



Negotiating Positive Living

a 10-country study by APN+ on
Issues Facing HIV-Positive MSM in the Asia Pacific

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Asia Pacific

Research Monograph

Volume 1: A Disrupted Biography

Martin Choo

Centre of Excellence for Research in AIDS (CERiA)
University of Malaya, Kuala Lumpur

The South East Asia and Pacific Technical Support Hub of KHANA
for the Asia Pacific Network of People Living with HIV (APN⁺)

August 2011

Acknowledgements

The Asia Pacific Network of People Living with HIV/AIDS wishes to thank the MSM Core Working Group members and advisors for their valuable inputs and reviews, the donors for their financial support and the APN+ Secretariat for making this report happen. This publication has been prepared in collaboration with many contributors at the country level. Special thanks go to all the individuals who agreed to be interviewed for this important research to improve the lives and wellbeing of positive MSM.

Without all your graceful contributions, the voices of positive MSM across the Asia Pacific would not have been heard.

Analysed and reported by:

Martin Choo

*Centre of Excellence for Research in AIDS (CERiA)
University of Malaya, Kuala Lumpur*

Analysis and conclusions presented herein are the author's own and do not represent the institution to which the author is presently attached.

For more information: please contact

The Coordinator

*APN+ Positive MSM Working Group
51/2, 3rd floor, Ruam Rudee III Bldg.
Soi Ruam Rudee, Ploenchit Rd
Lumpini, Pathumwan
Bangkok 10330 THAILAND*

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Participating Countries

01 Cambodia

02 China

03 India

04 Indonesia

05 Laos

06 Malaysia

07 Myanmar

08 Papua New Guinea

09 Thailand

10 Vietnam

Abstract

Background: There is now overwhelming evidence that the epidemic among MSM (Men who have Sex with Men) is well established and increasing. While some actions are now being put in place on a regional and country basis to address prevention amongst MSM, there has been very little work done in regards to the issues for MSM who are already positive. To fulfil this gap, community-based organisations of positive people linked to the Asia Pacific Network of People Living with HIV (APN⁺) through a participatory research methodology, learned to design and implement a study to explore the issues affecting positive MSM in the region.

Methods: As a result, 17 focus group discussions were peer-led in 10 countries: Cambodia, China, India, Indonesia, Laos, Malaysia, Myanmar, Papua New Guinea, Thailand, and Vietnam. In total 124 positive MSM (including 21 transgender), 19 of whom married and 72 on ARV, participated in discussions conducted in local language. These were recorded, transcribed and translated into English for analysis. Thematic analysis that was constantly compared between countries distilled a guiding orientation of issues faced by positive MSM across cultural differences and between countries.

Results: Findings suggest an emerging pattern that HIV has had a profound effect on positive MSM's sense of self and relationship with others: living with HIV changes you, changes the meaning you have about yourself, and who you are. In essence, there appears to be a *biographical disruption* (Bury 1982)—the confusion and disturbance to the stories we tell ourselves and others about who we are, and through these stories derive meanings about our lives—among those testing positive and living with HIV. Looking closely at the associations positive MSM have about being positive, results suggest that this confusion and/or disturbance can be enabling or disabling, depending on how well the individual integrates HIV into their lives. For the majority of positive MSM who participated in the study, the common disruptions post-HIV centred on the existential/moralistic (living/dying, right/wrong) and with sex/sexuality. The latter was found to be particularly disabling and commonplace, causing psycho-emotional distress and often socially disruptive; leading to social isolation and alienation that is fuelled by a moral responsibility towards safer sex. This disabling disruption suggests the possibility that positive MSM in the region may be suffering from a crisis of sexual identity as a result of HIV.

Conclusion: This study provides a timely critique on the lack of community-centred discussions surrounding sex, sexuality, and sexual identity. The ongoing global attention on quantifiable markers to health, universal access to treatment, medication adherence and condom use, while certainly important, only skim the surface of deeper quality of life for positive MSM; which necessarily depends on looking deeper into the meanings HIV has had on the lives and stories of those who have to live with it. Thus, it has been found that positive MSM in the Asia Pacific are left to mend their lives, their sexual identities, and relate anew post-HIV with the world outside, the best they can; in many cases with minimal social or institutional support. This gross injustice needs to be redressed if we are truly serious about being sensitive and responsive to the actual needs of communities affected by HIV. Perhaps only then will we have an enabling environment and politics that are yet to be.

Introduction

This study is a concerted effort by the Asia Pacific Network of People Living with HIV (APN⁺) to tell and make sense of the stories of positive MSM (Men who have Sex with Men) and their relationships with HIV, society and culture in the region. By focusing on community participation from the onset of study design to implementation, this study encourages mutual understanding by engaging positive MSM communities in the region and providing them safe spaces to tell their stories. By doing so, we have attempted to meet individuals and communities at their own levels, and facilitate a deeper understanding of their relationships with HIV.

Overview

In total, 124 MSM (including 21 transgender) participated in 17 peer-led focus group discussions (FGD) in 10 countries in the Asia Pacific region. These are Cambodia, China, India, Indonesia, Laos, Malaysia, Myanmar, Papua New Guinea (hereafter PNG), Thailand, and Vietnam. Of the total participants, 19 were married and 72 were on antiretroviral therapy (ARV). Conducted by community-based organisations linked to APN⁺, these discussions were carried out in local language, recorded, and transcribed, before being translated into English for analysis.

The report is laid out as follows: this introduction provides the background and objectives of the study. The following section on methodology sketches a brief overview of the participatory research method used to train community representatives to conduct the study, the rationale of employing FGD as data collection method, and summarises the outcome of collection and quality of data. Following from this, the theoretical framework that underpins data analysis is laid out. The subsequent two sections discuss the results of the analysis. The conclusion summarises the findings and suggests a way forward.

At the onset, given the amount and complexity of the data, it has to be noted that the analysis reported here is based on a generalised orientation. This means that only similar issues shared by MSM in all 10 countries have been included in the framework for analysis. Hence, the analysis does not purport to show variation between countries, nor does it highlight particular issues specific to MSM in selected countries. Comparative and country-specific analyses will be given in Volume 2 of this report.

It is hoped that the findings reported here will show that, even with the diversity in cultures, languages, and concerns of the Asia Pacific region, positive MSM here share a common trajectory and issue with regards to HIV. Thus, a concerted region-wide effort to support positive MSM by sharing a common platform of needs and goals is indeed necessary and possible.

Finally, this report also hopes to spur more high quality peer-led and community-based research endeavours to better understand the issues specific to the communities in the Asia Pacific region, and to promote and grow peer-led research capacity here.

Background

There is now overwhelming evidence that the HIV epidemic among MSM is well established and increasing (Baral et al. 2007). While some actions are now being put in place on a regional and country basis to address prevention amongst MSM, there has been very little work done in regards to the issues for MSM who are already positive, their care and support needs and the role they can play in the HIV response, including prevention.

Responding to this gap of information and the resulting lack of support, the Asia Pacific Network for People Living with HIV (APN⁺) has taken the lead by forming the APN⁺ MSM Working Group and conducting focus group discussions (FGDs) among local positive MSM in five countries in 2007: India, Indonesia, Malaysia, Myanmar and Papua New Guinea. These peer-led FGDs have pooled together information and highlighted issues that positive MSM face and hence the needs they have. The initial FGDs form the first step in the process of systematically documenting and analysing the impact of HIV, on MSM who are living with HIV, to which the present study expands.

To continue and expand on this groundbreaking process, it is now necessary to locate the collected data in the socio-cultural structures of each country—and to expand the project to other countries—to better assess the situation faced by MSM communities in the region. This will allow for a greater understanding of the interaction between social structures and individuals that limit options available to MSM within the Asia Pacific; and promote the formulation of an evidence-based response with a view to framing policies that can better address their needs.

The participation of positive MSM in each step of the research process and analysis remains a prerequisite. This overarching policy will (1) ensure validity of research findings; (2) foster greater positive MSM community empowerment as outlined in the principles of GIPA; and (3) encourage ownership of findings as tools for community development and advocacy.

Objectives

1. In consultation with local positive MSM communities, analyse the socio-cultural processes within country and how they impact on behavioural and treatment options available to positive MSM in the region;
2. Document the consequences of these socially mitigating circumstances on positive MSM and how these impact on their families and communities (focusing on health, disclosure, finance, social and sexual issues);
3. Identify the unmet needs of positive MSM;
4. Document the treatment, care and support services (health, welfare, counselling, etc.) positive MSMs are accessing and identify service gaps;
5. Consolidate this unique information base on positive MSM with their participation in all stages of the project.

Methodology

The research framework builds on the preceding 2007 Asia Pacific Network of People Living with HIV (APN⁺) focus group discussion project among Men who have Sex with Men (MSM). Initially implemented in five Asia Pacific countries—India, Indonesia, Malaysia, Myanmar, and Papua New Guinea—the original framework utilises a qualitative peer-led approach to systematically document and analyse the impact of HIV on the lives of MSM living with HIV in the areas of healthcare, social and economic constraints, sexual behaviour, and HIV status disclosure. The main purpose of this project is to assess information from the MSM community with a view to framing policies that can better address their needs.

Since the last study, APN⁺ has taken steps to enlarge the geographical reach of the discussion by including China and other countries in the Greater Mekong region—namely, Cambodia, Laos, Thailand, and Vietnam—to bring the total number of Asia Pacific countries to 10 in total. Keeping in step with this enlarged vision, the revised research framework proposes to (1) increase analytical capability of the project, (2) increase rigour in data collection by practical training in focus group discussion (FGD) as a research method, and (3) to introduce participatory action research (PAR) methodology into the research design to increase the involvement of positive MSM in both research design and research outcome as envisioned by the principles of GIPA.

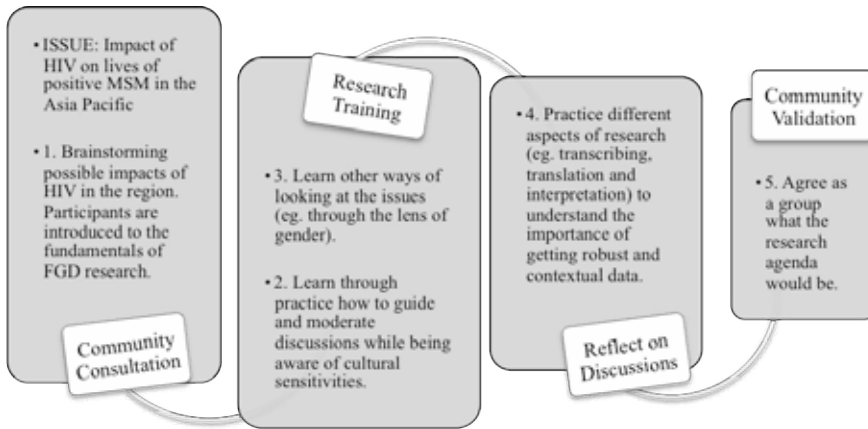
In order to achieve the abovementioned vision, representatives from community-based organisations in the 10 Asia Pacific countries convened for intensive research training in February 2010 in Bangkok. As part of the course, participants were inducted in social research fundamentals that provided them with a platform from which to investigate the issues affecting positive MSM in their communities. The fundamentals of the course have been elucidated in a separate report on consulting with the community prior to the study. In summary, the course consisted of grounding in the framework of PAR as a research methodology, discussion on the impact of socio-cultural contexts on the lived experiences of positive peoples as a research perspective, and the practice of using FGD as a research tool—including guides on transcribing and translating; it was envisioned that by putting these three components together, participants will be better equipped to undertake research in their own communities with more scientific rigour, and in the process systematically elicit information that may shed light on the situation of positive MSM in the region. The rationale behind the decision to use of PAR methodology, investigate socio-cultural contexts, the selection of FGD as research method, and how they work synergistically together in the field to create more rigorous research in the field is elucidated below.

Participatory Action Research (PAR) as the research methodology

Foundationally in concordance with the principles of GIPA and sensitive to the power dynamics in studying marginalised communities, PAR blurs the line between researched and researcher such that the researched becomes researcher (Baum et al. 2006); in line with the objectives of the project to build research capacity. The employment of PAR allows positive MSM decision-making over research process (its protocol) and to determine the research agenda. What community-based organisations may

lack in research experience, the methodology of PAR which values community-based knowledge equalises in the playing field (Walter 2009); technical knowledge in research are put on par with local knowledge. Besides being highly empowering especially for peoples marginalised by society, this makes clear what both researcher and researched brings to the table, and with the respect of each. Diagram 1 below depicts how the consultative process of this approach laid the foundation for the research methodology that underpins this study.

Diagram 1: Cyclical iterative PAR process as research methodology (Adapted from Walter 2009)



Socio-cultural contextualization as the research perspective

The estimated total population of the 10 Asia Pacific countries included in this study is 2.95 billion people, or nearly half of the world’s population (Wikipedia 2011). The Asia Pacific represents one of the most diverse socio-cultural conglomerations. Thus, to better cater to and understand the expected variation of responses from the FGDs—while maintaining cultural sensitivities—participants of the workshop had been given an overview of how socio-cultural contexts can impact on research subject perceptions, experiences, and views. In particular, the notion of gender had been an important focus since individual meanings and socio-cultural requisites for men were expected to be as divergent as the number of cultures within the region; and possibly even within a single country. Furthermore, it was deemed important to capture the differences in socio-cultural structures from family composition and expectations, economic realities, to healthcare provision in order to provide a balanced view of the issues affecting MSM in each participating country, and the Asia Pacific region as a whole.

Focus Group Discussion (FGD) as the research method

From the foregoing discussion, it is accepted that the research subject is inherently complex: The issues are complex because the issues of positive peoples are inherently complex due to the trajectory of HIV from an acute medical condition to that of chronic illness and the further bio-medical and socio-cultural effects from ARV medication itself (Flowers 2001); not to mention the necessarily compounding of issues surrounding negotiating care as part of a marginalised population; sex, sexuality and relationships; work and finances; and family and community; as a result of being positive and MSM

requires careful deliberation and sensitive portrayal (Caceres et al. 2008). Further, while there has been many research endeavours on the concurrent themes of MSM and HIV in the region, a quick survey of existing literature shows that few of them originate from the perspectives of positive MSM themselves.

The under-researched nature subject and the complexities summarized above calls for a qualitative research methods to sufficiently explore the dynamics of living as a positive MSM in the Asia Pacific, while respecting the voices of those with whom the research is conducted. Under the rubric of qualitative methodology, and based on resource limitations, three research methods came under scrutiny: in-depth interviewing, nominal group/expert panel discussions, and FGDs. Table 1 below (adapted from Power and Single 1996) compares them.

Table 1: Comparison of focus group discussion with other qualitative research methods

Criteria	In-depth Interview	Nominal Group / Expert Panel	Focus Group
Participants per session	1	6-10	6-10
Goal	individual views/experiences	consensus opinion	divergent views/experiences
Interaction quality	no	partial	yes
Level of group influence	N/A	medium	medium/high
Level of structure	low	high	low
Depth of experiences	deep	shallow	medium
Range of experiences	narrow	medium	wide
Level of moderator involvement	low	high	low

In view that the objectives of the study explicitly stipulate the principles of GIPA—the greater involvement of people living with HIV and AIDS—FGD emerged clearly the research method of choice. In comparison to other research methods, FGDs reach a larger number of participants in a short timeframe, fosters high interaction between research subjects, and offers the capacity for divergent and wide range of views and experiences to come to the fore through this interaction. FGD also has the added advantage of fostering a sense of community as occurs when individuals come together to share their stories around a common theme which is in line with community-based research. While the depth of experience that can be elicited using this method is admittedly not as deep as that of in-depth interviewing, this limitation was seen as an acceptable trade-off in light of benefits accrued.

Outcomes: Interactive relationship between methodology, context and method in the field

In keeping with the objectives of the study, the study design employed here attempts to unite the needs for scientific rigour and attend to socio-cultural variation while promoting the principles of GIPA through research capacity building among community-based organisations. Thus the results depicted in this report is built on the work and dedication of communities in 10 Asia Pacific countries, which included setting the research agenda and protocol, conducting and transcribing the FGDs, and translating the transcripts into English.

In particular, the PAR process culminated in the community consensus on more stringent ethical requirements of a written informed consent from each participating research subject, and a validated research instrument. The following are broad sections in the community-validated instrument:

- Health and treatment – exploring treatment availability, access, adherence, and coping
- Finances – exploring the financial burden of HIV
- Socio-cultural norms – exploring gender roles and legality of MSM activities

- Sex and sexuality – exploring perceptions of sexuality, safer sex, and HIV
- Disclosure – exploring the dynamics of MSM/HIV disclosure

Through the explanations on socio-cultural contexts, participants (and would-be FGD facilitators) were coached on how to select participants when setting up their FGDs to ensure diversity of responses. In particular, they were asked to think about characteristics such as if participants are currently on ARV, if they are transgender, their age group, marital status, and urban/rural living; and how these might impact on participant responses and group dynamics. Each country had to deliver at least one FGD which is audio recorded, transcribed in verbatim and translated into English for analysis. As agreed in the research protocol, each country representative had to submit their transcripts together with a reporting form that provided participant characteristics. Table 2 summarises FGD composition and data quality by country.

Table 2: FGD composition and data quality by country

Country	FGD	N	Participant Characteristics				Data Quality	
			Age Range	On ARV	Married	TG	Rating	Main Issue
Cambodia*	2	16	N/R	11	1	2	Moderate	Non-discursive
China	2	18	26 - 53	9	3	0	Good	-
India	1	8	27 - 44	5	2	2	Poor	Non-verbatim
Indonesia	2	14	20 - 49	8	1	7	Moderate	Translation
Laos	1	8	29 - 43	7	1	1	Good	-
Malaysia	1	8	22 - 51	4	1	0	Good	-
Myanmar	1	10	22 - 60	5	5	0	Moderate	Non-discursive
PNG*	1	5	N/R	2	1	N/R	Poor	Non-verbatim
Thailand*	5	29	N/R	13	4	9	Excellent	-
Vietnam	1	8	30 - 40	8	0	0	Poor	Non-verbatim
Total	17	124		72	19	21		

N/R – Not Recorded

* Information obtained from transcripts, FGD reporting forms not submitted.

There were wide variations in data quality directly attributable to localised lack in research capacity and experience, particularly in understanding complex research concepts and applying them systematically in the field: Major issues include: (1) FGDs not conducted in a discursive style (Cambodia, Myanmar); and (2) data loss from non-verbatim transcribing and/or poor translation (India, Indonesia, PNG, Vietnam). The Cambodian team had an added difficulty with a change in facilitator midway through the research to one who had not been trained. That said four countries did complete the research to a high standard. Of note is Thailand, which produced an ambitious five FGDs of high quality that were subdivided according to urban/rural living (and grouped by MSM, male-sex-workers, and transgender participants). China, Laos, and Malaysia each provided complete transcripts with rich contextual data. Nonetheless, it must said that taken together, the result from all 10 countries is remarkable given that the study has been peer-led and implemented across a diverse region in terms of cultures, languages, resources, and capacities.

Summary of Analytical Process

Analysis of FGD data began as soon as all FGD transcripts were received. Transcripts were read multiple times before being coded. Codes were grouped thematically according to participants' experiences and their relationships with HIV. Analysis of themes focused on accounting for similarities and variation; that is, similar experiences of positive MSM across countries, and variation of issues

between countries. To achieve this, two levels of analyses were carried out: (1) individual-specific, and (2) country-specific. A brief summary of the analyses as follows:

1. **Individual-specific:** Thematically grouped codes were constantly compared between country-level data to distil an overarching issue generally faced by positive MSM across cultural differences and between countries. These thematically grouped codes thus form a guiding orientation that is taken to be the predominant issue for positive MSM in the Asia Pacific region, and makes up the foundation of this report (Volume 1).
2. **Country-specific:** Analysis then focused on issues within country where the overarching theme is contextualised to uncover particular issues that were country-specific for positive MSM in Volume 2. In each of the 10-countries, attempts were made to provide an integral view of human development post-HIV based on a Four Quadrant (Integral) Framework (Wilber 2000 for a concise summary). Results depict how local cultures informs and is informed by personal meanings of HIV, and infer how these may affect individual and collective responses to the epidemic. Suggestions on possible participatory action programmes for each country to advocate for change are given at the end of each country-specific analysis. Attempts will be made to critically link this analysis to the leadership training programme designed by the UNDP's HIV/AIDS Group in resonance with the work of Ken Wilber (Gueye et al. 2005).

The next section, to which we now turn, provides an overview of the theoretical framework behind the analysis.

Theoretical Framework

The theoretical framework adopted here begins with Michael Bury's (1982) seminal work on biographical disruption as a result of chronic illness. To be clear, the theoretical framework outlined here has not been derived *a priori*—that is, theoretically deduced *before* data was collected. As described in the previous section on methodology, focus groups were conducted by community groups based only on the sole purpose of uncovering and understanding the issues that affected the lives of positive MSM in the region. In the course of data analysis however, the theoretical framework given below emerged as the best fit to explain the narratives collected as a result of constant comparison between data obtained from the 10 countries. In brief, the following overview explains the relationship between the disruption of HIV on individual narratives and sense of self, and the impact this can have on sexual identity.

Biographical Disruption from HIV

With the advent of highly active antiretroviral therapy (HAART), HIV has been successfully redefined as a medically treatable chronic condition. However, the ability to control viral replication by means of medication should not negate the importance of dealing with the social and psychological effects post-HIV, and the recurring issues of stigma, discrimination, adherence to treatment and the like, that punctuate the experience of living with HIV. These events have brought to the fore the importance of reconsidering the concept of biographical disruption—the confusion and disturbance to the stories we tell ourselves and others about who we are—that was coined by Bury to explain the intrinsic difficulties patients with chronic illness have to face. When studying patients with the onset of rheumatoid arthritis, Bury found that it changed the way they related with themselves, the people around them, and their world:

First, the meaning of the event of rheumatoid arthritis itself was seen in terms of an analogous shock to her life... Whilst she 'managed' or 'coped' with the disease – kept it at bay as much as possible – it continually intruded into her sense of self-confidence, upsetting an already precarious balance... a disruption of structures of explanation and meaning but also of relationships and material and practical affairs (1982: 175)

While admittedly rheumatoid arthritis as an illness does not share many symptomatic similarities with HIV, the quotation given above does however resonate with the experiences of positive peoples: if one were to substitute rheumatoid arthritis with HIV, the quotation could certainly serve as an apt and current description of a positive person's experience especially in the shock and uncertainty that come in the wake of HIV, and how it inadvertently restructures the way he sees and negotiates with the world. Indeed, writing at a time prior to HAART, Carricaburu and Pierret (1995) found that “the consequences for everyday life of being HIV-positive cannot be separated from how they interpret their situation” (2004: 301).

Unpacking the interpretation of HIV, especially for MSM, necessitates delving into the shared cultural meanings HIV and AIDS has had for gay men. In this respect, HIV has had a decidedly chequered history. From the earliest labelling of the virus as a gay disease (GRID) in the early '80s, to the

subsequent shift of perceptions of risk from associations with a particular group (of gay men), to individuals and their (risk) behaviours meant the inevitable moralising attitudes surrounding HIV and positive men have become intensely personal (Galvin 2002). At the same time, advances in medicine with HAART and the focus on prevalence and healthcare delivery have moved increasingly to objectify HIV outside and beyond individual perceptions and meanings to the realm of CD4 and viral load counts and statistical numbers (Flowers 2001). In short, while the preoccupation with empirical science has greatly improved quantifiable life chances of individuals living with HIV, it has contributed little to a deeper understanding of the quality of life of positive peoples that is predicated on successfully integrating the subjective and inter-subjective (cultural) meanings of HIV with our sense of selves; the failure of which has advanced the possibility of “biographical disruption as chronic illness” (Williams 2000).

Thus, while HAART has certainly changed the medical trajectory of HIV for the better, the interpretive difficulties brought about by HIV for individuals remain largely undisturbed. Findings given herein, therefore, provide a timely supplement to the current focus on Universal Access to treatment and Treatment 2.0—recommending treatment for positive persons at higher thresholds of CD4. While laudable, the focus on treatment needs to be balanced with a similar focus looking into the interior psychosocial aspects of HIV experience—chiefly, that of sexual identity—that may also have catalytic effects on HIV trajectories.

Identity Post-HIV

For positive peoples in particular, HIV is in actuality more than CD4 and viral load counts, prevalence figures, number of times one has had sex without condoms, healthcare capacity and costs, and so forth, important though as they are. Being diagnosed with HIV means the need to live with the virus, to expand individual meaning and narratives of self with the inclusion of HIV, to renegotiate support structures and relationships in the wake of HIV, to accept that HIV as part of life by successfully dealing with the inevitable fear, especially for gay men, that is unfortunately embedded in the historical and cultural meanings of HIV. On these subjective and inter-subjective meanings of HIV, the current dialogue is undeniably muted.

There is a need now to redress the balance. By encouraging dialogue on the interior of experiences with HIV—both the personal and inter-personal—positive people can reclaim a holistic sense of self that would otherwise be denied them as long as HIV remains reduced objectively external to the individual. To summarise, in unpacking the issues affecting positive MSM in the Asia Pacific, the analytical strategy here is (1) to understand how MSM in the region relate to being HIV-positive; and (2) to understand how being positive has changed them. Together, the analysis attempts to uncover what it means to be positive for MSM in the Asia Pacific and highlight the issues that positive persons face in the region. The analysis will bring to the fore the notion of biographical disruption: how, as a conceptual tool, it embodies the experiences of positive MSM in the region; how it may affect individual behaviour, how individual meanings that surround HIV are informed by those around them, and to what extent HIV affects the identities they will eventually adopt.

HIV as Biographical Disruption

Looking at participant testimonies, and the emerging pattern across 10 countries, it became clear that HIV has had a profound effect on individual sense of self and relationship with others. Table 3 provides a glossary of words and phrases participants associated with, and used to describe, their experience with HIV (a complete list of associations given in Appendix A). These were thematically grouped according to the type of disruption these could have for positive persons; that is, in terms of psychological, emotional, physical/health and social disruption HIV has had on them. Going through the list gives us a sense of the pervasiveness of HIV in effecting an individual’s relationship with himself, with others, and the world as he sees it. It is, thus, not difficult to imagine that living with HIV changes you; changes the meaning you have about yourself and who you are.

Changes in Meanings of Self

Our biography is made up of stories we tell others and ourselves about who we are, and through these narratives derive meanings about our lives—the crux of our identities. Arthur Frank, writing about illness and a subsequent need to revise our stories of self, notes that “[s]tories do not simply describe the self; they are the self’s medium of being” (1995: 53). Thus, by observing how individuals describe their situation after diagnosis and subsequently in dealing with everyday life, we are able to isolate the effective associations they have about HIV, and allow us a glimpse on the impact HIV has had on the meanings they hold about themselves.

Table 3: Biographically Disruptive Associations with HIV

Psychological Disruption	Physical / Health Disruption
afraid [of being] label[ed]	tired and exhausted
[fear] of transmitting to others	can't afford treatment
lost control	afraid [of other] virus[es]
cannot behave carelessly	thinking perhaps may die
[needs to be] understood	health loss
worry	physically weak
depression	extra precautions [in sex]
life now is contradictory	cautiousness
mental tension	saving own image
cannot cope	side effects
bothers me a lot	make[s] me look ugly
worry [about] every step	less attractive
felt useless	[less] working ability
didn't want to live	priority [on] my health
feel imperfect	warns me to be careful
a burden all the time	couldn't eat
Emotional Disruption	Social Disruption
painfulness	afraid [will] not be accepted
suffer	isolated / alienation
scornful	lonely
felt so lost	insecure / inferior to others
shame	hiding / hidden
sky was falling down	daylight ghost
cannot be happy	tell no one / secret
lost control of my tears	rejected / rejection
scared	life has been destroyed
terrible fear	avoiding
disgust	dismissed / discrimination
collapse	expecting rejection
crying alone	sneer[ed] with slanting eyes

Central to these meanings is one of mental and emotional suffering, social isolation, inadequacy and inferiority, and of being lost. Hence according to Kleinman, “[m]eaning is created in the context of serious illness out of the very stuff that makes up our personal and cultural dilemmas” (1988: 144). The dilemmas that Kleinman refers to are the disruptions that serious illness inevitably brings to our sense of self. Referring to Table 3, the words participants use give some indication to the extent of these

disruptions. When discussing HIV, participants admit that they have “lost control” of their life, “feel[ing] imperfect” and somehow “life now is contradictory”. This change can often be profound: Some describe it as a “collapse” as if the “sky was falling down”. This shifting of states from wellness to illness can create significant mental trauma to the extent of thinking, “perhaps [they] may die”. Physically, there is a realisation that their “working ability” has deteriorated which leaves them “insecure” and socially inferior. A Chinese participant explains:

I knew a person living with HIV... in the past, he wanted to do good work, and he had strong motivation to learn. Since he knew his HIV status, he has felt that he is inferior to others. (P8-1, China)

The profundity of these changes “[needs] to be understood” as it “bothers [them] a lot” and causes some “to worry [about] every step”. Part of the worry is moral; stemming from the “[fear] of transmitting [the virus] to others” and evoking the conscience in some that it is no longer business as usual; that one “cannot behave carelessly”, both towards oneself and others. HIV leaves positive persons with an added sense of responsibility—a moral imperative that translates to “cautiousness”—and “warns [some] to be careful” (Galvin 2002: 111, 129). Throughout the 10-countries, positive persons reported shifts in the “priority on [their] health” and taking “extra precautions [in sex]”. The concern about safer sex has been reported without exception in all the FGDs.

Changes in Relations with Others

As far as this goes, a shift in priorities towards health and safer sex are positive changes. Yet, there is a sense of foreboding in the social sphere as HIV comes between those who are positive and their social world; translating as “expecting rejection” in some, and “avoiding” social contact in many. Due to the pervasiveness of issues as depicted above, there is a high chance that the individual will develop a stigmatizing identity as a result. It is unsurprising, therefore, that those who are not able to reconcile with their new identities by successfully embracing HIV as part of their narratives may find that they “cannot be happy”—living, always as they are, under the shadow of HIV:

I am still afraid to open up about myself as I’ve just learned about the result... [am] afraid to get through the stage where we have to come forward about ourselves and this is a problem for the second gender girls... It takes quite [a lot of] pressure to do so... I am afraid to tell anyone that I am infected, and so I [am] kind of *afraid of everything, everyone*. (P4-3, TG, Thailand; *emphasis added*)

In short, without being able to reconstruct changes in their biography in the advent of HIV is also to prolong the suffering that HIV can and does inflict on individuals. Kleinman (1988: 160) puts this in rather stark terms: “The patient may resist the stigmatizing identity, or he may accept it; either way, his world has been radically altered.” Indeed for one participant, “life [he once knew] has been destroyed.”

Table 4: Disabling and Enabling Associations Post-Disruption

Disabling Associations	Enabling Associations
reckless / risky**	care [for] myself
expected [to be] positive*	understand [about] HIV
just wait[ing] to die*	enriched life*
suicide*	safer sex**
impossible [situation]	face reality / wake up call*
financial loss	pay attention to safety
limitations	forced to accept / life lesson *
suppress my many desires**	become wiser*
deserve to be infected*	disciplined living*
reminded am infected	sense of responsibility*
celibate**	repentance*
feeling guilty*	be better than what I am*
[led] a loose life**	courage to disclose
death sentence*	discovering religion*
burden on society	serious about the future*
led a life of pleasures**	there's still life, hope*
social dregs	accept who I am*
frightened [of sex]**	treatable illness
I don't care*	it is still me*

* existential / moralistic ** sex / sexuality

This radical alteration, or biographical disruption using Bury's terminology, can be prolonged and unrelenting especially for the chronically ill. Frank, in his study of illness narratives makes a poignant observation: "Disease interrupts a life, and illness then means living with perpetual interruption" (1995: 56). It is as if one is now living in a different world and must readapt anew to life. Bury explains:

My contention is that illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted... it brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support (1982: 169).

Frank and Bury's explanation are insightful in shedding light on how illness is always intrinsically social; perhaps more so for HIV due to the inherent stigma that inadvertently shadows it (Herek and Capitanio 1993; Aggleton 2009). Hence, positive individuals must learn to deal with biographical disruption from HIV the best they can. Typical of biographical disruptions, however, individuals not only have to face the fact that life is now different—and how to reconcile anew with the meaning of who they are or feel they should be—but also in coming to terms with their actions that contributed to the disruption. Inevitably, especially for those who are infected through sex, this means coming to terms with the fact that they played a role in becoming positive. The implication of this knowledge on the sense of self, in particular on one's associations with sex and pleasure—and by extension, sexuality—cannot be understated; a Malaysian participant sums up dryly:

When, when... you get naked you know, the first thing that [gets] into your mind is HIV. (P5, Malaysia)

Enabling and Disabling Changes

By paying closer attention to the words and phrases participants use to describe the effects HIV and how they coped with being positive we get an idea how well participants have adapted to their new biographies; and, by extension, the meaning HIV has had on their lives. Table 4 groups these thematically as disabling and enabling associations depending on the contributing effect they have had on participants' sense of self. Associations are deemed disabling if the meanings participants associate with HIV are perceived to constrict and/or recriminate, and enabling when they provide constructive meanings to participants.

As to be expected given the moral imperative discussed above, the majority of recorded associations can be categorised as existential or moralistic (*) in nature; that is, HIV has a reflexive impact on how well they have lived (including caring about themselves and their future, and if they will continue living), and whether participants consider themselves good or bad persons. Thus with disabling associations, there are tendencies for participants to think that life is over as signified by their usage of words like "suicide" and "death"; or that they are bad people for having been infected as signified by phrases like "expected [to be] positive" and "guilty". Existential and moralistic judgments can also provide enabling associations in signalling that being positive was a "life lesson" that provided a "wake up call", helped them "face reality", and gave some positive persons "hope" for the "future" to become "better" than who they previously were. For some, there were clear religious undertones in their reflections of self; for others, there is a need for reassurance that HIV has not fundamentally changed them; a respondent from PNG explains:

Felt useless... didn't want to live any longer... [but] got information (name of NGO) [and] I have [the chance of] *being the same again*. (Respondent unknown-1, PNG; emphasis added)

Crucially, when grouped thematically by sex and sexuality (**), participants' associations with HIV unanimously indicate a constricting self-sense: none of the participants actually iterated enabling associations with regards to sex and sexuality besides general notions of "safer sex"; which, more often than not, only means sex with condoms, or non-penetrative sex:

It changes me a lot. In the past, I never used condoms. Now I have to wear it every time. One more thing is I never take medicine. Now I take medicine every day and living in fear that other will know that I'm infected. In the past, I worried nothing. Now I worry every step. (*P1, Laos*)

Coupled with fear, safer sex is not necessarily the panacea it is made out to be. Without more constructive and sensitive discourse surrounding sex and sexuality beyond messages of safer sex, many positive MSM will continue to live in distress that their status will be revealed.

Before we go any further, it is perhaps wise to distinguish between sex and sexuality. It goes without saying that they are intrinsically intertwined; sex is the physical act that informs, and is informed by, the meanings one associates with oneself and others. These meanings are what we would collectively call sexuality. Indeed, the World Health Organisation formally defines sexuality as

...a central aspect of being human throughout life [that] encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. It is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors (WHO 2004; cited from Aggleton 2009: 3).

Based on this definition, discourse about sex and HIV in the Asia Pacific, as was found in this study, is largely silent on deeper meanings of safer sex beyond superficial focus on individual behaviour or action. Conspicuously scant too are discourses around sexuality and desire (Aggleton 2009: 8). These omissions are particularly unfortunate since, as alluded to previously, part of coming to terms with one's status is to accept the personal responsibility one has had in being infected; and open dialogue will certainly be therapeutic as individuals come to terms with their past actions. An Indonesian participant who has been able to make this, albeit bittersweet, transition tells us:

Yes, they (his ex-boyfriends) are more... caring... loving... even sometimes [they] ask me whether I have taken my tablets or not... (On disclosing to his current partner) Ya.. for sure he will make a distance... If he fear[ed] me it [would have been] ok actually, but I [will be] concern[ed] if he... mmm spill[ed] it out to the public. (*P1-1, Indonesia*)

Yet, as can be seen above, regardless of personal courage to disclose, the concerns about social perspectives on HIV is often never far away. An Indian participant clarifies:

I have seen in [the] case of other positive MSMs, how they were ill-treated in society. The fear that the same thing may happen in my case if my HIV status becomes known to all, bothers me lot. (*P4, India*)

Disabling Changes in Sex and Sexuality

Especially for MSM, the majority of whom get infected through sex, one's sexuality—by definition, inevitably becomes an area of scrutiny from self-reflection—and can lead to self-recrimination if one's sense of self becomes a harbour of disabling associations about being positive. Indeed, for many of the participants, negative connotations emerge as a result of testing positive. Associations such as being "reckless" and having "[led] a loose life" suggest that the disruption from HIV has had some negative effect. The resulting notions of celibacy, "suppress[ion]" of desire and "frightened [of sex]" in association with HIV are testimony to the disabling impact HIV can have on a persons' biography and,

by extension, their sense of self. In fact, the data collected points overwhelmingly to sex and sexuality being a potent source of possible problems that positive MSM are facing post-HIV.

Thus, while on the surface, disruptions around physical/health (see Table 3) can indicate that it is only a matter of shifts in health and self-image concerns; for example, the complaint that since HIV he has become “physically weak” and the medications “make[s] me look ugly”. Nonetheless, as highlighted in the foregoing discussion, when taken together these concerns point to deeper issues. When we consider the psychological, emotional, and social disruptions in relation to disabling associations surrounding sex and sexuality (see items marked by ** in Table 4), we can appreciate not only participants’ negative self-contraction, but beyond that to the ensuing contraction of social involvement (social disruption) that is marked by “isolation” and “alienation”:

At the beginning I was frightened and lost expectation but then it become better after I cope [with] it. I am hiding from everyone. (*P4, Cambodia*)

Furthermore, when we account for their existential/moralistic associations regarding HIV as well, we begin to understand how HIV can levy an added moral “sense of responsibility” on positive MSM in the “[fear] of transmitting [it] to others”. If one is able to accept this responsibility, then HIV is likely to have an enabling meaningful outcome in making one “better than what I am”; if not, it could just as likely lead to a disabling outcome as apathy—“I don’t care”—or outcast as “social dregs” and a “burden on society”.

Therefore, to conclude this section on biographical disruption, while it is indeed feasible for disruption as a result of HIV to produce enabling changes to the lives of positive MSM in the Asia Pacific, findings here overwhelmingly show that a major hurdle to biographical reconstruction is in integrating HIV successfully into their lives. A big obstacle to this process point to their successful rehabilitation of sexual identities post-HIV; to which we now explore.

Sexual Identities Post-HIV

To summarise the findings so far, biographical disruption from HIV has had discernable effects—both positive and negative—for individuals and their relationship with people around them. For MSM in particular, findings point towards the impact biographical disruption has had on sex and sexuality. Key to unravelling the extent of this disruption, and the lack of enabling associations positive MSM hold about sex and their sexuality post-HIV, is to explore the effect HIV has had on MSM sexual identities.

Sexual Identities in Crisis

In brief, our sexual identities are dependent on the culture in which we live, and the meanings we—and the people around us—have about sex and sexuality. It is ultimately how we as individuals negotiate and construct our own sense of self within these available meanings. According to Aggleton,

sexuality is not so much a 'thing' as a set of sensibilities and social practices that link to issues of identity, and tie into broader social relationships... Definitions of sexuality are thus dependent on the personal and cultural frames of reference that inform how individuals make sense of their desires... perhaps best conceived of as something that is constructed both by individual and by society more generally, in relation to available options and possibilities (2009: 3-4).

Thus, sexual identity is none other than the result of making these meanings part of who we are—to identify with them—within the existing demands set by other members of society. Indeed, Aggleton's notion of “available options and possibilities” can have very tangible results. A Vietnamese respondent tells how his family tried to curb his sexual identity:

My family prevented me from the beginning when they knew [about my] relationship between me and my gay (partner)... *when I was infected with HIV, they forbade us from [being] MSM somewhat strongly. I was beaten because of going out with my gay (partner) [but] I went out secretly... (P3, Vietnam; emphasis added)*

The quotation above also throws into relief how HIV, once known by others, can cast a shadow on MSM identities; likely starting inadvertently a whole new cycle of stigmatisation that further results in hidden sexual identities; with the possible result of a sexual identity in crisis.

Invariably, given the disabling disruptions and negative social repercussions that currently exist, it is an identity any MSM—just as much as the next heterosexual person—will want to avoid. This avoidance can elicit a false sense of security stemming from fear. A Chinese participant's story elucidates:

I am an old comrade. Two years ago... I met a graduate student... [w]e did not be[come]... BF (boyfriends)... [but were] basically... together one time each week... [He] told me that [there] is very little risk of HIV infection. [As] I had received his influence... [I] did not take [HIV] seriously... Two months later, there were some... things... on my body... (The CDC) told me the result... My tears fell immediately... After all, it's this disease... *Actually I was afraid of knowing myself as a[n] infected person... (P1-2, China; emphasis added)*

Hence, simply focusing on safer sex with a lack of discourse in sexual identification post-HIV and ignoring the biographical disruptions of positive individuals can precipitate a crisis of sexual identity; by instilling fear “of knowing myself as a[n] infected person” as it did above. The result is similar with the current focus on advancing treatment and enforcing adherence without proper understanding of the complexity of the social reality that positive MSM in this region still need to face:

The side effect that concern[s] and threaten[s] me most is swollen lymph (glands)... because [these] symptoms show to other people that I'm... infected. Even those who never know before will suspect and those who previously suspect will know for sure. It's like, *explosive* to the public. (P5, Laos; *emphasis added*)

Positive Sexual Identities?

It is therefore unsurprising why many positive MSM fear to disclose their statuses. In severe cases, the introduction of HIV can have disastrous results:

Unfortunately, my family kicked me off. I am totally on my own... My brothers and sisters also don't want me. MSM like us, I mean affected with HIV, face this kind of *denial* until to death. (P2, Myanmar; *emphasis added*)

And let us be clear: The “denial” this Myanmar participant speaks of is more than just social isolation; it is the denial of self. Foucault in his seminal history on sexuality speaks prophetically on how society controls sexuality in his now infamous line: “The sodomite had been a temporary aberration; the homosexual was now a species” (1979: 43). This rings as true today for positive people as it did for homosexuals. Thus, it can be argued that HIV not only increases the complexity of sexual identification, social repercussions as a result of HIV also inadvertently creates a new sexual identity; that of a positive person—just as homosexual repression did for gay sexual identity.

What will actually happen next for positive sexual identities in the Asia Pacific region is at this point still too early to tell. There is, however, clear indications that some positive MSM here has had enough of the discriminatory practices of people who do not—and would not wish to—understand them. One way is to remove oneself from parts of society deemed ignorant of the issues of positive people:

I won't seek advice from negative people. Better advice from the positive people... I have no problem with counselors but I don't share my problems with them. (P3, PNG)

It is also likely that there will be a concerted move towards tribalism of positive sexual identities. This has already been seen on an internet networking site called *Positive Voices* that is reported to transcend the language barrier by supporting a platform of widely spoken Asian languages. Thus, sooner or later positive MSM will learn to deal with—and transcend—their fears of social repression and isolation:

I had to be familiar with discriminat[ory] words from other people, try to be useful for the society in order to prove that I could care for myself, [by] being not a burden [to] society. (P8, Vietnam; emphasis added)

Key to doing so, nonetheless, still rests on the ability for positive MSM in this region to reconstruct their disrupted biographies successfully, and to come together to forge “a politics that does not yet exist” (Foucault 1982: 204).

Conclusion and Way Forward

Positive MSM in the Asia Pacific region share a common trajectory with regards to HIV. In all 10 countries sampled, and the 17 focus group discussion conducted, a pattern of biographical disruption from HIV emerged as a common issue faced by most of the 124 study participants. While biographical disruption—that is, changes to individual stories and meanings of self as a result of facing HIV—are individually and contextually situated, there is a common theme that runs through these stories.

An important common disruption that participants face are disabling associations surrounding sex and sexuality post-HIV. These negative associations have been found to have pervasive and far-reaching consequences in contributing to psychological, emotional, physical/health and social disruptions in the lives of positive MSM in this region. Taken together, these disruptions have had an effect on participants' sexuality and sexual identity—resulting in social isolation, alienation, and despair among many of those sampled.

Yet, the discourse surrounding sex, sexuality, and sexual identity is often muted by the current global focus on quantitative aspects of HIV; that of CD4 counts, viral load, condom use, and the like. While these quantifiable markers to health are certainly important, they only skim the surface of deeper quality of life for positive MSM; which inevitably involve delving into the deeper meanings HIV has had on the lives and stories of those who have to live with it. Thus, it has been found that positive MSM are left to mend their lives, their sexual identities, and relate anew post-HIV with the world outside, the best they can; in many cases with minimal social or institutional support. This is a gross injustice with the current foci and needs to be redressed.

Further, safer sex is often seen as the panacea to stopping the spread of HIV; but it is also insidious in foisting on positive people a deep sense of moral responsibility from the fear of transmitting the virus that can be debilitating. Given the lack of community-centred discourses in this region in areas of sex, sexuality, desire and pleasure, it is unsurprising that a significant number of positive MSM studied are unable to successfully come to terms with HIV on personal and social levels: HIV, for many, signals a crisis of sexual identity that remains disguised in the background, even as life—that can be relentlessly judgmental and discriminatory—proceeds apace.

Given that the findings given here on biographical disruption from HIV in the Asia Pacific have strong undertones in sexuality, that there is a lack of discourse on sexuality in the region, and the current foci on HIV treatment and safer sex, a deeper understanding of sexual identities post-HIV is crucial. Among gaps of information currently existing in this region is the options and possibilities available to positive MSM in each of the 10 countries in forming, identifying, and expressing their sexualities. To do this, we will need to explore the culturally situated meanings of MSM and the country-specific barriers that positive MSM are facing in embracing HIV. Only then, perhaps, a more balanced, open and just discourse will emerge from the region that will not only benefit positive MSM, but MSM in general.

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Appendix A

Affective Associations on Living with HIV by Country

Cambodia	India	Laos	Myanmar	Thailand
scare[d]	scared	painfulness	afraid that partner leaves	hiding
hiding	thinking perhaps may die	side effects	felt so lost	have to be well organized
health	terrible fear	make[s] me look ugly	just wait[ing] to die	eat healthy
transmitting to others	mental tension	scared	depression	suicide
secret	anxiety	less attractive	unwelcomed look	shocked
discrimination	health loss	worry	expelled	take better care of self
support	financial loss	working ability	remind to be strong	weaker than normal
fear	physically weak	discrimination	physical weakness	very scared
suicide	cannot cope	I worry every step	poverty	how to get through it
care [for] myself	forced to accept	deserve to be infected	hopelessness	keep it secret
looking for happy	become wiser	disgust	commit suicide	another world
no one know[s]	disciplined living	priority to my health	learn about spirituality	afraid to open up
cope	extra precautions	reminded am infected	heavy pressure	afraid of everything
sad	sense of responsibility	warns me to be careful	forget my status	keep my secret
normal	limitations	afraid not accepted	extra self care	suffered
tired and exhausted	repentance	depressed	don't think too deeply	couldn't eat
curable in future	cautiousness	life lesson	crying alone	didn't know what to do
understand [about] HIV	suppress my many desires		hidden	it is still me
lost control	cannot behave carelessly		depression	life has been destroyed
shame	discrimination		scornful	a burden all the time
expected [to be] positive	avoid sharing [my] food		suffer	side effect
risky sex	saving own image		reckless	protect so doesn't spread
	feeling weak		remind [to use] condoms	meet someone like me
	isolated		afraid [of] labeling	get out of this sickness
	ill-treated		insecure	improve myself
	bothers me a lot		tell no one	don't have the courage
	avoiding me		daylight ghost	feel imperfect
China	Indonesia	Malaysia	PNG	Vietnam
discrimination	rejection	dismissed	down	weak
[to be] understood	responsible	rejected	accept who I am	such plight
can't afford treatment	wake up call	safer sex	stopped partying	negative thoughts
tired	wanted to change	celibate	limited alcohol	sadness
afraid [of other] virus[es]	be better than what I am	discovering religion	rest more	[led] a loose life
alienated	courage to disclose	serious about the future	confused	knowing I was dying
depressed	scared	feeling guilty	accepted I am positive	wanted to kill myself
inferior to others	depressed	sex becomes boring	felt useless	death sentence
enriched life	cope	there's still life, hope	didn't want to live	burden on society
lonely	afraid	expecting rejection	cut down on friends	led a life of pleasures
impossible	avoiding	treatable illness	have to be responsible	frightened [of sex]
face reality	I don't care	commit suicide	feeling not to have sex	consoled me
anxious	just live it	collapse	no one knows	hide my disease
pay attention to safety				terrible disease
sky was falling down				social dregs
cannot be happy				sneer[ed] with slanting eyes
life now is contradictory				
lost control of my tears				

Appendix B

Summary of Findings by Country

Cambodia

- ARV / OI treatment and health-seeking behaviour
 - Treatment available – ARV/OI treatment reported available for free.
 - Fear that free treatment would end.
 - Usage of folk/traditional methods to deal with HIV common – eg. washing with soap after sex, steaming of anus and food with traditional herbs.
- Social support
 - Family support important to deal with disruption caused by HIV.
 - Lack of knowledge on HIV makes families fearful.
 - Lack of family support makes self-acceptance difficult.
 - Even if their family know their status, fear of discrimination stops many from disclosing to others.
- Earning a living
 - Many respondents interviewed had trouble finding or keeping steady jobs after being diagnosed with HIV.
 - Many reported having to work as sex workers or masseurs.
 - Difficulty in making a living and fear of loss of income should HIV status become known.
- Sex and condom use
 - Reported condom use with clients from sex work.
 - Awareness of law against those who have unprotected sex with others without disclosing HIV status.
 - Using condoms during sex would mean there is no need to disclose HIV status with partner.
 - Reported lack of sexual desire after being diagnosed.

China

- ARV / OI treatment and health-seeking behaviour
 - ARV treatment available for free but OI treatment and surgery are not.
 - Discriminatory behaviour of select doctors who are homophobic raises concerns about how honest patients can be about their risk behaviours.
 - Concerns over confidentiality of information with reports of the CDC informing the community about patient's HIV status.
 - Possible to negotiate with doctors regarding HIV medication.
 - Common use of traditional Chinese system of *yin/yang* to understand and deal with the effects of ARV on the body – eg. ARV generates heat (*yang*) that can be countered with drinking lots of water.
- Social support
 - Reported stigma against homosexuals is common and which leads some to lead double lives (by having gay encounters while being married).
 - Fear of stigma/discrimination if it is discovered that HIV infection was caused by homosexual behaviour leads some not to disclose their status.
 - Concern that HIV makes it difficult to find a partner and left to grow old alone.
 - Pressure from families to get married increases stress after diagnosis.
 - Reported acceptance from family after HIV disclosure but many prefer to rely on network of positive MSM for support.

- Earning a living
 - Find it difficult to work as hard as they used to before being diagnosed with HIV.
 - Concern over the need for regular check-ups and getting medication will interfere with work and arouse suspicion.
- Sex and condom use
 - Fear of transmitting HIV leads to loss of desire for sex.
 - Prefer to use condom during sex rather than needing to disclose status to partner.

India

- ARV / OI treatment and health-seeking behaviour
 - MSM are discriminated against – their turn to see the doctor delayed, there is neglect, and not given due respect. ARV reportedly delayed for 3 months even though he qualifies for treatment.
 - CBOs place representatives in local hospitals to assist patients.
 - Lack of privacy in consultation rooms, especially in government healthcare centres.
 - Poor adherence among MSM/TG as they take their medication secretly to avoid the family finding out their HIV status.
 - Inadequate information for MSM on ARV.
- Social support
 - Some patients are referred to counsellors who do not speak a language patients understand.
 - Families tend to make HIV into a big issue if they find out.
 - Fear of disclosure extends even to friends – do not disclose status directly but by pretending it concerns someone else.
 - Few can depend on family for social/financial support.
- Earning a living
 - Extra costs when seeking treatment (eg CD4 and viral load tests) are a burden.
 - Stress related to diagnosis make it difficult to hold down a job; burden also on the family.
 - Fear regarding the cost of second line treatment.
 - Have to make up excuses to visit the hospital for regular treatment.
 - No longer able to do jobs that require a lot of physical activity.
 - MSM are expected by their families to take on role as lead income earner.
- Sex and condom use
 - Choice, money, alcohol, and feeling of revenge are factors that motivate unsafe sex.
 - Feeling of physical weakness since diagnosis lessens sexual activities.
 - Discussion of safer sex without condoms – all agree that masturbation is the safest form of sex.

Indonesia

- ARV / OI treatment and health-seeking behaviour
 - Big difference in quality of healthcare depending on the hospital and area.
 - Main concern of those on ARV is the side effects.
 - Needing to look after health more since being diagnosed.
 - Reported cases of breach in confidentiality by healthcare staff.
 - Perform difficult/strenuous exercises to show to friends that strength has not been diminished after HIV diagnosis.
- Social support
 - Doctor rather than patient deciding on disclosure to family.
 - For those able to disclose to their families, tend to be able to rely on family for social/financial support and less expectation to marry.

- Reported lack of discrimination in the workplace. Colleagues have been supportive with HIV status disclosure.
- TG discriminated against by family members for cross-dressing and feminine behaviour.
- TG only have courage to disclose to friends who are close and know they will be accepting of status.
- Parents reported better treatment after they knew about HIV status – more caring.
- Earning a living
 - Didn't want to be a financial burden on the family.
 - Families who are poor depend on non-married children to support them.
 - Reliance on informal networks of friends for social support – although some communities have been reported supportive of MSM/TG causes.
- Sex and condom use
 - Clients of TG sex workers offer more money not to use condoms
 - Negotiating condom use made difficult by the worry that HIV status will be disclosed.
 - Some partners with good HIV knowledge reported able to accept HIV status.

Laos

- ARV / OI treatment and health-seeking behaviour
 - ARV is available for free but OI treatment is not.
 - Important to describe to doctors sexual behaviour (anal, oral sex) so that they will be able to give better advice on risk and treatment, although
 - Trust that doctors will keep personal information confidential.
 - Concerns over side effects keeps from starting treatment – especially changes in physique that makes men less attractive.
- Social support
 - Concern that disclosing HIV infection to others will lead to them to have negative opinion – eg. as someone who has multiple sexual partners.
 - Support from friends and family important to continue living as before HIV infection.
- Earning a living
 - Need to work far away from home to protect against disclosure of HIV status.
 - Some need to travel far for treatment, increasing financial burden.
 - Less ability to work hard since diagnosis creates less opportunity for work.
 - Homosexuals discriminated against in certain sectors of the job market.
 - Financial support from family limited because of poverty
- Sex and condom use
 - Condom use makes it possible not to disclose HIV status.
 - Distinction between making love and sex in whether condoms are used – preference to be “natural” when making love.

Malaysia

- ARV / OI treatment and health-seeking behaviour
 - All participants access healthcare in government / semi-government hospitals where ARV treatment is free, although CD4 and viral load testing not always available outside the capital, Kuala Lumpur.
 - Participants have no problems with access to doctors and to consult on HIV/STI in Kuala Lumpur – situation outside the capital unknown.
 - Stigma and discrimination more likely to be from healthcare staff rather than doctors.
 - Prefer to consult infectious disease doctor than local GP on sexual health issues.
 - Concern that others will know HIV status when visiting hospital for consultation – infectious diseases unit shares waiting room with other health issues.

- Social support
 - Some families reported to be traditional – making disclosure MSM status impossible.
 - Discussion on legality of homosexual behaviour with the government’s current persecution of former Deputy Prime Minister on charges of sodomy.
 - Current enforcement of mandatory pre-marriage HIV testing for Moslems has increased publicity on HIV.
 - Perception of stigma barrier to HIV disclosure – not always a reflection of reality.
- Earning a living
 - Concerns about taking time off work for regular check-ups – fear disclosure.
 - Some employers enforce HIV testing as part of job interviews.
 - Dismissal from job due to HIV is illegal. Legal aid will assist in mounting prosecution.
- Sex and condom use
 - Sexual behaviour has changed since HIV diagnosis – less/no sex
 - Intimacy with partners affected by thoughts of HIV.

Myanmar

- ARV / OI treatment and health-seeking behaviour
 - Big difference in reported treatment quality from hospital to hospital.
 - Free ARV not easy to get as number of slots and stocks are limited.
 - Free ARV, where available, is only for first line treatment. Fear that when treatment fails, will not be able to afford second line.
 - Information on HIV/ARV not consistent – conflicting advice from different providers.
 - Some healthcare staff will only provide service if they are given money.
- Social support
 - Stigma in families high for HIV and MSM.
 - Fear to disclose HIV status and for some who have disclosed, no support was received.
 - Some participants reported to have been cast out by their families after HIV disclosure.
 - Hiding of status between friends common – support not often guaranteed.
 - Informal networks of positive MSM give hope in being able to discuss issues and get advice.
- Earning a living
 - Job prospects become worse – not able to work as hard, dismissal from job, fewer customers – once others learn about diagnosis.
 - Costs of treatment (for OI, travelling to hospital, time it takes to receive treatment) increases already difficult financial burden.
 - Financial difficulties have led some to engage in sex work.
- Sex and condom use
 - Revealing HIV status as a way to encourage partners to use condoms. But fears of break-up cause many to do this only when other ways did not succeed.
 - Some reduce frequency of sex to decrease chance of infecting others.
 - To protect against disclosure, some participants increase the number of partners that they have and not staying with just one partner.
 - Condoms linked to having HIV/STI – attracts discrimination for those who possess it.

PNG

- ARV / OI treatment and health-seeking behaviour
 - ARV treatment available for free.
 - Government doctors and healthcare staff have reportedly discriminate against MSM – long waiting times for treatment.

- Becoming more responsible about health since becoming positive – resting more, drinking less.
- Social support
 - Family and social (night clubs) acceptance and understanding of HIV empowers.
 - Preference for to share issues with HIV-positive peers
 - Some report issues of trust with counsellors in understanding issues facing positive people.
 - Family accepts sexuality but name-calling in public is common.
- Earning a living
 - Depend on support from family but trying to be independent.
- Sex and condom use
 - Stop sex work since becoming positive.
 - Must consider STI as well in deciding to use condoms.
 - Respecting other important when deciding on sex and condom use.
 - Restricting penetrative sex.

Thailand

- ARV / OI treatment and health-seeking behaviour
 - ARV treatment available for free for those who have the public health card – Thai social service and NGO programmes help with other costs (travel, tests).
 - In certain treatment centres, doctors/healthcare workers reported to discriminate against positive people – treating us like creatures.
 - Different doctors give different advice/opinions – can be confusing for new patients.
 - Trusting of certain doctors and would prefer to consult only with him/her.
 - Having a good and caring healthcare worker makes it easier after diagnosis.
 - Have to rely on NGOs/community clinics for more information or getting the information myself – some doctors reported too busy to give information/advice.
 - No discrimination reported for sex work from healthcare workers.
 - VCT should be confidential but is not always the case in reality.
 - Concerns about the need to take ARV throughout life – need to be more organised in starting treatment.
 - Worry that ARV will affect physique.
 - Traditional/folk methods to promote health used at the same time as medical methods – clearing bowels often, cutting down on flour/carbohydrates as they impact on white blood cells and immune system.
- Social support
 - People in society will gossip if you don't look well – difficult to disclose.
 - Support from family – accepting of the choices made but must live with these choices.
 - Support groups available in hospital but better at hospitals outside capital, Bangkok.
 - Difficulty in disclosing to friends outside capital because community too small. Easier in Bangkok as more anonymous – reported being kicked out of the house by landlord in countryside.
 - Some participants report good community support since disclosing HIV diagnosis – eg. helping with carrying heavy stuff, telling to rest often etc.
 - Worried about sharing central serving spoon, nail clipper, toothpaste with family.
 - Feel different to the rest of society – a different world.
 - Family can be accepting of TG as they already realise it from an early age.
 - Some monasteries reported discriminatory against positive people.
- Earning a living
 - Being constantly tired stopped pursuing university education since diagnosis.
 - Should only focus on one thing – work or study; doing both too stressful.
 - Parents/family cannot offer financial support.
 - Working as sex worker can be stressful to stay at the top of the game.
 - Difficult to get a job outside the city since becoming positive.
 - Family understanding of financial situation – no need to send them money.

- Sex and condom use
 - Increase in condom use since diagnosis – will not have sex if partner refuses to use.
 - Use condom as don't want to spread it to others.
 - Broke up with boyfriend who cannot use condoms, as he is allergic to them.
 - Some rely on the look of the potential partner to decide whether to use condoms – chubby means healthy looking.

Vietnam

- ARV / OI treatment and health-seeking behaviour
 - ARV treatment provided for free by government
 - Government also provides condoms and lubricants, and monthly musical activities.
 - Doctors say we must accept physical side effects from ARV but can change regimen if they are life threatening – for lipodystrophy and swollen glands, these are considered normal.
 - Doctors are strict with ARV adherence – if missed doses, can be out of ARV treatment.
- Social support
 - Government focuses on integrating MSM with society with monthly activities.
 - With HIV, family can understand and be supportive – encourage us to be useful to society by going out to work and integrating.
 - Cannot disclose MSM status to family, as they will not accept – gay relationships forbidden if found out, have to meet in secret.
 - Few MSM dare to disclose they are gay to community – some get married but still have homosexual relationships.
 - Difference between public / hidden gay men – “public gays” do not come out in the day and “real men” are afraid of being seen with them.
 - Discrimination high for MSM who are HIV positive – even in families.
- Earning a living
 - Difficult to get a job after diagnosis – affects the payment of hospital fees.
 - Staying shorter time in hospital if cannot pay the fees – discharge earlier.
 - Employers who know about HIV status are afraid to hire – or will sack us.
- Sex and condom use
 - Use condoms as feel responsible to protect sexual/intimate partners from HIV.
 - Living a life of pleasures is the cause of becoming infected.
 - Aware that without condom use can become infected with other STIs (Hepatitis C, gonorrhoea, syphilis).
 - Afraid to disclose HIV status to partners – afraid of being beaten.

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APN+ Office

51/2, 3rd floor, Ruam Rudee III Bldg., Soi Ruam Rudee, Ploenchit Rd
Lumpini, Pathumwan, Bangkok 10330 THAILAND
Office: +66 2 2557477 Fax: +66 2 2557479 Email: apnplus.communication@gmail.com