides of the same coin, and make sure that they become organizations where people living with HIV can feel supported and at home. The target for HIV services should no longer be the number of contacts in the field or condoms distributed, but the number of new HIV cases discovered and successfully enrolled in care. HIV services should also be better integrated with other health services related to the health of MSM, from harm reduction to mental health services.
- » The Department of Health should change the testing algorithm and **abolish the use of western blot as confirmatory test** in favor of modern rapid tests. Anybody found positive after the screening test should be validated by a second rapid test.
 - » In line with the latest WHO guidance, being a man who has sex with men and having confirmed HIV (as per two rapid positive tests) should be a sufficient condition for immediate enrolment on ARV treatment; **there should be no wait for CD4 test or viral load test results** during which many clients potentially disappear from the reach of life-saving HIV services. Fortunately, at the time of writing of this report, a new Rapid HIV Diagnostic Algorithm was already being planned by the Department of Health.
 - » Many clients of HIV services complained about the lack of privacy, both at testing centres as well as at HIV treatment hubs. It is imperative that HIV services in general, and treatment hubs in particular, design **better systems to manage their patient flow in and out of the premises**, for example by designing it in a way that exit and entry points are on different sides of the building. This reduces the chance that clients bump into people they know. Another option is to create smaller and more private waiting rooms or areas for clients to wait, again reducing the chance of bumping into relatives, colleagues or friends.
 - » It is imperative that post-test counselling includes details of **different treatment centres and options** in terms of location, privacy, confidentiality and cost.
 - » The Government should consider **forbidding private clinics to conduct HIV testing if they cannot guarantee that clients also receive appropriate pre-test and post-test counselling**. This counselling should include a clear explanation of the next steps after testing HIV positive, different options to access HIV treatment, linkages to further HIV counselling and support groups, and explanations of how HIV treatment works and how under normal adherence circumstances can result in a normal life expectancy.
 - » It is important that HIV counsellors not only provide correct information about HIV testing and ARV treatment in their counselling, but also **carefully explore pre-existing ideas and misconceptions** that a client may have about either HIV, ARVs or any other issues that may influence his likelihood and ability to enrol or adhere to treatment, such as beliefs in herbal or other "medicines" or not being allowed to consume certain foods while taking ARVs.
 - » HIV counselling in general needs to be improved to **support better-integrated HIV services**. Counsellors should be trained to discuss and counsel on mental health issues such as bullying, harassment, and addiction to drug, alcohol and sex.
 - » There remains a strong need to **promote condom use among men who have sex with men**, as condom use was found to be very low.
 - » Although not a result of this study, it should be noted that the **introduction of PrEP as part of a comprehensive HIV prevention strategy** has made HIV testing even more important (and possibly more compelling and attractive to individual men who have sex with men). Men who have sex with men enrolling in PrEP need to test frequently, as testing negative (and staying on PrEP) or testing positive (and

enrolling in ART) become equally important. As of April 2017, a PrEP demonstration trial is undergoing ethics clearance and has not yet started in Southern Philippines. The results are to be used to undertake a major scale-up in Quezon City and other cities of greater Metro Manila.

- » Current community-based clinics funded by municipalities such as Quezon City should be encouraged to have a **“one stop” sexual health and harm reduction service** that provides harm reduction and drug counselling to MSM who use drugs as well as TB and viral hepatitis screening, vaccination and treatment and HPV prophylactic vaccination for young MSM, as well as mental health services.
- » It would be commendable if, in line with the situation in other countries, the Philippines would move to a system where medical files are centralized and kept online and can be accessed across facilities in order to prevent clients' files from getting lost or to prevent clients from getting lost in the system.

- There is a need to reform the testing and counselling framework in the Philippines to address the various challenges highlighted in this paper, including expensive out-of-pocket testing, geographically remote testing sites, and inadequate counselling procedures.

In the section below, specific recommendations based on each of the four chapters featuring case studies are presented.

Specific recommendations to promote HIV testing among men who have sex with men

- Too many Manila-based men who have sex with men still believe there is a link between how a person looks and his HIV status. There is a need to raise awareness and de-link HIV infection from physical looks or social position. This means that potential clients of testing centres should understand that being of average weight, overweight or not losing weight, or being a doctor, nurse or a prime minister does not say anything about whether one can get HIV or not – for HIV transmission, behaviour counts, not sexual positions or body shapes.
- HIV can be transmitted in several ways including unprotected anal sexual intercourse or sex with an infected person, and the sharing of contaminated needles. Some men believe if they are only tops, or if they have a limited number of sexual partners, they will not become HIV infected. These misconceptions also need to be addressed.
- To overcome the lack of communication on sexual matters between intimate partners, there is a need to promote and normalize regular HIV testing among gay couples, even those who are in supposedly monogamous relationships. Similarly, “negotiated safety” within a monogamous relationship should include at least six-monthly HIV testing of both partners regardless of self-reported (or self-confessed) sexual behaviours with third parties.
- It is important for men who have sex with men to be aware that they will not be the only one with HIV if they test positive. It should be made known among gay and other men who have sex with men that there are thousands of men who already have HIV in Manila; the availability of strong and confidential support groups for men who have sex with men with HIV, operating both online and offline, should also be promoted.
- Misconceptions about the side effects of HIV treatment should be corrected to encourage more men who have sex with men to come forward and get tested. Many men did not want to get tested for a long time due to their fear of side effects of ARVs, which were linked to worries that their families or others might find out about their HIV status because of these side effects. MSM should have information about possible side effects and how to address them.
- Awareness about the clear benefits of knowing one’s HIV status sooner rather than later should be raised; many men thought it would be OK to wait to get tested until symptoms of AIDS would develop. A proposed awareness campaign could play on the prevalent fear of side effects from ARVs and show that the likelihood of side effects is much stronger if the body has a very low CD4 count. This would strengthen the argument to test early and not postpone any longer.
- Moral convictions seem to be a barrier for some men to access HIV testing. Words or phrases that are associated with morality, such as “promiscuous” or “sleeping around”, should be avoided in campaigns or promotional

materials to promote HIV testing, as many men who have sex with men tend to view these words negatively and will not feel addressed if these terms are used. Instead, HIV testing should be positioned in terms of being healthy, responsible and smart – regardless of the specific reason someone has for being tested.

- The settings in which HIV testing takes place should be made more accessible. Among the different HCT centres in Manila, opening hours should be extended and diversified, so that the hour of day should never be an excuse not to have an HIV test. Since some participants worried that people waiting for an HIV test could read their test results from their faces after coming out of post-test counselling sessions, it should be considered to organize HIV testing facilities in a way where incoming and outgoing clients do not need to meet each other: this can be done by having the entrance at a different side of the building than the exit, allowing for a flow-through of clients that minimizes the chance clients meet people they know.
- The experiences of [a major MSM/TG NGO]’s Platinum Testing and the planned pilot project on community-based HIV screening should be utilized to further promote the idea of utilizing outreach workers as lay counsellors to do rapid tests at a location of the client’s choice.
- The planned rapid HIV diagnostic algorithm (rHIVda, more commonly known as same-day test results) should be quickly implemented and rolled out to prevent dropouts in the HIV service cascade as well as to address the high level of HIV transmission that occurs during acute HIV infection as an innovative HIV prevention strategy.
- A pilot test should be considered of the use of home-based HIV testing kits among men who have sex with men, possibly under supervision of online outreach workers able to provide pre-test and post-test counselling via Skype. Municipalities could trial the Lao PDR/FHI 360 Linkages Oral Solution Testing as a screening test in “hot spots” supported by community outreach workers and case managers (see <https://www.fhi360.org/sites/default/files/media/documents/linkages-success-story-oraquick-laos-may-2016.pdf>).

Specific recommendations to reduce the dropout between screening and confirmation tests

- The Department of Health should change the testing algorithm and abolish the use of western blot as a confirmatory test in favor of modern rapid tests. Anybody found positive after the screening test should be confirmed by a second rapid test. In line with the latest WHO guidance, being a man who have sex with men and having confirmed HIV (as per two positive rapid test results) should be a sufficient condition for enrolment on ARV treatment; there should be no unnecessary wait for CD4 test or viral load test results. Since RITM and its satellite clinic appear to already be working with two rapid tests; they should issue guidelines to other HCT service providers to do the same.
- It is important to provide better and clearer information online on the need to access treatment and how this can be done, and provide different options for doing this. Fears and misconceptions about the side effects of ART should be addressed online, as well as during HIV counselling.
- Counselling in private clinics, in particular, should be improved. The government should consider closing down private clinics if they cannot provide proper counselling, as a clinic like [private clinic B] bluntly states. HIV testing without counselling may do more harm than good, especially for the most vulnerable clients.
- In private clinics and hospitals, counsellors should provide the option for clients to access free treatment in government treatment hubs so as not to deter clients by mentioning the cost of treatment in their private facilities.
- It should be considered to find more client-friendly ways of delivering confirmatory test results, as for poorer clients the opportunity and transportation costs of going to RITM or [government hospitals] might be too high.
- Workshops and trainings should be conducted within HIV service organizations including [main MSM/TG NGO], ensuring that volunteers and workers living with HIV are not discriminated against and feel safe and at home. The scope of HIV service organizations should be broadened to include all levels of the HIV service cascade.

Specific recommendations to ensure more men who have sex with men in need enrol in ART

- It is important to provide better and clearer information online on the need to access treatment for men who have sex with men living with HIV and how this can be done, and provide different options for doing this.
- Clear and correct information about ARVs (as well as about the ineffectiveness of so-called “alternative” treatments for HIV) should be made available online, including about their benefits in terms of keeping the immune system strong and the body healthy, and most importantly, about the rare frequency of side effects. This might help reduce the impact these fears have on postponing treatment.
- Information campaigns for men who have sex with men should discard the prevalent idea of people with HIV who take medicines as “sick” or “weak”; taking and adhering to ARVs could be repositioned as the choice of people who are responsible, strong and wise.
- Several men in the study reported paying out-of-pocket costs for treating opportunistic infections. Messages should be considered focusing on how early diagnosis and early enrolment on ART can prevent OIs and their associated costs of treatment. ART enrolment is therefore not only the best option from a health perspective but also cost-effective. Furthermore, a review of pricing of medicines prescribed for OIs would be beneficial.
- Treatment adherence counselling should be improved. HIV testing without proper post-test counselling may do more harm than good for certain types of clients. It is important to explain different options for treatment, including their cost, and information about how rare side effects of ART are and what can be done if these occur.
- Counsellors and doctors should be regularly assessed – not only on their medical knowledge about HIV and its proper treatment, but also the way they treat clients. They should have empathetic and caring attitudes and should understand the fragile state of mind many people find themselves in when they are newly diagnosed with HIV, and the importance of a careful and caring attitude to ensure people do not lose hope and drop out of the HIV service cascade.

Specific recommendations to improve treatment adherence

- The importance of depression as a factor that leads clients to interrupt or cease treatment needs to be emphasized. Clients who commence ARVs must be told that symptoms of depression are common and should not be ignored but should be reported to health care providers and actively addressed. An assessment of mental health should be considered as a standard part of pre-ART procedures, in addition to CD4 and baseline tests.
- Clients need to be made better aware of what to expect when they start treatment. Improving ARV treatment counselling is an important way to educate clients that side effects are mostly temporary and hence reduce their chance of dropping out of treatment because they fear side effects are a permanent state.
- Counsellors and HIV advocates should strongly counter sensationalist and incorrect information about HIV and its treatment in their activities. Correct and unbiased information about ART and its obvious benefits (including the fact that side effects usually subside after a number of weeks of continued treatment) should be made available online. Misinformation online about side effects of ARV medicine, fear-based stories and pictures about people with HIV, and incorrect stories about alternative treatments were mentioned as factors that led people to discontinue treatment with ARVs.
- ARV home-delivered services should be widely promoted. Some clients who had issues with adherence had difficulty finding the time and resources to go to their treatment hub to refill their ARV supplies. The fact that [one of the social hygiene clinics], [private clinic E] and RITM now have services to deliver ARVs to homes may reduce the number of men who have sex with men on ARV dropping out on treatment for financial or time-related reasons.

- It is important that doctors, nurses and counsellors working to serve people living with HIV have the right personality and attitudes for their jobs; they should be monitored and regularly evaluated. In this regard, the planned HIV service rating system by [NGO Z], where clients can give scores to different HIV services for friendliness, professionalism, cleanliness, confidentiality and other criteria, should be welcomed, and will hopefully lead to unsuitable staff being removed or relocated to a different position where they can do less harm.
- The idea of asking newly diagnosed people with HIV to bring someone as a “treatment buddy” is excellent and should be continued, but it should not be a requirement for clients to be allowed to access ARVs, as seems to be the case at least at [public hospital A]. Treatment buddies should only be optional; some clients may not need one.
- Counsellors should discuss relevant family issues with clients when they enrol in ART. Some research participants feared that their family might find out about their HIV status if they took ARVs and experienced side effects; some also worried about having to make excuses to their family about why they had to go to the treatment hub and spend a lot of time there, and why they had to spend large amounts of money on laboratory tests. Counsellors should discuss different scenarios with clients and provide advice on how to deal with them – for example, how to hide ARVs and what to say to family members if clients elect to keep their HIV status hidden.
- Counsellors should ask questions about the family situation of a client and help the client make the right decision about his own health. If there was an ill or disabled parent or other family member in the family of a client, some participants chose not to be an “additional burden” on their family by requiring their attention, financial support and care for their HIV treatment; instead they postponed being on ART.
- Newly diagnosed clients should be strongly encouraged to join support groups for people living with HIV. Several of the men in the study found strong support and motivation to enrol in and adhere to HIV treatment after becoming members of support groups for men who have sex with men and transgender people living with HIV, such as REDx.

Annex 1



NATIONAL ETHICS COMMITTEE
Philippine Council for Health Research and Development
Department of Science and Technology

02 October 2015

DR. JAN WILLEM DE LIND VAN WIJNGAARDEN

Researcher

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A. Muang, Chiang Mai, 50000

RE: Exploring barriers hampering access to HIV testing, treatment, care and support interventions among men who have sex with men in Manila, Philippines

NEC Code: 2015-010-vanWijngaarden-HIV/AIDS

Subject: **Ethical Clearance**

Dear **Dr. van Wijngaarden**:

Greetings!

This is to acknowledge receipt of the revised protocol dated 25 September 2015 to include an action plan for results dissemination, translation and utilization. The above protocol was reviewed and found satisfactory.

The National Ethics Committee (NEC) hereby approves the following documents for study implementation:


- Full Proposal version date 25 Sept 2015
- Data Collection Forms (Questionnaires for HIV patients, Health Care Providers and HIV Services)
- Informed Consent Form (version and version date not indicated)
- Participants Information Sheet

This ethical clearance is valid for the period **02 October 2015** until **02 April 2016**. The NEC requires renewal of the ethical clearance of the study on or before the expiration date, if the study will be extended, and submission of a midterm progress report for monitoring purposes.

Amendments to the protocol, informed consent form or questionnaires shall be submitted to NEC for approval, and other implementation concerns like protocol deviations shall be communicated to the NEC for guidance.

Finally, the NEC requires the investigator to submit a final report upon study completion, which will contain a summary of findings and other issues encountered during study implementation.

Very truly yours,



MARITA V.T. REYES, M.D.

Chair

National Ethics Committee

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