RISKS & BARRIERS TO SERVICE UPTAKE AMONG WOMEN LIVING WITH HIV (WLHIV)

An Exploratory Study
Risks & Barriers to Service Uptake among Women Living with HIV (WLHIV): An Exploratory Study

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The number of people living with HIV (PLHIV) in the Philippines is exponentially increasing. Although majority of the cases are among males who have sex with males (MSM), data from the HIV/AIDS and ART Registry of the Philippines (HARP) has shown a steady increase in diagnosed women from 2015 onwards. Further analysis showed that women also had lower treatment initiation and retention rates compared to the males. As there were only limited studies among Filipino women living with HIV, this study was conducted to further explore their HIV risks, the events that led to their diagnosis, and the motivations and struggles to treatment initiation and adherence.

The study conducted 47 key informant interviews among women diagnosed from 2016 to 2018. Respondents were gathered from regions with highest female HIV cases in the Philippines, particularly: the National Capital Region (NCR), Region 4A (CALABARZON), and Region 3 (Central Luzon). The respondents’ ages ranged from 19 to 48 years old with the median being 29 years old. Thirty-nine (39) respondents were mothers and had children during the time of the interview. As for the treatment status, all but one have started antiretroviral therapy (ART) and were currently on treatment during the time of the interview. The interviews focused on seven areas of inquiry meant to highlight the experiences of women living with HIV towards ART retention: (1) women’s risk for HIV, (2) experience on the process of testing, (3) reactions toward diagnosis, (4) actions toward diagnosis, (5) initiation and adherence to treatment, (6) hindering factors in accessing treatment and struggles in adherence, and (7) looking into the future.

The results of the study revealed that the risk of Filipino women for HIV is an interplay of factors which include their sexual behavior, the sexual behavior of their partner, and the lack of knowledge on HIV prior to diagnosis.

Majority of these women reported unprotected sexual intercourse with varying numbers of and relationship ties with sexual partners. Respondents who were in a steady relationship (i.e. married) who were unaware of their partner’s HIV status practiced unprotected sexual intercourse stemming from the lack of awareness of their vulnerability to HIV. Meanwhile, among those with multiple partners, condomless sex was linked to the refusal of their partner to use condoms and the respondents’ inability to negotiate condom use with their partners.
In terms of their partners’ sexual behavior, the women were divided on their awareness of the risk posed by their partners. Some shared that they were aware that their partners had multiple male or female sex partners while others were not privy to their partner’s sexual behaviors and HIV status. What was common to both groups, however, was their inadequate awareness on HIV, and their knowledge and skills to protect themselves. Inadequacy of platforms for these women to access information and discuss their sexual concerns compounded their risk further.

Reported HIV testing among these women reflects efforts by the HIV program to reach and test at-risk female groups including pregnant women, female sex workers, Overseas Filipino Workers (OFWs), and those diagnosed with Tuberculosis (TB). However, the results of the study show that those who do not belong to the key population groups tended not to see the need for HIV testing. Their decision to subject themselves to HIV testing was thus predicated on their partner’s HIV status disclosure or the presentation of signs and symptoms of opportunistic infection(s) in the respondents, their partners, or children. This explains the late diagnoses seen among women living with HIV.

Access to treatment and resulting actions post-diagnosis depended on the women’s acceptance of their diagnosis. Women initially had difficulty coming to terms with their HIV status and what the implications would be for them and their families — which translated into seclusion and self-stigmatization. Compounded with their fears and preconceived notions around the side effects of antiretroviral drugs (ARVs), these affected the time it took for them to access care and treatment. Moreover, respondents articulated actual experiences of side effects during treatment that led to difficulties in their ART adherence. Lastly, they also identified facility-related barriers such as required laboratory tests and facility visits both at baseline and follow-up which presented as challenges to timely access and adherence to their medications.

Despite these struggles, women still accessed and continued with treatment. Motivations for this were primarily anchored on their responsibility to survive and live longer for their families. Support from friends, family, health care workers, and PLHIV support groups provided an additional push. Furthermore, the access to free services and financial assistance facilitated their treatment adherence.
Women remained hopeful for their future. Learning from experience, these women encourage other women living with HIV to be optimistic, to learn to accept their diagnosis, and to access and adhere to their treatment. Moreover, they identified the need to help women with the tools and the skills to protect themselves. Key to this, they said, is increasing HIV knowledge among women.

Much is to be gained in halting the onward transmission among women. The stories of these women provide valuable input on how the current HIV program can be improved. Efforts in improving HIV knowledge and risk awareness; access to condoms; and building skills towards discussing sex with one’s partner and effectively negotiating condom use can help reduce the risk of women for HIV. The results of the study also highlight the need to explore avenues to encourage testing among women with partners from key population groups as these women are not reached by current HIV testing strategies. Along with increased targeted testing of these women, it is critical to improve current counseling services to respond to their fears and their need for better management of side effects. Involving their families and engaging PLHIV support groups specific to women may prove to be beneficial in treatment initiation and adherence.
INTRODUCTION

The increase in HIV cases coinciding with the shift in male-to-male transmission in the latter part of the last decade has drastically changed the face of the Philippine HIV epidemic. Although the proportion of cases among women is lower compared to males who have sex with males, data from the HIV/AIDS and ART Registry of the Philippines (HARP) has shown a steady increase in diagnosed cases among women from 2015 onwards. Indeed, of the 3,937 total diagnosed females as of December 2018, 38% were diagnosed from 2016 to 2018.

The HARP provides much needed direction in terms of describing the population of women diagnosed with HIV. The median age of women diagnosed from 2016 to 2018 is 28 years old. Majority are literate, with 8 of 10 being high school (49%, n=287) and college (28%, n=166) graduates. Fifteen percent (n=223) of the HIV-diagnosed women reported to have worked abroad in the five years preceding their diagnosis.

There are a number of behaviors or characteristics that increase a woman’s risk of having HIV. The study conducted by Naicker, Kharsany, Werner, Loggenrenberg, Mlisana, Garrett & Karim (2015) identified that a woman’s age and relationship with more than one partner increase their risk of HIV. In the Philippines, diagnosed females from 2016 to 2018 were relatively older, with two-thirds (67%) of the cases being 25 years old and above. Meanwhile, 66% reported to ever have more than two partners before the time of diagnosis.

Reported risk behaviors from the HARP provide some indication of possible reasons for the increase in cases. Among women diagnosed from 2016 to 2018, only more than 10% reported engaging in risk behaviors associated with key populations. Eight percent (n=127) regularly accepted payment for sex at the time of their diagnosis, whereas 4% (n=54) injected drugs. Granted that underreporting may be possible, the absence of any other indication of a generalized epidemic in the Philippines points to a greater likelihood of ongoing HIV transmission among women from other key population groups.

Further disaggregating the HARP data among females by city of residence reflects the epidemic occurring in highly urbanized areas. Six of the ten cities with the highest cases among females were from NCR (i.e. Manila, Quezon City, Caloocan, Pasig, Taguig, and Makati), which bear the most burden of cases among males who have sex with males.
(MSM). Cebu City, where a high number of cases both among MSM and people who inject drugs (PWID) have been recorded, had the highest number of diagnosed cases among females reported in the HARP from 2016 to 2018 (n=159). This is further supported by the number of cases among pregnant women. Whereas at the national level, only 14% (n=207) were reported pregnant at the time of their diagnosis, this figure jumps to 25% and 20% for NCR and Cebu, respectively.

Equally important in determining the potential HIV transmission routes among women is their access to critical HIV treatment and care services. Post-HIV diagnosis, PLHIV are faced with anticipated and actual changes brought about by their HIV status and studies have shown that this adjustment period influences access to care services (Landry 2015; Wekesa & Coast 2013). Comparing the HIV care cascade among males and females, a smaller proportion of the total number of diagnosed females were initiated into treatment within six months after diagnosis (64% vs. 54%). Relative to males, a smaller percentage of diagnosed females continued to be on treatment as of November 2018 after they started with their antiretroviral therapy (46% vs. 69%). Findings suggest gender-specific needs that require tailored responses.

It can be argued that addressing emerging epidemics before they explode is more cost-efficient and important in resource limited settings such as the Philippines. It is therefore incumbent to generate strategic information to understand the current dynamics driving the transmission and impeding timely access to life-saving HIV treatment and care services among Filipino women.

This report provides an overview of the qualitative analysis of 47 interviews among women living with HIV diagnosed from 2016 to 2018 from three regions in the Philippines. The qualitative approach was used to explore their risk and source of HIV, the events that led to testing and treatment, and the changes and challenges brought about by HIV into their lives. Data collection was done with the support from Association of Positive Women Advocates Inc (APWAI) and from the regional health unit counterparts.
OBJECTIVES

The goal of the study was to gather stories of recently diagnosed Filipino WLHIV, with the aim of:

1. Complementing data from the HIV/AIDS and ART Registry of the Philippines;
2. Describing the risks and vulnerabilities of WLHIV prior to diagnosis; and
3. Identifying the facilitating and hindering factors in accessing HIV care services among WLHIV.

The results of the study will be beneficial in planning and strategizing HIV prevention and control programs in the country.
METHODOLOGY

Research Design
The exploratory study among WLHIV employed key informant interviews. The narratives of WLHIV were analyzed qualitatively through thematic analysis. Qualitative analysis allows for the surfacing of detailed accounts within cultural and social relationships, putting the narratives in context for a deeper and richer understanding of the complex layers of meaning that the participants were immersed in.

Data Collection

Recruitment and sampling. Data were collected among respondents who fit the following inclusion criteria: (1) a woman at least 18 years old, (2) able to provide informed consent, (3) and was diagnosed with HIV from 2016 to 2018. Moreover, the exclusion criteria from the study were as follows: (1) respondent was above 50 years old, (2) respondent was unable to express/communicate verbally to the interviewer, (3) claimed that she was diagnosed with HIV without a confirmatory test or if the respondent only identified that she was positive on an HIV test without an STD/AIDS Cooperative Central Laboratory (SACCL) code; and/ or (4) respondents whose permanent residence was outside the region of the site of interview. These selection criteria were placed to ensure a considerable degree of homogeneity in the sample of WLHIV, and as such more meaningful information can be derived from their narratives through thematic analysis.

The key informant interviews were conducted in three sites: NCR, Region 4A, and Region 3. Selection was based on the current burden of the HIV epidemic among females. Twenty interviews were targeted per site. These sites have been vetted and selected by the study Technical Working Group (TWG) in consultation with APWAI, guided by existing data on the HARP.

Interview instrument. An interview guide was developed together with APWAI, with English and Filipino versions (see Annex B). The questions included in the interview were composed of domains that potentially surface the experiences of women living with HIV, including their perceived barriers and facilitators to treatment. It covered the following:

- Demographic characteristics
- Age, educational status, civil status
- Number of children, last pregnancy, HIV status during last pregnancy
- Risks before and after diagnosis
- Risk and protective behavior milestones (i.e. first sex, condom use, drug use, injecting, and HIV test)
- Types and frequency of sex
- Profile of partners prior to diagnosis
- Sex work
- Forced sex
- Domestic violence
- Alcohol and drug use
- Migrant work
- HIV knowledge and prevention strategies before and after HIV diagnosis
- Context of HIV diagnosis (i.e. motivations for testing, experience of prevention of mother to child transmission interventions)
- Barriers and facilitators to access to care of WLHIV and their partner(s)
- Antiretroviral therapy (ART) Status
- Family planning
- Stigma and discrimination

Participants were initially asked an open-ended question at the start of the interview proper, and were then asked to narrate their HIV story. The follow-up questions served to fill in the gaps in their storytelling in relation to the above-mentioned domains.

**Study preparations and training.** All members of the research team were trained on the use of the prepared interview and documentation tools. The trainings aimed to standardize the conduct of the interviews. The training also served as a refresher course for the research team on psychological first aid. Given the sensitive nature of the topics to be covered, this part of the training was critical in ensuring that the team was equipped to handle and manage highly emotional conversations that the prepared instrument might elicit. Documenters were also part of the research team to assist in capturing the domains or themes presented in the audio recordings. A training was also conducted to all documenters on how to encode using a standardized template.

The exploratory study was primarily guided by the MIPA (meaningful involvement of people with HIV and AIDS) principle, anchored on the premise that the participation of the positive community is central to any intervention that envisions to better their condition. It is for this
reason that the development, implementation, and analysis of this assessment were conducted in close partnership with the Association of Positive Women with HIV and AIDS, Inc. (APWAI). In addition, APWAI members were recruited as interviewers for the study, recognizing their experience in networking and dealing with the WLHIV community. Moreover, a technical working group for the study was formed to serve as an oversight. The TWG were composed of stakeholders from partner government, civil society, and development agencies. It ascertained the technical soundness of the exploratory study design and tools as well as its responsiveness to the strategic information needs of HIV programs at the local, regional, and national levels.

Data collection proper. The data collection team was composed of eight members divided into three teams. Each team was assigned to gather respondents in their respective regional assignment (NCR, Region 4A and Region 3). The data collection team approached HIV testing and treatment facilities in each region, asked assistance from the HIV case managers, and/or waited in the facility for respondents who satisfy the inclusion criteria. Respondents were also gathered through referral. Eligible respondents were interviewed in a safe, private, and quiet places. Interviews were held from September 2019 to February 2020. The participants of the interview were all provided with written and verbal informed consent before beginning the interviews, and all of the respondents agreed to audio tape the interviews. The interviews then proceeded with the trained interviewers going through the prepared questions. After each interview, the interviewer validated with the participant what he/she has gathered from the interview by summarizing the story she has just heard from the participant. Each interview lasted for 30 to 60 minutes long. After the interview, the respondents were thanked for their time and provided with food and transportation allowance.

The data collection team together with DOH-EB met on a semi-monthly basis to give updates on the status of data collection. The meetings also served as an avenue for the submission of the materials gathered from the interviews (i.e. summary and voice recordings). The voice recordings submitted were then documented verbatim by a team of encoders. The transcribed data were compared to voice recordings and to the summary provided by the interviewers to ensure proper transcription of the interviews.
Ethics

Ethical considerations for the study were based on the recommendations of the following policies:

- The Philippine HIV and AIDS Policy Act of 2018 (RA 11166)
- 2017 National Ethical Guidelines for Health and Health-Related Research
- The Data Privacy Act of 2012 (RA 10173)
- 2017 WHO Biobehavioral Surveillance Guidelines

The study was submitted to and approved by the Single Joint Research Ethics Board convened by the Department of Health as part of the activities related to the 2018 Integrated HIV Behavioral and Serologic Surveillance (IHBSS).

Data security and privacy. The data custodian for all the data gathered from the study (e.g. recordings, summary notes, demographic data and other outputs of the interview) is the DOH-EB National HIV/AIDS & STI Surveillance and Strategic Information (NHSSS) Unit. Only the DOH-EB NHSSS Unit has full access to the exploratory study data. All electronic copies of the digital recordings have been surrendered by the APWAI and interviewers to the DOH-EB. Access to any raw data (i.e. forms, questionnaires) requires a signed confidentiality agreement with DOH-EB. All data files are encrypted, protected and will never be distributed without consent from DOH-EB. Recordings and transcribed interviews are stored in a password-protected digital file within DOH-EB servers. Hard copies of the questionnaires/forms will be stored in DOH-EB for ten years after which, these will be shredded and disposed of following the implementing guideline of the Data Privacy Act of 2012 (RA 10173) and the National Archives of the Philippines Act of 2007 (RA 9470).

HIV research among vulnerable groups such as women living with HIV inevitably confronts questions around rights primarily because of how central stigma and discrimination are to the daily experience of this particular population. This makes research in such settings necessary but also mired with possible ethical dilemmas. Thus, the study carefully considered ethical issues that may arise and incorporated mechanisms within the methods to adequately address these.

Fair participant selection, favorable risk-benefit ratio, and independent review. Guided by the MIPA principle, the methods employed necessitated a participatory, multi-stakeholder approach that included women living with HIV. In working with a vulnerable population such as WLHIV, fair participant selection is intimately linked to a discussion on favorable risk-benefit ratio. Risks, as mentioned above, are inherent to working with vulnerable populations. Engagement of community groups may inadvertently lead to
Disclosure of identities, especially in closely-knit support groups. Unfortunately, it is only through active engagement of WLHIV that viable and effective interventions be designed. It is thus argued that the benefits of focusing on WLHIV in this study is framed toward improvements to interventions directly benefiting the said group. There is a great potential public health benefit from an increased understanding of the HIV risks and barriers to service access women face. In this regard, the research team, in close and continued consultation with APWAI, has decided that the benefits of this study outweighed the risks involved.

Informed consent. All respondents voluntarily provided informed consent to be eligible to participate in the exploratory study. Informed consent was obtained at two specific time points: upon recruitment (verbal) and immediately prior to the interview. Moreover, respondents were informed that they can choose to withdraw at any point in the study even after the interview.

All respondents were informed of what the exploratory study is, its purpose, and who are involved in conducting the survey (i.e. DOH-EB and APWAI). They were informed that their participation is voluntary, that they may withdraw from the study anytime, and may refuse to answer any questions without incurring any penalty or loss of benefits. They were also informed that they are not required to join any organization or group involved in this study (APWAI, etc.).

Respondents who consented to participate were briefed that they will be interviewed for 30 mins to 2 hours, depending on their discussion. For better documentation, the conversation was audio recorded upon acquisition of consent to record from the respondents. The discussion revolved around their risk behaviors, and awareness and uptake of HIV services. They were informed that participation may result in some level of emotional distress, but the interviewers have been trained in psychological first aid and they can be referred to a professional counselor should they need it after the interview. Moreover, participants were told that the data they provide will be used to guide health policies and programs for them, and for the WLHIV community.

Anonymity. To ensure anonymity of the respondents, participants were informed that they can opt to use pseudonyms or codenames, and will be referred to by these names throughout the audio recording and written notes, as well as throughout analyses and reporting. Furthermore, only basic demographic information (i.e. current age, age at HIV diagnosis, month and year of diagnosis, city of residence, educational attainment, number of children, status of HIV treatment, treatment facility where services are currently being accessed) were collected. Absolutely no names and other identifying information were
collected in the study. Each respondent was assigned a unique code referred to as “Respondent ID” (RID) during analyses. Informed consent was obtained verbally as written consent would require provision of name and signature and will thereby compromise the respondent’s anonymity. The interviewer witnessed and signed the informed consent form on behalf of the respondent, and have the participant read the signed consent form. Copies of this signed form were given to the participant.

Respondents were assured that their anonymity was maintained throughout the process as no names were collected. They were informed that all the information they provided will remain confidential. The answers they provided during the face-to-face interview will remain between them and the interviewer. They were assured that the voice recordings of the conversation will be in the possession of the interviewer until the predetermined documentation is finished and will be surrendered to DOH-EB. The audio files were then forwarded to the DOH-EB to be further analyzed, secured, and stored thereafter. They were informed that other exploratory study team members will not be able to trace back their interview responses to them since only codes will be used to identify them.

**Confidentiality.** Confidentiality of study data and respondent identity was preserved, except in cases where participant requested for referral to a professional for further counseling. Conditions for breaking of confidentiality under strict and necessary guidelines were discussed thoroughly with the participant prior to data collection. Analysis of the data was only done by DOH-EB and APWAI. Moreover, each member of the data collection team from APWAI signed a confidentiality agreement reiterating non-disclosure of any information gathered during the interview to outside parties.

**Privacy.** During the interview proper, measures to ensure privacy were observed to ensure not only data confidentiality but also to avoid embarrassing the clients given the sensitive nature of the topics to be discussed. Measures include conducting interviews in a private setting at a certain distance from other people, and the use of pseudonyms.

**Benefits to Participants.** The respondents were informed of the benefits from participating in the study. Direct benefits from participating in the study included receipt of information on the services and assistance that she may need based on her narrative. The respondents were also given transportation and food allowance as the interviews were conducted in venues agreed by the respondents and the interviewers. Moreover, APWAI provided psychosocial support to the respondent. Indirect benefits included contributing to
the current knowledge on the female HIV epidemic in the Philippines, and contributing data on how to improve and strengthen the current programs of HIV among women.

**Safety.** The interview involved some psychological risk. Participants were reminded that they need not answer or elaborate on questions that they do not feel comfortable discussing. Moreover, interviewers were trained on counseling and psychological first aid. To ensure anonymity, the respondents were assured that all assessment documentation will not contain any personal identifier (apart from an identification number). No documentation was created containing codes that links to the participants’ demographic information, and the respondents’ names were not collected at any point in the study.

**Data Analysis**

Data collection and analysis were done simultaneously. Data analysis started as soon as an available transcript was made. The interviews were analyzed manually, guided by the Braun and Clarke (2006) six phases of analysis: familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Familiarization of the data consisted of the data analysis team reading and re-reading the transcribed interviews. The data analysis team then facilitated coding following one’s experience from pre-HIV situation to diagnosis, treatment, adherence to treatment, and life after diagnosis which covers their dreams and aspirations.

Open coding was conducted wherein data were described in forms of concepts and themes which were then further categorized (Williams & Moser 2019). Initial codes were based on the ideas, and concepts present in the verbalizations of the respondents, similar words and phrases or concepts were then joined together. Comparison of codes was also done between team members and the codes were either joined or modified. Multiple readers and listeners from the team helped provide additional inputs in identifying the possible themes. This was a recursive analytical process, with the team listening to the recordings and reading the interview notes multiple times to ensure completeness and richness of data. As the study wanted to explore and answer certain questions about women living with HIV, not all segments of the interview were coded. The team focused on coding relevant data or interesting data for the study. After initial coding, axial coding was done. Axial coding is when the open codes are refined, aligned, and organized together to create and categorize themes (William & Moser 2019). Patterns were analyzed, categories and subcategories were identified, and themes were built. After which, selective coding was done, which involved reviewing the categories, coding information, and organizing codes related to the
category. The themes and sub-themes generated were reviewed and discussed in relevance to the goal of the study. Gathering and analyzing data continued until saturation was reached. The team used MS Word and MS Excel in analyzing and organizing the themes presented since qualitative analysis software are more appropriate for large number of interviews and diverse data.

Limitations of the Study
While the results of the study provide direction on how to further improve the HIV program for women living with HIV, the study had some limitations. This includes sampling bias. Since the study employed a purposive sampling, there was no randomization of participants. Only women who satisfied the inclusion criteria and those who consented to participate were included in the study, which may have resulted in having limited ability to gain data access to other geographic scope and type of participants, especially those excluded from the inclusion criteria (minors). Moreover, the study was conducted only to a number of women in each of the three (3) regions. Due to difficulty in recruiting respondents, another limitation was that the results and the data gathered from these women cannot be generalized to all the HIV-positive women since few respondents were engaged among those who have not started HIV treatment.

Conflict of Interest Disclosure
The National HIV/AIDS and STI Surveillance and Strategic Information Unit of the Department of Health Epidemiology Bureau has been designated as the cooperating agency for the study, being mandated by the law (RA 11166) to monitor the HIV epidemic in the Philippines.

The authors declare that the collaborative study was conducted with oversight from the Technical Advisory Group (TAG). The DOH-EB declared participation in the conceptualization, protocol development, and dissemination of data as they were involved and always consulted for advice in consideration that the IHBSS is a periodic DOH survey done every 2-3 years since 2005. The data collection and management, consultations with the local government health counterparts and national or regional DOH HIV program coordinators, and engagement of the field epidemiologists and the site coordinators in all the survey areas were done by the implementing agency, the Field Epidemiology Training Program Alumni Association (FETPAFI).

Furthermore, DOH-EB provides and shares the report to the National AIDS/STI and Control Program (NASPCP) of the DOH Disease Prevention and Control Bureau (DPCB) who are the end users of the data.
RESULTS

A total of 47 interviews among women diagnosed with HIV were conducted from September 2019 to February 2020. The median age of the respondents was 29 (range: 19-48). All of them were diagnosed from year 2016 to 2018. At the time of the interview, 77% were single, 19% were married, and the rest were separated from their previous partners. All but one had at least some high school education. One-third of the respondents was employed during the time of the interview. Thirty-nine (39) of the respondents were mothers, with half of the respondents having two or more children. In terms of HIV treatment initiation and adherence status, all but one of them started and were currently on treatment. Among those who started treatment, 67% started treatment within three months after their diagnosis.

Further disaggregating the interviews by region of residence, there were 18 interviews conducted from NCR, 16 from CALABARZON, and 13 respondents from Central Luzon (Table 1).

Table 1. Disaggregation of respondents per region of residence and age during the date of interview

<table>
<thead>
<tr>
<th>Region</th>
<th>18-24 yo</th>
<th>25 yo and above</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 — Central Luzon</td>
<td>4</td>
<td>9</td>
<td>13</td>
</tr>
<tr>
<td>4A — CALABARZON</td>
<td>6</td>
<td>10</td>
<td>16</td>
</tr>
<tr>
<td>NCR — National Capital Region</td>
<td>5</td>
<td>13</td>
<td>18</td>
</tr>
</tbody>
</table>

For the full demographic characteristics of the respondents, see Appendix A.

This section is structured around the flow of their life-events — from the time before they were diagnosed to the present as women living with HIV. Specifically, these focus areas include: (1) their risk for HIV, (2) events that led to their diagnosis, (3) dealing with their diagnosis, (4) observed changes after diagnosis, (5) initiation and adherence to treatment, (6) hindering factors to and struggles in accessing treatment and adherence, and (7) looking into the future. Table 2 summarizes the categories, themes, and subthemes which emerged from the interviews.
Table 2. Summary of categories, themes, and sub-themes

<table>
<thead>
<tr>
<th>Category</th>
<th>Themes and Sub-themes</th>
</tr>
</thead>
</table>
| Women’s risk for HIV            | • Limited awareness on HIV  
• Sexual risk behaviors of the participant  
• Substance use  
• Partner’s sexual behavior  
• Experience of abuse |
| Events that led to testing      | • Routine HIV testing  
• Disclosure of partner’s status as impetus for HIV testing  
• Delayed HIV testing and diagnosis following onset of symptoms |
| Reaction towards diagnosis      | • Fear of abandoning one’s responsibility  
• Dissonance over unwarranted infection  
• Regret over their choice of partner  
• Acceptance of diagnosis |
| Changes after diagnosis         | • Anticipated stigma, disclosure, and support  
• Proactive steps to protect oneself and others  
  o Taking care of oneself  
  o Managing their perceived risk to partners  
  o Taking care of others: HIV testing and information  
• Experience of stigma and discrimination |
| Initiation and Adherence to Treatment | • HIV treatment = survival  
• Supportive social networks  
• Responsive services received |
| Hindering factors in accessing treatment and struggles in adherence | • Readiness to start medications  
  o Emotional readiness  
  o Physical readiness  
  o Financial readiness  
• Concern on ARVs and experience of side effects  
• Pill burden  
• Facility issues |
| Looking into the future         | • Bright future for the respondent and her family  
• Marriage and procreation  
• Advice to other women  
• Advice to women living with HIV |
I. Women’s risk for HIV

The interviews began with the respondents narrating their HIV stories and identifying the events that increased their risk for HIV. Five themes were identified from the intimated stories of the women participants: limited awareness on HIV, their sexual risk behavior, the sexual risk behavior of their partners, substance use and the experience of physical or sexual abuse before diagnosis.

A. Limited awareness on HIV

Majority of the participants reported that they had low HIV awareness before their diagnosis, while some had no knowledge on HIV at all. HIV was not openly discussed in their communities or with their partners. For many of these women, their diagnosis paved the way to learn more about HIV.

*Nung una hindi ko kasi… alam kung ano ba talaga yung HIV, wala akong idea. Pero ang alam ko HIV ay sakit. (R_019, 32 y/o)*

*Wala kasi akong ideya tungkol sa HIV nung panahon na ‘yun kasi hindi naman namin siya napag-uusapan ng partner ko. At saka ‘di ko naman talaga alam dahil wala namang education or awareness sa aming bayan tungkol sa HIV kaya wala talaga akong alam. (R_032, 32 y/o)*

Moreover, their HIV knowledge pre-diagnosis centered around the gay profile of the Filipino PLHIV as reported by mainstream media in recent years and the sex-negative and stigmatizing notions about HIV. They perceived HIV as an illness that mostly affects “bakla” or males who have sex with males (MSM).

*Ako po kasi senior high school pa lang may tips na about diyan kaya may knowledge na po ako dahil dun sa research namin and lagi po namin ‘to napapag-usapan kasi may mga beki o bakla. Di ko alam sa ‘kin pala tatama siya… Kasi di ba pag HIV, “ah madumi ka” parang ganyan, ‘di ba? (R_038, 19 y/o)*

*Mhmmm… kasi nung una feeling ako lang kasi ang naisip ko talaga sa mga transgender ang meron ng mga ganyang sakit. Hindi pumasok sa isip ko na puwede rin pala ang babae. (R_013, 25 y/o)*

They also viewed women who are HIV-positive as dirty and promiscuous (i.e. those engaged in transactional sex or have multiple partners). They diminished the likelihood of contracting HIV among more conservative women who do not belong to these stigmatized groups of women.
B. Sexual risk behaviors of the participant

The participants identified condomless sexual intercourse as their major risk for HIV. Some reported having multiple sex partners and substance use. Although, it was also pertinent to point out that majority of the respondents had only one sexual partner before diagnosis. Reasons for not using a condom stemmed from a lack of awareness and skills to effectively navigate their sexual partnerships.

However, this condomless sex was contingent on the type of relationship they had with their partners. For women who have been monogamous all their lives, there was no felt need to use a condom as this signify love and trust for their partner.

For respondents who had multiple sexual partners, condom use depended on their partners’ preference. This was particularly salient for women engaged in sex work wherein the power to decide is skewed in favor of the clients. As a result, women feel helpless and disempowered.

C. Substance use

Apart from sexual risk behaviors, some women also reported substance use. They shared that they engaged in drug use and needle-sharing before diagnosis, which thereby increased their risk for HIV.
D. Partner’s sexual behavior

Apart from the sexual behavior of the respondent, sexual behaviors of their partners were also revealed. Some were aware of their partners’ male-to-male sexual relations from the onset. Among these women, they framed their partners’ behavior either as a function of their sexual orientation (i.e. bisexuality, *silahis*) that they thought had ceased, or of financial need (i.e. sex work). As can be seen in the following quotes, the women echoed the negative judgment of gayness (and homosexual behavior) as something that diminishes one’s person and of gay men as vectors of HIV.

*Di ko alam. Baba na- Bumaba tingin ko sa kanya … Tapos nalaman ko na pumapatol pala siya sa mga bakla…basta mahilig siyang pumatol sa mga bakla. [pause] Dahil siguro sa pera. (R_047, 22 y/o)*

*Yung asawa ko po is parang silahis [crosstalk] parang pumatol po siya sa … ano, sa bakla po kaya nakuha niya po yung sakit na ‘yan. (R_018, 30 y/o)*

There were respondents, however, who were not fully aware of their partners’ sexual behaviors. Some participants, shared that they did not know their partners enough.

*Siguro isa na dun yung nagkaroon ako ng mga karelyason na hindi ko lubos nakilala yung pagkatao. Wala rin akong alam tungkol sa HIV. (R_036, 24 y/o)*

For others, the frustration at their partners’ non-disclosure not only of their male-to-male sex behaviors but even their HIV status was apparent. Women were taken by surprise as they did not have an idea on their partner’s status.


E. Experience of abuse

Some of the respondents also experienced physical and sexual abuse with their past partners which may have also increased their risk for HIV. The following women narrated their experience of abuse in relation to HIV.

*(Perceived source of HIV) ‘Yun nga ate. Dahil sa rape case ko. Doon siya nanggaling. Kasi nagkaroon yung anak ko na panganay. (R_015, 22 y/o)*

*(Referring to HIV-positive partner) Minsan lasing pa tuwing umuuwi siya tapos pinupwersa niya ako para lang makipag-sex sa kanya. (R_007, 32 y/o)*
II. Events that led to testing

The participants identified three main triggers for their experience on HIV testing: routine HIV testing, presentation of symptoms, and disclosure of their partner’s status.

A. Routine HIV testing

Specific female populations like sex workers, OFWs, and pregnant women said that HIV testing was something already familiar to them prior to diagnosis. Common to all three groups, the decision to undergo HIV testing was not borne out of a recognition of a specific risk. There was a general sense that HIV testing was not necessarily voluntary.

For both female sex workers and OFWs, as their employment and livelihood were contingent on subjecting themselves to an HIV test.

Kasi ‘di ba sa license namin. Eh sa bar nga ako nagta-trabaho kaya – Kasama sa requirements ‘yung HIV test. [pause] Kaya nadetect siya nang early. (R_031, 27 y/o)

Ano... [pause] Ah, sa ano po. Ahmm... Sa requirement... ano po, ah... dito po kasi sa ano... sa RHWC. ‘Yan pag renewal po, uhm... tini... hinihikayat po kaming ano.... magpa-test ng HIV. Basta every year po, minsan after every six months. (R_027, 28 y/o)

Female OFWs found themselves in very similar circumstances as their medical clearance required an HIV test.

Ano. Yun. Kasi nga dati hindi ko alam na may ano yang HIV nay. Ah nalaman ko lang nung mag-apply nga ako for abroad for medical. Nag-positive yung medical ko. Positive nga daw ako for HIV tapso inadvise din nila si husband at saka yung dalawang bata ipatest. (R_034, 31 y/o)


Ah automatic kasi siya sa work ko mandatory. Ano kasi OFW ako so kailangan ko talaga ‘yan magpa-test. (R_008, 32 y/o)

For pregnant women, HIV testing has become more available through antenatal care service delivery points following DOH Administrative Order 2016-0035. Whereas the
policy merely stipulated offering HIV testing, participants had the sense that this was mandatory.

Yung sa ‘kin, ano, yung pagbubuntis... five, magsi-six ganun. (months of pregnancy) 'Yung sa ‘kin kaya nagkaroon ako ng test sa HIV dahil required sa government yung mga buntis magpa-HIV test. (R_039, 28 y/o)

Nung buntis ako, tsaka yun. Kasi nakapapagpa-test na ‘ko nung una. Syempre required yun sa—ng duktor talaga e. Na... magpatest ng HIV pag buntis. Lalo sa mga check-up, ‘yun talaga nire-require although alam ko na nga na meron nga ako. (R_007, 32 y/o)

Tapos nung nag-asawa na ako nagkaroon ako ng anak na lalaki. Isa. Tas nung, 'yun nga yung dumating na sa point nung nakaroon na ng HIV. And then, nag, nagkaroon na ako ulit ng pangalawang anak. Tapos nung buntis ako nun, nung six months pa lang yung tiyan ko, nagpa-check up ako. Tapos yun nga tine-test na pala yun kasi dati po yun hindi tine-test yun na kung may HIV ka o ano. Tapos tinetest nila yun. Tas pagka-test sa akin, nag-positive ako. (R_015, 22 y/o)

B. Disclosure of partner’s status as impetus for HIV testing

Disclosure of their partner’s status also served as an impetus for their HIV test. Some of the HIV-positive partners were open about their HIV status and informed their partner to get tested.

‘Yun sinabi niya sa’kin, kailangan ko daw magpa-test, magpa-test rin para malaman ko kung nahawa niya ako. Nag-away kami nun, after three days nagpacheck-up ako. (R_037, 35 y/o)


Actually, dati naririnig-rinig ko na ‘yan eh [pause]. Hindi naman ako yung... ay magpatest ako kasi alam ko naman wala ako eh. Nag-kaya lang naman ako nagpa-test niyan dahil nalaman ko yung ano ko... yung ex ko... si boyfriend ko, positive siya. (R_046, 21 y/o)

However, disclosure was not always easy for some of the participants’ partners. Some of the women had to find out about their partner’s condition from a friend, family or doctor, and only after they were tested.
Delayed HIV testing and diagnosis following onset of symptoms

In general, participants who were not sex workers, OFWs, and pregnant at diagnosis, and those who were not aware of their partner’s status did not see the need to be tested. Only the presentation of symptoms—themselves, their partner’s, or children’s—served as their primary trigger to avail of HIV testing services. This points to delayed diagnoses among women.

The signs and symptoms of opportunistic infections experienced by the women alarmed them a great deal, to the point that they thought that they were going to die.

(Experiences before starting treatment) Opo bale madalas po talaga ako magkaroon ng ubo, lagnatin. Ang big parang yun kasi yung difference ng noon sa, nung dalaga ako na talagang hindi talaga ko po nagkakasakit. Lalo nung nagbuntis po ako dito, yung, bihira po talaga ako magkaroon ng ubo pero nung sa nagbuntis ako sa anak ko, dun talaga nagstart na ang bilis ko talaga kapitan ng ubo, sipon, tas lalagnatin po. Tas parang yung trangkaso ko umaabot talaga siya ng one week. Ganun po. (R_002, 28 y/o)

For others, only when their children started getting critically ill were they offered an HIV test.

(Referring to child) Inuubo nga yun ma’am, alam nyo — ‘yung time na ano siya... parang hindi naman sa fifty-fifty pero pwede sa ganon. ‘Dun ko lang po kasi talaga nalaman ‘yun, kung hindi pa na-confine yung anak ko hindi ko pa malalaman kaya salamat sa anak ko. (R_041, 29 y/o)

Anak ko po namatay po siya ng 2016 so dun po kami, dun po namin nalaman lahat na may ganon po kami [crosstalk] So ngayon po nagpa-check up po ako na [pause] sa akin din po pala nakuha ng baby ko [Interviewer: uuhm] nahawa po kami sa asawa ko po [crosstalk] [pause] ‘yun po (R_018, 30 y/o)
For others still, they only considered testing only after their partner showed signs and symptoms of poor immunity.

Uh, nagsimula po dahil po sa ano po, uh, nagkasakit din po yung asawa ko. Then, dun ko po nalaman na nag-positive siya then nagpa-test din po ako para malaman ko rin po na, kung nag-positive o nag-negative din po ako. (R_005, 42 y/o)

(Referring to partner) Nung nagkasakit po siya... na ayaw umalis ng mga lagnat niya, nagka-impleksyon na po siya sa dugo. Tapos po nung lampapit na po sila dito, nag-positive po siya. (R_029, 19 y/o)

(Referring to partner) Oo mga ganon... nagkaroon siya ng pneumonia. [pause] Tapos 'non... tuloy-tuloy... tuloy-tuloy lang yung gamot tapos... dahil ako nga 'yung kasama niya... ini-screening siya... for HIV. (R_046, 21 y/o)

III. Reaction towards diagnosis

The participants’ HIV diagnoses elicited generally negative reactions. They struggled with making sense of their positive test and what this says about them and their behavior. Participants were shocked about their HIV status and hoped their results were wrong.

Syempre po [pause] yung... ano [pause] na... gulat [pause] bakit sa dinadami ng tao is... ako pa [pause] tapos [pause] naging hopeless na po. (R_035, 30 y/o)

‘Yun ang hindi ko matanggap na... ‘yung hindi ko kasi ine-expect na darating ako sa... ano... sa sitwasyon na ganito. (R_019, 32 y/o)


HIV diagnosis weighed heavily on most of the women, bringing them to think of ending their lives.


Naisip ko that time nung sa loob pa lang ako ng (ospital) ko na magpasagasa sa tren. That time. Gustong gusto ko talaga that time. (R_039, 28 y/o)
These struggles draw mainly from three themes identified from the interviews: fear of abandoning one’s responsibility as a mother or carer, dissonance over their “unwarranted” infection, and regret over their choice of partner.

A. Fear of abandoning one’s responsibility

Central to the hopelessness and fear the women felt was their concern for the families for whom they feel responsible. They knew HIV would have great repercussions on their family’s lives, and with the misconception that having HIV meant that they were dying, some lost the will to live or work.

Parang, kinuha agad ‘yung buhay ko nang walang kalaban-laban. ‘Yun po yung naisip ko. (R_038, 19 y/o)

Nalungkot kasi siyempre kala ko end of the world na. ‘Di ba parang ganun naman talaga eh. Na nalungkot ako kasi iniisip ko yung anak ko, yung pamilya ko, yung umaasa sa ‘kin. (R_032, 32 y/o)

Paano po ‘yung buhay naman lalo na may anak ako. ‘Yung maiiwan ko po, kasi akala ko po ‘non kapag may sakit kang ganon... Opo parang sandali na lang ‘yung buhay. (R_042, 30 y/o)

Kasi unang-una nung narinig ko yung sakit ng HIV. Nagcheck ako agad sa internet. Eh nabasa ko na pag meron daw nun, 10 years na lang y-uung a-ano ko buhay ko. Natakot ako para sa sarili ko. Tapos natakot din ako para sa mga anak ko kasi nalaman ko na pati sila positive. (R_034, 31 y/o)

For one participant, these negative feelings were compounded even more by the knowledge that her child was also infected with HIV.

Mayisip ko na lang talaga na magpakamatay, number one. Tas nalaman mo pa yung sa anak mo. Grabe gustong-gusto ko na talagang magpakamatay pero iniisip mo pa rin ‘yung anak mo na pag mawala ka sino mag-aalaga sa kanya. (R_015, 22 y/o)

B. Dissonance over unwarranted infection

Faced with their diagnosis, some participants very much drew from the moralistic stereotype that women with HIV are typically “dirty” sex workers.

Noong una po, na-shock ako. Hindi ko po alam ang gagawin ko... para kasing hindi totoo, parang panaginip lang—Kasi hindi naman ako maruming babae. (R_047, 22 y/o)

Corollary to this would be the idea that HIV is punishment for engaging in such behaviors.
Those who did not engage in sex work and perceived themselves different from the stereotype, found it difficult to grasp why they had to bear the burden of their HIV infection.

C. Regret over their choice of partner

Along with the negative emotions felt by the respondents, they also regretted their relationship with the partner who they perceived as the source of the infection.

D. Acceptance of diagnosis

While tumult and regret characterized this initial stage of the lives as women living with HIV, their feelings changed over time. Women eventually found the strength and hope to continue with life, “tuloy ang buhay, ganun” (R_022, 29 y/o). Again, their responsibility to their families, especially their children drove them on.

(Reaction after diagnosis) Ay– masakit... sobrang sakit [with emphasis] pero kailangan lumaban [para] sa mga bata. (R_028, 40 y/o)
IV. Changes after diagnosis

Incorporating HIV into their identity brings about change to the lives of these women and to the people around them. Four pertinent events or actions were done after diagnosis: disclosure of status, actions to protect self and others, change in the perspective of self, and the experience of stigma and discrimination.

A. Anticipated stigma, disclosure, and support

The process of eventually disclosing their status was very much linked to the negative HIV stereotypes internalized by the participants. Integrating HIV into their new identity thus surfaced feelings of inadequacy and low self-worth. HIV-positive women felt ashamed and judged themselves to be loathsome ("nakakadiri"). These thoughts were further compounded by the stigma they anticipated to receive from others.

Opo. Nalungkot lang po talaga ako pero nilakasan ko po 'yung loob ko. Tapos ano po, lagi po ako nagpi-pray na sana may gamot po ito at sa awa ng Diyos, yung pray ko naman po sa kanya na totoo naman pala na may gamot kaya hindi dapat kinatatakutan at pinandiririhan at bukod sa hindi dapat kinatatakutan at pinandiririhan, hindi po yan basta-basta nakakahawa. (R_005, 42 y/o)

Ano 'yung…. ‘yung ngayon parang ano ‘nung una-una na ano ko parang feeling ko iba ako sa kanila ganyan ‘yung parang ano, nagse-self-pity ako. Ah, medyo bumaba ang self-esteem ko. (R_045, 33 y/o)

Syempre una, kapag sinabing… positive ka iba yung tingin, hindi pa nila tanggap (coughs), nandiyan pa yung pandiri, lalayuan ka ng mga tao. Iba yung tingin nila sa ‘yo. Iba yung magiging… basta lalayuan ka eh. (R_020, 32 y/o)

Yes po, kinabahan sa discrimination sa sasabihin ng ibang tao, sa family ko po kung ano ahhh kung ano po ‘yung iisipin nila sa akin kumbaga ‘yung syempre po ‘yung… judgment nila. (R_018, 30 y/o)


Ayoko na ire-reject nila ako, ayoko na hugusgahan nila ako. Kasi ang pagkakakilala po nila sa akin… ano… matinong tao (baby sound in the background) ganon-ganon. Eh dahil nasabi ko nga po kanina na hindi naman lahat ng tao pare-parehas ng iniisip, merong mga tao na judgmental. (R_019, 32 y/o)
As a result, respondents chose to conceal their HIV status and, in some cases, women opted to isolate themselves from people with the intent of protecting themselves from potential stigma. They were scared of unnecessary talk and gossip, “Baka pag tsismisan pa nila ako” (R_006). But mainly, this seemed to have been driven by the belief that people, even close relations, would see them in a different light, judge them, and fail to understand what they were going through.


Their thoughts spiraled into possible negative consequences for their families specifically, rejection from their partners and the possible dissolution of their families.

Seryoso... ganon 'yung pakiramdam ko. Parang gusto ko nang lamunin ng lupa... kasi hindi ko alam paano ko 'to i-e-explain sa asawa ko... and then... 'yun... 'di ko alam kung tatanggapin niya ba ako... syempre alam ko masisira na yung pamilya namin... kawawa naman 'yung anak ko, yung mga ganan. (R_046, 21 y/o)

Beyond the discrimination they anticipated to receive, they also saw non-disclosure as a means to protect those they love. They were certain that with word getting around, their children might be on the receiving end of discrimination as well.

Para sa anak ko... ayokong maano sila na... ma-bully. Na... in case na kunwari wala na ako... ayokong maging history sa kanila na... ay si ganyan... 'yung mother niya ganyan. Ayoko po ng ganon... (R_016, 26 y/o)

While women reported delaying the disclosure of their status to their partners and trusted people (i.e. family, friends etc), participants reported positive outcomes when they did decide to disclose to their trusted circles. This, they said, improved their self-perception and helped them accept their diagnosis. Family and friends provided much-needed emotional support after they revealed their HIV status.

Niyakap lang nila ako. [shaky voice] Yakap at sabi, “Kaya mo yan. Laban lang.” (R_025, 22 y/o)

Pamilya ko. Pamilya ko lang tumulong sa akin, pati yung partner ko. Tinulungan nila akong maging malakas, maging matatag. (R_015, 22 y/o)

Na-ano lang po nila yung loob ko, pinagaan na ganoon talaga, kailangan tanggapin... na ka-hit anong mangyari nandiyan pa rin po sila. Na nakaalalay pa rin po sa likod ko (R_020, 32 y/o)
Health workers and religious groups also provided emotional support and guidance to the respondent.

_Yung... sa hub naman po, nagti-treat naman po kino-comfort... yun nagko-comfort sa amin kasi nga, yon kasi lalo na kung first time kasi parehas nung first time ko po, as usual iyak ako nang iyak, hindi ko po matanggap kasi wala din akong kaide-ideya. Nagsisimula pa lang ulit ako, nagsisimula pa lang akong mag-research nun about... about HIV. (R_012, 31 y/o)_

_Tsaka si pastor (provided support). Na-ano lang po nila yung loob ko, pinagaan na ganoon talaga, kailangan tanggapin... na kahit anong mangyari nandiyan pa rin po sila. Na nakaalalay pa rin po sa likod ko. (R_020, 32 y/o)_

Despite the indication that awareness on PLHIV support groups was low, those reached by WLHIV support groups were relieved to know that they were not the only women with the condition. Coming from the assumption that they were alone, getting to know people who were going through similar struggles and who understood them (“may karamay”) consoled them.

_Yung pagkakita ko nga po sa kanila (PLHIV group) hindi talagang umiyak po talaga ako kasi sabi ko, ay hindi lang pala ako talaga. Meron pala talagang iba. Kasi feeling ko po talaga that time ako, hala ako lang ata yung ganito kasi wala akong naririnig. Wala. Tapos pagka nags-research ako sa Facebook parang ano, parang puro bi, parang ganun. Parang feeling ko ako lang yata yung nanay na ganito. Tapos yun po. Si— through sa kanila, tas sinali na nga po ako ni nanay sa group ng APWAI. Dun po, parang dun po na ano yung acceptance na ay, wow, hindi pala ko—hindi ko pala dapat na masyadong dibdibin naman pala. Talagang nakatulong din po yung mga support group. (R_002, 28 y/o)_

WLHIV groups helped them in coming to terms with living with HIV.

_Tinulungan akong mas, mas tanggapin kung ano man yung naging sitwasyon. (R_031, 27 y/o)_

It was, for them, a misstep, which they struggled to overcome. But support groups greatly facilitated this process of getting up and moving on with their lives ahead of them.

_Tinulungan akong bumangon. At saka andiy an man, hindi naman nawawala yung suporta. (R_031, 27 y/o)_

_B. Proactive steps to protect oneself and others_

Post-diagnosis, participants often reported behaviors that were often oriented towards protecting people from their perceived consequences of their HIV status. It is telling that the
responsibility and concern they felt for their families and their partner served as the primary motivation for taking proactive steps to take care of themselves. They adopted a healthier lifestyle and practiced protected or less frequent sexual intercourse. They also encouraged their children or partner to get tested for HIV and educated others on how to protect themselves from HIV.

**Taking care of oneself**

Participants verbalized that they practiced healthier eating habits, followed doctor’s orders, removed or lessened vices, and were cautious about everything they did to strengthen their immunity and prevent further complications of HIV.

> Nung newly diagnosed ako syempre 26 na ako... cautious ako sa mga... kinakain ko tapos nag-iwas ako... 'yun nga nag-iwas ako sa vices ko... [K]umbaga sumusunod ako sa ano ko sa routine na para at least... mapalakas ko 'yung resistansya ko. (R_045, 33 y/o)

Alongside these proactive steps the women took was their need for information. However, they reported that while they actively sought information, these were not often readily available. Central to their concerns were basic questions around transmission and treatment, death and how much time they had left, as well as how to get their lives back to normal. Some of them relied on online information to gather answers to their queries about HIV.

> Kung saan ko siya (HIV) nakuha? Tapos ilang taon ba yung ano... yung itatagal ko bilang HIV patient? May gamot ba? Yun yung mga gusto kong malaman, tsaka kung paano ko mahahawa yung aking mga... kung mahahawa ko ba yung aking family, yung aking asawa, o anak. Kung mata-transfer ko ba yung sakit na 'yon? (R_019, 32 y/o)

>> [M]arami pa po, marami pa po akong gustong malaman. Kung paano ako mamumuhay ng normal... (R_047, 22 y/o)

**Managing their perceived risk to partners**

The need for safer sex became more salient with the participants' post-diagnosis. The fear of infecting their partner is an important consideration for them and this translated to behavioral adjustments that include abstinence, reduction of sexual contact, and the use of condoms.
Notably, some participants were already aware of the idea of undetectability. If it were up to them to decide, they would opt to delay sex until after their viral load level is undetectable. Indeed, they refused to have sex on occasion, but as with condom use prior to their diagnosis, negotiating this may not always end in their favor.

*Taking care of others: HIV testing and information*

Apart from changes in their behavior, they also ensured the safety and protection of their partner and family from HIV and encouraged them to get tested for HIV.

Further efforts to protect others include increasing their awareness on HIV. Respondents had the desire to educate others, correct their misconceptions, and provide advice on how they can protect themselves from HIV.
In providing advice and information to people in their immediate circles, some women inevitably drew from their experience and their understanding of how they contracted HIV. These were often colored with the same doubts and fears that they had to manage. But more importantly, their advice often fell back on the moralistic, sometimes sex-negative ideas (i.e. sex before marriage increases your risk to HIV) that they likely heard from others.

**C. Experience of stigma and discrimination**

Participants later found that their fear of being on the receiving end of stigma were warranted. Misconceptions on the transmission of HIV heavily fueled these stigmatizing attitudes. People who were aware of their status maltreated and humiliated them and even their relatives.

“Baka mahawa ‘yung mga apo ko sa ‘yo.” Pati yung pamangkin ko sinasabihan, “Pag kakain ‘yang mga ‘yan, wag ninyong sasaluhin”. (R_034, 31 y/o)

They felt acquaintances slowly distancing themselves from them, reinforcing further the feeling of isolation they had to hurdle when they were diagnosed.

Nagulat din sila tapos parang nag-iba din yung pakikitungo nila sa ‘kin [pause] parang... nag-start po sila na lumayo [pause] hindi na po nila akong masyadong... kinakausap tapos parang... nandidiri na sila sa ‘kin [pause] ganon po [pause] tapos dini-discriminate nila [crosstalk]. (R_035, 30 y/o)

Their experience of discrimination was not limited to acquaintances but close relations as well. Disclosure to some relatives resulted in discrimination within the household, with relatives segregating things used by one participant so as to avoid contracting HIV.
V. Initiation and adherence to treatment

The decision to start and stay on HIV treatment appeared to be a confluence of intrinsic motivations to survive, social facilitation from family, friends, and health providers, and responsive services. The positive impact of HIV treatment was not lost on the participants of the study. The women clearly were versed in the biomedical discourse around treatment, echoing not only the life-saving function of ART but even that of treatment as prevention. But the women attest to the facilitative role of supportive social networks and service providers as well as services that are responsive to their non-biomedical needs.

A. HIV treatment = survival

Survival was the primary motivation of women to access and adhere to treatment. They knew that without treatment, they run the risk of further HIV-related complications and even death. They characterized their new lives as WLHIV as a fight they decide to wage, a condition that they have control over. They chose to take action—because letting HIV take their life was not an option.

*Ano, naggamot ako para—para gumaling ako ganon. Para lumakas ‘yung pangangatawan ko. Hindi ako magpapaapekt sa sakit na ‘yan ganon. Kailangan laban ko yan.* (R_041, 29 y/o)

*Dumating din ako sa point na, iniisip ko na ‘pag hindi ako kumilos, hindi ko siya ginawaran ng or hindi ako mag-research about dito or hindi ko ‘to a-aksyonan, aantayin ko na lang ba yung ano ko [chuckles], pagkamatay ko.* (R_012, 31 y/o)

*Di ako puwedeng mamatay nang ganito lang or hindi ako puwedeng hindi lumaban so ‘yun ‘yung naging ano ko... naging... naging adhikain ko talaga sabi ko hindi ako puwedede mamatay nang ganito lang.* (R_045, 33 y/o)

They also were very much aware of the threat of opportunistic infections. While this obviously is corollary to their need to survive, to succumb to opportunistic infections meant a reversal of their role as carer to receiver of care, which they wanted to avoid.
For most of the respondents who had children, at the core of this need for survival was the recurring theme of continuing to fulfill their nurturing role for their families. The following respondents verbalized that they accessed treatment due to the concern on the family member(s) who will be left behind. These respondents felt the need to be there for their families.

This concern is echoed in a very salient fear of transmitting HIV to their baby, particularly among those who were diagnosed when they were pregnant. Treatment not only protected themselves but their children as well. Starting with treatment was seen as a responsibility to their child.

For the majority of women, the role of family members in encouraging them to start with their HIV treatment and adhere to it was crucial.

B. Supportive social networks

Women highlighted the crucial role of family members in encouraging them to start with their HIV treatment and adhering to it. The HIV treatment literacy of their close relations was a
key element in this. But this obviously required close communication between health providers and the family, specially at the onset.

Para po mapigilan or mabawasan ‘yung virus sa katawan. ‘Yung doktor po then ‘yung magulang ko po (told respondent) na uminom na raw po ako. (R_011, 19 y/o)

Yung parents ko yung nagsabi sa’kin na ano...sabi niya, inumin mo yan kasi...para din naman sa’yo yan, para sa anak mo...kung iinumin mo yan wala namang mawawala sa’yo. (R_017, 22 y/o)

(Referring to conversation with friend) Yun...parehas kaming nag-iyakan tapos sabi niya “Ikaw kumusta ka na? Naggamot ka na?” “Hindi.” “Tanga ka, doon sya...” wag daw akong...wag ko daw hayaan...kasi daw...lalo daw akong mahhirapan. (R_046, 21 y/o)

This can only be nurtured and sustained within an environment of trust, where ART is normalized. For women within such contexts, family members also served as treatment partners who ensured that they consistently took their medications. Women alluded to their treatment adherence as being a shared responsibility of the family.

(Referring to child) pero syempre 11 na siya ngayon ‘di ba. [interviewer speaking] Kaya siya pa minsan ‘yung nagpapaalala sa ‘kin na, “Ma, yung gamot mo.” (R_003, 31 y/o)

Yun, asawa ko din. Asawa ko lang rin yung nagtulong sa ‘kin [in taking ARV]. (R_039, 28 y/o)

C. Responsive services received

While motivation, whether intrinsic or extrinsic, heavily shaped the decision to avail of services, the women interviewed for this study underscored the equal importance of responsive services. Cost and quality were central considerations particularly to their ART adherence. Free ART and subsidized medical services (e.g. laboratory tests) provided by the government through Philhealth, access to financial support from the Department of Social Welfare and Development (DSWD), and their positive experience with accommodating and supportive health care workers, were just some of the factors raised by the women. It is critical to note how important it is for women to feel safe in service delivery points:

Okay naman po kasi sila doktora ma’am... mabait... ‘yung mga staff doon. Okay naman... feel ko na safe ako. (R_046, 21 y/o)
VI. Hindering factors in accessing treatment and struggles in adherence

Data from the HARP in the last three years (2017-2019) show that women take longer to be initiated into ART (median number of days from diagnosis to treatment initiation: 45 days) than men (median: 39 days). For women in this study, knowing where to go for treatment did not necessarily translate to timelier ART initiation. Readiness to start, concerns with side effects, pill burden and issues in accessing services were the main reasons they identified for not being able to start treatment immediately and in some cases, not being able to stay on their HIV medication.

A. Readiness to start medications

Central to the reasons for the delay in treatment initiation experienced by women in this study was their emotional readiness to accept their condition and their need for daily medication. For many of the respondents, they were still in shock and in denial about their condition. Moreover, not only did they have to deal with the negative feelings brought about by their diagnosis, they also had to come to terms with their need to commit to lifelong treatment. Secondly, physical readiness was one of the highlighted reasons for the delay in starting treatment. Particularly those who were diagnosed late, treating their opportunistic infections (e.g. pneumonia) had to be done before they were started on their HIV treatment. And lastly, financial readiness affected their access to medications. While treatment itself is free, indirect treatment costs like those for transportation and completion of their laboratory requirements to start treatment were often a burden to the women.

Despite the recently passed adopted policy on same-day initiation, the women in this study surfaced the emotional burden of having to start with HIV treatment. Starting treatment required mental preparation but this decision is also heavily shaped by the extent to which they have accepted their diagnosis. To start with HIV treatment is to want to live. But for most of them, it took them some time before they reached this headspace. Unfortunately for some of them, only the onset of opportunistic infections made them realize how important HIV treatment is.

*Uh, ano pa ‘ko nun eh, parang hindi pa po ‘ko, syempre parang ‘di pa po kasi ako makapaniwala noon. So hindi ko po agad naasikaso yung gamot ko—yung gamutan ko noon.* (R_004, 24 y/o)

*Ayun nga po, in denial. Hinintay ko pa na magkaroon ako ng pneumonia bago... bago talaga ma... mappagamot ako. Kasi hindi ko pa talaga tanggap dati, parang isinawalang bahala ko muna na baka mali lang.* (R_020, 32 y/o)
The prospect of life-long treatment also daunted the women in this study. Concerned that one cannot skip or stop taking the medications once one starts, some of them opted to start later. One participant in particular struggled with the idea of having to comply with taking ARV on a daily basis while another respondent verbalized her concern on daily compliance, knowing how forgetful she is.

For some who delayed their ART, their health providers had to treat their opportunistic infections first.

The financial burden of having to go to the facility as well as paying for the required laboratory tests also contributed to the delay in treatment initiation. As such, some participants had to borrow or save money first. Despite Philhealth coverage for some of the laboratory tests through the Outpatients HIV/AIDS Treatment (OHAT) package, this option was not always readily available to some of the women because of incomplete monthly contributions.
Concerns on ARVs and experience of side effects

Another factor that affected treatment initiation and adherence among these women is related to the anticipated side effects of the medications. Some were uncertain as to whether the medications would really reduce HIV transmission.

Ahm ano... nung time na 'yon ano halo-halo medyo ano ako ah ano 'yung magiging kahihinatnan sa'kin kung magworry work ba sa... 'yun 'yung worried ako nung time na 'yon... magwo-work out ba 'to or baka mamaya baka 'di mag-work out ano magiging ano ahm magiging response ng katawan ko sa gamot 'yun yung unang pumasok sa isip ko. (R_045, 33 y/o)

Nung malaman ko... [pause] nagdadalawang isip. Yun yung una, dalawang isip kung anong makakareulta. Baka hindi maganda yung resulta kasi nga maraming side effects di ba? Yung inorient kami. Yung sinasabi na yung, yung mga facts ba. May times na hindi ano sa katawan, baka hindi matanggap ng katawan mo ganito. (R_001, 29 y/o)

For respondents who had started treatment, almost all of them verbalized that they had difficulty adjusting to the medications as the side effects affected their daily routines (e.g. work, sleep, etc). One of the respondents was tempted to stop medications due to difficulty experienced from the side effects.

Tas parang gusto ko na siyang itigil. Kasi nga nahihirapan ang katawan ko na pag-inom-inom ng gamot eh. (R_015, 22 y/o)

Despite these negative experiences, they continued to take ARVs and were able to successfully adjust as their bodies have adapted to the medications after some time.

Opo. Kasi kapag ininom ko 'yon... nahihilo, nasusuka... hindi ko po talaga kayang tumayo, pero... wala naman po syang naging... rashes sa'kin. Ano po yon... mga... kalahating buwan din po akong ganon, sa gamot. Hanggang sa nasanay na po 'yung katawan ko. (R_017, 22 y/o)
C. Pill burden

Some women also struggled with pill burden. Respondents found it difficult to take the medications because they had to take their ARVs everyday, some pills were too big, and the formulation required them to take multiple tablets/pills. Having multiple pills in their ARV regimen was even worse for those with opportunistic infections that had to be managed. As a result, some respondents had to prioritize one condition before the other. The following responses highlight the struggles about taking the ARVs daily:

*Nakakapagod, lalo na pag-inom araw-araw... Nakakasawa.* (R_009, 36 y/o)

*Wala po, nakakasawa lang uminom ng gamot. Ang laki kasi.* (R_019, 32 y/o)

*Yung lang mahirap lang talaga minsan uminom ng gamot kasi ako twice a day eh. Minsan naisip ko... kasi nga dahil sa trabaho nakakatulog, nakakalimutan.* (R_020, 32 y/o)

D. Facility issues

Women verbalized the difficulty in accessing the treatment services. Concerns on the laboratory requirements or processes and struggle to get medication arose. Before accessing the medications, women were required to complete the laboratory test requirements and processes of the facility. This in turn has contributed to the delay in starting treatment. Moreover, narratives from these women highlighted that they found it inconvenient to go through traffic, go back to the treatment facility, and wait in long queue lines every time to get their medication. These women verbalized that they would need to allot a day every week or every month just to get their medications and would repeat this process again during their next pick-up or visit. Issues in the limited number of pills provided by the treatment facility also arose.

Women described the need to complete the laboratory tests before accessing treatment in these excerpts:
The following respondents expressed the difficulty and inconvenience experienced on the need to go back to the treatment facility:

**Reason for delay in starting treatment**

Kasi bago ka bigyan ng gayung gamot, i-ano po kayo, lahat ng laboratory mo kailangan maging ok. Tapos, ico-counselling ka po, ico-counselling pa po. Bago po kayo bigyan kailangan may alam kayo kung pa’no niyo gamitin ‘yung isang gamot. (R_005, 42 y/o)

Kailangan po na kumpleto yung mga test bago ako pinainom ng gamot. Merong pang-TB-DOTS, may sa laway, tapos may x-ray... ano pa ba? ... Kailangan pa makita ‘yung mga result ng lab tests. (R_019, 32 y/o)

The following respondents expressed the difficulty and inconvenience experienced on the need to go back to the treatment facility:

**VII. Looking into the future**

The women in the study have described their stories and continued to fight the virus. As someone who went through HIV diagnosis to treatment, they were looking forward to what the future might bring and to share their learnings from their experience.

**A. Bright future for the respondent and her family**

These women were hopeful about their future. They dreamt of a bright future for themselves and their family. They wished to be successful, get married, have children or more children, and finally be cured from HIV.
These women were aspiring for a successful life for themselves and their families. Success for them is determined by financial stability, employment, and the capacity to travel, as verbalized by these respondents.

"Pangarap magkaroon ng sariling bahay. Maging successful sa buhay. Mabigyan ng magandang buhay 'yung mga magulang ko. Makapasyal sa ibang bansa. (R_036, 24 y/o)"

"Pero ang gusto ko, magkaroon din sana ako ng... makapasok na ulit ako sa trabaho, para naman sa pamilya ko, makatulong ako dun sa asawa ko, kasi meron na nga akong baby ngayon na kailangan sustentuhan, pagatasin, kasi bawal naman na sa akin ang breastfeeding. (R_019, 32 y/o)"

For the mothers, they wished for a bright future for their children—which includes having good health, and finishing their studies.

"Plano namin na ano... 'yung... mapag-aral pa 'yung anak ko, mapalaki ko pa sila nang maayos [pause] ganon po tas mabigyan ko pa sila ng magandang buhay [pause] despite of this condition [pause] ganon po. (R_035, 30 y/o)"

"Kahit ganito may sakit ako. Magulang pa rin ako. Andun pa rin yung status na bilang magulang, na sana makapagtapos ng pag-aaral 'yung mga anak ko at makatulong sa mga pamilya nila, pamilya ko. (R_007, 32 y/o)"

Along with the dream to have a better future, is the aspiration to finally be cured from HIV.

The respondents were looking forward to the day when HIV will have a cure.

"Na... opo. 'Di ba? Kasi kapag sinasabi sa 'kin ng doktor na walang cure, ine-experiment pa raw kung may gamot. Sabi ko nga e, sana nga po may gamot diyan. Kasi ako na po 'yung masayang tao kung may gamot. [laughter] (R_041, 29 y/o)"

"Kahit kami na meron, nabubuhayan ng-ng loob kasi may chance na magkaroon kami ng cure. (R_023, 21 y/o)"

**B. Marriage and procreation**

HIV diagnosis has brought changes into the perspective of the respondents regarding relationships and procreation.

Regarding new relationships, women were divided as to those who no longer want to have a new partner, and those who are willing to engage in a new relationship and get married. Some women fear engaging in a sexual intercourse with their partner for fear of transmitting HIV to their partner. Moreover, those who were currently not in a relationship fear...
transmitting HIV to their future partners; hence they were no longer planning to engage in future relationships.

_Naging in denial ako nang sobra nun eh... ‘yon, hindi ko alam ‘yung iisipin parang... kumabaga parang... hindi pwede eh, kasi may asawa ako pero paano kung mahawaan ko siya? Ayon yung lagi kong... kaya lagi kong iniisip, paano kung... pero ‘yun awa ng Diyos, hindi naman. (R_046, 21 y/o)_


For some women, they were still aspiring to get married, provided that their partner will accept them and their condition. It is also important to note that there were respondents who did not want to have a partner during the time of the interview as they would like to focus on themselves. However, they were open on the idea of having a future partner or what the future might bring. One of the respondents verbalized the need to find a partner so as to find someone to spend her life with.

_Ang pinakapangarap ko talaga sa buhay ko is magkaroon ng asawa. [laughter] Kasi alam mo te na-feel ko na [pause] ‘yung kalungkutan talaga is ang hirap labanan. Opo, gusto ko kasi ng kasama sa buhay. Kasi lumaki ako akong mag-isa. Wala kasi ako akong parent, ano kasi eh tawag don. (R_008, 32 y/o)_

Another respondent who plans to get married discussed her intention on disclosing her status to her future partner and hopes that he will accept her.


Regarding procreation, women were both hesitant and willing to have more children. For some, the possibility of transmitting HIV was enough reason to not want more children. Respondents, especially those diagnosed during pregnancy or those who already have children, would rather contain the virus than have their child go through HIV and medications. Also, reflections after diagnosis show that they no longer wished to have more children.
However, there were respondents who were hoping to have children or more children. As women, they believed that bearing a child is one of the milestones that will complete womanhood. There were respondents who would want to bear another child, but only with the assurance that they cannot transmit HIV to their child. Moreover, bearing a child is based on luck or will depend on God’s will.

(Plans on having children) Ahmm... syempre. Kung kukumpleto sa ano... ‘yung sinasabi na kukumpleto sa ano... pagkababae. (R_027, 28 y/o)

(Plans on having more children) Oo naman [laughs]... kung bibigyan ba... why not? syempre sabi naman ng doktor ko eh... puwede pa rin naman daw akong... siguro lakas lang maka-confident na naging undetectable ako. Kasi... may tiwala naman ako sa mga doktor. (R_046, 21 y/o)

Kung hindi, kung makakasigurado na, kung magkakaroon lang ako ng assurance na hindi macocontaminate yung baby, kung maging ok ‘yung lifestyle at ‘yung buhay namin, siguro masusundan pa ‘yung baby namin. Gusto pa rin. (R_039, 28 y/o)

C. Advice to other women

The advice provided by the women in the study to those who do not have HIV were: to protect themselves, to act rationally and not be driven by emotions, and be more knowledgeable on HIV. They believe these are the things that can help prevent them from acquiring HIV.

The most common advice provided by these women is to use protection. They emphasized on the need to learn to use protection and to use condoms during sexual intercourse.

Ano bang tawag ‘don? Ingat talaga ‘yung the best word dyan. ‘Yung safest way is protect, magprotection talaga. (R_021, 28 y/o)
Along with using protection, women were advised to act rationally and not be driven by emotions. They emphasized the importance of knowing your partner and knowing who to trust. It was highlighted that any person can have HIV.

**Matuto silang gumamit. Di porke’t gwapo, go. [laughs]** (R_024, 39 y/o)

Lastly, women were advised to be more aware and knowledgeable about HIV. Increasing knowledge on HIV and how it is prevented and transmitted may inform the HIV-negative women on how to protect themselves from HIV. One of the respondents narrated that she could have avoided HIV if she had known what HIV is.

**D. Advice to women living with HIV**

Other women diagnosed with HIV were encouraged to disregard the negative ideas attached to HIV. They reminded that a woman diagnosed with HIV can live normally and can still continue and enjoy life.
Women diagnosed with HIV were advised to learn to accept their condition. Difficult as it may be, actions toward treatment and management come after acceptance of their diagnosis.

Women living with HIV were reminded that they should start and adhere to their medications. They need to protect themselves so that they can protect others.

Lastly, WLHIV were advised to be optimistic, have faith, and be hopeful despite the condition. Laban lang. As one of the respondents said, “There’s tomorrow after HIV (R_046, 21 y/o).”
DISCUSSION

The study aimed to know the stories of Filipino women diagnosed with HIV. Findings from the qualitative data provided insights into the women’s risks for HIV, the events that led to their testing and diagnosis; and their motivations to access and adhere to their HIV treatment.

Findings from this study need to be framed within the context of the country’s concentrated epidemic among MSM and transgender women. There is no epidemiological data to support that the Philippines is transitioning to a generalized epidemic. However, data from the country’s active and passive HIV surveillance systems point to an elevated risk among a segment of the female population. The December 2018 HIV/AIDS and ART Registry of the Philippines (HARP) indicates that 44% of diagnosed HIV cases were transmitted either through males having sex solely with women (16%), or males who have sex with both men and women (28%).

Meanwhile, among MSM in physical cruising sites, the 2018 IHBSS found that 31% reported having had sex with women in the past 12 months. The discussion of risks and service uptake that follows thus pertains to a mere subset of the country’s female population.

I. Risks for HIV

There is no one “face” of WLHIV that emerged from the stories gathered from this study. Findings from the study illustrate the diverse risks women living with HIV faced prior to their diagnosis. Some belong to key populations (i.e. sex workers) while for others, their HIV exposure was through their intimate partners who were at higher risk (i.e. MSM, male sex workers [MSW], or PWID). In some cases, these partners of key population members were aware of the risks their partners were engaging in—but this was not the case for everyone.

Common general risks were found across the different stories such as the challenges around the use of condoms and the necessary knowledge on HIV that could have protected them. However, the contexts and processes where these risks occurred varied. It is also important to note how abuse and rape were shared by some women.

In the absence of Pre-exposure Prophylaxis (PrEP) interventions in the country during the time of data gathering, HIV prevention among women was very much limited to abstinence,
monogamy, and condom use. Condom use was very much influenced by the type of relationship they had with their partners. In general, married and co-habitating women did not see the need to use condoms as it signifies trust and affection for their partner. Indeed, the perception of being in a safe relationship built on love translates into low perceived risk for HIV as this forms an environment of “trust, commitment, and loyalty” and consequently becomes a barrier to condom use (Lofti et al. 2012; Smith 2004).

Condomless sex was also found to be influenced by the partner’s refusal and the participants’ inability to effectively negotiate condom use. As sexual activities are joint activities, partner’s participation and consent are also critical factors to condom use (Farrington et al. 2016). Thus, the inability to say no to unwanted sex or negotiate condom use serve as barriers to condom use (Lofti et al. 2012). In the Philippines, women have been found to have difficulty with condom use negotiation (Farr & Wilson 2010). This provides a frame with which to understand why despite the knowledge of some women with regard to the risks of their partner, they opt for condomless sex anyway. For female sex workers on the other hand, negotiating condom use is particularly difficult given how condomless sex may translate to increased income. In other settings, suggesting condom use may increase resistance and at times, may escalate to violence (Sarkar 2008).

The experience of sexual abuse also affects the risk of women for HIV and the study documented cases of rape among women interviewed. Forced sex increases the likelihood of contracting HIV due to tears in the vagina or anus that can accelerate disease transmission (Higgins et al. 2010).

Information on HIV prevention and transmission could have informed women on how they could have prevented HIV. However, participants generally felt that they were not equipped with the knowledge to prevent HIV. They had limited to no knowledge on HIV prevention and transmission before they were diagnosed. Narratives from these women are consistent with previous studies noting that HIV is not something commonly discussed about in the community or schools (Junio 2019, in Mirasol 2019). Contributing to this lack of awareness is the lack of motivation to proactively learn more about it.

With a concentrated epidemic mostly affecting Filipino MSM and transgender women (Gohil et al. 2020; Restar et al. 2018), it is unsurprising that HIV was beyond the purview of some of the WLHIV before their diagnosis. Coupled with the sex-negative stigma associated with
HIV (e.g. immorality, promiscuity), it was easy to dismiss HIV as a remote possibility that only affected other people. They did not feel vulnerable to it. The findings thus surface the challenges in reaching female partners of MSM and other key population groups, within a KP-targeted prevention landscape.

Participants of this study acknowledged the need to be educated and to increase their awareness on HIV. They recognize the urgency of better HIV prevention messages around HIV/AIDS and other STIs in general but zeroed in on condom use in particular (Altschuler 2017). There is much taboo around talk of sex in the country, but only through more open discussions and strengthened HIV information campaigns especially among the youth can misconceptions be dispelled. Additionally, women should be trained on empowerment and condom negotiation. Evidence shows that women who were confident and had the capability to negotiate condom use with their partner were more likely protected from acquiring STI, HIV and unintended pregnancies (Exavery et al. 2012). Apart from using condoms, participants pointed out the unwieldy role of trust especially in the context of monogamous relationships. Being in a relationship does not remove the risk of HIV (Leslie 2019).

II. Testing

The circumstances surrounding the diagnosis of the participants reflect the country’s intensified key population-focused HIV programs. Secondary analysis of national demographic health survey data from 2013 underscores the need to promote HIV testing among women as only 2% of Filipino women ever had an HIV test (Pepito & Newton 2020). Under the Philippine HIV and AIDS Policy Act (RA 11166), health care providers offer HIV testing to clients practicing high-risk behaviors or to persons vulnerable to HIV. Provider-initiated counseling and testing (PICT) is offered to the following: clients practicing high-risk behaviors (e.g. having multiple sex partners, injecting drugs, having a history of STI, having a partner with multiple sex partners), those assessed for STI, pregnant women, people accessing community-based services, TB patients, patients showing signs and symptoms consistent with HIV, and children born to HIV-infected mothers. Demand generation for testing uptake is also in place for female sex workers and OFWs. Findings from the study show that a segment of WLHIV was not testing-naïve prior to their diagnosis as they were reached with PICT and other demand generation activities for testing.
Despite the gains just described, some women in need of testing were not reached by services in a timely manner. Testing strategies and messages need to be cognizant that some of these women may not acknowledge or recognize their risks. Indeed, despite knowingly engaging in certain risk behaviors, some women did not see the need to get tested, which speaks directly to the remoteness of HIV to their lived experience discussed earlier. For others, either they were completely unaware of the risks their intimate partners were engaging in or this wasn’t explicitly discussed given taboos surrounding the behaviors (e.g. male-to-male sex).

Consistent with findings elsewhere (Oraby & Abdel-Tawab 2016), a segment of WLHIV interviewed for this study became aware of their own status only upon the diagnosis and disclosure of their intimate partner. This is generally facilitated by current testing protocols wherein HIV-diagnosed clients are advised to encourage their partners to get tested. To a certain extent, there is a trickle-down effect of heightened testing among men to exposed women, especially those who belong to key population groups (e.g. MSM) and other vulnerable groups (e.g. OFW, TB patients, husband with multiple sex partners).

However, the effectiveness of such protocols has to contend with the difficulty of disclosing one’s HIV status even to intimate partners. This difficulty appears to be rooted in the inadequate HIV treatment literacy diagnosed clients have, the mental health issues that arise following diagnosis, and the pervasive stigma around HIV in general. As a result, women who were unaware of their exposure through their partners and were thus blind to their own vulnerability, often found themselves in the dark with regard to their own HIV status. For others still, testing only became necessary when they—or their intimate partners or children—already had opportunistic infections. Such late diagnoses pose a challenge to craft ways to effectively reach women of similar profiles much earlier and encourage them to go for HIV testing. Late diagnoses present missed opportunities for treatment and prevention and increases financial burden not only to the client but to the health system as well.

III. Treatment initiation and adherence

Actions toward HIV treatment and management after diagnosis depend on the readiness (Lundgre 2006) and acceptance of the respondent of her condition (Horter, et al. 2017; Kutnick et al. 2017). Consistent with the results of numerous studies, women had difficulty
accepting their HIV diagnosis. Women initially experience fear, shock, despair, and had suicidal thoughts after being diagnosed with HIV (Wekesa & Coast 2013; Oraby & Abdel-Tawab 2016; Kutnick et al. 2017; Horter et al. 2017). Although the initial emotions towards diagnosis did change with time, this duration varied per respondent and in turn, delayed treatment access. Aside from mental readiness and acceptance of diagnosis, the need to be physically prepared also affects treatment initiation. Additionally, these women would have to cope with the additional pill burden for the other present conditions which can lead to selective treatment (Abdool Karim et al. 2010).

Another concern affecting access and adherence to treatment is the fear of ARVs. Respondents were hesitant to take medications before initiating treatment due to concerns about effectiveness and the possibility of experiencing side effects. This fear was further verified as they physically experienced these side effects. As they took treatment, majority of the women experienced gastrointestinal symptoms (e.g. nausea and vomiting) and central nervous system side effects (e.g. dizziness, headache, vivid dreams). The inconvenience brought about by the treatment has interfered with their daily lives and quality of sleep. Although majority of the respondents were still on ARV during the interview, they struggled with adjusting to the effects of their medications early on treatment. Moreover, respondents also experienced pill fatigue and expressed difficulty in drinking multiple and large medications daily. Many studies found that experience of side effects and high pill burden are the reason for non-adherence (Croome et al. 2017; Fonsah et al. 2017; Phillips et al. 2016; Kim et al. 2016; Duran et al. 2001). Along with the fear and experience of side effects is the fear of committing to lifelong treatment. The prospect of having to take their ARVs for the rest of their lives was daunting for the WLHIV participants of the study, similar with findings elsewhere (Glendinning et al. 2019). Although treatment facilities have ART counseling services in place, findings point to the need to revisit these and determine how effective they are in assuaging reservations and fears clients may have. Services need to be able to draw out emerging concerns and address these before initiating treatment (Glendinning et al. 2019). These also need to be able to provide support for the management of side effects during follow-up visits (Phillips et al. 2016). An effective relationship with women and their health care providers may prove to be beneficial to resolve issues concerning ARVs.

Additionally, facility and service-related issues affect access to treatment. Women who experienced difficulty accessing medical care and services may negatively impact
adherence to their medications and follow-up visits (Boileau et al. 2008 in Logerenberg et al. 2015). Issues relating to ARV refilling (i.e. issues in drug supply, waiting time at facility, long distance to facility, and ability to get to clinic due to work constraints) are barriers to ART adherence (Croome et al. 2017). All of these were articulated by the respondents in the study. Respondents experienced accessing limited pills due to shortage of supply at the facility, long waiting lines, the traffic and distance of the facility to their homes, and the availability of the respondent to refill her medications. Efforts in looking for alternative ARV distribution methods to these women would relieve them of the inconveniences and difficulties they experienced in refilling their ARV supply.

The women from this study are a testament to how WLHIV are able to overcome the barriers to and struggles with starting and staying on treatment. Their desire to fight and live longer provided an overarching theme that cut across motivations for accessing and adhering to ART services. As described earlier, some of them already had opportunistic infections before diagnosis and treatment initiation. Accessing treatment thus meant improving their health status, being relieved from the discomfort experienced from these infections, and preventing further complications.

Previous investigations focus mainly on underlying health-related reasons as to why this is so. For instance, women have been found to have more pronounced health-seeking behaviors and desire to improve their situation, that may lead to accessing treatment (Bila & Ergot 2009). Moreover, the perceived transformation from being “sick” to “well” after taking ARVs encourage adherence to treatment (Logerenberg et al. 2019; Croome et al. 2017). It is worth noting that the finding on better health-seeking runs contrary to the general poorer outcomes among Filipino WLHIV.

It is here where local gender roles and norms become important considerations. As majority of the respondents were mothers, they feared for the future of their children without them. Death was therefore not an option. Their responses emphasized their internalized role as carers—for their children and other family members. This drove the decision to start and stay on treatment. Indeed, in developing countries, the primary caregiver and breadwinner role that women play within the family structure was associated with adherence to their medications (Cambiano et al. 2013; Barth et al. 2008 in Moosa et. al 2019). Related to this, pregnant WLHIV feared passing on the virus to their children and being informed of the preventive function of ART for their children buttressed their decision to start with treatment.
Indeed, in other settings, women felt “more responsibility, sensitivity and concern regarding the transmission of the disease”, and as such took actions to prevent transmission (Barkish et al. 2019). Since majority of the motivations of these women include their family, counseling and strategies involving the family in treatment may be taken into consideration.

This study also reflects the importance and effect of social support in accessing and adhering to treatment. Numerous studies have highlighted the key role of social support to treatment initiation and adherence (Van Loggerenberg et al. 2015; Croome et.al 2017, Horter et. al 2017). In this study, family, friends, and social groups encouraged these women to accept their diagnosis, to access treatment, and to continue or remind them to take their medications. Support from social groups or PLHIV communities have also been seen beneficial as these women felt that they were not alone in battling HIV. Women who were members of specific support groups transitioned effectively in accepting HIV, as these collectives provided affirmation, emotional support, and knowledge on how to manage HIV better (Kako & Stevens 2011). Awareness on PLHIV groups among the respondents in this study is limited as only a few were aware or were reached out by the PLHIV groups. As such, much is to be gained from increasing women’s awareness on WLHIV support groups.

Moreover, women shared their experiences on the services provided by the treatment facility. Provision of emotional support and alleviation of fears on HIV and treatment has created a supportive and caring environment. Many of the respondents continued treatment because they were satisfied with the service and support received from the health care workers. An approachable and supportive healthcare environment enhances the likelihood that participants will be retained in care (Logerenber et al. 2015; Croome et al. 2017). In light of these findings, client-centeredness will be key to ensure that services continue to remain responsive to the needs of women. Sensitivity to their varying backgrounds and the different approaches and messages they will require will be critical toward this end.

Finally, the financial burden experienced by women is also central to starting and keeping them on HIV treatment. Financial assistance through grant or livelihood support and free ART treatment are facilitators to adherence (Croome et al. 2017). Majority of the participants were able to access free HIV treatment and financial assistance from government offices. However, despite these different forms of assistance, some participants in the study still felt the financial burden in completing the necessary laboratory tests and adherence counseling sessions.
IV. Reproductive health and WLHIV

Being diagnosed with HIV affected their views toward relationships and procreation. Views on finding new partners, marriage, and having children varied. Some of the women were now hesitant to have children consistent with a study elsewhere (Snow et al. 2013). While there were concerns about the economic burden of raising a child, the persistent fear of transmitting HIV generally underpinned this view, regardless of the women’s viral load status.

That being said, others maintained the hope to have more children one day, despite the fear of transmitting HIV. Previous studies among WLHIV had similar findings, illustrating how central motherhood is to some HIV-positive women (Alvarez-del Arco et al. 2018). This is said to be anchored on the held belief that having a child completes womanhood. Awareness on the Undetectable=Untransmittable (U=U) unsurprisingly shaped this view. Knowing that HIV treatment works allowed them to feel hopeful to one day have children. This points to the need for improved guidance and counseling on reproductive options for WLHIV.

V. Stigma and discrimination

This study will be remiss without a discussion of stigma and discrimination. Stigma was a consistent thread running through the different themes captured in this study, palpable in the different stories the women shared. Stigma figured in how the women found themselves in risk situations, in how they had to struggle with their diagnosis and treatment initiation, and in living with HIV everyday.

The local stereotypes on WLHIV (i.e. promiscuous women, sex workers) were not lost on the participants and most of them subscribed to such beliefs prior to their diagnosis. Indeed, actual engagement in paid sex does not determine people’s views about HIV-positive women (Chan et al. 2009). It’s almost automatic for people to assume that WLHIV are immoral and engaged in sex with multiple partners and behaved irresponsibly (Lopez et al. 2017; Carr & Gramling 2004). Such stereotypes, as the findings show, render the risk to HIV as a distant possibility because it is easy to draw clear lines differentiating oneself from those who can contract it. These stereotypes also fueled the denial a lot of the women faced upon learning about their HIV status which had repercussions on the service uptake.
Upon diagnosis, anticipated stigma heavily influenced the treatment trajectory of the women interviewed for this study. Internalized negative notions about HIV and expected negative reactions from other people prevented them from immediately seeking help. As with other studies (Carr & Gramling 2004), stigma led to shifts in their self-perception and selective disclosure, and self-isolation among the WLHIV interviewed. They anchored this on the notion that this is a protective strategy that insulates them from discrimination from other people.

The study also captured concrete instances of discrimination the women had to face following their diagnosis, showing that the fear and anxiety they had at the onset were warranted. Misconceptions persist in the general population and these often prevent more affirming and accepting interactions between WLHIV in this study and those around them. These unfortunately have great implications on the mental health of WLHIV. Findings thus point to how critical mental health programs are to PLHIV interventions. But at the same time, they also underscore the need for client-centeredness. Programs need to be responsive to WLHIV-specific fears and concerns.
CONCLUSION & RECOMMENDATIONS

Through the rich narratives of women living with HIV, this study shed light on the circumstances of their HIV infection, the changes brought about by their HIV diagnosis, and the struggles they had to overcome both in relation to the biomedical and psychosocial aspects of their condition. The accounts put human faces to the numbers and statistics, which are often dwarfed by the sheer number of men in the country’s MSM-concentrated epidemic. In turn, their stories provide a sense of how existing systems and services can better serve their needs.

I. Risk for HIV

The study identified different profiles of risk among women. Women belonging to key populations like sex workers, knowingly engage in risks which are very much tied to economic needs. With this awareness comes an acknowledgment of their need to avail of services, too. For others, recognizing and mitigating the risk are made difficult by taboos around sex. These women are thus often naïve to essential HIV information and services. While condomless sex and a reduced ability to negotiate condom use are common to both these groups of women, their underlying reasons for opting not to use condoms vary.

Cognizant of these different risk profiles, tailored approaches to reach women will be necessary. Efforts to empower and encourage women to use condoms and to provide them with skills to negotiate condom use during sexual intercourse also need to take into account the different contexts women find themselves in. Women also stand to benefit from an enhanced general population information campaign that incorporates the most recent science around prevention (i.e. PrEP) and treatment (i.e. Prevention of mother-to-child transmission [PMTCT], basic ART literacy, U=U).

II. Testing

Women have benefited from the country’s scaled-up testing efforts. Routine testing among sex workers and pregnant women, and provider-initiated counseling and testing (PICT) among symptomatic individuals are just some of the means through which most of the women in the study were reached with HIV testing. To a lesser extent, the increase in testing and diagnosis among males facilitated case detection among women following the disclosure of the male index case. However, testing and diagnosis is affected by the same
low perceived risk described above. As a result, late diagnosis is common among women. This introduces unnecessary complications brought about by opportunistic infections.

Two main recommendations are forwarded to improve HIV testing and case detection among women. First is to improve case finding among women in general through PICT not only among pregnant and those who experienced STI, but as well as to women who are sexually active. Second is an enhanced partner notification that provides clients — particularly MSM with female partners — the tools to properly disclose to their partners will provide an avenue to reach more undiagnosed WLHIV.

III. Treatment initiation and adherence
One’s readiness to accept one’s HIV status, treatment literacy, and experience in accessing services influence women’s decision to start and stay on treatment. Readiness span emotional, psychological, physical, and financial considerations. It is for this reason that social support post-diagnosis from the health facility and the immediate social network is critical. Treatment literacy, the preconceived fears on the effect of the medications (e.g. response, ability to address symptoms, side effects), and the need to commit to lifelong treatment immediately after diagnosis are but some of the considerations that were found to delay treatment initiation.

Addressing the issues identified will entail a review of treatment counseling provided to women. Evidence- and rights-based advice on reproductive health and childbearing are but some of the necessary women-specific input participants in the study articulated. Guidance must also be strengthened to assuage concerns and fears with regard to treatment. A shift to better treatment regimens with less side effects, and better formulations to reduce pill burden will be beneficial for these women and reduce falling out of treatment. Providing better mechanisms to access financial assistance can expedite barriers to timely initiation. Addressing challenges to convenient refilling through more access points and multi-month dispensing can also prevent loss to follow-up.
IV. Aspirations

Aspirations on having a partner, getting married, and having a child or more children are greatly hindered by women's fear of transmitting HIV to their partners and children. Hesitancies surrounding these future endeavors are also brought up by fear of not being accepted by their partner. Moreover, worry for the baby, especially on having the need for early medication, surpass the desire for having more children.

Alleviating fear, worry, and hesitation of a WLHIV to bear a child may be a complex process. Strengthening and scaling-up of PMTCT services, especially on raising awareness on the availability of these services, may greatly benefit WLHIV in their pursuit of future plans of having children. With these, there may be a need to develop, review, or refine existing programs and policies on maternal and child health, and possible inclusion of HIV in the Philhealth maternity care package. Aside from counselling, antiretroviral medication, advice from a medical expert, and assurance of safe pregnancy, delivery, and post-partum: support from partner, significant others, and peers, may enormously help WLHIV to transition on accepting the role of child-bearing and parenting.

V. Stigma, discrimination, and support

Most of the women in the study were able to overcome the struggles and difficulties they encountered and were adherent to their medications at the time of data gathering. This outcome appears to be a result of a personal desire to fight, complemented by the emotional support received from family, friends, and loved ones. Central to the identities of the WLHIV in this study was their role as carer and in a lot of ways, this pushed them on. WLHIV or PLHIV support groups also played a significant role in the accounts of some of the women. The assistance provided by the support groups not only helped them navigate an unfamiliar system but also offered psychosocial support during emotionally trying times.

We end this report by highlighting how stigma and discrimination cut across the experiences of women across the HIV care cascade. Stigma, whether actual, perceived, or internalized, impacts not only women’s HIV cascade outcomes but also contributes to feelings of shame, guilt, and social withdrawal thereby affecting the general well-being of women living with HIV. This primarily prevents them from optimizing the benefits of living a healthy and satisfying life.
Considering that the country’s current policy related to HIV discrimination is in place, monitoring of stigma-related incidence must be reinforced. This will help measure the country’s effort on lessening public stigma. Addressing stigma would entail numerous strategies and partnership with relevant government and civil society groups to raise awareness on HIV in the schools, workplace, and the community.

As a summary, findings from the narratives of the women in this study suggest that there is a need for the HIV programs across the different levels of implementation to shift from a biomedical lens to a more holistic approach—taking into consideration the personal, socio-cultural, economic, and structural factors in addressing the challenges women face in accessing HIV services and in ultimately, living normal and healthy lives.
REFERENCES


Website

## APPENDIX

### A. Demographic characteristics of respondents by region

**Region 3 respondents**

<table>
<thead>
<tr>
<th>Year diagnosed</th>
<th>Age</th>
<th>No. of months before ART initiation</th>
<th>Civil status</th>
<th>Educational attainment</th>
<th>With children</th>
<th>Employed</th>
</tr>
</thead>
<tbody>
<tr>
<td>2017</td>
<td>19</td>
<td>2 months</td>
<td>Single/ Live-in</td>
<td>High school graduate</td>
<td>With children</td>
<td>Unemployed</td>
</tr>
<tr>
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<td>21</td>
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<td>With children</td>
<td>Unemployed</td>
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<td>Unemployed</td>
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**Region 4A respondents**

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<th>Civil status</th>
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## NCR respondents

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<td>36</td>
<td>1 month</td>
<td>Married</td>
<td>College level</td>
<td>With children</td>
<td>Unemployed</td>
</tr>
<tr>
<td>2016</td>
<td>37</td>
<td>2 months</td>
<td>Single/ Live-in</td>
<td>College level</td>
<td>With children</td>
<td>Unemployed</td>
</tr>
<tr>
<td>2018</td>
<td>42</td>
<td>4 months</td>
<td>Single/ Live-in</td>
<td>High school level</td>
<td>With children</td>
<td>Unemployed</td>
</tr>
<tr>
<td>2016</td>
<td>48</td>
<td>1 month</td>
<td>Single/ Live-in</td>
<td>High school level</td>
<td>With children</td>
<td>Unemployed</td>
</tr>
</tbody>
</table>
### B. Interview guide

**a. Bago magsimula ang interbyu siguraduhin ang mga sumusunod:**

- Matahimik at walang distraksyon sa inyong lugar
- Nasagutan ng respondent ang demographic sheet
- Siguraduhin na ang respondent ay edad 18 years old pataas at na-diagnose noong 2016 to 2018, puwede ito makita sa demographic sheet
- Nabasa, naintindihan ng respondent ang consent form. Kapag pumayag na ang respondent pipirmahan ito ng interviewer
- Humingi ng permiso sa respondent kung puwede i-record ang interbyu
  - Kung pumayag ang respondent, simulan at i-record ang interbyu

<table>
<thead>
<tr>
<th>QUESTIONS</th>
<th>NOTES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. PAGKILALA SA MGA RESPONDENT</strong></td>
<td></td>
</tr>
<tr>
<td>1. Kumusta po kayo?</td>
<td></td>
</tr>
<tr>
<td>‣ Ngumiti at tignan ang respondent sa mata, maging attentive habang nakikinig</td>
<td></td>
</tr>
<tr>
<td>2. Nais sana namin kayo makilala. Paano ninyo po mailalarawan ang sarili ninyo?</td>
<td></td>
</tr>
<tr>
<td>‣ Kung nahihirapan ang respondent, maaaring magbigay ng mga halimbawa (“masayahin,” “masipag,” “nanay,” etc)</td>
<td></td>
</tr>
<tr>
<td>3. Kung handa na po kayo, maaari niyo pong simulan ang inyong kuwento</td>
<td></td>
</tr>
<tr>
<td><strong>ALTERNATIVES:</strong></td>
<td></td>
</tr>
<tr>
<td>‣ Magagamit ang mga ito kung mukhang nahihirapan ang respondent magsimula sa kanilang kuwento</td>
<td></td>
</tr>
<tr>
<td><em>Ano po ang kuwento ng inyong pagkakasakit?</em></td>
<td></td>
</tr>
</tbody>
</table>
**Maaari niyo po bang ikuwento sa akin ang inyong karanasan patungkol sa inyong kalagayan?**

- Manatiling tahimik at huwag sirain ang daloy ng pagsalaysay ng respondent
- Maaaring magpakita ng verbal cues ("Ahh," "Uh-huh," "Ganoon po ba?" etc) at non-verbal cues (pagtungo, pagtitig sa mata ng respondent, etc. habang nagsasalita ang respondent)

**Hayaang magkuwento ang respondent.** Kapag natapos na sila, itanong sa huli:

1. Mayroon pa po ba kayong nais idagdag?

2. Mayroon pa po ba kayong naaalala na sa tingin niyo ay mahalaga tungkol sa inyong karanasan sa pagtuklas at paggamot ng HIV?

3. **Kung MAYROON:** Hayaan silang magkuwento


**II. BAGO MA-DIAGNOSE NA MAY HIV**

1. Anu-ano ang mga bagay na sa tingin niyo ay higit na nagpataas ng tiyansa mo na magkaroon ng HIV?
2. **PROBE:** Itanong ang mga **TAO, BAGAY, PANGYAYARI, SITWASYON** na sa tingin ng respondent na nakadagdag sa pagtaas ng kanilang tiyansa makaroon ng HIV

   a. Trabaho ng respondent, saan at kailan
   b. Sakit, pisikal na kundisyon
   c. Kundisyong emotional/psychological/mental

3. **PROBE:** Itanong ang mga detalye patungkol sa kanilang **SEXUAL PARTNER**, at mga sumusunod na impormasyon patungkol sa kanila:

   a. Sino ang kanilang partner, kasal ba o hindi, nobyo, etc
   b. Ilan ang naging partner ng respondent **bago ng diagnosis, at pagkatapos ng diagnosis**
   c. Ang **sexual history ng kanilang mga partner**: Ilan, babaeng o lalake, gay, MSM, etc
   d. Trabaho ng mga partner, lugar ng pinagtrabahuhan
   e. Kung saan nakatira ang partner, kung nagsasama sa iisang bahay

4. Anu-ano ang mga bagay na naghikayat/nagudyok sa inyo na mag-pa-test para sa HIV?

5. **PROBE:** Tanungin ang mga **TAO, BAGAY, o PANGYAYARI** na nag-udyok sa kanila na magpatunging/magpa-test

Bago lumipat sa susunod na bahagi ng interview, siguraduhin ang mga sumusunod:

- Nakuha ang impormasyon tungkol sa:
  - **Risk factors ng respondent**
  - **History ng partner: sexual, trabaho, etc**
<p>| | |</p>
<table>
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<tbody>
<tr>
<td>o Ilan ang previous partners ng respondent, at ng kanilang partner ngayon</td>
<td></td>
</tr>
<tr>
<td></td>
<td>III. HIV DIAGNOSIS</td>
</tr>
<tr>
<td>1. Kailan mo nalaman na ikaw ay may HIV?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>[Tignan ang demographic sheet kung tugma ang petsa na isinalaysay ng respondent]</td>
</tr>
<tr>
<td>2. Ano po kaya ang mga naramdaman ninyo noong nalaman niyo na kayo ay may HIV?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Kung nahihirapan ang respondent, maaring magbigay ng mga halimbawa (“kaba,” “lungkot,” “saya,” etc)</td>
</tr>
<tr>
<td>3. Anu-ano ang mga bagay na naisip ninyo noong kayo ay na-diagnose?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Kung nahihirapan ang respondent, maaring magbigay ng mga halimbawa: “hindi alam ang iisipin,” “walang maisip,” “paghahanap ng solusyon sa problema,” etc</td>
</tr>
<tr>
<td>4. Anu-ano ang mga ginawa ninyo noong kayo ay na-diagnose na may HIV?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Kung nahihirapan ang respondent, maaring magbigay ng mga halimbawa: “nagdasal,” “tulala,” “may kinausap” etc</td>
</tr>
<tr>
<td>5. Sinu-sino ang mga tao na sinabihan mo ng inyong status?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Halimbawa: mahal sa buhay, kamag-anak, kapitbahay, ka-trabaho, kasama sa komunidad, kasama sa simbahan, etc</td>
</tr>
<tr>
<td>6. Anu-ano ang kanilang mga naging reaksyon?</td>
<td></td>
</tr>
</tbody>
</table>
7. Bakit ninyo napili na sabihin sa kanila ang iyong status?

   a. Anu-anong mga katangian ng mga taong sinabihan ninyo tungkol sa iyong status?

6. Anu-anong mga ginawa ng mga sinabihan mo tungkol sa iyong status pagkatapos nilang malaman ito?

7. Papaano nakaapekto ang iyong pagkakaalam ng iyong status na positive sa relasyon mo sa ibang tao?

   a. Sa pamilya mo?
   b. Sa mga kaibigan?
   c. Sa mga kasama sa trabaho?
   d. Sa mga tao sa iyong tahanan/barangay/lugar na tinitirahan

8. May napansin ba kayong mga pagbabago sa kanilang pakikitungo sa iyo?

9. May napansin ka bang pagbabago sa pakikitungo mo sa kanila?

10. May balak ba kayong sabihin sa iba pang tao ang iyong status?

   a. Ano ang mga bagay na humahadlang sa inyo na sabihin ito sa iba?

11. Anu-anong mga bagay na kailangan mo ng malaman noong ikaw ay nagkaroon ng HIV?

12. Sinu-sino ang mga taong tumulong sa iyo noong mga panahon na ito?
13. Anu-ano ang mga ginawa ninyo pagkatapos niyong malaman na ikaw ay may HIV?

14. Anu-ano ang mga bagay na nagbago o binago mo sa buhay mo nang malaman mo na ikaw ay may HIV?

   
   a. Paano at saan niyo nalaman ang mga ito?
   
   b. Sa inyong palagay, sapat ba ang inyong kaalaman tungkol sa HIV upang maprotektahan ang ibang tao?
   
   c. Kung hindi, ano pa ang sa tingin mong nais o kailangan pang malaman?

### IV. GAMUTAN PARA SA HIV

#### Para sa mga nagsimula ng ART

1. Bago kayo magsimula ng gamutan, anu-ano ang mga hadlang/ problema na encounter niyo? [Halimbawa: access sa treatment hub, kailangan makumpleto ang mga tests etc]

2. Gaano katagal bago kayo nagsimula sa paggamit ng gamot para sa HIV? [Tignan ang demographic sheet kung tugma ang petsa na isinalaysay ng respondent]
   
   a. Anu-ano ang mga dahilan kung bakit hindi kayo nagsimula ng ART pagkatapos malaman na kayo ay may HIV?
b. **PROBE:** Ano ang inyong mga **nararamdaman** noong mga panahon bago kayo magpapagamot?

c. **PROBE:** Anu-ano ang inyong mga **ginagawa** noong panahon sa pagitan ng inyong diagnosis at pagpapagamot?

d. **PROBE:** Anu-ano ang inyong mga **naisip** noong mga panahon sa pagitan ng inyong diagnosis at pagpapagamot?

e. **PROBE:** Kung isinalaysay ng respondent ay mga **gawain,** itanong kung ano ang mga **nararamdaman niya tungkol sa mga gawain na ito patungkol sa paggamot ng HIV**

f. Anu-ano ang mga nagtulak sa inyo na magsimulang uminom ng gamot para sa HIV?

g. **PROBE:** Tanungin ang mga **TAO o PANGYAYARI** na nagudyok sa kanila na magsimula uminom ng gamot

3. Kumusta ang inyong karanasan sa pag-inom ng gamot?

   a. Tanungin ang mga **PISIKAL, EMOSYONAL,** at **MENTAL** na mga karanasan

   b. Anu-ano ang mga naging problema, kung mayroon, noong kayo ay nagismula uminom ng gamot para sa HIV?

4. Anu-ano ang mga dahilan upang kayo ay manatili sa inyong treatment plan?

   a. **PROBE:** Tanungin ang mga **TAO, BAGAY, PANGYAYARI, etc** na sa tingin nila ay nakatulong sa
pagpatuloy ng kanilang pag-inom ng gamot?

5. [Tignan sa demographic sheet siya ay nag-undergo ng Viral load test. Kung OO, itanong ang mga sumusunod]. Ano po nangyari sa pinakahuli niyo na viral load test?

a. Ano ang naging epekto ng resulta ng iyong viral load test? (If result is still >1000, there is usually change in ART regimen or lifestyle)

b. PROBE: Tanungin ang mga TAO, BAGAY (GAMOT), SEX LIFE, etc na binago nung nalaman ang resulta ng viral load testing

c. Tanungin ang mga PISIKAL, EMOSYONAL, at MENTAL na mga karanasan

Para sa mga hindi pa nagsisimula ng gamot para sa HIV

1. Alam mo ba na may gamot para sa HIV?

2. Anu-ano ang mga naging hadlang sa inyong paggamot para sa HIV

V. MGA SERBISYO PARA SA HIV

1. Anu-ano ang mga serbisyo para sa mga taong na-diagnose ng HIV ang inyong nakuha na?
2. Anu-ano ang mga isyu or problema na inyong naranasan nang ikaw ay kumuha ng mga serbisyo ito?

3. Paano naapektuhan ng mga isyu o problemang ito ang inyong pagkuha ng serbisyo?

4. Nabuntis ba kayo pagkatapos ninyong ma-diagnose ng HIV?

5. Kung **OO**, kumusta ang inyong pagbubuntis?

6. Kung **OO**, kumusta ang inyong panganganak?

7. Nakakuha ba kayo ng libreng serbisyo para sa mga buntis?

8. Anu-ano ang mga bagay na kinailangan ninyo sa inyong pagbubuntis?

9. Anu-ano ang mga bagay na kinailangan ninyo sa inyong panganganak?


11. Kumusta naman po ang inyong anak?

**VI. TUNGKOL SA PANGHINAHARAP**

1. Anu-ano ang iyong mga pangarap o plano sa mga susunod na taon? (Example: sa susunod na taon, sa loob ng limang taon, sa loob ng sampung taon). Hayaan na magsalaysay ang respondent.
2. **PROBE**: Kung hindi pa kasal, itanong kung nais niyang magpakasal sa kasalukuyang partner

3. **PROBE**: Kung kasal na: itanong kung gusto ng respondent ng iba pang partner

4. **[Tignan sa demographic sheet kung may anak ang respondent]**

   d. **Kung MERON**: Gusto niyo ba magkaroon ng isa pang anak?
      
      i. Bakit?
      
      ii. Ano ang inyong plano sa pagbubuntis? [FAMILY PLANNING]
      
      iii. Sino ang tumutulong sa iyo sa pagdedesisyon tungkol sa bagay na ito?

   e. **Kung WALA**: Gusto niyo ba magkaroon ng anak?
      
      i. Bakit?
      
      ii. Ano ang mga bagay na humahadlang sa inyo para magkaroon ng anak?
      
      iii. Anu-ano ang inyong mga rason para sa desisyon na huwag magkaanak?
      
      iv. Sinu-sino ang mga kasama mo sa pagdedesisyon tungkol dito?

16. Kung ikaw ay magbabalik-tanaw, ano ang mga bagay na sana alam mo na
makakatulong sa iyo sa mga panahon na iyong?

17. Kung makakausap mo ang sarili mo bago ka ma-diagnose ng HIV, ano kaya ang mga bagay na sasabihin mo sa sarili mo?

**Pantapos**

1. Malapit na po tayo matapos. Bilang panghuli, at base sa mga napag-usapan natin ngayong interview na ito, mayroon pa po ba kayong gustong idagdag?

2. Mayroon po ba kayong gustong ibahagi sa amin bilang mga researcher patungkol sa inyong karanasan na sa tingin niyo makakatulong sa ibang WLHIV?

**Pagkatapos nang interbyu, siguraduhin ang mga sumusunod:**

- Siguraduhing napunan ang lahat ng patlang sa NOTES section ng interview na ito.
- **Bigyan ng summary ang respondent ng kanilang mga naisalaysay sa inyo.** Balikan ang inyong notes at basahin ang inyong notes sa respondent.
- Basahin mula ang inyong mga notes, at kung may hindi malinaw, humingi ng paglilinaw sa respondent.
- Itanong mula sa respondent kung mayroon pa silang gustong idagdag.
- **Pasalamatan ang respondent para sa kanilang panahon, sa kanilang pagbabahagi ng kuwento.**
- Ibigay sa respondent ang kanilang travel allowance, merienda, at iba pang materials.
C. Informed consent form (English)

2019 Women Living with HIV (WLHIV) Exploratory study
Informed Consent Form - ENGLISH

Introduction
Hello, I am ______, I am inviting you to participate in a study headed by the Department of Health-Epidemiology Bureau about women living with HIV and AIDS.

Purpose of the Survey
We are conducting this survey to help the government plan better health services for HIV and AIDS, especially for women. If you agree to participate in this survey, I will ask you open-ended questions about your life before and after being diagnosed with HIV.

Participant Selection
You have been identified as eligible to participate based on your answers to the questions I asked earlier.

Voluntary Participation
Your participation in this study is VOLUNTARY, if there are questions that you do not want to answer, just let me know and I will proceed to the next question. You can stop and withdraw from the interview at any time.

Confidentiality
All information that you provide will be strictly CONFIDENTIAL. Your anonymity will be maintained as we will not ask for your name, nor will we ask you to sign your name on any document. You may also prefer to use a pseudonym during the interview. The interview will be voice recorded so as to facilitate documentation, but rest assured only people involved in the study will have access to the recordings. All records will be surrendered to the Department of Health-Epidemiology Bureau, who will properly store this data for 10 years, after which will be deleted or disposed of following the guidelines in Data Privacy Act of 2012 (RA 10173) and the National Archives of the Philippines Act of 2007 (RA 9470). Moreover you may choose to refuse voice recording during the interview.

Do you have any questions?
If you AGREE, I will sign this line on your behalf to indicate that I explained the consent form and you gave your consent voluntarily.

NAME & SIGNATURE OF INTERVIEWER

If you have any further questions/comments after the survey, you may contact any of the following:
Name of Principal Investigator/Contact Info: Dr. Mary Elizabeth G. Miranda (443.214.3440/office@ersn.gov.ph)
Name of Research Ethics Committee/Contact Info: Single Joint Research Ethics Board (SJREB) (02) 651 7820 (ext. 1328)/sireb@lish.gov.ph

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Read the following statements, and place a check on the box if you agree

1. I understand that the interview is a study headed by the Department of Health-Epidemiology Bureau about women living with HIV and AIDS and that I have been given a chance to ask questions.

2. I understand that the questions in the interview will revolve around your life before and after being diagnosed with HIV. The interview will take an hour or two hours depending on our conversation.

3. I understand that my participation in this study is voluntary and I am free to withdraw from the interview at any time and would not need to explain.

4. If there are questions that I deem too private and in which I do not want to answer, I will just inform the interviewer that I am not comfortable to answer the question and we will proceed to the next question.

5. All information that I will provide will be strictly confidential. I will not be asked for my name, nor will I be asked to sign my name on any document. My personal information will remain confidential, private, and will be kept in a password protected computer.

6. I understand that the interview may be recorded using a voice recorder, but the team will ensure that the voice recordings will be surrendered to the Department of Health-Epidemiology Bureau who will keep all the data up to 10 years. And only the persons involved in the study will be able to listen to this. However, I am free to refuse voice record the interview.

7. If I agree to participate in this interview, I will receive information from support groups and be informed about the facilities that offer appropriate treatment. I will not be paid for participating in this study, but I will be provided transportation fees to the venue where the interview was conducted.

8. I understand that if I check "I agree to participate in the study" and if the interviewer signs at the bottom will indicate that the consent form was explained and I am voluntary consenting to participate in the interview.

Place a check in the box if you will participate in the study/interview:

I agree to participate in the interview
I do NOT agree to participate in the interview

Name of Interviewer
Date
Signature

Interviewer:
Telephone/Cell Number:
Email:
Informed consent form (Filipino)
E. Summary form

2019 Women Living with HIV (WLHIV)
EXPLORATORY STUDY

Before Diagnosis

Risk factors for HIV

- An OFW/Worked abroad
- A female sex worker
- Used drugs and/or shared needles
- Had a partner that is HIV positive

Diagnosis and care

Thoughts and feelings upon diagnosis

Problems encountered

Motivations to get tested

- Actions or changes initiated after diagnosis

Pregnancy (if respondent got pregnant)

Thoughts and feelings on pregnancy

Actions during pregnancy and delivery

Problems encountered
<table>
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<tr>
<th><strong>Accessed treatment</strong></th>
<th><strong>Has not yet accessed treatment</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Motivations to start treatment</td>
<td>Thoughts and feelings on whether to start treatment</td>
</tr>
<tr>
<td>Feelings on taking ART</td>
<td>Barriers from accessing ART</td>
</tr>
<tr>
<td>Motivations to stay on treatment</td>
<td>Plan for the future on treatment</td>
</tr>
<tr>
<td>Problems encountered on starting/maintaining on treatment</td>
<td></td>
</tr>
</tbody>
</table>

**Future**

DREAMS/ASPIRATIONS/PLANS

Looking back now, what are the things you wish you knew that you could have told yourself before you were diagnosed?
TIMELINE of RESPONDENT

Other risk factors

Partners

Milestones

Quotable Quotes