

# THE PHILIPPINE PEOPLE LIVING WITH HIV (PLHIV) STIGMA INDEX 2.0 (2019)

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## **I. BACKGROUND OF THE STUDY**

The 2017 National Demographic and Health Survey found that 7 in 10 Filipino women aged 15-49 who have heard of HIV hold discriminatory attitudes towards people living with HIV. For example, more than half think that children living with HIV should not attend school with children who are HIV negative. They will also not buy fresh vegetables from a shopkeeper who has HIV (PSA and ICF, 2018). While not representative of the whole population, such findings bring to fore the stigma attached to HIV and people living with HIV.

Stigma is loosely defined as the set of ‘negative attitudes’ against people who have or are perceived to have a particular ‘disgraceful’ or shameful trait or feature, and it effectively creates a division in society between people who are considered as ‘normal’ and those who are not (Goffman 1963). Stigma and discrimination are closely interrelated, since discrimination is often the by-product of stigmatization, or discrimination is seen as “enacted stigma” (Link and Phelan, 2001). Stigma and discrimination occur when a person is unjustly treated or deprived of his/her human rights due to the society’s negative perception of his/her belongingness to a particular social group/category (e.g. race, gender, age or sexual orientation) (APA 2017).

People living with HIV (PLHIV) experience stigmatization primarily because of the fear that HIV is a highly contagious disease, and that casual contact with an infected person could result to others contracting the disease as well (Bollinger 2002, Pedroso et al. 2010, Lee, Kochman & Sikkema 2008). PLHIVs and those who are at high risk of HIV infection, such as people who inject drugs, sex workers, men who have sex with men (MSM) and transgender people, are therefore devalued and often excluded in their immediate social spheres (UN AIDS 2014 and Trinidad et al. 2011). The stigma also extends to those who are merely associated with the PLHIV such as their families. HIV-related discrimination occurs in institutional settings, when a PLHIV is unfairly or unjustly treated in the workplace or at school, and when for instance he/she loses his/her job and other employment opportunities in view of his/her real or perceived HIV status (UN News 2018; UNAIDS 2014 and Quinto et al. 2010). Such discrimination can also occur in health settings when medical services are denied to a PLHIV because of his/her status.

The experience of stigmatization and discrimination among PLHIVs has dire consequences. It can lead this vulnerable population to hide their status due to shame, which could therefore keep them from being diagnosed, informed of their condition and treated accordingly (Trinidad et al. 2011 and Quinto et al. 2010). This trend, in turn, could cause the epidemic (which started in 1984 and grew tremendously around 2007-2009) to further spread in society (Santos 2016; Quinto et al. 2010; Trinidad et al. 2011).

The continued increase in the rate of HIV infection in the Philippines (which is the highest among Asia-Pacific countries in 2017) (Reuters 2017) and the growing number of HIV cases documented by the Department of Health (DOH) (Modesto 2018 and Santos 2016) serve as alarming testaments to what HIV, coupled with stigma and discrimination can do when left significantly unaddressed. Since 1984, the HIV and Art Registry in the Philippines (HARP) has already recorded a total of 56,275 confirmed HIV-positive Filipinos; 2,705 of which have already died (Modesto 2018).

From 2010 to 2016, the total number of cases increased by 140 percent (from 4,300 in 2010 to 10,500 in 2016) (Reuters 2017 and Santos 2016), and the Department of Health (DOH) estimates that the total number of HIV cases in the country will reach 142,400 by 2022 (Santos 2016).

In June 2018 alone, there were a total of 993 HIV cases in the Philippines, and 77 of these people have already died; 977 cases contracted the disease through sexual contact (594 from male-to-male sexual contact, 267 from both male-female sexual contact and 116 from male-to female sex), seven were due to sharing of needles among injecting drug users and two from pregnancy (Modesto 2018). Furthermore, in April 2017, 80 percent or 513 of 629 cases were youth ages 15-34 who did not have any information about HIV and its symptoms (Morales 2017 and Santos 2016).

In response to the HIV crisis, Republic Act 8504 or the Philippine AIDS Prevention and Control Act of 1998 was enacted to uphold the rights of PLHIVs in the country, protect them against all forms of discrimination, and provide them with basic health and social services (Quinto et al. 2011). The Philippines has also reaffirmed in 2016 its commitment to respond to the global call of ending the AIDS epidemic<sup>1</sup> (UNAIDS 2018, UNESCO 2018 and UNAIDS 2002). However, more and more HIV activists and other groups are lobbying for amendments in the law, such as lowering the age of consent for HIV testing<sup>2</sup> (Ilas 2017 and Morales 2017) and increasing condom use especially among men having sex with men (MSM) (Ilas 2017).

Legislators this year have responded to these concerns by repealing RA 8504 and approving the “2018 Philippine HIV and AIDS Policy Act” in the third regular session of the Seventeenth Congress of the Philippines. Two of its key provisions include: (1) permitting HIV testing for 15-18 year olds even without the consent of a parent/guardian (except in cases where the individual is mentally incapacitated) and (2) more intensive information dissemination in schools and during the delivery of health services to further mitigate stigma and discrimination against PLHIV in society (Roxas 2018).

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<sup>1</sup>The reaffirmation was done along with other ASEAN countries during the ASEAN Summit held in Lao PDR on

<sup>2</sup> “Under the law, those 18 years old and below need parental consent before they get tested for HIV” (Ilas 2017).

The need to address stigma is also being recognized, as it is viewed as the ‘silent killer’ that fuels the spread of the HIV epidemic not just in the Philippines but across other affected nations (Trinidad et al. 2011). The need to intensify HIV prevention campaigns through public information and education drives and sex education in schools, and the need to establish grievance mechanisms for cases of discrimination are also being proposed (Ilas 2017 and Santos 2016), but it is also imperative that a study regarding the current situation of PLHIV in the Philippines be undertaken in order to inform these proposed amendments. Sound data and updated information about HIV stigma and discrimination could contribute to the creation of policies and intervention programs that could effectively respond to the needs of PLHIV and substantially lead to controlling the spread of the disease in the country (Trinidad et al. 2011).

## **II. REVIEW OF RELATED LITERATURE**

There were only a few recent studies that aimed to specifically tackle the issues that plague those who are infected with HIV in the Philippines (Quinto et al. 2010; Trinidad et al. 2011 & Koirala et al. 2017 and UNDP 2017). In 2010, Pinoy Plus Association Inc., Philippines (in collaboration with Positive Action Foundation Phils Inc., Babae Plus, Sister Plus Angeles City, Crossbreeds Bacolod, Pinoy Young Positives and Mindanao Advocates) conducted the first baseline study on the stigma and discrimination experiences of people living with HIV and AIDS in the Philippines to be able to inform policy and intervention programs. The study conducted a survey among 80 PHLIV and in-depth interviews with seven PLHIVs. They were selected through purposive sampling and all of them have contacts or were referred to by the PLHIV community or network (Quinto et al. 2010).

The study utilized the *People Living with HIV Stigma Index*, a tool created by the Global Network of People Living with HIV (GNP+), International Community of Women Living with HIV (ICW), International Planned Parenthood Federation (IPFF) and Joint United Nations Programme on HIV (UNAIDS), which aims to comprehensively assess and compare the experiences of PLHIVs from across all nations affected by the spread of the disease. The topics covered by this measuring tool include: experience of stigma and discrimination from other people; access to work, health and educational services, internal stigma; knowledge on rights, laws and policies pertaining to HIV; effecting change, testing and diagnosis, disclosure and confidentiality, access to treatment and having children (Quinto et al. 2010).

The initial study involved more male than female respondents, and majority of the participants are in the ages 25-39. The study showed that the respondents, especially women, young people, sex workers, unemployed, migrant workers and those who have low educational attainment have all experienced being socially excluded, insulted, gossiped about, isolated, and poorly treated by the people around them. Some of them have also lost their jobs,

have had their HIV positive status disclosed to others without their consent, and some have attempted or thought of committing suicide (Quinto et al. 2010).

The study emphasized the need to raise public HIV awareness because stigmatization and discrimination of PLHIV often occur due to the lack of knowledge about the issue. This social ignorance also causes most PLHIVs to experience internal stigma, (shame, guilt and fear of discrimination) which further discourage them from seeking help and treatment. Ironically, some of the respondents themselves did not even know that they have been stigmatized or discriminated in their communities until they became involved in the study. The study therefore affirms that the silence of the PLHIVs, the lack of knowledge and awareness in society, the lack of support from the community, and the ignorance and contempt of other people against PLHIVs fuel the growth of the epidemic in the country (Quinto et al. 2010).

Meanwhile, Trinidad et al. (2011) drew from the data collected by the said baseline PLHIV Stigma Index in 2010 to tackle the experience of internal and external stigma in the Philippines. They argued that more respondents have experienced internal stigma (or the “felt, imagined, self stigma” which involves “internalization of shame, blame, hopelessness, guilt and fear of discrimination associated with being HIV-positive”) (Trinidad et al. 2011:46), compared to external stigma or being socially excluded by the community. Most of the PLHIV have also reported having their closest kin experience stigmatization/discrimination on account of being related to someone like them who is diagnosed as HIV-positive (Trinidad et al. 2011).

In terms of external stigma, most of the respondents experienced being gossiped about and insulted in their community, and only a few have been discriminated within their families (mostly those who have been living with HIV for less than three years). However, the family is still seen as the primary safety net of the PLHIVs. Although some experienced being abandoned by their family, this only occurred for a short time, usually, right after learning about their status, but after some time, they would be accepted and taken cared of by their family. Meanwhile, migrant workers were reported to have experienced significant instances of discrimination and have even been banned from working abroad due to their HIV status (Trinidad et al. 2011).

On the other hand, majority of the respondents who are living with HIV for less than three years reported more feelings of shame and guilt compared to those who have had it for more than three years already. This was found to occur more among men who are having sex with men (MSM) than non-MSMs. This is alarming, because the internalized shame, guilt and anxiety that also cause PLHIV to avoid social interaction, often lead them to isolation, depression, and to some, to suicidal ideations (Trinidad et al. 2011)

Another study which conducted in-depth interviews with 48 MSM in Metro Manila (UNDP 2017) showed that depression or the ‘loss of will to live’ can discourage PLHIV from undergo-

ing treatment. The participants in the study were also discouraged from accessing and continuing antiretroviral treatment (ART) because of the stigma and discrimination and poor counseling and treatment experienced from the medical staff in the community. The Community Access to Treatment Study (CATS) conducted in 2014 in Bangladesh, Indonesia, Lao, Nepal, Pakistan, Vietnam and in the Philippines also provide evidence that internalized stigma, “related to sex work and sexual orientation, discrimination, sex work environment, criminalization of risk behaviors (injecting drug use and sex work), and negative attitudes towards HIV treatment” also hinder or demotivate PLHIV from continuing ART/HIV care (Koirala et al. 2017). Therefore, addressing both the internal and external experience of stigma is crucial because they are some of the most important key factors that could hamper the treatment of PLHIV, the prevention of HIV in society and the eventual control of the epidemic in the country.

### **III. CONCEPTUAL FRAMEWORK**

This study posits that stigma and discrimination and how it is experienced by PLHIVs impact on their decision to either conceal their status or disclose it, get tested and seek treatment. Thus, stigma and discrimination when unaddressed leads to the rise of HIV cases. Stigmatization is experienced (1) internally, as shame, hopelessness, worthlessness and guilt; and (2) externally when a PLHIV is socially excluded, insulted or harshly gossiped about (Trinidad et al 2011). Meanwhile, discrimination is experienced mainly when a person is deprived of his/her human rights (i.e. socioeconomic opportunities such as employment, promotion at work, education, among others) and treated unfairly (i.e. in health facilities) due to his/her HIV status (APA 2017). Both HIV-related stigma and discrimination discourage many PLHIV to seek help or access treatment out of fear of being further stigmatized or discriminated (Koirala et al 2017, Trinidad et al 2011, and Quinto et al 2010).

When PLHIV choose to conceal their status, lose their motivation to be diagnosed or treated and isolate themselves due to stigma and discrimination, HIV transmission could persist. Only by curbing stigma and discrimination could the disease be controlled (Trinidad et al 2011) and the PLHIV could be provided with the chance to live a more dignified and meaningful life.

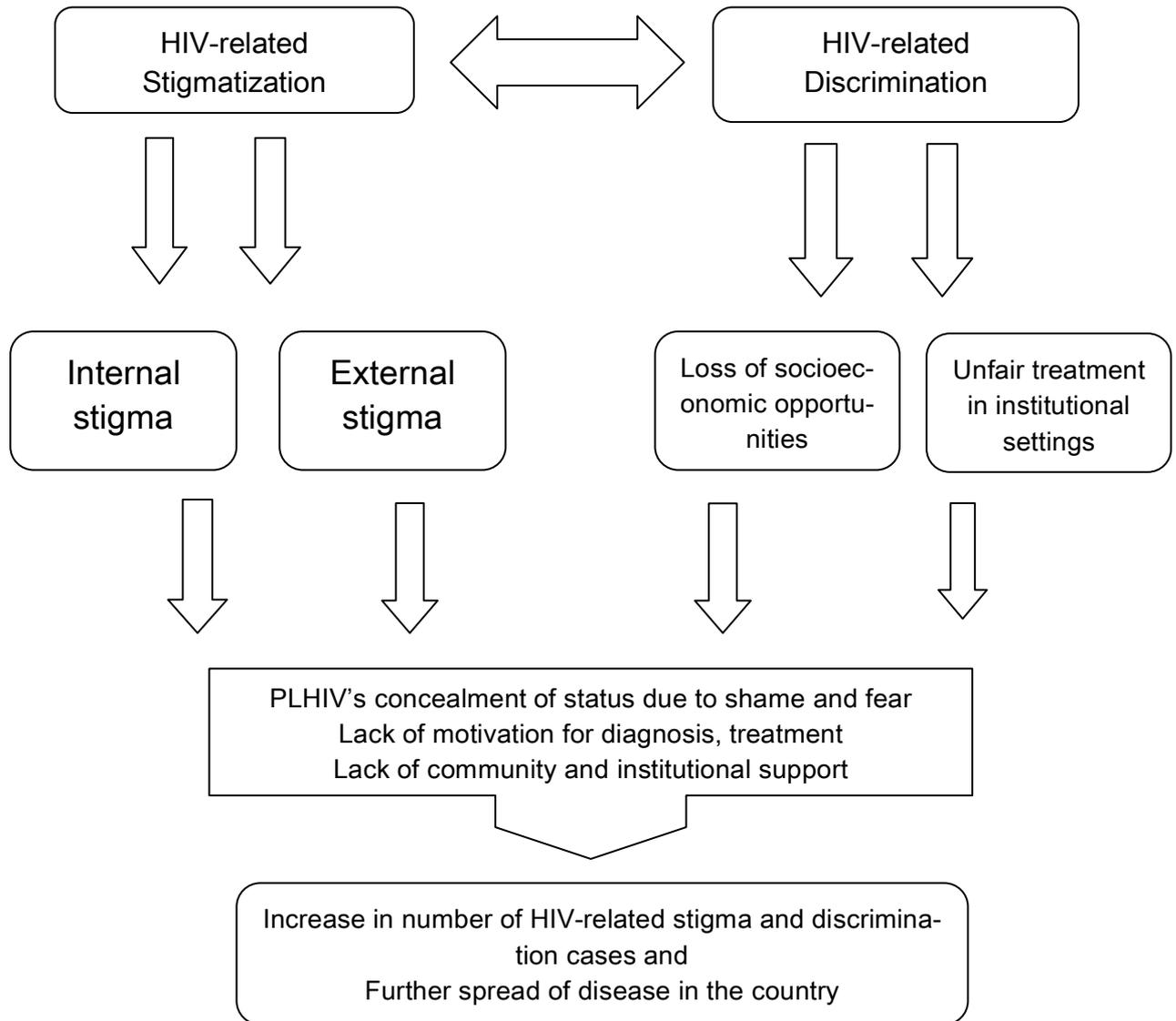


Figure 1. Conceptual framework on the link between stigma and discrimination and the spread of HIV in the country

#### IV. OBJECTIVES OF THE STUDY

The Demographic Research and Development Foundation (DRDF), Inc., and Pinoy Plus Advocacy Pilipinas, Inc. conducted the second round of the PLHIV Stigma Index in the Philippines with the following aims:

1. Document the various experiences of PLHIVs in the Philippines regarding stigma and discrimination;
2. Provide an evidence-based information for policy change and program interventions; and

3. Measure the progress and impact of intervention programs to reduce HIV-stigma and discrimination in the Philippines, through comparing relevant and comparable results with the previous stigma index.

## **V. RESEARCH DESIGN**

The study adopted and upheld the GIPA (Greater Involvement of People Living with HIV) principle (International Partnership of GNP+, ICW and UNAIDS 2018) which called for interviewers to actively guide the interviewees as they fill in the questionnaire instead of performing the traditional face-to-face interview survey (wherein interviewees do not see the questionnaire and write on it). The GIPA principle is based on the idea that the survey “is not designed merely to collect information for the index – although this is the main objective – but also to be part of a process of empowerment for the interviewees and interviewers” (International Partnership of GNP+, ICW and UNAIDS 2018:13).

The interviewers of the study were HIV-positive which created a comfortable space for interviewees to share their experiences. They underwent rigorous training to ensure that they would be able to facilitate the filling-in of the questionnaire and deal with participants who would be deeply and emotionally affected by the interview process (International Partnership of GNP+, ICW and UNAIDS). Overall, the study consistently made use of the PLHIV Stigma Index 2.0 User Guide (2018) throughout the stages of the research to ensure that it adhered to the global principles of conducting HIV stigma research.

### *Sampling*

This study employed purposive, non-probability sampling in selecting its respondents since there is no definite population of people living with HIV from which we could draw a probability-based sample (International Partnership of GNP+, ICW and UNAIDS 2018). The respondents were recruited by the PLHIV networks or member organizations of the implementing partner, Pinoy Plus Association and other peer support groups, testing sites and AIDs service organizations in (1) Metro Manila (60 respondents), (2) Angeles City, Pampanga (10 respondents), (3) Cavite in Luzon (10 respondents); (4) Iloilo (22 respondents), (5) Cebu (20 respondents) in Visayas and (7) Davao (30 respondents in Mindanao). A total of 152 HIV-positive respondents from across different age-groups, sexual orientation, cultural backgrounds and educational attainment were included in the study to be able to cover various experiences of stigma and discrimination.

This therefore implies that the findings of this study will not be representative of the experiences of all people living with HIV in the Philippines since the selection and participation of respondents are contingent on their links with the social networks that the researchers were able to reach due to the lack of a definite sampling frame. However, since the study included

a larger number of participants compared to the 2010 baseline study, it would reflect more experiences of PLHIVs and would be able to demonstrate how the quality of their lives have improved or declined for the past ten years since the last stigma index study.

### *Research Instruments*

This study utilized an updated version of the People Living with HIV (PLHIV) Stigma Index 2.0 questionnaire which has eight major sections: “(a) about the interviewee and their household; (b) experiences of disclosure of HIV status (c) experience of stigma and discrimination related to HIV status; (d) internal stigma or how the respondents feel about themselves related to their HIV status; (e) experiences in relation to accessing healthcare services and of related stigma and discrimination incidents due to their HIV status (i.e. HIV testing, care and treatment, general health status, service delivery experiences and sexual and reproductive health); (f) experiences of human rights abuses related to their HIV status; (g) experiences of stigma and discrimination related to reasons other than their HIV status, with sections addressing men who have sex with men, gay/homosexual and bisexual men, transgender people, women who have sex with women, lesbian/gay and bisexual women, people who have had sex in exchange for money or goods or who identify as a sex worker, and people who have injected or used drugs. The last section also provided a space for the interviewee to share further information about their experiences related to stigma and discrimination” (International Partnership of GNP+, ICW and UNAIDS 2018:30-31).

The informed consent forms, information sheets and interview survey questionnaires were all translated to Filipino and the researchers ensured that these were culturally and gender sensitive. The forms and questionnaires had undergone pre-testing and several revisions to make sure that the participants were able to better comprehend the scope and objectives of the study and respond more comfortably during the survey.

### *Case Studies*

The study also conducted five case studies to underscore particular issues and challenges faced by selected PLHIV in their daily life (International Partnership of GNP+, ICW and UNAIDS 2018). The qualitative interviews were not formally structured and were therefore conducted in such a way that allowed the respondent to freely talk about his/her life experiences.

### *Analysis of Data*

Data from the survey were encoded in the GNP plus Stigma Index portal (<http://dev.ecp-geo.nam.org.uk/login?r=/stigma-entry/ph/new/?version=2>) which allows for a direct and convenient downloading of the Microsoft excel file that tabulates all the responses in each of the sections of the survey after they are all encoded. This excel data sheet was converted to STATA data format for analysis. Meanwhile, the audio recordings of the interviews were

transcribed and themes were drawn from each of the transcript and comprehensive reports on each of the respondent were written.

## **VI. ETHICAL CONSIDERATIONS**

The study followed the ethical guidelines on informed consent and confidentiality provided by the People Living with HIV Stigma Index 2.0 Guide (International Partnership of GNP+, ICW and UNAIDS 2018). The principle of informed consent required the researchers to fully inform the interviewee about the nature of the study, but since this project deals with sensitive issues, only the verbal consent of the respondent was obtained. The signed consent was not required so as to avoid any leakage of sensitive information.

In practice, both the *interviewer* and a *witness* of the consenting process were asked to sign a form that confirms that the respondent has verbally agreed/has given his/her verbal assent to share private information that will be eventually used as data by the study (International Partnership of GNP+, ICW and UNAIDS). The National Ethical Guidelines for Health and Health-Related Research in 2017 also suggested that only verbal informed consent be obtained, “as long as it is witnessed and properly documented with appropriate and specific codes” (PHREB 2017). It was also emphasized to the respondents that their involvement in the study is purely voluntary and that they can withdraw their participation at any point of the research process (International Partnership of GNP+, ICW and UNAIDS 2018 & PHREB 2017).

The PLHIV Stigma Index 2.0 Guide (2018) also admonished the researchers to refrain from interviewing people below 16 years, those with mental disabilities and those who are prisoners or are detained in drug rehabilitation centers, for they would have difficulty providing true informed consent/might just be forced to or unwillingly participate in the study due to their insecure circumstances (International Partnership of GNP+, ICW and UNAIDS 2018). Other vulnerable and politically and socioeconomically marginalized groups (i.e. children, elderly and people from ethnic and racial minority groups) were also excluded from participation in this study.

In terms of privacy and confidentiality, only codes and not the names of the interviewees were written on the questionnaire forms and only those who processed and analyzed the data had access to the list that contains the participants’ personal information (International Partnership of GNP+, ICW AND UNAIDS). This list was kept in an electronic file and a security password was put in place to protect it. Having HIV-positive interviewers also helped maintain privacy and confidentiality for “people living with HIV are generally best placed to know and understand the problems that might be caused by any leakage of information about their peers” (International Partnership of GNP+, ICW AND UNAIDS:18). Anonymity of the re-

spondents when presenting the data in future dissemination forums will also be observed in order to ensure that “further stigmatization” could be avoided (PHREB 2017:144,145).

The participants who were emotionally triggered by the research process or who are in precarious circumstances (i.e. mentally, physically or emotionally troubled), were referred for counselling or to appropriate organizations/institutions that could respond to their needs (International Partnership of GNP+, ICW and UNAIDS 2018). The quantitative respondents received a P200 as a token for their participation in the survey interview. Meanwhile, the case study respondents received P300 as token for their participation.

## **VII. JUSTIFYING THE NEED FOR SOCIAL SCIENTISTS DURING THE INTERVIEW**

Substantial knowledge on strategies in interviewing could be drawn from previous PLHIV Stigma Index done by over 90 countries.<sup>3</sup> All of them have adhered to the “side-by-side interviewing approach” (International Partnership of GNP+, ICW and UNAIDS 2018) and have acknowledged its significance in ensuring successful conduct of the project. Poland, in particular, noted the importance of strictly facilitating the interviews *with* the participants and not allowing for ‘self-administering’ of survey questionnaires due to the resulting poor quality of some interview responses in their stigma index in 2012.

Bangladesh has slightly deviated from the requirement to have only HIV-positive individuals as interviewers by employing a team consisting of (1) an anthropologist and (2) a PLHIV facilitating each interview in its stigma index in 2009. According to its country report, the presence of the HIV-positive interviewer created a safe and comfortable space for the respondent to disclose their experiences to the interviewers, while the anthropologist assisted the PLHIV in the interview flow (James P. Grant School of Public Health 2009).

This study followed the example of Bangladesh and hired HIV-positive interviewers and social scientists as observers. This arrangement ensured the smooth interview transition from one section of the questionnaire to another. The social scientist made sure that all the parts of the questionnaires are filled and that the parts that were not applicable to the respondents were skipped.

Meanwhile, although the HIV-positive interviewer did not directly disclose his/her status to the interviewees as part of the introductory script/during the process of asking for informed consent, the fact that the respondents were recruited from the various PLHIV networks made them instinctively know that their interviewers were also fellow PLHIV. The social scientists who observed the interview had to introduce themselves to the respondents and guarantee

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<sup>3</sup> For access to the complete stigma index country reports, visit: <http://www.stigmaindex.org/>

them that they would not interrupt unless both the interviewers and interviewee needed help in clarifying the meaning of some of the questions in the survey questionnaire.

## **VIII. LIMITATIONS OF THE STUDY**

As mentioned earlier, the lack of a definite sampling frame hinders generalization from the survey findings of this study. Furthermore, the study failed to cover the experiences of PLHIV in the rural areas and those who most likely do not have immediate access to information drives, trainings and seminars, since the PLHIV networks recruited stigma index survey respondents who mostly come from urban areas which benefit from numerous HIV-related initiatives.

The sampling of the study would inevitably reflect the majority of PLHIVs from urban areas and exclude experiences of PLHIV from other backgrounds. This would most likely result to lesser report of stigma and discrimination since urban areas are generally more knowledgeable about HIV and could therefore respond accordingly to HIV-related issues.

Another point to consider is that there are respondents who reside in a particular place but choose to access ARV treatment in another location to protect their identity and status. Since the survey does not ask about the location of the respondents, the study findings are essentially blind when it comes to the particular contexts where stigma and discrimination was experienced.

The stigma index study also failed to cover PLHIV from higher socioeconomic classes since they would normally not associate themselves with PLHIV networks from the lower classes. This was raised during the initial planning and design of the study but the research team did not have the means to reach out to this group of PLHIV.

Lastly, the requirement to strictly adhere to the structure or format of the survey questionnaire to ensure standardization and comparability with index studies from other countries hindered the research team from substantially rephrasing and asking follow-up questions that could have been the key to capture and present nuances in the Filipino experience which the global and standard question could not fully cover.

## IX. KEY SURVEY FINDINGS

Survey results are discussed in each section below and selected quotes from the last part of the questionnaire<sup>4</sup> featured in text boxes to provide a picture of some of the respondents' remarkable experiences in relation to each topic.

### A. PROFILE OF THE RESPONDENTS

This section provides an overview of the demographic and socioeconomic profile of the PLHIV Stigma Index Survey respondents.

#### *Gender*

Majority of the respondents in the survey were males (88%). Their ages range from 18 to 61 years, and the mean age is 33.4 years old.

Aside from their sex at birth, respondents were also asked on how they identify themselves in terms of gender. As shown in Table 1, among those who are males at birth, majority said their gender identity is male; 5.3% described themselves as transgender while 2.3% did not identify themselves as female/male/transgender and two respondents preferred not to disclose their gender identity. All those who are females at birth on the other hand reported their gender identity as females. (See Table 1).

Table 1. Percent distribution of respondents by gender identity and sex at birth

Gender identity	Sex at birth		
	Male (%)	Female (%)	Both (%)
Male	91.7	0.0	80.7
Female	(0.76)	100.0	12.7
Transgender	5.3	0.0	4.7
Do not identify as male or female	2.3	0.0	2.0
No. of cases	132	18	150

() 1-2 cases

<sup>4</sup> Section H of the questionnaire asked the respondent to freely write anything that they feel comfortable sharing in the space provided. In some cases, the respondents openly shared their experiences, but they did not write on the questionnaire. Instead, they asked their interviewer to write down their thoughts as they speak. Only the most comprehensible and sensible quotes pertaining to the more relatively recent HIV-related experiences were included in the report for brevity purposes.

Compared to the 2009 survey, there were fewer females in the 2019 stigma index study. This is reflective of the nature of the epidemic during the previous period, wherein more female sex workers or OFWs were diagnosed of HIV.

*Education and socioeconomic status*

The respondents are generally well-educated, with 66% gaining tertiary/university level education. Twenty one percent have either reached or completed high school while 10.5% had trade/vocational education.

Table 2. Percentage distribution of respondents by educational attainment

Educational attainment	Number	Percentage
Primary/Elementary/Local equivalent	4	2.6
Secondary/High school/Local equivalent	32	21.1
Trade/vocational school	16	10.5
University/Tertiary education	100	65.8
Total	152	100.0

More than a third are engaged in full time work, as employees. However, a similar percentage also reported to be unemployed (Table 3). When asked about their inability to meet their basic needs such as food, clothing and shelter, majority (46%) reported having difficulty some of the time. Compared to male PLHIVs, more females reported that they have difficulty most of the time in meeting their basic needs (Table 4).

Table 3. Percentage distribution of respondents by employment status

Educational attainment	Number	Percentage
In full time work (as an employee)	53	35.1
In part time work (as an employee)	14	9.3
Working full time, but not as an employee	14	9.3
Doing casual or part-time work (self-employed)	17	11.3
Unemployed	53	35.1
Total	151	100.0

Table 4. Percentage distribution of respondents' inability to meet their basic needs in the past 12 months, by sex

Inability to meet basic needs (food, shelter, clothing) in the past 12 months	Male	Female	Both
Never	45.1	27.8	43.1
Some of the time	46.6	44.4	46.4
Most of the time	8.3	27.8	10.6
Total	18	133	151

### *Number of years as PLHIV*

The longest reported number of years as PLHIV is 22 years and the average is 4.5 years. Twenty eight percent of the respondents were PLHIV for one year or less and 41% were PLHIV for two to five years. About a quarter are PLHIV for 5 to 9 years, and only about 8% have been living with HIV for 10 years and more.

The research team decided to categorize the reported number of years in this manner to be able to isolate the experiences of those who were recently diagnosed to those who already have a wealth of experience in relation to their HIV status. Those who are living with HIV for a year and less are most likely still in the adjustment period and are still getting to learn more about the illness, how to access treatment and how to better take care of their health. They would also most likely be dealing with mental and emotional stress and anxiety upon learning and trying to cope with their new identity as PLHIV.

This is significant to tease out and infer the extent by which intervention programs especially in the recent decade have impacted the PLHIV in the country. Since the last stigma index was conducted in 2009, we assume that those who have been living with HIV for over 10 years have more frequently experienced stigma and discrimination since information drives, trainings and programs during the past decade were not as numerous and as thoroughly and more frequently conducted compared to the recent years. Furthermore, we assume that those who are living with HIV for two to five years and six to nine years are those who are somehow already well-adjusted to their status.

The other key findings will therefore be disaggregated by this particular variable and relevant findings from the 2009 stigma index that were deemed comparable to the more recent findings will be presented to be able to deduce how the quality of life or nature of stigma-related experiences of PLHIV has changed throughout the 10-year gap between the first and the last survey.

### *Sexual Relationship/Marriage*

Forty three percent of the respondents are currently in an intimate or sexual relationship (married or unmarried). Among those who are in a relationship, half are certain that their partner is also HIV-positive; 39% said their partner is not HIV-positive and 11% is unsure about the HIV status of their partner.

Four in 10 respondents are taking care of children at home. Of this percentage, majority (80%) are taking care of 1-2 children.

### *Being a member of a vulnerable group*

Membership in vulnerable groups is not common among the respondents. Only 7% reported that they belong to the group of individuals living with disability such as vision, hearing, physical, but not because of their HIV status. This is followed by membership to racial, ethnic, or religious minority (5%), and indigenous/aboriginal group (4%).

Table 5. Percentage of respondents according to membership in vulnerable groups

	Percentage	No. Of cases
Racial, ethnic or religious minority	5.4	147
Indigenous/Aboriginal group	4.0	145
Living with a disability (Vision, hearing, mobility, intelligence, but not HIV)	6.6	151
Refugee or asylum seeker	(0.7)	151
Migrant workers	2.6	151
Internally displaced person	2.0	151
Incarcerated/ In prison	(0.7)	150
Total	151	100.0

() 1-2 cases

### *PLHIV Support Group Membership*

Majority of the respondents are members of a network or support group of people living with HIV (64%). This is reflective of the sampling method of the research that mainly tapped the PLHIV networks to draw in respondents for the survey. Since most of the respondents are part of a support group, this most likely implies that they already have high awareness with regard to their rights as PLHIV and are well-versed when it comes to HIV-related issues.

## B. DISCLOSURE

Respondents were asked whether their family, friends, neighbors, employers, co-workers, teachers, school administrators, classmates and community leaders know about their HIV status. Among those who mentioned that a certain group of people know about their status, they were also asked if the disclosure was done with their consent. Table 6 presents the percentage who have identified a particular group of person to have known their HIV status according to the length of years that they have been diagnosed with HIV. Overall, there is higher disclosure within the immediate family, such as with husband/wife/partner and other family members. Out of 152 respondents, 77 have husbands/wives/partners, and of this number, majority admitted to have informed their husbands/wives and partners about their status. PLHIV who have been diagnosed for 10 years and more have the highest percentage of disclosure with their partner at 88%.

Across all other sets of people, the same pattern is observed. More respondents who are PLHIV for 10 years or more reported these people know about their status compared to those who are either newly diagnosed or have been PLHIV for less than 10 years.

Table 6. Percentage of respondents who mentioned groups of people who know about their status by no. of years diagnosed as PLHIV

	All	One year and less	2-5 years	6-9 years	10 and more years	No. Of cases
Husband/Wife/Partner	77.9	70.6	83.3	70.6	85.7	77
Children	25.6	11.1	18.8	37.5	50.0	39
Other family members	63.3	60.0	62.7	63.3	80.0	139
Friends	63.9	61.0	62.1	60.6	91.7	144
Neighbors	10.7	(2.6)	12.3	9.1	36.4	140
Employer	46.1	34.6	46.0	44.4	87.5	89
Co-workers	46.2	32.0	48.7	41.2	80.0	91
Teachers/School Administrators	33.3	(20.0)	(50.0)	(25.0)	(50.0)	15
Classmates	(7.1)	0.0	0.0	0.0	(33.3)	14
Community leaders	18.6	11.5	18.8	25.0	(25.0)	86

() 1-2 cases

### *Disclosure with consent*

In general, disclosure of HIV status was done with the PLHIV's consent. Among those who reported that their HIV status is known by their husband/wife/partner, 98% said that the disclosure was done with their consent. All PLHIVs who reported that their children know about their status (26%), the disclosure happened with their consent.

### *Disclosure without consent*

However, there are also cases where the disclosure of status was made without the PLHIVs' consent. This is more common among co-workers: 46% of PLHIVs said that their co-workers know about their status but of this number, 15% reported that the disclosure was without their consent. Similarly, about the same percentage of PLHIVs reported that their status was disclosed without their consent among their family members (14.5%). Substantial percentage of disclosure without consent also happened among friends and neighbors (11% and 12%, respectively).

Table 7. Percentage of respondents whose HIV status was disclosed without their consent

	Have disclosed HIV status	Disclosed status without consent	No. Of cases
Husband/Wife/Partner	77.9	(1.8)	56
Children	25.6	0.0	12
Other family members	63.3	14.5	83
Friends	63.9	10.7	84
Neighbors	10.7	11.8	17
Employer	46.1	10.0	40
Co-workers	46.2	15.4	39
Teachers/School Administrators	33.3	0.0	4
Classmates	(7.1)	0.0	1
Community leaders	18.6	(14.3)	7

() 1-2 cases

### *Experience in disclosing status*

Experience of disclosing status was assessed based on disagreement or agreement to a series of statements regarding people's experience in disclosing HIV status to people they are close to and to people they don't know very well. The results show higher agreement to the statements that disclosing to people one is close to is a positive experience and that they are supportive once they learned about PLHIV's status. In contrast, more than half disagreed to the statements that people whom the PLHIV does not know very well will be supportive of his/her status once he/she learned about it and that disclosing to them is a positive experience. Almost half of respondents agree to the statement that disclosing HIV status has become easier over time. Across length of years as PLHIV, the percentage agreeing to this statement is higher among those who have been PLHIV for some time. (See Table 8).

Table 8. Percentage of respondents who agree to the following statements on experience with disclosing HIV status by length of years as PLHIV

	All	1 year and less	2-5 years	6-9 years	10 years and more	No. of cases
In general, disclosing your HIV status to <u>people you are close to</u> (e.g., partner, family, close friends) has been a positive experience.	73.4	64.1	75.0	75.0	91.7	143
In general, <u>people you are close to</u> were supportive when they first learned about your HIV status.	76.7	74.4	74.6	81.2	83.3	142
In general, disclosing your HIV status to <u>people you don't know very well</u> has been a positive experience.	25.2	15.2	22.2	32.1	50.0	127
In general, <u>people you don't know very well</u> were supportive when they first learned about your HIV status.	29.9	27.6	29.2	35.7	25.0	117
In general, disclosing your HIV status has become easier over time.	47.1	39.5	44.1	51.6	75.0	140

() 1-2 cases

## DISCLOSURE

Although survey results generally point to the support received by respondents when disclosing their status, there were a few who had very unpleasant and painful experiences when it comes to letting their loved ones know about their HIV infection, as shared by the respondents below:

*"Hiniwalayan at pinandirihan ako ng aking karelasyon dati at pinaalis niya ako sa tinitirhan namin. At hanggang ngayon wala kaming komunikasyon sa isa't isa dahil iniwasan niya ako."* 25-year old male, has known his status for 5 years

*"Nung time kasing yun nagpapaalam ako sa supervisor ko na mag-absent pero di ko sinabi sa kanya kung anong reason bakit (sic) ako a-absent, parang piniga nila akong mag disclose sa kanila or else di nila ako papayagan umabsent and after na magdisclose ako ng reason sa kanila na may HIV ako at kailangan kong umabsent para kumuha ng gamot ko pinayagan nila ako, not knowing the next day lahat na ng mga tao sa opisina ko alam na na may HIV ako, at pinetition nila akong lahat para matanggal sa trabaho. After that pinag-force resignation ako ng company na pinapasukan ko."* - 37-year old male, has known status for 5 years

### C. EXPERIENCE OF STIGMA AND DISCRIMINATION

The survey respondents were asked if they have experienced stigma and discrimination due to their HIV status in 11 scenarios. These include exclusion in social activities, being gossiped about, verbal and physical harassment, refused employment or denied promotion and discrimination experienced by wife/husband/partner. Among those who said that they experienced discrimination, they were further asked whether or not such event happened within the past 12 months.

In general, there was low report of stigma and discrimination among the respondents. Among those who did experience stigma and discrimination, most of them reported experiencing being the topic of gossip of other people, or receiving discriminatory remarks from other people (36%). This is followed by receiving discriminatory remarks or being gossiped about by family members (32%); verbal harassment (18%); refused employment or losing a source of income (12%) and being blackmailed (11%).

Table 9. Percentage of respondents who experienced stigma and discrimination

	No	Yes, within the last 12 mos.	Yes, but not in the last 12 mos.	No. of cases
Excluded from social gathering or activities	93.2	3.0	3.8	132
Excluded from religious activities or places of worship	97.0	(0.8)	2.3	132
Excluded from family activities	94.8	3.7	(1.5)	135
Discriminatory remarks or gossiping from family members	68.4	17.3	14.3	133
Discriminatory remarks or gossiping from other people	64.4	19.3	16.3	135
Verbally harassed	82.4	10.3	7.4	136
Blackmailed	89.5	7.5	3.0	133
Physically harassed or hurt	95.6	2.2	2.2	137
Refused employment, lost a source of income or job	88.5	4.1	7.4	122
Job description or nature of job was changed	95.5	(0.9)	3.6	112
Wife/husband/partner experienced discrimination	94.0	3.7	(2.4)	82

() 1-2 cases

### *Exclusion from activities*

Among those who experienced being excluded from social gatherings, (6.8%), 3% said the incident happened within the past year while 3.8% said it happened a long time ago.

Those who experienced being excluded from religious activities, 2.3% said the incident occurred not within the past year.

Among those who were excluded from family activities, 3.7% said that it happened within the past year.

### *Being gossiped about*

About a third were aware of family members making discriminatory remarks or gossiping about them, and 17% reported that this happened within the past year.

Thirty six percent were aware of being gossiped about by people other their family members, 19% of which happened within the past 12 months.

### *Harassment*

Ten percent experienced being verbally harassed (e.g. yelled at, scolded or was verbally abused) within the past year while about 8% experienced being blackmailed because of their HIV status just recently or within the past year.

Two percent experienced being physically harassed or hurt (pushed, hit, was physically abused) because of their HIV status within the last 12 months. The same percentage also reported experiencing physical harassment because of their HIV status but not in the past year.

### *Deprivation of opportunities*

Four percent experienced being refused of employment or losing a source of income or job in the recent year while less than 1% experienced being denied a promotion or having their job nature or description changed because of their HIV status, also in the past 12 months.

### *Discrimination experienced by partner*

Aside from their own experience of discrimination, PLHIVs reported that their partner, wife or husband is also susceptible to discrimination due to their association with them. Six percent of respondents said that their wife/husband/partner experienced discrimination, 3.7% of which occurred in the past year.

*Experience of stigma and discrimination by number of years as PLHIV*

When cross-tabulated with the number of years as PLHIV (Table 10), it was found that those who have been living with the illness for one year or less tend to experience receiving discriminatory remarks from family members than those who are PLHIV for more than 1 years but less than 10 years. This experience is highest among those who have been PLHIV for 10 years and more. As expected, in almost all scenarios, those who have been PLHIV for a long time, especially those PLHIV for 10 years and more reported the highest percentage.

Table 10. Percentage of respondents who experienced stigma and discrimination by length of years as PLHIV

	One year and less	2-5 yrs	6-9 yrs	10 yrs and more	All
Excluded from social gathering or activities	(3.2)	9.3	9.7	0.0	7.0
Excluded from religious activities or places of worship	0.0	(3.6)	(6.4)	0.0	3.1
Excluded from family activities	(3.0)	5.4	9.7	0.0	5.3
Discriminatory remarks or gossiping from family members	31.4	29.5	31.0	54.6	32.6
Discriminatory remarks or gossiping from other people	21.2	38.2	41.9	58.3	36.6
Verbally harassed	9.1	25.0	16.1	16.7	18.2
Blackmailed	(3.0)	13.0	10.0	25.0	10.8
Physically harassed or hurt	(5.9)	5.4	0.0	(8.3)	4.5
Refused employment, lost a source of income or job	(6.9)	12.0	14.8	16.7	11.9
Job description or nature of job was changed	0.0	(2.1)	16.0	0.0	4.6
Wife/husband/partner experienced discrimination	(9.1)	(5.7)	0.0	(16.7)	6.1

() 1-2 cases

### *Towards an assessment of the severity of experienced stigma and discrimination*

In order to quantify the severity of the stigma and discrimination experienced by the respondents, the study team came up with an index based on the 11 scenarios of discrimination used in the questionnaire. In this initial step, all scenarios are assumed to have equal weight. An affirmative response to each statement would garner a score, thus, the total score would range from 0 to 11.

Based on the results, the maximum number of discrimination scenarios experienced is 6, thus, discrimination index categories were created as follows: scores of 0 is low level, 1-3 is medium and 4-6 is high. Following this scoring scheme, 55% of the respondents were found to have low level of discrimination experienced and only 11% experienced a high level of discrimination. Although this could be a good initiative to calibrate the level of stigma and discrimination experienced by PLHIV, literature reviews and comparative analysis of experiences across countries could be done to re-assess and consider the possibility of creating a stigma index that *adequately* quantifies or *evaluates how stigmatized or discriminated a PLHIV is* depending on the various types of stigma one has experienced in *different settings*. The context where the PLHIV experienced stigma and discrimination is highly significant to determine which settings as of present remain unaware about the PLHIVs' plight.

When number of years of being PLHIV is considered, the level of discrimination experienced varies. Those who were diagnosed recently or are PLHIV for one year and less have the highest percentage reporting low level of discrimination. In contrast, respondents who are diagnosed as HIV positive more than 10 years ago have the highest percentage reporting medium and high level of discrimination.

#### **EXPERIENCE OF STIGMA AND DISCRIMINATION**

Some of the respondents took the time to further describe the stigma and discrimination that they recently experienced within their social spheres:

*"Ayaw pahawak o pakarga sa akin ang pamangkin ko. Ayaw akong pinapagluto. Hinihiwalay ang pagkain. Hiniwalay ang mga utensils. Ayaw gamitin ang kumot at unan."* – 22-year old male, has known his status for 1 year

*"Meron akong karanasan sa mga taong hindi buong naunawaan ang sakit na HIV/AIDS na sa pagkasabi mo pa lang nito ay pinandirihan ka na agad. Ang sakin (sic) lang sana lubusan muna nilang unawain bago sila manghugsa"* - 23-year old male, has known his status for a year

*"Naranasan kong pandirihan ng aking sariling kapatid dahil sa aking status even na tanggap ako nila mama at papa kahit ako'y HIV positive, dumating sa point na sinisigawan ako ng aking kuya at pagsabihan ng masasakit na salita dahil sa aking status at sa di ko makakalimutan ay ang hiwalay nga yung mga personal na gamit*

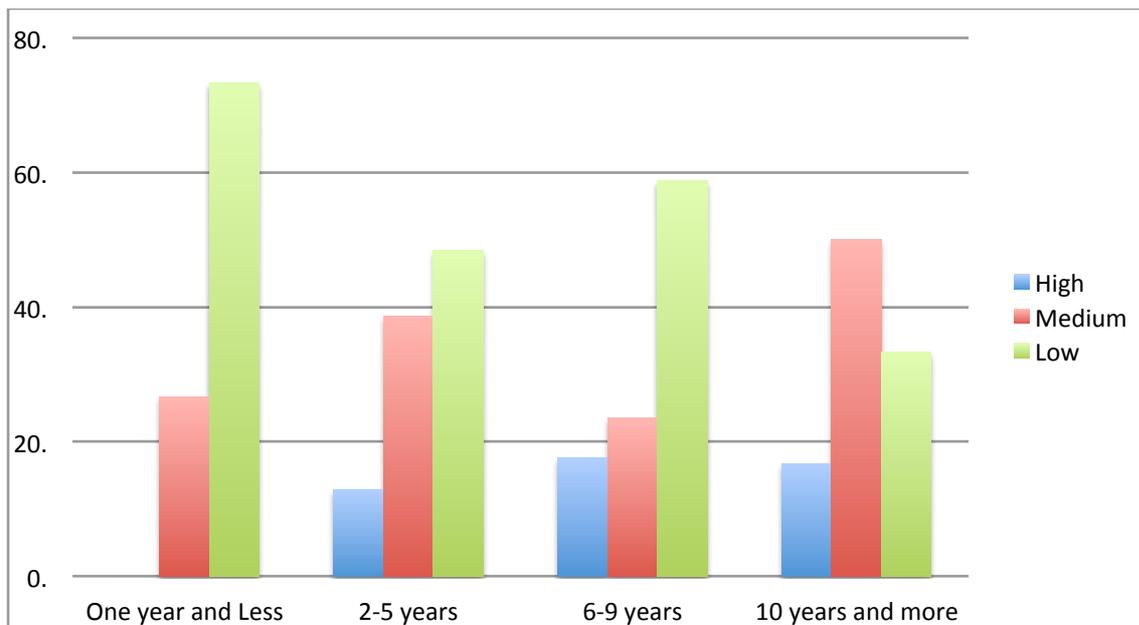


Figure 2. Level of discrimination by length of years as PLHIV

#### **D. INTERNALISED STIGMA (THE WAY YOU FEEL ABOUT YOURSELF) AND RESILIENCE**

The survey respondents were asked about ten statements that assessed their level of self-efficacy, or the ability to succeed in specific situations or accomplish a task. In particular, the statements explore how HIV status affected their self-confidence, self-respect, ability to respect others, ability to cope with stress, to find love, to have secure and close relationship with others, desire to have children, achieve personal and professional goals, among others. Table 11 presents the results.

Table 11. Percentage of respondents who reported on how their self-efficacy was affected by their HIV status

	Has been positively affected	Has not been affected	Has been negatively affected	No. of Cases
My self-confidence	36.6	32.4	31.0	145
My self-respect	35.9	39.3	24.8	145
My ability to respect others	35.6	52.1	12.3	146
My ability to cope with stress	34.2	35.6	30.1	146
My ability to have close and secure relationship with others	32.2	41.6	26.3	137
My ability to find love	34.1	37.0	28.9	135
My desire to have children	30.5	33.9	35.6	118
My achievement of my personal and professional goals	38.0	31.7	30.3	142
Ability to contribute to my community	37.1	43.4	19.6	143
My ability to practice my religion/faith as I want to	47.2	46.5	6.2	144

#### *Confidence and respect*

Thirty seven percent of the respondents reported that their HIV status positively affected their self-confidence while a slightly lower percentage (31%) has the opposite effect. Almost a similar percentage also reported that their HIV status has a positive effect on their self-respect. In terms of their ability to respect others, majority said that their HIV status does not have an effect in this aspect.

#### *Stress and relationships*

Three in 10 said that their HIV status has a negative effect on their ability to cope with stress. In the same token, slightly more (34%) also reported that their HIV status has a positive effect or does not affect their ability to cope with stress (37%).

Forty two percent of respondents reported that their HIV status does not affect their ability to have a close and secure relationship with others. A slightly lower percentage (37%) also said that being HIV positive does not affect their ability to find love. However, 36% said that their HIV status negative affected their desire to have children.

*Professional and community life*

Interestingly, more respondents said that their HIV status positively affected the achievement of their personal and professional goals (38%) while 3 in 10 said that it has no effect or has negatively affected the achievement of their personal and professional goals. HIV status was also seen by majority as having no effect on their ability to contribute to community and the ability to practice their religion/faith. Almost half even reported that being HIV positive has a positive effect on their ability to practice their religion and faith. During the interviews, the research team observed that those who were diagnosed specifically for one year or less try to make sense of their status by looking at the brighter side of their circumstances, often arguing that the illness had made them stronger.

In Table 12, special focus is given on the response that the HIV status negatively affected self-efficacy according to the length of being PLHIV. Results show that more of those who have been PLHIV for a longer period reported that being PLHIV affected their self-efficacy in a negative way. Specifically, this is true when it comes to their self-respect, ability to respect others, cope with stress, to have a close and secure relationship with others, find love, desire to have a child and their ability to contribute to community.

Table 12. Percentage of respondents who reported that their HIV status negative affected their self-efficacy by length of years as PLHIV

	One year and less	2-5 yrs	6-9 yrs	10 years and more	All
My self-confidence	26.8	35.0	28.1	33.3	31.0
My self-respect	12.2	33.3	18.8	41.7	24.8
My ability to respect others	10.0	11.5	9.1	33.3	12.3
My ability to cope with stress	31.7	31.7	21.2	41.7	30.1
My ability to have close and secure relationship with others	21.2	22.4	27.6	58.3	26.3
My ability to find love	26.3	24.6	30.0	60.0	28.9
My desire to have children	43.7	29.4	32.1	57.1	35.6
My achievement of my personal and professional goals	27.5	32.2	31.2	27.2	30.3
Ability to contribute to my community	20.0	19.0	15.2	33.3	19.6
My ability to practice my religion/faith as I want to	7.3	6.8	(3.0)	(9.1)	6.3

( ) 1-2 cases

*Self-exclusion/deprivation*

One of the most common reactions of PLHIVs in dealing with their status is to isolate themselves from others or to exclude themselves from social activities. Nineteen percent of PLHIVs reported that they have chosen not to attend social gatherings in the last 12 months, have isolated themselves from

their family and decided not to have sex. Similarly, about 8% said that they have chosen not to seek health care, 14% decided not to apply for a job, and 13% did not seek social support. Higher proportion of self-exclusion and deprivation is found among those who are recently diagnosed (data not shown).

Table 13. Percentage of respondents who reported that they have done the following in the last 12 months due to their HIV status

	Number	Perce nt	No. Of cases
Chose not to attend social gatherings	28	19.3	145
Chose not to seek health care services	12	8.3	145
Chose not to apply for a job	19	13.7	139
Chose not to seek social support	18	12.8	141
Have isolated self from family	28	19.3	145
Decided not to have sex	25	18.7	134

#### *Experiencing internal stigma*

An overwhelming majority (83%) believed that it is difficult to tell people about their HIV infection and reported that they hide their status from others (81%).

Being HIV positive made 26% of the respondents feel dirty, while more than half (54%) feel guilty; 38% feel ashamed and 36% feel worthless because of being HIV positive.

Table 14. Percentage of respondents who agreed to the following statements, according to number of years of being PLHIV

	Number	Per cent	No. Of cases
It is difficult to tell people about my HIV infection	121	82.9	146
Being HIV positive makes me feel dirty	39	26.5	147
I feel guilty that I am HIV positive	80	54.1	148
I am ashamed that I am HIV positive	57	38.5	148
I sometimes feel worthless because I am HIV positive	54	36.5	148
I hide my HIV status from others	120	81.1	148

## INTERNALISED STIGMA

Some of the respondents admitted that being HIV-positive initially led them to lose their confidence in themselves and to become hopeless about their future. However, with the support of family and other PLHIV, some of them gradually regained their strength to achieve their personal goals and live a more meaningful life:

*“Sa una ako ay nawala ng kompiyansa sa sarili sa kadahilanan ng ako ay isang PLHIV. Gusto ko sumuko na o mamatay. Pero sa tulong ng aking pamilya nabuksan ang aking isipan na kahit ako ay HIV+ marami pa ring nagmamahal sa akin sa ngayon. Ako ay lumalaban. Para sa aking pamilya at sa aking sarili at sana maging bukas ang kaisipan ng iba tungkol sa PLHIV na maaring mabuhay ng mahaba.” - 34-year old female, has known his status for 1 year*

*“Nung na-HIV ako maraming stigma nangyari sa akin lalo na sa akin katawan. Marami ako rashes sa katawan at payat ako na akala nila may TB ako.. naranasan ako pagtsismisan ng kapitbahay ko n a may TB ako at pinandidirian dahil dami ko peklat sa akin katawan. Kaya hindi ako lumalabas ng bahay para hindi ako makaramdaman yung sa akin na pinandidirian ka. Iniisip ko na lang magpakamatay dahil feeling ko mag-isa lang ako na wala ako makikita suporta ng ibang tao. Nagdadasal na lang ako kay God na sana kunin na lang ako kaysa maramdaman ko ito...” -28-year old male, has known his status for 2 years*

*“Nagkaroon ako ng stigma at diskriminasyon sa sarili ko nung malaman kong HIV positive ako kasi naisip ko na baka pandirihan ako ng lahat at yung iniisip ko na ako nakahawa sa partner ko. Pero dahil sa tulong ng HIV counselor namulat ako sa adbokasiya at tumutulong na din sa ibang HIV positive na nakakaranas ng stigma at diskriminasyon.” - 35-year old female, has known her status for 2 years*

## E. INTERACTIONS WITH HEALTHCARE SERVICES

### *HIV Testing*

Eight in 10 had themselves tested for HIV out of their own decision; 5% were pressured to be tested while and 15% were tested without their knowledge. One respondent got the HIV infection through mother to child transmission. (Figure 3)

One of the main reasons for HIV testing is because the respondent suspects that he/she is at risk for HIV (30%). This is most likely because of the nature of their work (being engaged in commercial sex work) or because he/she has multiple partners and has heard of the risk for HIV among peers or even through social media. About a quarter also said that they got themselves tested simply because they wanted to know their status.

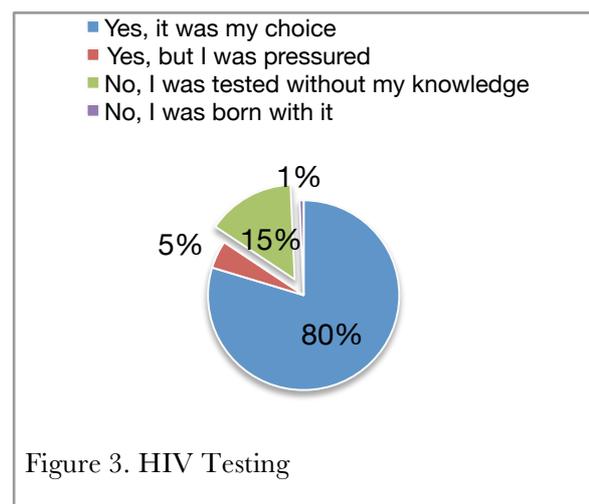


Table 15. Main reason for HIV testing

	Number	Percent
A provider recommended it	30	23.4
I believed I was at risk for HIV	39	30.5
I felt sick and I/my family thought it is due to HIV	13	10.2
Part of or because of community activity	5	3.9
It was a requirement	10	7.8
I just wanted to know	31	24.2
No. Of cases	128	100.0

The length of time between thinking about taking the test and being actually examined for HIV for those who are younger is only six months. The access to HIV testing determines the decision to undergo the exam, since those who reside near the treatment hubs or testing centers would most likely have themselves tested immediately compared to those who live far and have no direct access to such services. 17.1% of the respondents said they immediately accessed treatment after the diagnosis. But an alarming finding is that 8% waited for two years upon diagnosis before they actually accessed ARV.

More than half (59.4%) of the respondents reported that fears about how other people (e.g. friends, family, employer or community) would respond if they tested positive made them hesitate to get tested for HIV.

#### *Accessing Treatment*

Respondents were asked what factors have made them delay or have prevented them from accessing HIV treatment. Forty three percent were worried about other people (other than their family or friends) knowing about their status while 35% were worried about their partner, family or friends knowing their status. A few said they were just not ready to deal with their HIV infection (29%); 23.2% said they were afraid health workers would treat them badly or disclose their status without their consent; and 8% said they had a previous bad experience with a health worker.

Seventeen percent of respondents started accessing HIV treatment immediately after diagnosis. A third started within a month while a slightly lower percentage did it within 1 to 6 months. Nine percent however started treatment only after two years.

Table 16. Length of time between diagnosis and start of ARV treatment

	Number	Percent
Immediately	25	17.4
>1 day to a month	46	31.9
>1 month to 6 months	43	29.9
>6 months to 2 years	15	10.4
> 2 years	13	9.0
Can't remember	2	1.4
No. Of cases	144	100.0

Majority of respondents (85.4%) said they were told the benefits and chose to start as soon as they were offered the ARV; 5.6% said they decided to wait for a while before beginning the treatment; while 2% said they were pressured or forced by health care staff to take ARV treatment.

Ninety five percent of respondents are currently taking ARV treatment while 5% reported they have not started yet since they were diagnosed only recently. Other reasons for not currently taking ARV treatment include the inability to collect their medications and the fear that someone will find out about their status. This fear was also cited by 17.5% of those who are currently taking ARV as the reason why they sometime miss a dosage of their ARV treatment.

Over half (58%) of the respondents have not yet undergone a viral load test and about 5% did not know what a viral load is.

#### *General Health Status*

Most of the respondents described their health as good (61.5%). This is true for those who are HIV positive for more than a year. Eight percent of those who have been positive for 10 years and more said their health is poor.

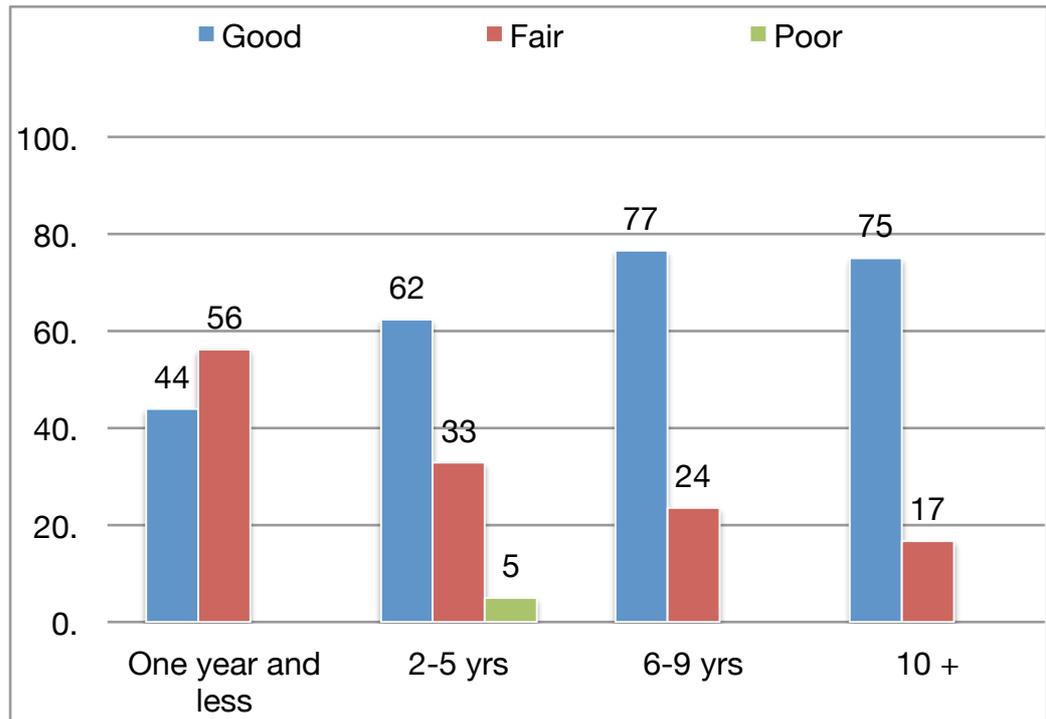


Figure 4. Self-assessed health status by number of years as PLHIV

In the past 12 months, 17.3% said they were diagnosed of tuberculosis, 3.9% of hepatitis, 22.6% of sexually transmitted infections, and 27.4% of mental health conditions]. Of those who reported that they were diagnosed of these conditions, 67.2 percent sought treatment.

#### *Mental Health Status*

Respondents were asked how frequently they felt nervous, anxious, and lethargic or depressed in the past two weeks, with the following options: never, once or twice, several times and most of the times. In all situations, more reported they never experienced or felt the situation in the past two weeks. However, substantial proportion reported feeling or experiencing the situation most of the time in the past two weeks. Nine percent said they felt nervous, anxious or on edge; 8.6% could not stop or control worrying; 7.3% reported they had little interest or pleasure in doing things; and 9.3%] said they felt down, depressed or hopeless *most of the time*.

Sixty percent of those who experienced nervousness, anxiety, worrying and feeling depressed sought help, the most common of which is counselling.

Table 17. Percentage of respondents feeling nervous, anxious and depressed most of the time in the past two weeks

	Percent	N
Feeling nervous, anxious	9.2	152
Not being able to stop worrying	8.6	151
Little interest or pleasure in doing things	7.3	150
Feeling down, depressed or hopeless	9.3	150

### *Service Delivery Experiences*

An overwhelming majority of those who are accessing treatment, usually receive their regular HIV care and treatment in government or public clinic or facility (98%). Others access treatment in private clinics/hospital/doctor (2%).

### *Stigma and Discrimination when accessing HIV-specific Health Care*

When asked about their encounters with health care providers for HIV specific health care, 15% of respondents said they were advised not to have sex because of their HIV status. Three percent also said that they experienced being gossiped or talked about while 2% reported verbal abuse and avoidance of physical contact (2%).

Table 18. Percentage of respondents reporting stigma and discrimination when accessing HIV-specific health care

	Percent	N
Being advised not to have sex	14.7	150
Being talked badly or gossiped about	2.7	149
Verbally abused	2.0	149
Physical abuse	(0.7)	149
Avoiding physical contact	2.0	149
Telling other people about HIV status	(0.7)	147

() 1-2 cases

### *Stigma and Discrimination when accessing non-HIV Health Care*

In the past year 36 % said they sought health care for non-HIV related needs such as malaria, flu, dental services, vaccination and injury. Among them, 11.5% experienced being talked badly or gossiped about while 8.2% were denied of health services. About 5% also reported that they were advised not to have sex and their status was disclosed to other people.

Table 19. Percentage of respondents reporting stigma and discrimination when accessing non-HIV related health care

	Percent	N
Being denied of services because of HIV status	8.2	61
Being advised not to have sex	4.8	62
Being talked badly or gossiped about	11.5	61
Verbally abused	(3.3)	61
Physical abuse	(3.3)	61
Avoiding physical contact	(3.3)	60
Telling other people about HIV status	4.9	61

() 1-2 cases

About a quarter said they disclose their status whenever they go outside of the treatment hub for non-HIV related concerns.

In general, majority of respondents (94%) believed that their medical records are kept confidential.

#### *Sexual and Reproductive Health-related Stigma and Discrimination*

In the past 12 months, 1.5% of the respondents were advised not to have a child because of their HIV status and about 4% reported that they were told by a health professional that in order to get their ARV treatment, they had to use a specific method of contraception.

### **INTERACTIONS WITH HEALTH CARE SERVICES**

Health care facilities in the previous years were a breeding ground of stigmatizing and discriminatory acts against people living with HIV, since it was only in the recent decade they were bombarded with trainings and information drives to raise awareness about the PLHIV's plight. Most of those who are PLHIV for a longer period of time were the ones who experienced severe stigma and discrimination. On the other hand, those who are recently diagnosed would often just ask that the process of accessing ARV treatment in the hubs be improved since it usually takes them a day to get their ARV refills; thus causing them to lose their one day's worth of income.

*"Sa ngayon wala pa akong naexperience na stigma at discrimination. Pero sa aking treatment hub ang challenge ay matagal kumuha ng gamot."* – 56-year old male, has known his status for 1 year

*"Sa kabuuan hindi pa naman ako nakakaranas ng stigma discrimination. Pero nalulungkot ako pag pumupunta ako sa hub treatment ko dahil nauubos ang isang araw para lamang sa pagkuha ng ARV."* - 37-year old male, has known his status for 3 years

*"Based on my experiences of having HIV infection, I was diagnosed at PNRC and the doctor told me that I had only 4 years to stay. because of getting HIV+. She got angry with me because of having multiple sex partners. However someone came to me, a counselor who guide me and give me encouragement that life must go on."* – 40-year old male, has known his status for 9 years

*"May bad experience is yung magpapabunot ako ng ngipin sa dentist then noong magdisclose ako regarding sa status ko nirefuse niya ako. At sana mayrong basic information trainings pa para sa mga (HIV AIDS) at health workers."* 43-year old male/transgender, has known status for 13 years

## F. HUMAN RIGHTS AND EFFECTING CHANGE

Respondents were asked if they have experienced any form of abuse and if the incident happened within the last 12 months or a long time ago.

Table 20. Percentage of respondents who experienced abuse in their rights

	Yes, within the past year	Yes, but not in the past year	N
Forced to get tested or disclose status:			
To obtain a visa	2.1		145
To apply for a job	2.1	2.1	145
To get health care	(0.7)	1.3	149
Got detained quarantined because of HIV status		(0.7)	147
Denied a visa to enter another country	(0.7)	2.8	143
Was forced to disclose HIV status			147

() 1-2 cases

There is very low level of report on experience of abuses on rights. Among those who experienced abuse, the most common was being denied a visa to enter another country and this even occurred not within the last 12 months (2.8%). Being forced to get tested or disclose status in order to obtain a visa was another form of abuse reported by 2% of the respondents. This happened recently, or within the last 12 months. A similar percentage also said that they were forced to get tested or disclose their HIV status in order to apply for a job: 2.1% said this happened within the past year and another 2.1 reported that it happened to them but not in the past year. Slightly 1 percent said they were forced to get tested or disclose their status in order the get health care.

Among those who reported experiencing some forms of abuse, majority did not do anything about it. They cited as reasons the following: 1) they did not know where to go, 2) do not know what are the processes involved and 3) they are worried about the repercussion of taking action.

Awareness of laws protecting PLHIV is very high, as 95 percent of respondents said they are aware of the existence of such laws.

In Table 21, the percentage of respondents who reported to have done something to affect change is presented. Providing emotional, financial and other type of support in order to help someone with HIV deal with stigma and/or discrimination is the most common action done by respondents. Twenty eight percent said they have done this within the past year, while 18% have done this activity more than a year ago. Participation in an organization or educational campaigns that address stigma and discrimination against people living with HIV is the

second common activity done by respondents. A quarter of them reported to have done this in the past year, while 16% said they have done this more than a year ago.

Table 21. Percentage of respondents who have done something to affect change

	Yes, within the past year	Yes, but not in the past year	N
Challenged or educated someone who was engaging in stigma or discrimination against you	14.2	9.5	148
Challenged or educated someone who was engaging in stigma or discrimination against other people living with HIV	14.3	14.3	147
Provided emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination	28.3	17.9	145
Participated in an organization or educational campaign working to address stigma and discrimination against people living with HIV	25.0	16.2	148
Encouraged a community leader to take action about issues of stigma and discrimination against people living with HIV	8.8	4.0	148
Encouraged a government leader or a politician to take action about issues of stigma and discrimination against people living with HIV	4.9	7.7	143
Spoke to the media about issues of stigma and discrimination against people living with HIV	0.0	7.4	148

## HUMAN RIGHTS AND EFFECTING CHANGE

Upon diagnosis, a PLHIV undergoes mental and emotional stress as he/she tries to comprehend and adjust to his/her current situation. After a few years, most of the respondents are able to successfully adapt to their predicament and even exert efforts to lift the spirits of their fellow PLHIV and educate those who tend to stigmatize and discriminate them, as attested by some of the respondents below:

“...open kasi ako sa lahat ng tao lalo na sa komunidad ko. Feeling ko kasi doon ako nakakatulong how to educate the people about HIV/AIDs.” *36-year old male, has known his status for 5 years*

“Bilang isang aktibong miyembro at kabaahagi ng mga Peer Educators at HIV Counselors ng Dept. of Health, masasabi kong maayos naman ang proseso at pagpapatakbo ng sangay ng gobyerno para makatulong sa mga FLHIV's ang kakulangan na lang ay ang tama at wastong pagpapalaganap ng mga impormasyon patungkol sa HIV/AIDS masipalaganap pa ang mga impormasyon ng mas maayos para mas mapatibay pa ang ating pagsugpo at pagpigil sa mas lumalalang HIV infection para sa ninanais na makamit na 0% new HIV infection, 0% HIV/AIDS related death, at 0% stigma & discrimination.” – *28-year old male, has known his status for 6 years*

“Isang pagkakataon ng stigmatizing ako noong 2015-2016 sa isang grupo ko ng isang clan. Pero pagkalipas ng isang taon, nag-apologize naman yung taong nastigma sa akin dahil naeducate ko siya nang husto.” - *31-year old male, has known his status for 9 years*

“Pag-uwi ko sa Pinas, doon nila nalaman. HIV status mahirap naranasan ko, sa mga kapatid, pamangkin, at sa iba tao, akala nila makahawa ako sa kanila, matagal hindi ko matanggap, mulay, mga gamit ko tinapon. Tiniis ko lahat, palagi ako nagdasal sana makaya ko ito stigma sa ibang tao, so pumasok sa advocacy, any brg, community, ngayon nagwork ako sa OWWA. Mga OFWs testing para mag aware sila palagi sa abroad. Ngayon tuloy pa rin testimonya, happy naman ako sa ginawa ko, makatulong sa mga OFWs, palabas sa ibang bansa” -*59-year old female, former OFW, has known her status for 19 years*

## G. STIGMA AND DISCRIMINATION EXPERIENCED FOR REASONS OTHER THAN HIV STATUS

Respondents were asked whether they experienced stigma and discrimination due to their gender identity, sexual preference, involvement in sex work and drug usage. The results for women respondents who identified themselves as lesbians are not presented due to small number of cases (5).

Table 22 presents the results among transgender.

### *Being transgender*

The most common form of discrimination they experienced is that of having family members making discriminatory remarks about them because of their being transgender (27%). This is

followed by verbal harassment (25%). Both of these are recent occurrences as these happened within the past year.

Table 22. Percentage of respondents who experienced stigma and discrimination due to being transgender

	Yes, within the last 12 months	Yes, not within the last 12 months	N
Excluded from family activities	(8.3)	0.0	12
Ever felt that family members made discriminatory remarks	27.2	(9.1)	11
Ever felt afraid to seek health services	(7.7)	0.0	13
Ever avoided seeking health services for fear that people will find out about your status	(9.1)	0.0	11
Ever verbally harassed by someone because of sexual orientation	25.0	0.0	12
Blackmailed by someone because of sexual orientation	(8.3)	0.0	12
Physically hurt by someone because of sexual orientation	(8.3)	0.0	12

( ) 1-2 cases

Majority of transgenders said that other transgender group/s, their family or friends and other people in the community know that they are transgenders (70%). Forty five percent of transgender respondents are members of a network or support group for transgender people.

### *Being an MSM*

Among MSM, receiving discriminatory remarks from family members is also the most common form of discrimination they received. Fifteen percent reported to have experienced this within the last 12 months, while 13% said this occurred to them but not in the past 12 months.

Eighty three percent of respondents who identified themselves as MSM said that other MSM in their community know that they are MSM. Similarly 72% said that their family members or other friends are aware of their sexual preference while 52% reported that other people in

the community know that they are MSM. Four in 10 are members of a network or support group for MSM.

Table 23. Percentage of respondents who experienced stigma and discrimination due to being MSM

	Yes, within the last 12 months	Yes, not wit hin the last 12 mon ths	N
Excluded from family activities	(3.8)	(1.9)	53
Ever felt that family members made discriminatory remarks	14.8	13.0	54
Ever felt afraid to seek health services	(1.9)	(1.9)	53
Ever avoided seeking health services for fear that people will find out about your status	(1.9)	(1.9)	53
Ever verbally harrassed by someone because of sexual orientation	7.6	(3.8)	53
Blackmailed by someone because of sexual orientation	(3.8)	0.0	53
Physically hurt by someone because of sexual orientation	(3.8)	(1.9)	53

( ) 1-2 cases

### *Being a Gay/Homosexual*

Among those who identified themselves as gay/homosexual, the most common experience of stigma/discrimination is receiving discriminatory remarks from family and verbal harassment. Thirty seven percent said they ever felt that family members are making discriminatory remarks within the last 12 months. The same percentage also reported verbal harassment, but not within the last 12 months although 12% reported experiencing verbal harassment recently, or in the past 12 months.

Majority said that other gays in the community, their family members and friends, as well as other people in the community are aware that they are gay. Six in 10 of respondents who identified themselves as gays are members of a network or support groups for gays/homosexual.

Table 24. Percentage of respondents who experienced stigma and discrimination due to being gay

	Yes, within the last 12 months	Yes, not within the last 12 months	N
Excluded from family activities	(6.2)	0.0	16
Ever felt that family members made discriminatory remarks	37.5	(6.2)	16
Ever felt afraid to seek health services	0.0	(6.2)	16
Ever avoided seeking health services for fear that people will find out about your status	0.0	0.0	16
Ever verbally harrassed by someone because of sexual orientation	12.5	37.5	16
Blackmailed by someone because of sexual orientation	0.0	(6.2)	16
Physically hurt by someone because of sexual orientation	0.0	(6.2)	16

( ) 1-2 cases

### *Being bisexual*

Among respondents who identified themselves as bisexual, getting discriminatory remarks from family members, verbal harassment and physical harassment are the common forms of discrimination they received. Thirteen percent reported to have received discriminatory remarks within the last 12 months, while 17% experienced this more than a year ago.

Table 25. Percentage of respondents who experienced stigma and discrimination due to being bisexual

	Yes, within the last 12 months	Yes, not within the last 12 months	N
Excluded from family activities	0.0	(3.8)	52
Ever felt that family members made discriminatory remarks	13.5	17.3	52
Ever felt afraid to seek health services	0.0	5.8	52
Ever avoided seeking health services for fear that people will find out about your status	0.0	5.8	52
Ever verbally harrassed by someone because of sexual orientation	7.7	11.5	52
Blackmailed by someone because of sexual orientation	(1.9)	(1.9)	52
Physically hurt by someone because of sexual orientation	5.9	(3.9)	51

() 1-2 cases

Seventy six percent of respondents who are bisexual reported that other bisexuals in their community know of their sexual preference. Meanwhile, 65% said their family or other friends are aware that they are bisexual while 45% reported that other people in the community know that they are bisexual.

#### *Involvement in sex work*

Among those who ever had sex in exchange for money or goods or identified themselves as sex workers, the most common experience of stigma/discrimination within the last 12 months is verbal harassment (14%); followed by receiving discriminatory remarks from family members (11%); and being blackmailed by someone (11%).

Only 22% of them said that their family and other friends know about their involvement in sex work. Also, only 16% of them belong to a network or support group for those involved in sex work.

Table 26. Percentage of respondents who experienced stigma and discrimination due to involvement in commercial sex

	Yes, within the last 12 months	Yes, not within the last 12 months	N
Excluded from family activities	(2.9)	(2.9)	34
Ever felt that family members made discriminatory remarks	11.4	(2.9)	35
Ever felt afraid to seek health services	(2.9)	(2.9)	35
Ever avoided seeking health services for fear that people will find out about your status	(5.6)	(2.8)	36
Ever verbally harassed by someone because of commercial sex	13.9	13.9	36
Blackmailed by someone because of commercial sex	11.1	(2.8)	36
Physically hurt by someone because of commercial sex	5.6	0.0	36

( ) 1-2 cases

### *Usage of drugs*

Among those who ever injected or habitually used drugs (e.g. heroin, cocaine or methamphetamines) and who identified themselves as a person who uses or used drugs, the most common experience of stigma/discrimination within the last 12 months is receiving discriminatory remarks from family members (17%); followed by feeling of fear in seeking health services (9%).

Sixty seven percent of them said that their family and other friends know about their drug usage. Also, only 28% of them belong to a network or support group for those using drugs.

Table 27. Percentage of respondents who experienced stigma and discrimination due to drug use

	Yes, within the last 12 months	Yes, not within the last 12 months	N
Excluded from family activities	0.0	(9.1)	11
Ever felt that family members made discriminatory remarks	(16.7)	(16.7)	12
Ever felt afraid to seek health services	(9.1)	(9.1)	11
Ever avoided seeking health services for fear that people will find out about your status	(8.3)	(8.3)	12
Ever verbally harassed by someone because of drug use	(8.3)	(8.3)	12
Blackmailed by someone because of drug use	0.0	0.0	12
Physically hurt by someone because of drug use	0.0	(8.3)	12

( ) 1-2 cases

### EXPERIENCE OF STIGMA AND DISCRIMINATION FOR REASONS OTHER THAN HIV

Some of the respondents shared how the collusion of their gender identity and HIV status has caused them to experience stigma and discrimination. It is disheartening how being a homosexual or having multiple partners in some instances causes other people to assume that a person is HIV-positive. Such preconceived notions trigger stigma and discrimination which point to the need for education and information drives in all platforms to decrease negative prejudices against LGBTQI and PLHIV in the country:

*“Ilang tao sa barangay o kapitbahay ng client ang minsan nagpaparinig na ang client daw ay may AIDS. Nag-sasabi ang mga tao sa barangay na dati, babae ang gusto at bakit ngayon lalaki na ang kanyang gusto” – 27-year old male, has known his status for 2 years*

*“Tinuturo sa church na kinabibilangan ng client na hindi pupunta sa langit ang mga bakla (Methodist). Sinasabi rin na ang HIV ang bunga ng kasalanan dahil sa pakikipagtalik sa kapwa lalaki. Ang sakit na HIV ang sakit ng mga bakla. Minsan pinagtsismisan na dahil meron siyang sakit sa balat ay baka may AIDS daw siya.” 44-year old male, has known his status for 2 years*

*“Minsan nagpaparinig ang mga tambay na siya ay may HIV dahil alam nila na ang partner niya ay lalaki Nang malaman ng kanyang lola, sinabihan na hihingi ng shelter for PLHIV” – 32-year old male, has known his status for 6 years*

*“I was excommunicated in our church because of my status and was discriminated for involving myself in campaigns for LGBT and HIV.” – 27-year old male, has known his status for 7 years*

## **X. CASE STUDIES**

The proponents decided to conduct qualitative interviews with five respondents who had striking HIV-related experiences that the survey failed to capture. One of the case studies was about a gay PLHIV who experienced being stigmatized and discriminated by his neighborhood and extended family. On the other end, we have another case study which features a straight male PLHIV who did not at all experienced stigma and discrimination but feel a bit hopeless about career and marriage due to his HIV status. Three more case studies feature the stories of three HIV-positive mothers; two had children who were HIV-positive at birth while one shared how she prevented the transmission of the virus to her child during pregnancy.

These case studies in no way depict the overall situation of the PLHIV in the country. However, presenting these stories could help us see the unexplored aspects of the experiences of PLHIV and could eventually help us re-assess our approaches to studying their lives. For instance, mother-to-child transmission was not really one of the major focus points of the stigma index but the case studies suggest that conducting a separate and more in-depth research on the said topic could shed light on how government interventions could help both the mother and the children cope with HIV.

### **CASE STUDY 1: JOHN<sup>5</sup>**

Poverty and lack of support from relatives forced John to offer his body in exchange for money when he was still a high school student. His father was diagnosed of cancer, his younger brother had polio, and his mother struggled to make ends meet. It was already when he was in college that John learned about his status, and he blamed the lack of government efforts on awareness-raising during his teenage years for the precarious circumstance in which he now finds himself in. He added that if it weren't for the spike of HIV cases in the country especially during the 90s and early 2000s, the government would have remained passive about the emerging outbreak. "...kasi nga wala talaga ni isa na nag-seseminar, na magcoconduct ng mga awareness, wala talaga, ever since. So siyempre kami naman ang alam lang namin, TB, that time, kasi yun yung laging kinoconduct na seminar. Pero yung sinasabi nilang HIV, wala, nganga. Ngayon nga lang sila nagcoconduct ng mga ganito-ganito eh, yung mga awareness, kung hindi pa tumaas [ang number ng cases]. Yun eh kung noon pa nila kinonduct yun, sana noon, hindi ako nagkaganito... As in zero. Kung may nagcoconduct ng awareness before, noong kapanahunan ko, hindi siguro ganito karami yung sa atin. As in zero talaga yung ano ng government sa atin."

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<sup>5</sup> Not his real name. Pseudonyms are used to protect the identity of the respondents

If given the chance and if provided with adequate knowledge, John said he would have taken the necessary steps to protect himself. But it was already too late. Straight out of high school, he worked at a mall and eventually contracted tuberculosis, causing him to lose weight and become terribly weak. At one point he fainted at work, was rushed to the hospital, and ended up in the ICU. The doctor asked his mother's permission for him to be tested for HIV to confirm his suspicion. When the results came, the doctor talked to her mother who was accompanied by their neighbor. His mother wept loudly as she lost grip of the confirmatory letter. Out of curiosity, their friend/neighbor picked up the form and learned about John's status.

Their neighbor disclosed what is supposed to be a well-kept secret, and ever since that day, John and his family had to put up with bullying, stigmatization and discrimination in their neighborhood. Neighbors would often cover their faces with their hands when they see John walking in the street. Others would even lump together and utter insulting remarks while John would pass by. These incidents even escalated to the point that no one would hire him for catering work and no one would buy the dishes offered by their small carinderia anymore, for the fear of being infected with the disease through physical contact or from eating the food prepared by John. "Lalo na nung nalaman, kasi hindi maiiwasan eh, na natsismis sa kapitbahay yung status ko. Wala ng pumapasok sa bahay namin, takot sila. May business ako niraraket ko, pero walang nagpapaano sa akin, takot sila. Minsan kahit anong bait mo nakakapuno," John recollected.

The number of his "non-reactive" (not HIV-positive) friends also eventually dwindled. The isolation and discrimination experienced by John caused him to feel severely depressed, but John said that the suffering he endured due to these incidents were actually more bearable compared to the pain that he felt whenever he realizes just how much his family has been negatively impacted by his illness, owing to the fact that their own relatives have already immediately cut ties with them after knowing about his status. Their extended family members eventually excluded them from family gatherings, and John's own cousins would even prohibit his nieces/nephews from making physical contact with him. They would often hold birthdays without any kin celebrating with them.

John and his mother also realized that they had to fend for themselves in times of trouble, and they would often just *bitterly* think and pretend that they *do not have* relatives/family anymore. "Kaya nga ang sabi namin, 'Wala na tayong kamag-anak. Kahit kailan.' So parang kahit na anong mangyari sa amin magkasakit kami, talagang wala na silang masasabi sa amin kasi, hindi na kami humihingi ng tulong. Kaya kung di ka marunong dumiskarte, wala eh. Kaya ako marunong na ako dumiskarte. Kasi nga wala kang ibang maaasahan kahit kamag-anak mo. Hindi ka kilala."

As the years went by, John and his mother encountered more financial difficulties due to being stigmatized and discriminated in the community which prevented them from earning money from their former small business. Later on, John figured out a way to earn by connect-

ing with other PLHIV who helped him increase his social networks, and by offering his services and catering knowledge to non-reactive individuals on Facebook who had no clue about his status. John said it is a relief that he is able to earn from opportunities that come from areas other than his neighborhood. He said his mother also continues to work as a sewer and seller of rags. John considers his mother as his inspiration and ultimate reason why he never gave up.

Although they are in a much better place now financially and emotionally over a decade after the disclosure of his status (and their experience of being stigmatized has already become infrequent), John says that they still could not forget the pain that their relatives and neighbors had inflicted on them. “Oo pinatawad namin sila sa mga ginawa nila sa amin, pero hindinhindi ko makakalimutan yung ginawa nila sa amin. Oo mapapatawad kita, pero yung sakit na ginawa mo, tanda namin... Sabi nga ng pari, ipanalangin mo lang yung nga taong nagkasala sayo, or may galit sayo.. hindi ko magawa. Kasi nandun pa rin yung sakit... Kasi sa akin na lang huwag sa pamilya ko... Gusto kong maramdaman nila yung naramdaman kong sakit... Kasi masakit talaga. Nandun yung galit noh? Yung diin, inis ako eh?! Hanggang ngayon, ewan ko kung ano yung meron na galit na galit sila sa pamilya ko.

In spite of everything that John had gone through, he wishes that HIV patients would remain *uncured*. In a way, John says that HIV changed his life for the better, made him and his relationship with his mother stronger, and taught him how to depend on God and control and discipline himself. He thinks that living with this illness will have a similar positive impact to other individuals like him, “Wag na sana magkaroon ng cure sa HIV. Dahil ang ugali ng Pilipino, wala na eh. Halimbawa nandyan na nacure ka na, babalik uli ako sa dati. Wag na. Masaya na ako dito... Hindi ko sinasabi para dumami kami. Kung 'di, para ma-embrace mo yung pagkakamali mo, maituwid mo. Kung baga kagaya ko. Oo pare pareho tayo ng pananaw, kung baga sa sarili ko, kahit papano, may nangyari. Hindi man ganon. Kung hindi ko man nakuha yung goal ko na pangarap ko, may nangyari naman sa sarili ko. Ito ako ngayon.”

Although he admits it is still difficult for him to restrain himself from having sex, John says he can control himself more compared to before. “Kasi ngayon ang mga bakla, hindi maiwasan tao kasi eh, kahit din naman ako nagtataka, nakakalimot ka, ganyan. At least ngayon may ano ka eh, control na sa sarili mo. Before nun wala ka eh. Parang ano sige ‘okay lang, babuyin mo ko.’ Eh ngayon maiisip mo na. ‘Ah wait lang. Wait lang ihi lang ako. Syempre mag-dadalawang isip ka "na ano ba, gagawin ko pa ba 'to o hindi?' Ngayon tama na.”

John also does his best to inspire other PLHIV to not give up on their lives, emphasizing the need for them to take full responsibility for their past actions. He knows of many PLHIV that have gone on to self-destruct, but he refuses to give up on persuading them to do otherwise, “Nagagamot pero itinuloy pa rin nila yung bisyo nila. Puyat dito, alak dito, yosi dito, lalaki. At least kami, hindi ko sinasabi na malinis ako, na nabago ko kung sa sarili na oo nakikiinom

ako pero pag sinabi ko bawal na, dun lang ako. Kunyari sex, hanggang dito lang po kaya ko ah. Bawal po yung ganito. At least alam mo sa sarili mo, yon yung nakakatawang bagay na masarap ipamukha sa mga kagaya ko. Na magbago na kayo. Tapos maghahangad kayo na mawala yun, nahihiya ka. Eh ginawa mo yon eh. Yan yung bunga ng kasalanang ginawa mo. Kasi ibig sabihin kaya ka binigyan niyan para magbago. Dating marumo yung dingding, napinturahan ng bahagya, luminis pa rin.” He was also able to disclose his status and share his experiences with groups of students in a municipality to encourage them to take care of themselves and make the right decisions in their lives especially when they grow older.

When asked about his future life expectations, John readily said that he is already contented with his current status and he does not fear the reality of dying someday. He also reiterated that he is grateful to God for his illness since he attributes the change in his attitude and outlook in life to the many struggles that he endured and overcame as a PLHIV. “Yung sabi ko nga kay God, salamat ah. Ngayon ko lang narealize na meron pa lang something para magbago ako... At least nagbago ako. Kaya nga sabi nila, hindi mo pala kailangan humingi ng kahit ano. Sapat na yung magbago ka,” John said at the end of the interview.

## **CASE STUDY 2: MARCO**

Life has never felt drastically different for Marco after being diagnosed with HIV, although he admits that the illness had discouragingly narrowed the possibilities for his future and made him feel stagnant careerwise and relationshipwise. Growing up in a broken home where parents would day-in and day-out quarrel became the norm for Marco and his seven other siblings. Poverty forced him to earn a few hundred pesos through offering casual sex mostly to interested gays when he was still in high school. He eventually managed to graduate from college through a government scholarship, but life still became extremely hard for their family, especially that his father would always physically hurt their mother and Marco would be the only one in the family defending her. Marco would be occasionally beaten by his father as a result. The physical abuse stopped only when his father was diagnosed of cancer and was eventually hospitalized. However, one of his older siblings who took the responsibility of caring for their father and at the same time providing financially, eventually died due to over-fatigue. Until now, Marco is still not in good terms with his father. Smoking, hanging out with friends and video game addiction became Marco’s emotional outlet and coping mechanism. “... Dun ko dinala yung sarili ko, yung galit ko sa tatay ko. Kumbaga sa rebelde pero di talaga totally rebelde. Yung galit gusto kong ibuhos sa mga ganun, makalimutan yun na nga,” he said. Marco eventually became sexually promiscuous, and this led to him being infected by the virus.

He eventually got sick with tuberculosis and lost weight. His brothers, suspecting that what he is experiencing is a sign of being infected with HIV, urged him to undergo a test right away. After undergoing the examination and upon learning that he tested positive, paralyzing fear

immediately swept over Marco. The lack of knowledge about HIV exacerbated his fear and anxiety of being disowned by his siblings. “Yun nga yun, na di ko rin alam na may ganun. Kasi baka maano sila sa akin. Parang ako rin natatakot rin ako. Di ko alam na yun din pala kinabababa ng immune system ko.”

Contrary to his expectations, his mother and siblings expressed their acceptance and they continue to support him emotionally until today. However, he never really attempted to disclose his status to his father. He felt like his mother and siblings’ support are more than enough. “Na natuwa naman ako naaccept naman nila hindi nila ako... imbes na mapanghinaan ako, dun ako lumakas na parang uy, kasi minsan may pamilya na, itatakwil ka. Kinocomfort nila ako. Everytime sinasamahan nila ako. Yung iba kasi wala. Para din akong natuwa na mas mapalad pala ako kahit may ganun ako, di nila ako tinakwil.”

The intake of ARV completely changed Marco’s easy-go-lucky lifestyle. He learned to take care of himself and become more conscious about what he does, what he eats and how many hours he sleeps. He initially struggled to discipline himself when it comes to his medicine intake, but he eventually got used to it. “Yung noon sige lang sundin mo yung past time mo, wala kang gagawin kahit may sakit ka iinom ka lang ng gamot okay na. Ngayon, iba na sa ngayon, kumbaga noon wala akong iniisip sa sarili ko, pero ngayon kasi nakita ko na kailangan may pagbabago kasi naisip ko ganun rin naman yun eh, maintenance ka ng maintenance.”

Marco also gained the support of his friends. He told them that nothing really changed in him, that he perceives himself as *normal* and even physically stronger than some non-reactive individuals. His friends somehow agreed. “Pero sa akin, parang normal lang yan eh. Kumbaga, mas malakas pa nga ako sa walang sakit eh. Uy mas normal pa rin kami kaysa sa... Kumbaga, sila nga walang sakit pero minsan, sila pa yung unang mawawala sa amin. Yun yun eh. Kaya naano ko normal din pala. Tapos ayun. Wala naman akong cancer. Di naman ako cancer na mahahawa o ano. Yun yung sabi nila. At least thankful pa rin ako.”

Marco sees his illness in a positive light, as he says HIV gave him another chance to change his life. He recalls the way he allowed his health, time and body to waste away in the previous years, but the illness served as his much-needed wake-up call. He even refers to it as a “gift from God,” and “a new life phase.” “Yung dati kasi parang inom-inom lang lagi di kakain sa tamang oras. Kumabaga walang pakialam sa sarili. So yun yung sinasabi ko na bagong yugto na binigyan ako ng Diyos ng bagong buhay eto yun. Na baguhin yun kasi sa binibigay sa akin ng Lord. Yun yung regalo sa akin. Yun yung nagbibigay sa akin ng strength. Nandyang lang naman sina kuya. Kung ano man ang mangyari sa akin, lahat tayo mamamatay rin. Dun din tayo papunta. Kumbaga sabi nila maikli lang ang buhay natin. Tayo yung gagawa ng lakas natin. Ito yung gagawin ko na tumagal pa din yung buhay ko... “Kasi yung bagong yugto parang panibagong buhay na binigay sayo na dapat pangalagaan mo. tulad ng pag-inom ko ng

meds. Maging healthy ka na sa lahat ng bagay tapos yung mga lahat ng gagawin mo, morning mag-exercise ka, nagiging masaya ako dahil nga nababago.”

He never felt angry towards God for allowing the illness to infect his body. Marco says God probably intended to actually strengthen and teach him to redeem his life through HIV. “Hindi hadlang yung sakit dahil ayun nga yung nagbibigay sa akin ng ano eh ng lakas. Di ako napanghihinaan. Kasi kaya binigyan tayo para siguro ano matuto tayo sa lahat ng bagay. Kasi sa akin yun talaga eh. Kumbaga di ko sinisisi si God. Kumbaga ginawa ko to, ako yung gagawa ng ano na ibalik yung dati kaya yung bagong yugto na nagsimula ngayon. Na hindi ko talaga sisisihin si Lord.”

Marco also thinks this is God’s way of striking him, disciplining him and urging him to return to serving at church. “Di na ako nagseserve. Di na ako nagsisimba. Minsan lang ako magsimba. Iniisip ko parati trabaho lang. Siguro inano ako ni God. Simba ka naman na. Ibalik mo yung dati kasi eh siyempre maganda na iba naman yung mag-serve sa choir pero siyempre ako di nga ako makapagsimba dahil nagkaroon nga ako ng sakit eh. One time nagsimba uli ako parang siguro pinalo talaga ako, di ka na nagseserve parang ganon. Pero wala pa rin talaga akong galit kay God na ano.”

The support gained from selected family members and friends kept Marco from experiencing any form of external and internal stigma and discrimination. He also did not experience any difficulties in accessing ARV from his hub. However, if there is one negative impact that HIV has made in his life, Marco says it would be that he now has difficulty gaining fulltime employment due to his inability to perform and endure highly strenuous physical work which was never a problem to him prior to becoming a PLHIV. Furthermore, he fears that working fulltime would disrupt his ARV intake and would therefore compromise his health. This is why he now financially depends on his brothers but in return does all the chores at home and cares for his nieces and nephews. “Di nga ako pwede magtrabaho kasi pag nagtrabaho ako, hatid dito hatid doon. Pero sabi ko nga, exercise lang yun pero may mga part time naman siguro na walang ganun. Kaso yung tour kasi ano alas dos gising ka siyempre di na kaya matutulog ka nang maayos. Hindi pwedeng iinom ka ng meds tapos wala kang tamang tulog.”

He previously tried to work as a water station delivery boy and thought of becoming a call center agent or a factory and mall staff but feared that these potential work settings might negatively impact his health. “Laging pawis yun eh laging palit ng ano eh hindi ako nagpapalit ng damit kaya minsan baka bumalik yung ano ganun. Dun sa baga mo kaya tinigil ko na. Kasi yun talaga yung pwede kong kunin na trabaho. Hindi ako pwedeng mag-call center kasi pag call center di ka pwedeng matulog ng anong oras. Di rin ako pwedeng magtrabaho sa factory o SM kasi nga umiinom ako ng meds di naman pwede. Magdadahilan ka iinom ako ng ganyan. Eh yun din iniisip ko gusto kong magtrabaho sa ganun. Baka malimutan ko yung inumin ko baka mawala ako sa oras ng inom pag ginawa ko yun. DI na lang ako nag ano.”

This is why he feels that financial assistance for small livelihood ventures should be provided for people like him to be able to earn income without worrying about their ARV intake and their health in general. “Siguro yung livelihood so sana magkaroon ng ano, sariling fishball yung mga ganyan mga pwede kong trabaho na kasi may time ako at least andudun lang ako. Makakainom ako ng hindi ako pupunta kunwari sa mall hindi ganun. At least alam ko na yung oras ng pag-inom ko makakainom ako ng gamot. Sana yun yung gagawin kong pam-buhay para sa mabuhay ako hangga’t maaga pa makabili ako ng gamot ko.”

Marco never sought to be an active member of any PLHIV network due to his financial incapacity. Furthermore, he lost all hope and confidence that he would be able to realize his dream of having his own family someday for the fear of transmitting the illness to his potential wife and children and the lack of financial resources to support them. “Gusto ko magkaroon ng sariling family kaso dahil nga dun sa nahihirapan ako mahihirapan din yung asaw-edi magkakaroon din siya kung magkakaroon kami ng pamilya. So gusto ko din sana kaso ang iniisip ko rin naman... Ayaw ko naman magkaroon ng sarili kong anak ng may ganun ako. Kahit asawa ko magkakaroon.”

Although he hears about cases of people who were not infected by their PLHIV spouse, the fear of *potentially being blamed* when circumstances become suddenly antagonistic keep him all the more pessimistic. “Pero siyempre isipin ng kunwari, ‘San ko nakuha to? Sayo lang ‘di ba?! Siyempre parang sisihin pa ako.”

And although he enjoys caring for and spending time with his nieces and nephews, he feels deep down that having his own would bring more joy and security in the future, “...pero gusto ko talaga magkaroon ng sarili kong anak. Sarili kong baby kasi siyempre sa pagtanda siyempre, sinong mag-aalaga sayo?”

Despite all these frustrations, Marco is determined to live his life the best that he could. His faith in God is what keeps him going despite the uncertainty in his future and the likelihood of living alone someday. “Yung normal na ginagawa. Yun nga yung sinasabi ng doctor sa akin na lifestyle gawin mo lahat yan para mabuhay ka lang. Tulungan mo sarili mo, na ganyan para lumakas ka. Mahalin mo na lang yung sarili mo, tapos wag mo na siyang abusuhin para maging maganda na yung katawan at buhay mo. Yun sana yung mashare ko sa lahat. Ako rin yung magbibigay ng daan para gumalaw ako sa mundo. Yung nangyari sa akin, kasi nga binigyan pa ako ng bagong yugto at bagong simula at tsaka mas takot yung sakit sa akin. Kumbaga dun ako nagpapasalamat. Kasi nga binigyan ako ng ganitong sakit na di ko inaano [sinisisi] si God,” Marco said.

### CASE STUDY 3: CAROL

A series of casual flings is the root cause of the irreversible fate that suddenly gripped Carol's family just a few years ago. Carol witnessed how marital infidelity wreaked her own family when she was younger, so learning about her husband's affairs was not a novel shock anymore. They separated for some time but got reunited and eventually had their third child. Carol's diagnosis came when she got terribly sick during the first few weeks of her pregnancy which necessitated the submission of a medical certificate for official leave to be filed in the office where she worked as a secretary. One of the mandatory tests was on HIV and Carol was unfazed. She narrated, "Kampante naman ako sa sarili ko kasi alam ko naman yung sarili ko eh. Alam ko yung naging ano ko, katawan. Tapos ayun na nung kinuhaan na ako ng dugo nung medtech, nung nakita niya na yung result tinanong niya ako, 'Call center agent ka Ma'am?' sabi ko 'Hindi po'... nandun yung kaba, dun ko lang naramdaman yung kaba na yun tapos sabi niya, 'Kasi yung lumabas sa result mo is reactive...'"

She was asked to undergo confirmatory tests but instead of doing so, Carol went straight home due to overwhelming fear and anxiety. "...Natakot ako, kasi yung acceptance hindi ko kaya pa... parang binagsakan ako ng langit at lupa nung araw na yun, sabi ko 'Bakit? Anong nangyari? Ba't ako nag-kaganun?'" Carol immediately showed the results of her initial tests to her husband and his actions somehow confirmed Carol's suspicions about how she got infected with the disease, "Niyakap niya lang ako, wala siyang sinabi kasi siguro alam niya sa sarili niya. Kasi bago siya nagtrabaho sa [company], nagtrabaho siya sa bar, dun talaga kami nagkakilala. Waitress ako tapos siya bartender tapos siguro yung taon lumilipas, pero bago kami naghiwalay nun sa bar pa rin siya, ang naging reason ng paghihiwalay namin is nagkaroon siya ng babae na dancer sa club, yun. Tapos siguro pakiramdam ko, ang sa akin lang, since kilala ko naman ang sarili ko, tingin ko alam niya, di ko rin naman mai-open up sa kanya, kung bakit, san mo nakuha, sino ba sa atin talaga? Basta ang ano ko, sa kanya ko nakuha. Tapos yun na, niyakap niya lang ako, wala siyang sinasabi pero alam mo, ramdam mo na, nalungkot siya siguro tapos (nafeel niya na hala dahil sa akin), parang ganun. Tapos iyak lang nang iyak."

Carol became severely depressed but she managed to report to work and continue her pregnancy. However, she never had herself medically checked out of fear and trauma. The feeling of being *the only* female person with HIV also sank in. She was in a state of denial and all she felt was shame and worries for her and her family's future. This prevented her from disclosing to her other relatives and from seeking help from other people. "Tapos hanggang sa nanganak ako di ko pa rin tanggap kasi feeling ko kami lang ng anak ko, kami lang yata yung may ganito, ayaw ko siyang i-disclose sa iba pero sinabi ko siya sa kapatid ko, close na kapatid ko talagang babae, tapos yun na."

She also did not disclose her medical condition to her ob-gyne and this led to her undergoing a normal delivery instead of a c-section (which is what is required for pregnant women with HIV to reduce the chances of transmitting the virus to the baby). "...supposed to be kailangan mo siyang idisclose kasi kailangan... caesarian ka para may chances na hindi makuha ng bata yung virus, eh ako sa lying-in lang parang sabi ko bayaan ko nalang, siguro okay na 'to, parang in-denial stage ako nun tapos ang iniisip ko baka nagkamali lang kasi ang sabi sakín ng medtech may ganitong instances..."

It was only after a week when her one-month old baby contracted pneumonia and was confined in the hospital that she felt extremely alarmed about the possibility of her baby being infected with HIV, which urged her to personally seek help online. "Tapos sabi ko magsearch kaya ako nung merong kayang may ganito [rin na situation]. May nakita akong post na, isang ano, nanay rin siya. May anak din siya... Tapos chinat ko siya... Siya yung nag-reach out sa akin, 'Pumunta ka na sa San Lazaro girl. Wag kang mag-paano. Sa una talaga. Kung ako sayo kung ayaw mo na makakuha pa ng ibang sakit ngayon pa lang agapan mo kasi lalo na yung anak mo nagkakasakit na." She still did not immediately follow the advise of the said stranger, but shortly after her son was admitted five times in the hospital due to pneumonia without even turning a year old yet, she met other parents in a similar situation in that same hospital who reached out to her and encouraged her to seek help.

"Nung nakita ko yung mga patient dun sa San Lazaro, ay ang dami pala namin, hindi lang pala ako, sabi kong ganun. Pwede pala, na mag-continue sa buhay mo kasi hindi lang ikaw yung may ganyan." She underwent the HIV test along with her son and both of them were positive. She urged her husband to have himself examined too, and when she learned about her husband's CD4 count (200 compared to her own count of 700) later on, she confirmed right there and then that her husband already had the illness for a long period of time and that he did transmit the virus to her.

Their diagnosis did not immediately persuade them to access treatment. Carol's husband, for one, felt that taking the medicine would be a hassle for his work since it would require time monitoring, discipline and consistency which he knows he could not fully meet due to his job which consumes most of his time since it involves traveling to different places. When a close friend offered to provide him with his own motorcycle, he enrolled himself as a Grab food deliverer which allowed him to manage his own time and transactions. It was only then that he started ARV treatment. Meanwhile, Carol became preoccupied with caring for her youngest son, and it was only about over a year later after her diagnosis that she finally started her ARV treatment. "Hindi rin ako agad nagstart eh. Kasi ang ginawa ko inuna ko muna talaga yung anak ko. Kasi mahirap 'pag nagsabay kami. Mamaya, yung anak ko lalabasan ng rashes, ako rin, macoconfine ako acoconfine anak ko, walang mag-aasikaso sa amin eh di ko naman dinidisclose sa family ko," she said.

Only her mother eventually knew of their HIV status. She became afraid of disclosing to her other relatives and friends as she witnessed their negative reactions whenever the topic of HIV is raised. She knew that they find people with HIV *disgusting*. “Nag-uusap yung kaibigan ko tsaka yung ate niya. Kasi na-weirduhan din siya sa sinabi ng isa naming kaibigan. Sabi niyang ganun, ‘Ay di naman yan HIV na nakakahawa ang laway.’ Napangiti lang ako. Ay ganun din pala ang tingin nila. Pati yung mga tita ko. Marami pa rin talagang mga tao na ‘pag nalaman yung HIV parang mandidiri sila sayo.’”

She continued, “Yung pinsan ko ngang isa, sa lugar namin nagkaroon ng HIV testing naglo- lokohan din sila ng asawa ko tsaka biyenan ko. Yung pinsan ko kasi babaero rin siya tapos nagkakaroon ng, di nga multiple partners eh. Bi, niloloko siya ng asawa ko, though alam na- man ng asawa ko yung status niya. Magpa-test ka na mamaya may HIV ka na. Alam mo yung pinsan ko takot na takot siya kasi nga yung HIV nakakahawa daw yun, nakakamatay.”

Her strict and very conservative aunts (from her mother’s side) also had preconceived fear of HIV. This is why up until now, Carol has not attempted to disclose their status to them. “Naku nakakatakot yung ganyang sakit.’ Hindi nila alam yung nasa harapan nila pati yung hinahalik-halikan nilang apo nila, meron. Kaya iniisip ko paano kaya pag nalaman nila?”

Furthermore, Carol felt that disclosing their status would spell trouble especially for her husband, since their relatives already had a particular aversion towards him. Knowledge of their status would certainly point all the blame to his husband and his marital infidelity. Somehow, despite what he has done, Carol still wanted to protect her husband. She even partly blames herself for her husband’s behavior since she felt that in the past years she prioritized her siblings more than him. “Ayoko, ayokong malaman nila. Kasi galit sila sa asawa ko eh. Kasi alam nilang nambabae. Yun lang naman yung problema sa kanya pero yung pagiging responsible sa family okay siya. Wala naman siyang bisyo, ni minsan di niya naman ako nasaktan kahit lasing siya.”

Carol also knew that her relatives would blame her for her son’s fate just the same. “Tsaka hindi maiiwasan na isisi sa akin yun. Nagbigay ka ng sakit sa anak mo,” she said.

When asked about when she thinks is the right time for her youngest son to know about his situation, Carol suddenly bursted into tears and weepingly talked about her fears of being gone and her son being left alone to fend for himself. “Parang hindi ko pa tanggap, parang ayoko pang malaman niya. Paano na lang di ba kapag lumaki siya tapos wala na ako? Siyem- pre hindi mo malalaman sabi nga ng asawa ko, hindi mo malalaman kung hanggang kailan ka. Yun din yung reason kung bakit nung una ayaw na niyang magpagamot kasi kahit magpagamot ka, kung talagang oras mo na, oras mo na. Yun yung reason, yung yung outlook in life niya.”

Her oldest daughter aged 6, has started bombarding her with questions about their medicines. Carol feels that she needs to explain everything to her someday. “Ngayon inuunt-unti ko yung anak ko kasi alam niya na may iniinom kaming gamot. Tinatanong niya, ‘Mama bakit parehas kayo ni baby ng gamot? Bakit pareho yung bote niyo ng gamot? Anong sakit niyo? Eh si Papa? Bakit ngayon may gamot na rin siyang ganyan?’”

She would often reply that those are just vitamins and she would also even request her to remind them about their intake, “Basta anak lagi mo kaming i-reremind ni Papa na uminom kami ng gamot. Kasi kailangan namin yun. ‘Pag nakalimutan namin yang gamot, magkakasakit kami.’”

Still, many people would not suspect that Carol’s youngest son has HIV due to his healthy frame. “Hindi nila akalain na ganon yung anak ko kasi mataba siya. Tapos pogi. Tapos makinis. Kasi yung ibang mga bata maraming rashes, maraming peklat-peklat. Yung anak ko kasi makinis. Siguro yung breastfeeding nakatulong talaga yun kahit na positive ako tapos brineastfeed ko siya.”

However, she is adamant in her conviction that no one should know about her son’s status, especially when he grows older. Carol would often think of his son’s future and how he would deal with the possibility of him experiencing stigma and discrimination. “Ayokong in the future malaman ng ibang tao na ganun siya tapos ‘di ba baka hindi niya maano [makayanan], tapos [paano] kung wala na ako? ... as nanay may ganoong factor na maiisip mo siya,” Carol said.

#### **CASE STUDY 4: JANICA**

After losing his husband to pneumonia, Janica had to face the impending reality that she too had the same disease that abruptly took away his husband’s life. Janica’s relatives (on her husband’s side), however, were the ones who first learned the truth-her husband died due to HIV and passed without even knowing about his own condition. Meanwhile, the doctors feared and suspected that the virus is already running through the veins of Janica and possibly her three children, and so Janica’s mother and sister-in-law urged her to undergo medical examination to confirm their suspicion.

Janica narrated, “Kasi nung time na nasa ospital siya nung sabi ng kapatid niya na kakausapin ako ng doktor tungkol sa sakit niya [ng asawa ko]... Ang sabi mag-pacheck up daw ako, eh ang alam kong kinamatay pneumonia ganun, eh pumapayat na rin ako nung time na yun bumabagsak na rin katawan ko, tinanong ko sa barangay namin kung meron ba akong TB, tapos yung isa kong anak nagkakasakit na talaga siya... Hindi nagkaroon ng tyansa na mag-abot kami ng doktor na masabi niya yun sa akin, tapos hanggang sa nakaburol na siya sabi ng mga kapatid niya dapat daw ako mag-pacheck up kasi may sakit daw ako. Alam ko yung sa

HIV kasi sa trabaho ‘di ba may medical, pero wala talaga sa isip ko na ganun ang kinamatay.”

Even before the confirmation of Janica’s status, however, her mother and sister-in-law already took custody of her three children, reasoning out that Janica’s ‘illness’ would compromise her ability to take care of them. Unbeknownst to Janica, her relatives have already been bringing her children to the hospital to consult doctors regarding the possibility of the children being infected. But the doctor asked for the mother to be tested first before her children could undergo the same examination. Janica’s relatives told her to come to the hospital, but did not disclose at first that she will actually undergo an HIV test. Janica shared, “Kaya nasa isip ko wala naman akong trabaho, wala akong isusuporta sa mga anak ko kasi nag-gagatas pa rin, yun dinadala na pala nila dyan sa [ospital] kasi dun sila tinuro ng doktor ng asawa ko. Kaya nung kailangan nilang ipa-test yung bata pero sabi ng doktor di muna nila itetest yung mga bata dapat ako muna.

Janica continued, “Sumama daw ako sa ospital, may pipirmahan daw ako. Eh ang alam ko bago nila kinuha yung bata sa akin nagkaroon na siya ng primary [tuberculosis]. When they arrived at the hub, Janica was overwhelmed by dread and anxiety when all she saw was posters on HIV plastered on the walls. In the end the doctor asked her mother-in-law to explain the reason they were there. “Nagulat ako kasi sa hub namin may makikita kang mga [nakapaskil] na HIV mga ganyan, naglalaro na sa isip ko ‘Bakit ganon?’” Tapos nung kausap na kami ng doktor, ang sabi niya, "Alam mo ba kung bakit ka nandito?" Sabi ko, ‘Hindi.’ Hindi ko naman talaga alam eh. Ang alam ko lang, may pipirmahan ako. Yun kasi ang paliwanag sa akin. Tapos ang sabi ng doktor dun sa biyenan ko, 'Nay, kayo ang magsabi, kasi hindi pwedeng ako ang magsabi.' Ayun, sinabi ng biyenan ko na maysakit kang HIV. Kaya doon ako nabigla, wala talaga akong alam.”

Despite discovering the unfortunate truth about her and her middle child who was found to have been the only one infected among the three, no sign of remorse and anger could be glimpsed from the way Janica expressed her opinion on why her relatives initially hesitated to disclose the lifetime struggle that is about to be endured by her family. Interestingly, Janica also seemed to have never attempted to question how her husband got infected, and her words imply that her husband was as clueless as she is with regard to their situation, “Wala ring alam yung asawa ko, kasi kung alam niya, siyempre maggagamot siya. Alam niya naman na may mga anak kami. Kasi alam niya na nagkakasakit na eh. Sasabihin niya naman siguro sa akin na may... pero wala siguro siya talagang alam din.

Janica instead partly blamed the lack of HIV screening (for pregnant women during her time) for her and her 6-year old son’s predicament at present. She said if they have known earlier, life would have been completely different. “Kung alam ko eh bakit idadamay ko pa yung anak kong lalaki? Kasi napakahirap talaga, kasi ilang beses nang naconfine ang anak ko, lima na.” Janica’s child frequently suffered from pneumonia before the diagnosis and endured itchy rashes until he was provided with the second line of ARV treatment.

The child, however, is already becoming curious as to why he has to take in tablets while his siblings do not need to do the same, “Nagtatanong ang bata. ‘Bakit ako umiinom ng gamot si Ate hindi umiinom ng gamot? Siyempre di ba mahirap sagutin?!’ She asked for the help of her son’s pediatrician, and the doctor gently told the child, “Kailangan mong uminom ng gamot kasi kailangan mong lumakas.’ Syempre hindi mo pwede sabihing may HIV siyempre wala pang knowledge yung bata.”

However, Janica feels that her 11-year old daughter already has a clue about their situation, as she once brought her to a DSWD event commemorating the World Aids Day, and her daughter also once saw a clip of a *Maalala Mo Kaya* (MMK) episode featuring the life of a PLHIV. Janica did not yet attempt to explain everything to her daughter and youngest son. Disclosing the truth would be very difficult especially to her infected son, she says.

Her relatives on her husband’s side continued supporting her emotionally, and two of her friends also expressed their support and never rejected her since they already have some knowledge about HIV due to a TV series/episode that they have watched previously. “Nagulat sila. Pero nakakapanood na sila so alam nila na hindi naman sila mahahawa sa mga pag-uusap, ganon” Janica said.

When asked if she can recall any experience of discrimination or stigmatization, Janica immediately shared how newly diagnosed PLHIV in their own hub started tactlessly questioning her why her son had HIV. Janica immediately shrugged them off thinking that they do still do not know anything about the disease at all. “Nagugulat sila. Bakit may batang may HIV?! Bakit sila nahawaan? Hindi nila alam na pwedeng mother to child. Siguro dahil bago sila akala nila sex to sex lang... Dedma na lang kasi di pa sila masyadong naorient kaya hindi pa nila alam.”

Janica also had to eventually reclaim custody of her children, as her relatives lived in the province and it would be extremely difficult for her sick son to move back and forth just so she could get the medicine or undergo occasional laboratory tests. More importantly, she wanted to monitor her son’s intake of ARV. However, Janica admits that her son initially struggled with the tablet due to its large size and bitter taste. Janica made a practice of crushing the tablet to make it easier for her son to consume the medicine. She recalled that at one point her son cried when he felt that she was about to make him drink the large tablet again. “Masakit daw sa lalamunan niya... Natrauma yata,” she said.

Although there are ARV syrups intended for children’s consumption, there are no syrups available for the second line of ARV being taken by both Janica and her son at the moment. Furthermore, Janica worries that going to school in the near future and having to take the medicine everyday would immensely stress his son out. “Every 12 hours dapat uminom siya eh. Halimbawa ‘pag pang-umaga siya eh di madaling-araw pa lang gigisingin mo siya para

makainom ng gamot. Eh dalawang gamot yun eh kailangan may pagitan na 30 minutes. Tapos pag umalis, eh siyempre lulusawin mo pa yung gamot. Eh siyempre pag nakita ng mga tao mamaya tanungin. Hindi naman yun antibiotic 'di ba? Kaya mahirap.”

When asked about when she feels is the right time for her son to know about his situation, Janica said that she is counting on a partner organization of Pinoy Plus to explain everything to his son and two other children once his middle child reaches the age of 12. This particular partner organization conducts counseling sessions for children living with HIV (along with their siblings) to help them cope with their situation. Through this organization and her network of parents and children living with HIV, Janica was able to gain more emotional support.

However, being in such a network has also made her become hyperaware of their predicament, especially when she witnessed the passing of two of the children in their group. One is a five-year old girl who died due to meningitis and another is already an 18-year old girl who passed due to tuberculosis. Their deaths have made her personally reflect on and fear about her son's fate. Janica tells of the late five-year old, “Parang ang sakit sakit kasi kahit sabihin mo na hindi ko siya anak, kasa-kasama mo siya, alam mo na siya may sakit na ganun, alam mo na yung anak mo may ganun din. Paano yun? Parang nalungkot kami kasi pareparehas kami na may inaalagaan na ganun. Nakakalungkot kasi parang sila na rin yung itinuturing mo na pamilya eh. Kasi sila yung pinagtatanungan mo... Kaya malungkot din sa amin pag may nawawala. Lalo na pag bata.”

She wishes that a cure for HIV would be developed and made available someday. “Ako kahit di ko maabutan yung gamot na talagang ano [makakapagpagaling], kahit yung sa anak ko na lang. Ayaw ko namang habambuhay na.. Sana dumating talaga yung time na, magkaroon yung bata. Kasi dati nga yung TB wala eh, paano pa kaya yan? Na dumadami yung [kaso ng HIV]. Napakadami...”

Still, Janica feels that her family's situation and the presence of her children alone forced her to become emotionally strong, “Wag susuko. Dumating din ako sa point na susuko pero naisip ko yung mga anak ko. Wala na nga silang tatay tapos mawawala pa ako. Tatagan mo lang yung loob mo kasi ganyan naman talaga 'di ba kahit sa mga walang sakit. Hindi naman porket maysakit kang ganyan, wala ka ng pag-asa... Kung wala lang akong anak, matagal na siguro akong uminom ng ano, pero yung iba nga diyan 'di ba gusto pa nilang mabuhay nang matagal, ako pa kaya na may anak?” she said.

## **CASE STUDY 5: DANIELA**

What was intended to be a 2 year-contract as a Filipino band vocalist in South Korea became a disappointing 7-month stay when doctors diagnosed Daniela of HIV over a decade ago. Daniela, a single parent and battered wife, was deported with her many dreams for her three little children being shattered and her supposedly brighter future suddenly becoming completely dim and uncertain. What made her situation even more precarious is her doctors and employer did not directly disclose that she had HIV, and only referred to her illness as a “blood infection.” Her employer told her that she needed to go home because they could not shoulder her treatment.

Daniela slowly went back to how her life once used to be but she continued trying her luck again for opportunities abroad. Out of curiosity and restlessness, she asked her Filipino manager why she still did not get any response from her applications. The manager was puzzled that Daniela did not have a clue at all as to why she was deported and why she could not go abroad anymore. Upon knowing the truth, overwhelming anxious thoughts flooded Daniela, including as to how she got infected by the disease when she “did not even have multiple partners,” “Sabi ko papaano po yun? Although alam ko yun, nasa denial stage kasi ako ng time na yun, kasi ang iniisip ko isa lang naman ang naging partner ko before ako umalis... Yung former boyfriend ko lang na Australian. So yung dumating na ako papano nangyari yun, isa lang naman naging karelasyon ko kasi at that time wala talaga akong alam tungkol sa HIV, pagkakaalam ko lang is multiple partners lang ang alam ko. Iisa lang naman naging partner ko so nasa denial stage ako that time pero dahil sa kagustuhan ko na magpatuloy at mag-abroad yun na yung pagkakataon na nag-apply ako... Nung nafind out na nagreactive talaga ako sa HIV, syempre di na ako pwedeng umalis ng bansa. Dun ko na finally naaccept na totoo nga na nagreactive nga ako, na positive ako sa HIV.

Daniela sunk into depression and hopelessness, but the thought of her young and innocent children kept her from taking away her life. “...syempre dumating din sa point na nag-suicidal attempt ako, andun yung gusto ko na tumalon na lang sa LRT, mag-pasalpok sa tren, kasi nga parang gumuho lahat ng pangarap ko para sa mga anak ko, syempre pa’no na lang mga gustong ibigay sa kanila, yung mga pangarap ko para sa kanila parang sa isang iglap lang nawala na lang bigla. Pero at the back of my mind kung gagawin ko yun kawawa naman yung mga anak ko, wala na nga silang kinalakihan na tatay pati ba naman ako mawawala, so yun yung parang nagmotivate sa akin para magpatuloy.”

Internal stigma and the feeling of being alone and of no one completely understanding her situation tormented Daniela. She felt ashamed because she thought she is *the only female person* in the world who has HIV, and that she is *a woman* who has HIV. She said she perceived of HIV as an illness that is affecting more of and is more rampant among *gays* than women.

She attributes the turning point in her life to her involvement in Pinoy Plus a few months later after confirmation of her diagnosis. The counselors, who encouraged her to access treatment, join trainings and become an active member of the PLHIV network for women, became significant instruments for Daniela to become the inspiration for female PLHIV that she is today. She narrated, “Tapos isa sa mga staff ng Pinoy Plus ang kumausap sa akin at that time, kasi nga hindi ganun ang thinking ko sa HIV, kasi nga *akala ko more on like bakla* lang na nagkakaroon so feeling ko nag-iisang babae lang ako na positive or with HIV so aloof ako sa karamihan, pag may nakita akong mga patient di ako masyadong lumalapit pero may isang staff... nilapitan niya ako sabi niya ‘Bago ka?’ Tapos di ako masyadong nagsasalita kasi yung trust ko hindi mo na masyadong ano kasi nga pagkakaalam ko ako lang yung nag-iisa. Sabi niya, ‘Okay lang yun kung ayaw mong magsalita tapos nagpakilala siya tapos nag-open up siya sa akin regarding sa status niya, parang nagkaroon na ako ng lakas ng loob kasi naisip ko na ay meron pa palang ibang taong katulad ko pero inopen up ko sa kanya pero nahihiya ako kasi *kababae kong tao* tapos karamihan ng nakikita ko mga bakla. Sabi niya ‘Wag kang mag-alala may mga babae rin, gusto mo pakilala kita?’

To cut the story short, Daniela accessed treatment and became an active member of Babae Plus, an organization for women living with HIV. The organization dissolved but was replaced by Association of Positive Women Advocates Incorporated which at present also includes transgender women. Daniela is the first president of this organization and she had undergone trainings and became a volunteer in many PLHIV initiatives which prepared her for the said responsibility and opened up employment opportunities that helped her provide for her children. At present, she is one of the frontline personnel in the social hygiene clinic of a city in Metro Manila, which allows her to share her personal story and encourage newly diagnosed PLHIV.

In particular, Daniela’s life is a source of hope for those who dream of having their own family and children but fear that their illness will infect their spouse or child. Upon learning of her diagnosis, Daniela reunited with one of her former boyfriends and he knew of her status but still accepted her. Daniela had an unintended pregnancy, and decided to stop taking her ARV treatment thinking that it would be safest thing to do for her baby. However, her ob-gyne panicked upon knowing that she stopped her treatment, saying that only the ARV could actually prevent the virus from mutating and infecting the child. “Yun yung takot ko nung itinigil ko kasi, buti nga hindi sila nagising nung ilang buwan kong itinigil. Di ba kung nagising yun kawawa naman yung baby ko pero inisip ko na rin yung kung ano yung kalalabasan, kasi naisip namin ng dating partner ko na kung sakaling mahawaan man ng baby tanggap na namin kasi ginusto naman namin pareho yun eh. Pero thankful ako kasi hindi eh,” she said.

Daniela points to a healthy lifestyle, early and consistent ARV treatment prior to pregnancy and having a caesarean delivery as the keys to prevent transmission of HIV to the child. Although she made the mistake of not taking her ARV treatment during her pregnancy and considers the outcome of her situation lucky, she advises other pregnant PLHIV when given

the chance to take care of their bodies and access treatment to ensure the well-being and safe delivery of their child. She says that HIV should not be a hindrance to realizing one's dream of having a family. "Siyempre, gusto ko pang mabuhay ng matagal para matagal ko pang makasama ang mga anak ko. Yun yung parang iniisip ko. Kailangan kong alagaan ang sarili ko para makasama ko pa ng matagal ang family at the same time ang anak ko. So yun ang ginawa ko. .. Through my story, naiinspire sila na akala nila is katapusan na yung pagkakaroon ng status na ganito hanggang dun na lang. Pero nung nalaman nila yung story ko, kasi before din ako napunta sa ganitong work, nag-outreach din ako sa Babae Plus before, so ang ginagawa namin is nakikipag-usap kami sa women PLHIV na mga pregnant.

She said HIV should also never be a hindrance to employment and productivity. "Kaya ngayon nagwowork pa rin ako kahit ganito ang kalagayan ko. Hindi ko yun ginagawang hindrance dahil productive pa rin naman ako. Gusto kong patunayan sa kanila na kahit na ganito ang status ko, kaya ko pa. Kaya ko pang panindigan kaya ko pang i-provide yung mga pangangailangan ng anak ko. Apat yun ako lang mag-isa." Daniela is now single but one of her former spouses supplements her earnings to meet their children's needs.

All her family members also know of her status and continue to emotionally support her, including her four children ages 18, 17, 14, and 8, whom she considers as her "treatment partners" who remind her daily to take take her ARV treatment. At an early age, Daniela brought her children to seminars and trainings for them to understand her situation. "Sinasama ko sila sa trainings para alam nila yung mundong ginagalawan ko... Ako mismo ineducate ko sila at an early age. Kasi ako nakakapag-educate nga sa tao, what more pa kaya yung mga sarili kong anak at mga kapatid ko? Para lang magkaron sila ng awareness regarding dun. Siyempre, ayoko na lang magkaroon sa family ko huwag naman sana, pero siyempre nandito na ako sa advocacy na ito, so siyempre priority ko yung family ko."

However, Daniela admitted that it was difficult for her to disclose her status to her mother at first, because she is terribly sick and Daniela feared the disclosure would worsen her condition. Daniela sought the help of the Pinoy Plus counsellors and brought her mother to the Pinoy Plus office when she decided that it is already the right time for her mother to know of her illness. Her mother understood and accepted her and Daniela felt grateful, but also could not help but look back on other PLHIV who unfortunately did not have a similar experience. "Marami akong kaibigan na ganyan, from the time na dinisclose yung status nila, dinisown na sila ng family. Yun yung nakakalungkot lang kasi yung iba, namatay na lang dahil sa depression. Yun yung number one killer talaga sa amin eh. Depression, masstress ka, tapos yung discrimination pa."

Daniela recounts of the single time she experienced discrimination, and it was in a hospital when she delivered her youngest child. Daniela was in the ward with the other mothers who just underwent delivery. However, she was the only mom who did not breast feed her baby and this irked one of the ward nurses who eventually loudly accosted her, drawing the the at-

tention of everyone in the room. “Sumigaw siya, ‘Hindi mo ba nakikita ikaw lang ang hindi nag-breastfeed dito, *bakit, maysakit ka ba?* Daniela felt really angry deep inside for she thought the nurse should have known of her status, “Sa isip-isip ko gusto ko siyang saksakin ng syringe. Dala-dala na niya yung chart niya di niya ba muna chineck, kung ano ang sitwasyon ko kung bakit ako nagbottlefeed? Nakalagay naman siguro dyan kung ano ang status ko kung ano reason kung bakit ako nagbottlefeed?! Nanahimik na lang ako, buti na lang mahaba ang pasensya ko pero grabe na rin kasi yung stress ko eh, yung sakit na nararamdaman ko sa mga tusok-tusok sa akin, tapos yun pa yung maririnig mo sa health provider?!”

She opened up to her doctors and the incident led to the said nurse being warned and almost fired from her job. Daniela asked the head nurse not to dismiss the nurse, because she said her purpose for complaining is so that the staff would become aware and would know how to treat other women PLHIV who would someday be in her place. “Hindi naman yun yung purpose ko ang sa akin maging aware lang siya para sa susunod na may kaparehas ko sitwasyon, at least maging aware sila kung paano kami i-treat. Na hindi parang i-treat na naiiba sa karamihan kasi normal din po kami, ang meron lang po sa amin is meron po kaming virus. Yun lang ang pinagkaiba namin. Pero bilang trained nurse, dapat alam po nila kahit ituturn over na kung maiiba yung shift ng nurse, dapat alam po nila yung trabaho nila. Kami nga sa counselling nag-eendorse kami ng pasyente. Hindi nga kami lisensyado pero nagagawa naman naming yung trabaho namin.”

At present, Daniela said that she has not heard of a similar incident happening to pregnant PLHIV from her networks. She continues to inspire and share her experiences through media interviews and at one point as a consultant for a TV series that featured the story of a PLHIV couple who successfully prevented the transmission of the illness to their child. However, she requests for anonymity in her media interviews, since her children are still young and she wants to protect them. “Ayoko na magsuffer sila so pinangalagaan ko, pero siguro in time. Silhouette na lang muna ngayon.”

At the end of the interview, Daniela shared the encouraging message that she usually tells women with PLHIV in her talks or during seminars. “Don’t lose hope lang. Siyempre isang wake-up call na rin ito sa amin dun sa mga nakakalimot, Siyempre di naman tayo bibigyan ng ganitong pagsubok o trials kung di natin kayang lampasan. Hindi hadlang ang pagkakaroon ng HIV para itigil ang buhay, para hindi magpatuloy. Hindi naman namin kasi kailangan ng awa. Ang kailangan namin is yung pagtanggap, yung pang-unawa... Hindi ibig sabihin na namumuhay kang positive, wala ka nang dignidad,” Daniela said.

## **XI. SUMMARY AND RECOMMENDATIONS**

The number of PLHIVs in the Philippines is increasing, and with this, the negative attitudes of the general population towards PLHIVs continue to persist.

The Philippine Stigma Index Study 2.0 is an attempt to document and to an extent possible measure the level of stigma and discrimination experienced by PLHIVs. Since it's first stigma index study in 2010, the current initiative also aims to measure changes, and assess the impact of intervention programs to reduce HIV stigma and discrimination. While there have been changes in the instruments and the design of the two surveys, comparable and relevant indicators could provide some measure of change. Some of the main findings are summarized in this section.

1) Compared to 2010 survey sample, the current survey covered more respondents and in terms of their demographic characteristics, they are predominantly males, better educated, and a third are in full time employment.

The mean number of years as PLHIV is 4.5 years, with the longest reported number of years of 22 while 28% of the respondents have been diagnosed for one year and less. The length of years as PLHIV is a determining factor in assessing the results of some of the indicators covered by the survey.

2) In terms of disclosure, there is higher report of disclosure of status, especially within the immediate family, such as husband/wife/partner and other family members. PLHIVs who have been diagnosed for more than 10 years have the highest percentage of disclosure, compared to those who have been PLHIVs for one year and less, 2-5 years and 6-9 years. The findings also show that the disclosure of status is usually done with consent although among those who reported that their status was disclosed without their consent, the most common is among their co-workers and other family members.

3) In general there is low level of report of stigma and discrimination among the respondents. However, among those who did experience stigma and discrimination, most of them reported that they became the topic of gossip of other people, or they received discriminatory remarks or being gossiped about by their own family members. This is higher particularly among PLHIVs who have been newly diagnosed, or those who have been PLHIVs for one year and less. Higher, PLHIVs for more than 10 years have the highest percentage of reporting that they experienced different kinds of discrimination and stigma.

4) The level of self-efficacy or the ability to succeed in specific situations among PLHIVs varies substantially. Higher percentage of respondents said that their HIV status did not affect their self-respect, ability to respect others, ability to cope with stress ability to find love and

ability to have a close and secure relationship with others. However, higher percentage of respondents reported that their HIV status negatively affected their desire to have children. Self-exclusion is a common recourse among PLHIVs. This is reported by about a fifth of respondents, especially in activities such as attending social gatherings, isolating self from family and deciding not to have sex.

5) When it comes to accessing health care services, more respondents in the 2019 survey reported that it was their decision to get tested compared to 2010 survey (80% vs. 56%) . Similarly, the percentage of those who were tested without their knowledge went down from 30% in 2010 to 15% in 2019. Getting tested without their knowledge is more common among PLHIVs who have been diagnosed for more than 10 years.

For majority of respondents, it took them 6 months and less to take the test after they thought about it. Those who are recently diagnosed tend to take the test shortly after they thought about it. However, there is 5% who reported that it took them 2 years to be tested. The fear of how other people would react to their HIV status is the number reason why they are hesitant to get tested.

Almost all of the respondents are currently taking their ARV treatment. Majority also describe their health status as “good”. Almost all received their regular HIV care and treatment from a government or public health facility.

Thirty six percent reported that they have sought health services from non-HIV related concerns in the past 12 months. Of this number, a small but significant percentage reported that they were talked badly or gossiped about, denied of service because of their HIV status and was their status was disclosed to other people. About a quarter also reported that they disclosed their status whenever they go outside the treatment for non-HIV related concerns.

Within the treatment hub, majority are confident that their medical records are being kept confidential. However, 4% said that they were told by a health professional that in order to get their ARV treatment, they had to use a specific method of contraception. Another 1.5% reported that they were advised not to have a baby by a health care professional because of their HIV status.

6) Reports of human rights abuses are quite low among PLHIV. Among those who reported, the most common was being forced to get tested or disclose HIV status in order to apply for a job and being denied a visa to enter another country. Most of those who experienced such abuse however, did not do anything about it for reasons such as not knowing where to go, what are the process involved and worry about the repercussion of taking action. There is very high level of awareness on the existence of laws that protect PLHIVs among survey respondents.

7). For effecting change, the most common action done by the PLHIVs is the provision of support to help someone living with HIV deal with stigma and/or discrimination. Participation in an organization or educational campaign working to address stigma and discrimination against PLHIVs is another form of action taken by survey respondents.

8) Aside from being PLHIVs, stigma and discrimination was also experienced by respondents because of their gender identity, sexual preference, involvement in commercial sex work and use of drugs. Across different gender identities and sexual preferences, the common form of discrimination was receiving discriminatory remarks from family about their sexual orientation and gender identity. This is followed by verbal harassment. Among those who are engaged in commercial sex, there is also substantial proportion who reported being blackmailed due to their involvement in commercial sex work.

There have been several initiatives in the past 10 years to address the needs of PLHIVs in the Philippines. While HIV testing has expanded and access to ARV treatment has been made available, there is still a lot that needs to be done to reduce stigma and discrimination among PLHIVs and their families. One, a sizable proportion still reported that they are being advised by health care professional not to have or to have a child because of their status. Continuous training and advocacy towards a more PLHIV friendly health care setting is necessary to totally eradicate these biases. Second, while PLHIVs are confident that their status are being kept confidential in the treatment hub, no assurance is guaranteed once they get out of the hub for non-HIV treatment. This is another concern that needs to be focused on. Medical practitioners need to be continuously reminded of the rights of PLHIVs to health care, and as such services should be provided without biases on their status, gender identity and sexual orientation.

The family, while it remains steadfast in its role as safety nets for PLHIVs has been cited as the most common venue for discrimination. There is a need to understand the underlying factors for these in order to create family-based and community based programs to support PLHIVs.

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